

# *Through our eyes*

Thirty years of people living with  
HIV responding to the HIV and  
AIDS epidemics in Australia

EDITED BY  
**Dr John Rule**

**napwha** national association of  
people with HIV australia



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## ACRONYMS

People living with AIDS were initially referred to as PWAs. Very soon the word 'living' was included so that the shortened version became PLWA. In the mid-1990s the word HIV was added to ensure that all those with the virus were included, not only those with full-blown AIDS. PLWHA was then used as the terminology for all 'people living with HIV/AIDS'. NAPWHA, following international guidelines, now uses the term PLHIV as a shorthand for 'people living with HIV'. In this document the term PLHIV will be used, or the longer version people living with HIV, or HIV-positive people. The exceptions in this document are, where historically, or in official documentation, the words PWA, PLWA or PLWHA might have been used.

NAPWHA, the national organisation representing PLHIV in Australia, has undergone a number of name changes. The first incarnation of the national organisation was called the National People Living with AIDS Coalition (NPLWAC). When the organisation incorporated in 1993, the name changed to the National Association of People living with AIDS (NAPWA). In 2011 there was a further name change and the name of the association is now the National Association of People With HIV Australia (NAPWHA).

Different acronyms are used as writers may have been referring to the different time periods where there was NPLWAC, NAPWA or NAPWHA.

AAC	AIDS Action Committee
ACON	AIDS Council of NSW
ACT UP	AIDS Coalition to Unleash Power
ADC	Anti-Discrimination Campaign
ADEC	Australian Drug Evaluation Committee
AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
AIVL	Australian Injecting and Illicit Drug Users League
ANCA	Australian National Council on AIDS
ARC	AIDS-related complaints
ARV	antiretroviral
ART	antiretroviral therapy
ASHM	Australasian Society for HIV Medicine
ATPA	AIDS Treatment Project Australia
AZT	zidovudine
BBV	blood-borne virus
BTS	Blood Transfusion Service
CALD	culturally and linguistically diverse
CDC	Centers for Disease Control
CMV	cytomegalovirus
ddC	zalcitabine
ddl	didanosine
DSMB	Data and Safety Monitoring Board
DSP	Disability Support Pension
ESPRIT	European/Australasian Stroke Prevention in Reversible Ischaemia Trial
FDA	Food and Drug Administration
GES	Gay Education Strategies project
GIPA	Greater Involvement of PLHIV
GP	general practitioner

GRID	Gay Related Immune Deficiency
GSG	Gay Solidarity Group
HAART	Highly Active Antiretroviral Therapy
HCV	hepatitis C virus
HIL	Highly Inappropriate Laws
HIV	Human Immunodeficiency Virus
IAS	International AIDS Society
IPN	Indigenous Positive Network
KS	Kaposi's sarcoma
LGBT	lesbian, gay, bisexual, transgender
LGBTI	lesbian, gay, bisexual, transgender and intersex
MAC	mycobacterium avium complex
MHAS	Multicultural HIV and Hepatitis Service
MIPA	Meaningful Involvement of People living with HIV
MSM	Men who have sex with men
NACAIDS	National Advisory Committee on AIDS, (then became the National Advisory Council on AIDS)
NCHSR	National Centre in HIV Social Research
PATSIN	Positive Aboriginal and Torres Strait Islander Network
PBS	Pharmaceutical Benefits Scheme
PCP	Pneumocystis carinii pneumonia
PEP	Post Exposure Prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief
PI	protease inhibitor
PIE	Positive Information and Education project
PNG	Papua New Guinea
Poz Action	A NAPWHA-initiated effort to reinvigorate the HIV-positive-led response across Australia launched in 2013
poz	positive
poz het	positive and heterosexual
PrEP	Pre Exposure Prophylaxis
PSB	Positive Speakers Bureau
QPP	Queensland Positive People
SILCAAT	Subcutaneous, Recombinant, Human Interleukin-2 in HIV-Infected Patients with Low CD4+ Counts Under Active Antiretroviral Therapy
SMART	Strategies for Management of Anti-Retroviral Therapies (clinical trial)
SAPA	Social Aspects of the Prevention of AIDS project
SSO	Sydney Star Observer
START	Strategic Timing of AntiRetroviral Treatment
STI	sexually transmissible infection
TON	Treatments Outreach Network
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UNDP	United Nations Development Program
VAC	Victorian AIDS Council
VAC/GMHC	Victorian AIDS Council/Gay Men's Community Health Centre (then became Gay Men's Health Centre)
WAAC	Western Australian AIDS Council
WAD	World AIDS Day
WHO	World Health Organization

## ABOUT NAPWHA

### **Our vision**

NAPWHA's vision is for a world where people with HIV live their lives to their full potential, in good health and free from discrimination.

### **Our mission**

NAPWHA is Australia's national HIV peer-based organisation. NAPWHA's mission is to provide national advocacy, leadership and representation across the diverse needs of all people living with HIV in Australia.

### **Our principles**

NAPWHA embraces the values of compassion, integrity and respect in all activities and aims to build consensus, partnerships and coalitions.

NAPWHA promotes the meaningful involvement, visibility and centrality of people living with HIV; utilising the diverse experiences of all people living with HIV to advocate for them in order to reduce the impact of the disease.

NAPWHA strengthens the national response to the HIV epidemic by ensuring the meaningful involvement of all people living with HIV and plays an active role in realising a partnership approach in all aspects of our response.

NAPWHA is committed to the principles of the Ottawa Charter, the Meaningful Involvement of PLHIV (MIPA) and its own Declaration of Rights for People Living with HIV/AIDS.

NAPWHA recognises and values the unique status of Aboriginal and Torres Strait Islander people as the original owners and custodians of the land and waters of Australia. NAPWHA believes it is important that the historical and cultural position of Aboriginal and Torres Strait Islander people is recognised and incorporated in the Association's official protocols.



## FOREWORD

It is my honour as the current President of NAPWHA to present this collection of personal perspectives of the response to the HIV epidemic in Australia. It reminds those of us actively engaged with the response that we are custodians of the rich legacy of those who worked tirelessly throughout the course of the epidemic, and that the work we do is based upon these contributions.

The engagement of HIV-positive people has been a critical part of the Australian HIV response from the beginning of the epidemic. Clinicians, researchers, community advocates, policy-makers, friends and families have supported and partnered with HIV-positive people to address the many tribulations and challenges that HIV has dealt us. This partnership has uniquely characterised the Australian approach to the epidemic that is the model for the global response.

NAPWHA, an organisation of people living with HIV, is proud of the role that it has played over time, representing and advocating for HIV-positive people and demonstrating the importance of the experience of living with HIV in understanding and addressing the epidemic. Knowledge is our most powerful tool and those of us with HIV have always had the most immediate and intimate knowledge of the effect of this disease. Positive people will continue to drive the response in order to end HIV to ensure that others do not have to experience HIV as we have.

The diversity of contributors to this project, each of whom has played their part in the HIV response, demonstrates the vitality and strength of the response in this country over the course of the last thirty years. I would like to thank the contributing authors from around Australia for their involvement and support. The end result is an impressive historical record, with eyewitness accounts by those who have been deeply involved in the epidemic. What links this group together is their belief in the ability of people directly affected by HIV to make a difference, to collaborate for a greater good and to do so selflessly and generously.

I would like to thank Jo Watson, Brent Beadle and John Rule: Jo for envisioning this document and her continual encouragement that has brought it to fruition; Brent for the research and collation of archival material and images; and John for applying his passion and skills in drawing out the range of contributions, and editing them.

The production of this book, and including the NAPWHA history exhibition at the World AIDS Conference 2014 in Melbourne, has been supported by a grant

from the Commonwealth Department of Health. I would also like to thank Angela Bailey, a professional curator, who has ably assisted Brent and John in preparing the accompanying exhibition – ‘Positive Voices’, ‘Art and Politics’ and ‘Policy, Projects and Collaborations’.

Published by NAPWHA, this book will have a life beyond the Conference and will stand as the most comprehensive coverage to date of personal perspectives of the Australian response to the HIV epidemic over the past three decades. NAPWHA is committed to circulating this material because understanding the past is necessary to inform the future. I commend this collection to anyone wishing to understand the depth and breadth of the Australian response and the commitment shown in responding to this epidemic. I hope that it provides inspiration for continuing the battle against HIV.

Robert Mitchell  
NAPWHA President

## INTRODUCTION

From a time when PLHIV were largely invisible, except as visibly sick and disfigured, to today when Poz Action and the representation and participation of PLHIV is embedded in the Australian HIV response, there is not one story, it is many voices and the need to remember others now long silent.

The challenge for NAPWHA in trying to give adequate and just coverage of a history that has imbued lives and communities with despair is to also capture and value what has been remarkable and unique about individual and community responses to that scourge. Many people have wanted to see us construct a record for NAPWHA and the PLHIV response at the national level. This document is but one form of how that can be developed, but it is a critical way of capturing voices from times past.

This document represents what, in research or historical work, is described as a collection of primary sources. Considerable rigour has been applied to gather and present the material in this document and so it will stand alongside other such attempts – and hopefully be an encouragement to others to do this in this area. Given the breadth and number of contributors, it is a unique document in Australia.

“What is meant by reality?”, Virginia Woolf once asked, and these contributors show that a personal reflection on an experience answers by offering their contributions as: “This is what I saw happening, and lived through.” We are very proud to have been involved in constructing this – something more now exists, something new exists, which will serve those in the future wanting to know what happened in that time and that place. *Through our eyes* is a significant contribution to the annals of the epidemic – it provides evidence of a rich and varied Australian community response to the AIDS epidemic in Australia, and especially how the HIV-positive community response has been ‘central and vital’.

The notion of peer is central to a PLHIV response, peer as “persons who are experiencing a similar set of circumstances, and who associate with one another to find outcomes to common areas of concern”. This series of reflections gives voice to peer connection, and allows contributions from those who have partnered and worked with PLHIV over many years. Thus it honours connections and the work delivered in the name of people living with HIV.

It is a tapestry that provides direct evidence of a time and place, to bring a history and culture to life, and it is produced by the eyewitnesses who were also the participants. There will be more voices and views to come in the future and the

tapestry can be woven wider from the various years and numerous standpoints. Multiple voices should be part of this evolving record because the realities of this history are rich and complex, each person has their own narrative, and the reality for now and into the future will be influenced by how we give acknowledgment and respect to those times past. Handling these multiple narratives here, now, with care, has been part of the rigour demonstrated through the production of this document.

This book has been shaped through a process that involved PLHIV from across Australia who suggested a structure and identified material for contributions. In the first instance the NAPWHA Board and member organisations nominated the time periods in which the stories would be told and identified people they thought could make a genuine and useful contribution to the work. More than eighty people were invited to contribute; of these more than fifty agreed to work on the project. Every person contributing was invited to provide a personal perspective, in their own capacity, and if they were attached to an organisation, not as a representative of their organisation. The result is a diverse range of writers, the majority of whom are HIV-positive. Other contributors have been working closely and steadfastly alongside PLHIV over many years.

Passion, commitment and solidarity shine through these contributions, and underlying them all is profound respect and love offered to ensure we do not forget those who have been part of our lives, our losses and our memories. *Through our eyes* demonstrates that an historical record can also be preserved with intimacy and care, because for these writers and so many others, it is very personal, and it speaks to a record of so many lives.

Jo Watson, Brent Beadle and John Rule



# Ban doctors who discriminate, says PLWA

Doctors who refuse treatment to people because of HIV status should be struck off the medical register, according to the newly-formed People Living With AIDS organisation.

PLWA's convener, Robert [Name obscured], doctors into AIDS...

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## WHITE PAPER ON AIDS

Again, with proudest you have in most states...  
Q How long do you think it will be until AET will be considered as a standard treatment for people with AIDS?  
A I think it will be within the next few years...  
Q How long do you think it will be until AET will be considered as a standard treatment for people with AIDS?  
A I think it will be within the next few years...

## forms PLWA

A People Living With AIDS group has been formed in Tasmania. Members have already had an interview the state's new Minister for Police, Mr Ken Weidt. They asked him to support the establishment of a needle exchange programme. "A lot of people think the only junkies in Hobart are tourists from the mainland who come over here, shoot up, and then go home," a spokesperson said. "But that just isn't true. We have also established a safe house near the [Name obscured] where people from other country areas can [Name obscured]...  
...move, any HIV [Name obscured] Tasmanians can [Name obscured] Tasmanian AIDS [Name obscured] free of charge and direct say in the [Name obscured] of the organisation.



**ACT UP**

# HIV/AIDS STOP MEDIA LIES!

**DEMONSTRATE WHEN: 4PM FRIDAY 26TH JUNE**  
**WHERE: MELBOURNE MAGISTRATES COURT CNR ELIZABETH & LONSDALE STS**

### MEETING OF PLWA'S

What do you think of the health services you receive?  
Any complaints?  
What works well?  
The AIDS Bureau (NSW Department of Health) is conducting a planning study for the development of HIV/AIDS services to meet your needs.  
We want your views on what you want and on problems you currently encounter. We are holding a half day meeting to listen.  
When: Wednesday 6th December  
Time: 1 - 5 pm  
Where: YWCA, 5 Wentworth Avenue DARLINGHURST  
Enquiries: Tel. 399 4655 and ask for Mrs. Margaret or Ian.



Asian and New York ACT-UP demonstrators delayed the opening of the 1994 AIDS Conference. Their action, Australian delegates said, Hotel, Restaurateur Jung Dowling, Nanette & Barry, and guests Graham, Bruce and Ron. (Pics: David Wilkins)

## STILL TALKING POSITIVE

Living Well Support Groups conducted by the AIDS Council. These groups are for people who want to...  
No. 150, Friday 14 June 1991

## Double AIDS funding, experts tell govt

The Federal government's AIDS experts have told it more than double the amount of money it is currently spending on the disease.

## D-DAY ATTACK

More than 700 people around Australia took part in private sporting events to raise awareness of HIV/AIDS.

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### hundreds protest around Australia

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### Hospital discharges PWAs 'much too high'

More than 200 people marched through Sydney city streets in protest.

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# The Beginning

c1982-1989

*We were a silent part of the epidemic  
until a few brave people started to  
speak up and change things in 1988.*

**David Menadue**

## IN THIS SECTION

**Bill Bowtell** *The radicals were right*

**David Menadue** *Stigmatised but largely invisible*

**Ross Duffin** *Best of times and worst of times*

**Susan Kippax** *Partnership was central to our work*

**Beverly Greet** *HIV-positive people now had a national voice*

**Martyn French** *Responding to a health emergency*

**Jennifer Hoy** *Altruism shown by so many individuals*

**Bill Paterson** *Through my eyes*

**Elizabeth Reid** *The role of caring and living with the dying*

## INTRODUCTION

It came out of nowhere. No one knew what it was, what caused it, or how to deal with it. But it was a guaranteed killer. The first recorded case of AIDS (Acquired Immune Deficiency Syndrome) in Australia was in Sydney in October 1982.

It had different names in those days, in the early 1980s – among them were ‘GRID’ (Gay Related Immune Deficiency), ‘the Gay Plague’, or simply ‘the black plague of the eighties’. Nowadays, what we know as HIV was then simply called AIDS, and its appearance at a time when gay men’s sexual and emotional lives were still illegal in most Australian states and territories meant that those most affected – gay men and their communities – were sure to be targeted.

Luckily, the gay and lesbian communities in Australia had a history of activism. From the early 1970s, the gay liberation movement had marshalled itself around a range of issues, taking on the four pillars of oppression – the church, the police, the medical profession and the media – over how they dealt with lesbians and gay men. Such an activist past provided a strong foundation for the various communities to pull together for a political response to HIV. In fact, the linkages between gay rights, human rights, and responses to HIV were identified at the very beginning of Australia’s response to the epidemic.

Also important were the so-called Denver Principles, a 1983 statement of self-empowerment articulated by some Americans affected by the epidemic. They had met in Denver, Colorado, and issued a clarion call to arms:

We condemn attempts to label us as ‘victims’, a term that implies defeat, and we are only occasionally ‘patients’, a term that implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS’.

In Australia, rapid responses to the new ‘disease’ occurred in most states. 1983 saw the formation of an AIDS Action Committee (AAC) in both Sydney and Melbourne. Around this time the Victoria Prostitutes Collective had produced the AIDS peer-education pamphlet *Facts on AIDS for the Working Girl*. In Sydney, in an effort to put pressure on politicians to change laws, some Sydney doctors ensured that needles and syringes were provided to injecting drug users. Ita Buttrose had been appointed as the chair of the National Advisory Committee on AIDS (NACAIDS) in 1984. By 1985 the Australian Federation of AIDS Organisations (AFAO) had been formed.

There was so much to do, and so little time. People in Australia’s gay communities were dying, and there were constant attacks from the ignorant and prejudiced. There was awareness that any work in HIV prevention, care and support required an ‘enabling environment’, and this would involve working with successive state and federal governments to develop HIV strategies.

One critical early aspect was to shift the focus away from being a morality issue to a public health issue, and here the various communities were greatly helped by having



pragmatic health ministers at various levels, such as Neil Blewett, the federal health minister.

Getting relevant information out was an important aspect of the various communities' and governments' responses, and education became the key focus, for the wider Australian public as well as for those initially most affected, gay men. There were television advertisements, such as the controversial 'Grim Reaper' campaign of 1987, where Death, with scythe and bowling ball, mows down an Australian family. Perhaps it was 'overkill'.

Within the gay communities there were other responses to assuage the grief and anger. Organisations to provide support were established, their names commemorating either people who had died early – such as the Bobby Goldsmith Foundation in NSW, set up in 1984 – or who had led community responses – the David Williams Fund in Victoria, set up in 1987. During this period, groups such as Ankali and Community Support Network appeared. PLWA (people living with AIDS) also formed groups and began organisations. AIDS Coalition to Unleash Power (ACT UP) also emerged, protesting the delays in getting what were the few drugs available.

The epidemic was a worldwide phenomenon, and there were numerous global responses. One such was World AIDS Day, set on 1 December every year; it was conceived in 1987 by two officials at the Global Programme on AIDS at the World Health Organization (WHO). Another response was the Quilt Project, conceived in San Francisco in 1985 and officially started in 1987. Its panels are a memorial to and celebration of the lives of people lost to the AIDS pandemic, and it was often the only opportunity survivors had to remember and celebrate the lives of their lost ones. In Australia on World AIDS Day in 1988, the first such quilt panels were displayed.

Conferences played an important role in those early years, as places for the exchange of information as well as for the contestation of 'certainties'; perhaps one of the most important was the Third National Conference on AIDS in Hobart, August 1988. It was the scene of a dramatic development when, at the closing plenary session, a group of people walked onto the stage and declared that they were HIV-positive and that they were no longer content to remain invisible.

Later, at the Living Well conference (a conference organised by – and for – people with AIDS, ARC and HIV . . . and their lovers, partners, family and close friends), on 27-28 August 1988, at Fairfield Hospital in Victoria, many motions were passed and these related to themes that have variously remained important throughout the epidemic.

Those themes covered: • Funding structures • Testing, research and access to medicine • Social security • Hospital clinics and health services • Relationships and sexuality • Day care centres • Friends and lovers • Family • Long-term survivors • Injecting drug use • Women, and • National Initiatives, including the agreement to ". . . form a National Coalition of PLWA".

It was a momentous occasion: the silence of the 'invisibles' was broken, and a very public fight to die – and to live – with dignity, was under way.

**Bill Bowtell**

## *The radicals were right*

Could there have been any effective, sustained response to the emergence of HIV/AIDS without the advice, perspectives and consent of those most immediately affected by the disease? It is absurd to even pose that question today. Thirty years ago, the idea that those with, or closest to, HIV/AIDS might even be consulted, let alone have a determinant and final say in national HIV/AIDS policymaking was deeply radical and strongly resisted. We were told promoting the rights (and responsibilities) of those with HIV/AIDS was irresponsible and would accelerate the spread of the virus. But it turned out that the reverse was true. The radicals were right. Thanks to the visionary activism of those in the early days of AIDS, and the profound insights of those living with HIV, many thousands of young people were saved from infection, and the lives of positive people transformed by the earliest possible access to effective treatments. And, very importantly, a new model for dealing with other diseases was created, and shown to work outstandingly well. It is a legacy of which we can all be proud.

**David Menadue**

## *Stigmatised but largely invisible*

More recently diagnosed people with HIV or their friends may be surprised to know that, despite quite a lot of publicity around HIV in the 1980s, very little attention was given to people with HIV themselves during those early days. We were a largely invisible group of people except for the occasional negative media story, such as when an HIV-positive person was jailed for having unsafe sex with someone.

Few people wanted to publicly admit that they were HIV-positive in such a hostile environment. There were no people-living-with-AIDS organisations; AIDS Councils did advocacy on our behalf but mainly concentrated on issues around care and support, and people with the virus didn't see themselves as having any particular rights or identity. We were a silent part of the epidemic until a few brave people started to speak up and change things in 1988.

Like most people diagnosed with HIV in the mid-1980s (just after the blood test became available), I kept my diagnosis largely to myself at first. It was a scary and volatile time in the public's understanding of the virus – most obviously shown in the media and community reaction to the news that four babies had been infected in Queensland through a blood donation from a gay man (who wasn't aware he was

HIV-positive) in November 1984. Gay men were blamed for passing on the virus, with some media having the gall to suggest it had been deliberate!

I was diagnosed a month before this, after noticing swollen lymph glands under my arms for longer than three months – a leaflet from the Victorian AIDS Action Committee (established in 1983) had informed me this was a sign that could mean I had contracted HIV.

I'd also known about the existence of the virus (under a series of acronyms such as GRID and HTLV 3 until finally called HIV) since 1982 from a series of articles written in the Melbourne-based *Gay Community News* by Gary Jaynes and Adam Carr about a kind of 'gay cancer' occurring in gay men in New York and San Francisco, with early theories including the possibility of a link with the use of amyl nitrate.

In July 1983 I had also attended a meeting at the Dental Hospital in Melbourne where a panel of doctors had tried to explain what was known about the virus from overseas experience as there had not, at that stage, been any Australian cases. Little did many of us in the audience know that we had already contracted HIV. The Victorian AIDS Action Committee was established soon afterwards at a meeting at the Laird Hotel, which I attended, but I was not ready to become involved with the organisation, because of my work commitments.

Given events such as the Queensland babies' blood donation crisis, which were to engender significant hostility towards people with HIV, I was grateful that the gay community had established our own advocacy groups. These groups, replicated in most states and territories, liaised with governments to fight attempts from some public health officials, media commentators, and the inevitable religious right spokespeople such as the Reverend Fred Nile, to regulate and contain people with HIV. The nastiness and homophobia that was directed at gay men was alarming, and could have been far worse, but for the intervention of one enlightened politician: the Minister for Health under the Hawke government at the time, Neal Blewett.

Advised by a savvy gay man, Bill Bowtell, Blewett rejected the advice of his own National AIDS Taskforce, constituted largely of medical professionals and chaired by Dr David Penington, which wanted to compulsorily notify authorities of the details of everyone diagnosed with HIV, including their addresses. Things could have got out of control and led to measures such as quarantining HIV-positive people. Instead, Blewett set up a National Advisory Committee on AIDS (NACAIDS), chaired by Ita Buttrose and including community representatives. NACAIDS eventually prevailed and implemented funding for AIDS Councils and community HIV prevention education campaigns, and in time, anti-stigma initiatives to change society's views about HIV-positive people.

Against this background of hysteria and political conflict over HIV, I was feeling isolated and in need of support. Disclosure of your status was difficult, even within the gay community. There were no specific peer groups for HIV-positive people (in fact none for gay men either, for some time into the '80s), and as well as education campaigns, AIDS Councils tended to focus on care and support services for people

with HIV, particularly those who were ill.

A group of us, individually, attended a counsellor at Fairfield Hospital to talk through the stresses of being HIV-positive at that time. He decided it would be a good idea to get all of us to meet and establish our own peer support group. We would meet in the homes of group members.

Melbourne Positive Friends was established in 1986 and close to 40 people joined up until it finished in 1993. It was an important vehicle for me to get rid of some of the stigma I was feeling about hiding details of my status from others, including from my family. There is nothing like talking about the fears and frustrations with your peers living with the virus. One day when we were watching a TV show during a meeting in 1987, the Grim Reaper campaign advertisements came up. We could see the point of the campaign but we knew it would increase people's fears about people with HIV as much as their fears about the virus. We coped by trying to destigmatise the way it made us feel – with black humour, describing each other as 'tragic victims' and 'sufferers', reclaiming the language and trying to laugh it off.

Inevitably though, in a group of positive people at that time, people started to get ill. We weren't ready for such confronting situations, with most of us in denial, thinking we would not get sick. People would lose weight suddenly, get mysterious conditions we had never heard of before and the reality of AIDS became clear. These friends usually suffered quietly and relatively anonymously, not wanting others to know what was going on. Even their funerals often didn't mention the cause of death, usually at the request of family.

Something had to give, to break this world of anonymity and shame. I was amazed when an HIV-positive person named Les Taylor appeared on the TV show *Good Morning Australia* to plead for access to be given to the drug AZT, which was the first potential drug being used to treat HIV in the USA. It was a brave thing to do and it broke the ice for others to make further media appearances showing the reality of AIDS from someone with the virus.

At that time, HIV-positive people were involved in the response in different ways. Many were involved in AIDS Council working groups, employed as staff or contributed as volunteers. Their contributions were also recognised, such as with the establishment of the David Williams Fund at the Victorian AIDS Council (VAC) in honour of David Williams, a major instigator of the care team system in the Support program, who died in 1986. This fund still delivers significant financial assistance to people with HIV in Victoria.

The first major 'coming out' of people with HIV was at the Third National Conference on AIDS in Hobart in August 1988. At the end of the Conference, a large group of positive people came out the front at the instigation of activists Chris Carter from Melbourne and Terry Giblett from Sydney, among others. Many of these delegates had not told others of their status until that time, and it was the first public statement of its kind in Australia.

The energy that the Hobart conference generated was obvious when the delegates returned to their home states. I was talked into becoming involved by Keith Harbour

to attend the Living Well Conference at Fairfield Hospital, held after the conference in Hobart. The idea of establishing a national movement of people with AIDS (people didn't call themselves people with HIV in those days) had its genesis at the Living Well Conference.

This was probably the first real consciousness-raising event I had been to, where the need for visibility of HIV-positive people was discussed, with the agenda of increasing the participation of positive people in the governance and policy-making work of the HIV sector.

Within months a People Living with AIDS project was established at VAC, which later became People Living with AIDS Victoria, with Chris Carter the first Convenor. In NSW, individuals such as Terry Bell and Paul Young were instrumental in establishing People with AIDS NSW, and Robert Ariss became its Convenor.

The National People Living with AIDS Coalition (NPLWAC) had its first meeting in late 1988. I think the first Convenor was Chris Carter and individuals such as Bev Greet (who had already established Positive Women Victoria) and representatives from other states were involved. I became a part of the committee in 1989. In that year too, I became Convenor of People Living with AIDS Victoria. There weren't that many of us prepared to do this activism and often we would end up wearing several hats.

Many people with HIV were becoming ill at this time, and it was difficult to keep up the energy to keep these organisations going through such a time of grief and loss. The need for the federal group NPLWAC and the various state people living with HIV organisations was clear though, as increasing numbers of people were prepared to be out about their status and prepared to fight for the rights of their peers, including the right to access treatments such as AZT.

These early days of NAPWHA are seared in my memory as both liberating on a personal level – there is something very empowering to work with peers on what was really a fight for our lives, at the time – but frustrating and saddening as we tried to survive with limited resources (usually provided under programs or the goodwill of AIDS Councils) and tried to cope with the increased mortality of our friends, which was occurring all around us.

Thank goodness we did survive as a movement and that people with HIV have become central to the response to the epidemic; empowered to fight for our rights and to improve the lives of so many people.

**Ross Duffin**

## *Best of times and worst of times*

*It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to Heaven, we were all going direct the other way.*

**Charles Dickens, *A Tale of Two Cities***

Indeed, the 1980s were like that. They were a peak time for ‘gay’ and ‘community’. They were also the time that we got to understand the HIV epidemic, and by the end of the decade its horror. Yet paradoxically for much of the 1980s the HIV epidemic formed the glue that solidified ‘gay’ and ‘community’ and bought us new friends amongst sex workers and people who inject drugs – groups then considered to be more at risk of HIV infection. For people with HIV, however, it wasn’t until the end of the decade that we began to be open about our HIV status and to organise.

The first report of something happening occurred in June 1981 when the Centers for Disease Control (CDC) in the USA reported in their publication the *Morbidity and Mortality Weekly Report* (MMWR) five cases of *Pneumocystis carinii pneumonia* (PCP) amongst gay men<sup>1</sup>. This was followed up by an article in *The Lancet* documenting Kaposi’s sarcoma (KS) amongst gay men<sup>2</sup> and a second MMWR report of both KS and PCP amongst gay men<sup>3</sup>.

The latter report generated a story in *The Sydney Morning Herald* describing a ‘gay cancer’. I was involved with a gay radio program on 2XX Canberra and we constructed a lot of hilarity about the notion that cancers had a sexual preference and dismissed the story as trash.

In the middle of 1982 I travelled across North America. I went to a national gay conference in Toronto, Canada. One evening during the conference there was a session at the Hassle Free Clinic on what had become known as ‘GRID’ (gay related immune deficiency). The presenter put up a chart of notifications, which showed them increasing during 1981 and then falling away during 1982. “It could be just like toxic shock syndrome – a small burst of disease which goes away,” the presenter conjectured. The reason for the shape of the graph was a delay in reporting. In fact, the cases were rising sharply – but the big message was ‘don’t panic’. From there I went to San Francisco for Pride. I remember being transfixed by photographs of KS lesions in a shop window in Castro Street, and on seeing a couple of men with KS in a bar. Visibility makes a big difference – something we had to learn about living with HIV in Australia – and interesting, considering a lot of re-invisibilisation that seems to have occurred this century. Before the parade, I interviewed a doctor from Bay Area Physicians for the radio program. He had been at a meeting where an epidemiologist involved in tracking the epidemic talked about a cluster of infections

in Orange County based on a group of men who had mostly attended the same sex-on-premises venue and had sex with each other. It was the first convincing evidence that 'GRID' was a transmissible disease. I sat there dumbfounded, thinking it was the end of the world as we knew it (words that later became an '80s song). Gaetan Dugas, the Canadian flight attendant described as being significant to the early spread of HIV, was not connected to this network, unless by many degrees of separation. He was the first example of victim blaming I remember, a phenomenon that sadly became frequent – and in some places still persists.

I came back to Australia determined to be involved in a response to the looming storm. I moved to Sydney – into a household with four other gay men – one in his mid-20s (my age), and three close to 20. What I didn't know was that HIV was already spreading rapidly and silently in Sydney. By the early 1990s the three youngest people in the household had died of AIDS. They came out and started being sexual at precisely the time when HIV was spreading, without us being aware of it. It belies all the attempts to categorise and describe people with HIV as somehow 'bad' – for many it was just bad luck.

After a period of denial and activism around the blood bank exclusions, gay men started to take what was happening seriously. There were very early campaigns in both Melbourne and Sydney funded by the community. Gay journalism, particularly by *Outrage* HIV writer Adam Carr, played a significant role in education and overcoming denial. A key article by Adam was published in *Outrage* in the second half of 1983. Adam described writing the article recently<sup>4</sup> at the 30th anniversary of the Victorian AIDS Council.

The result was an article 10,400 words long, probably the longest ever to appear in the gay press, which covered the full gamut of what was then known about AIDS. Just to remind you of how long ago this was, I wrote that article with a pen, on paper, and then had to get someone to type it for me. The process of researching that article was for me a journey into a very dark place. I learned that in the US this new disease, AIDS, had already affected nearly 1,500 people, of whom over 70% were gay men, and of whom 40% were already dead. I learned that the number of cases was doubling every six months. I learned that the average time from diagnosis to death was less than a year. I learned that the cause of this disease was unknown, and that that no one had any idea of how to treat it.

It didn't take much imagination to see where this was leading. An untreatable disease with a high mortality rate, doubling in numbers every six months, was a description of a catastrophe about to happen.

Soon after, attendance at gay venues went down dramatically for a period, the incidence of gonorrhoea and syphilis amongst gay men plummeted, and historical back projections show a rapid decline in the rate of new infections of HIV at this time.

The key interference to HIV's inexorable spread was taken before any government action. It was these efforts, as well as efforts by sex-worker activists in getting

condoms into brothels and injecting drug user activists in establishing world-first needle exchange programs, that prevented a much larger epidemic in Australia. Histories of HIV often make heroes of doctors and governments, and ignore the key role played early in the epidemic by communities at risk – a role that had more impact on diminishing the HIV epidemic in Australia than anything else until the arrival of effective treatments. Indeed, some early state government bureaucrats in NSW actively resisted community prevention efforts. That changed a lot later.

The year 1984 saw the establishment of the AIDS Council of NSW (ACON) – an organisation I was involved with for the next 12 years. I'm not going to focus on ACON in this essay, as I want to get to the beginnings of the organisations of PLWHA in Australia. At ACON's formation meeting I most remember the first open person with HIV disease. It was prior to HIV testing being available – he had been diagnosed by having a low CD4 count and a set of symptoms that would later be described as ARC or AIDS-related complex. His name was Bruce Belcher, who I knew from Melbourne. I most remember Bruce as a Sister of Perpetual Indulgence walking up Oxford Street – a nun with a full beard. He was approached threateningly by some young Italians, whereupon he raised his voice and said 'Hands off sister'. They were so surprised they let him pass. He got up and gave an impassioned plea for people with the disease to be significantly involved in the community response. It was a tension between 'gay' and 'HIV' that persisted for 30 years – HIV was bigger and broader than 'gay' and some parts of 'gay' felt threatened by it.

It was also when the storm of HIV truly arrived. There were a number of parallel epidemics throughout the 1980s: the epidemic of media sensationalism and bad reporting, the epidemic of highly inappropriate laws (HIL), the epidemic of the dance party, the epidemic of gay bar closures, the epidemic of HIV diagnoses, and towards the end of the decade the epidemic of AIDS and death.

From 1983 onwards AIDS was the news story of the decade – and the next one. Every week there were many media cuttings on HIV. The initial narratives of the media were often victim-blaming. 'Die, faggot, die' screamed the headline about a young man who had donated blood, unaware he might have HIV; he'd had sex three times, once with an American. We'd gone from a world where infectious diseases were seen to be mostly solved through antibiotics and vaccinations to a new unknown and deadly disease. Moral panic and blame set in. The stories were endless – sensation and victimisation of an HIV-positive sex worker, the sad story of discrimination of a young girl whose family was effectively forced to move to New Zealand. When treatments started to arrive, the narrative changed to one of 'breakthroughs' and 'potential cures'. We've now had a few thousand breakthroughs and a lot of potential cures.

When HIV antibody testing arrived in 1985, so did notification and transmission laws. The main testing clinic in NSW went from being full one day to empty the next. Compulsory notification laws had been announced. While systems to prevent duplication in epidemiological statistics were indeed necessary, it didn't have to



mean compulsory notification. It led to a huge debate about testing – when there were no treatments, there didn't seem to be a medical reason to get tested. The second set of laws were transmission laws and often the 'updating' of public health acts. These laws were bad in the 1980s – now they are totally counterproductive. People on treatments with undetectable viral load are the least likely to transmit HIV. These laws discourage testing – and people with HIV who do not know are much more likely to transmit HIV due to higher viral loads. The epidemic of highly inappropriate laws left us with consequences that still persist.

The arrival of AIDS also heralded large changes in gay community and socialisation. If you stood on Taylor Square (a busy intersection in the middle of what was then Sydney's 'gay area') and looked at a map of gay venues you would see more than 60 venues listed. By 1984, you would see less than 15. Many thought HIV caused this, but it was migration to Newtown, a change in investment strategy by some of the owners of gay businesses, and the introduction of arcane licensing laws. While gay venues may have declined, gay warehouse parties took off. There was often one or two a week – huge gatherings of tribal celebration. I had many discussions about HIV and coping at these events.

The arrival of testing also resulted in the first wave of the epidemic of known HIV infections. Of the first 1000 tests done in gay clinics in inner Sydney, nearly 50% were HIV-positive. This was close to the San Francisco level. But as more men got tested, the figure approached 15% – the first wave of people tested were those most at risk. In a short period, thousands of men found news of a diagnosis they had to make sense of when there was a lot of conflicting information and a lot not known. Making it harder was discrimination, a hostile environment, a media storm, new inappropriate laws and an ethic of 'don't ask, don't tell'. It's hard to get support when you're not meant to talk to anyone. It was from this period and these experiences that the beginnings of an HIV-positive movement were formed. I got my positive diagnosis soon after this period – and I knew at once that although the rules for our safe-sex culture were defined as 'assume everybody is HIV-positive', what we were actually doing was assuming everyone was HIV-negative. Thousands of positive test results changed that, but it was not an easy adjustment, especially as the period started to overlap with the beginnings of a lot more illness and death. AIDS diagnoses started to take off in 1988, and peaked during the 1990s.

The ritual of reading the weekly gay newspaper and opening up to a double page of obituaries began.

In 1986, we got the first news about a potential treatment for AIDS. We heard about a drug where 'people on their death bed were mowing the lawns the next week'. It was AZT – and with stories like that it was no wonder that there was a demand for it. The first US trial showed some benefit for people with AIDS and the drug was quickly approved by the US Food and Drug Administration. The key question was could AZT delay progression to AIDS, if given to people earlier in the course of their HIV disease. By 1988, a trial for people with fewer than 350 CD4 cells was established but there were insufficient places on the trial. We had queues

of angry people at ACON seeking help to get a trial place.

The Executive Director of ACON (Bill Whittaker) and President (Ralph Petherbridge) quickly organised the first treatments access demonstration. Although treatments approval and funding were ultimately a federal responsibility, we chose to demonstrate outside NSW parliament. Within hours, an extra 200 places were being funded by the NSW government. It was a real demonstration of how much power we then had – a new infectious life-threatening illness was scary. It's a power that by and large no longer exists – and as health funding is under threat – it is often now more about illness competition than rational decision-making to allocate available resources.

The demonstration marked the beginning of a long process to reform Australia's drug approval and regulation systems. State funding was a temporary fix – the real problem lay in Australia's arcane and out-of-date drug regulation system, which did not give priority to people with life-threatening illnesses and delayed approval for years so that any problems would be known overseas first. My role changed from preventative education to treatments education and access.

The promise of AZT was ultimately a let-down. At the doses used, it produced considerable side-effect problems. And for most mono-therapy (single drug) treatment regimes, HIV was able to quickly develop resistance. Drug companies needed to work together to develop combination treatments – something they were very resistant to do. Sadly, drug companies did not learn the lessons of co-operation, as can be seen in Hepatitis C where a treatments revolution is under way at long last. Treatments access; education; approval regulation and reform; and ensuring expanded and early access while trials occurred and importing overseas drugs via a buyers' club became a big agenda for the community sector and overlapped with the birth of the PLWHA movement.

The Third National Conference on AIDS was held in Hobart in 1988. Some brave PLWHA wore badges saying 'talk with us, not about us'. At one point, Terry Giblett (an open HIV-positive man), asked people with HIV to take to the stage. We suddenly discovered that 50% of the staff at ACON at the time were HIV-positive. It was a scary moment.

There were a number of key people in the emergence of the PLWHA movement in NSW: amongst whom were Robert Ariss, Andrew Morgan, Gerald Lawrence, Paul Young, Amelia Tyler and Vivienne Munro. There were many more but I most remember the names I've listed. Paul Young became the first HIV-positive media person in NSW. In my opinion, it took a lot of guts in that environment. Out of the new activism a lot of things occurred.

PLWA(NSW) – later PLWHA (NSW) and now Positive Life – was formed and a major project – the HIV Support Project – was established. During the years 1989 to 1996 it saw about one-third of the people with HIV in NSW and trained over 500 facilitators. Half of whom died during those years; the toll of being in the epicentre was very large.

Because positive organisations were established after the big increase in

community-based organisations, they were often the poor cousins and not adequately resourced. Governments preferred not to deal with extra organisations, but for people with HIV the need for our own organisation was clear. Sadly, the funding disparity was often never properly fixed.

At the formation meeting of PLWHA (NSW) the biggest debate was whether people had to be open about their HIV status in order to be full members. It was a reflection of the stigma at the time – and led to a national HIV stigma campaign where a number of brave PLWHA featured openly in TV and print advertisements.

As the 1980s ended, death rates were skyrocketing. HIV sero-conversions had returned, often fuelled by the increased viral load of people whose illness was advancing. Treatments were still mostly mono-therapy and had a lot of drug-limiting side effects. Treatment activism had been born and the PLWHA movement had begun, which played a huge role in the dramatic changes that occurred during the 1990s.

And my choice of songs changed from *It's the end of the world as we know it* to *Things can only get better*. They did – but there's a memory we all carry that many of us struggle with.

#### NOTES

1 CDC. *Pneumocystis pneumonia: Los Angeles*, *MMWR* 1981;30:1-3

2 Hymes, KB, Greene JB, Marcus A, et al. 'Kaposi's sarcoma in homosexual men: a report of eight cases', *The Lancet* 1981;318:598-600

3 CDC. 'Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men: New York City and California'. *MMWR* 1981;30:305-8.

4 'The Courage of our Convictions: lessons from the AIDS panic of the 1980s'. Speech by Adam Carr on the occasion of the 30th anniversary of the VAC.

Available at <http://psephos.adam-carr.net/speech>

## Susan Kippax

### *Partnership was central to our work*

I began working in HIV-related research in 1984 when a member of the AIDS Council of NSW (ACON) approached members of the School of Behavioural Sciences at Macquarie University to help ACON and members of the gay community respond to HIV and AIDS. With funding support from the NSW Department of Health, the Social Aspects of the Prevention of AIDS (SAPA) project was set up. It was a highly successful study: it informed the gay community and the AIDS Councils that supported it, and in the long term led to the formation of the National Centre in HIV Social Research (NCHSR) as it was then called.

We, Bob Connell (now Raewyn Connell), Gary Dowsett, June Crawford and I, were guided by and worked closely with a group of gay men – in particular, Don Baxter and Lex Watson – and were intellectually supported and encouraged by them and by John Ballard and Dennis Altman and many others.

It was a great learning experience for all of us. The researchers learnt about the central importance of reflexivity in doing their research; we learnt to see the world from the point of view of gay communities in Australia as well as from the position of social scientists. The gay men with whom we worked informed us about their social and sexual lives and practices and about living with HIV, and in this way helped us design and develop the SAPA project, the findings from which were useful to them and their communities. It also built the foundation for the successful partnership that followed.

Partnership was central to our work: a partnership between researchers and gay men living with HIV and affected by HIV. While much has changed in the intervening thirty years – there has been a marked drop in HIV incidence, and there is now an effective treatment for HIV and a number of new HIV-prevention technologies have been developed – the partnership continues to be central. The need for research that focuses on the social and cultural contexts that shaped gay community members' understandings of HIV and their responses to it remains, as does the need for social action. It was gay men's actions, both HIV-positive and HIV-negative men, that changed the course of the HIV epidemic in Australia, and it is their collective action, their practice, which will continue to keep HIV at bay.

## **Beverly Greet**

### *HIV-positive people now had a national voice*

I was diagnosed with HIV in 1984 at a time when it was thought HIV was a gay men's disease. Initially, in 1985 I joined a group called 'positive friends'. I was the only woman in the group.

In August 1988 the Third National Conference on AIDS was held in Hobart. At this time there was much doom and gloom, a scary time when no treatments were available. Funerals were the norm. I went to this conference with my dear HIV-positive friend, Lloyd James, who later became my husband. We were a group of approximately 30 HIV-positive people and it was there I met another positive woman, Dianne Lloyd. Our motto was 'don't talk about us, talk to us'. And we wore 'Alive and Visible' badges. Michael Callan, a then long-term survivor from the United States, spoke and said survival was due to the love of a good man and Coca

Cola. When Lloyd and I met with Michael he believed high daily doses of acyclovir, in light of nothing else being available, was the key to long-term survival.

There was a sense of urgency at this time, as stigma and discrimination were rife and we had all been given a death sentence. In the closing ceremony, we bravely got up on stage and declared our HIV-positive status to the audience. We said that we must be part of the solution to the AIDS crisis.

This was a groundbreaking act and later the first-ever conference organised by and for people with AIDS, ARC and HIV, and their lovers, partners and close friends was held at Fairfield Hospital in Melbourne. I spoke at this conference, representing the newly formed Positive Women Vic. We, as women living with HIV, were no longer invisible. It was at this conference that the National People Living With AIDS Coalition (NPLWAC), later to be named NAPWA, was formed. HIV-positive people now had a national voice.

## **Martyn French**

### *Responding to a health emergency*

I came to Australia from the United Kingdom in 1986, specifically to engage in Australia's response to the emerging HIV epidemic. I did this because I was, and still am, a Clinical Immunologist who is interested in the causes, diagnosis and treatment of immunodeficiency disorders. However, I soon came to realise that HIV/AIDS was much more than that. Having to deal with patients who had severe and unusual infectious diseases, cancers and neurological disease was both challenging and mentally stimulating. The impact of the disease on family, friends and community was something that I had not experienced before.

The health emergency posed by HIV/AIDS in the 1980s, and Australia's response to it, was also challenging but enormously rewarding. I learnt how valuable it could be to engage with people who had HIV infection in determining policy on clinical trials of therapy and research on disease causation. That was a steep learning curve for health professionals and health administrators, which has benefitted not only HIV patients but also patients with many other medical conditions.

Working in Western Australia also presented challenges. I have spent many hours over the last 25 years or so flying across the continent to try and ensure that there were not disparities in access to treatment, clinical trials and research studies between Western Australian and other Australian HIV patients. The Australian contribution to global research on treatment of HIV patients and understanding the cause of HIV disease has been outstanding, and Western Australian health professionals and patients have made large contributions to this.

**Jennifer Hoy**

## *Altruism shown by so many individuals*

I left Fairfield Hospital in 1984 to complete my Infectious Diseases training in the United States – when there were no patients with AIDS – and returned in 1988 to take up the position of Head of Clinical Research. What a difference four years made. Our clinics were overflowing. Ward 4 at Fairfield Hospital was full of brave men fighting a disease that we learnt something new about every day. We learnt so much about humanity as well – the stigma and discrimination experienced by those with HIV and their families, and the stark contrast of some members of the general public offering their homes to care for dying patients whose families had rejected them. We relied so much on the volunteers and carers who rallied to help individuals remain at home if that was where they wanted to be. We saw patients more often than our friends – our patients often became our friends, and we attended so many funerals in those early days. We fought together for a better quality of life, then a longer and better quality of life, to now – a good quality of life for the majority.

The early trials were essential for access to new treatments for many people. The altruism shown by so many individuals who would line up for recruitment into research study after research study was amazing. The involvement of People Living with AIDS (PLWA) was critical to ensuring ethical conduct of those trials. For the first time we saw access to new antiretroviral agents for those who had been initially randomised to placebo, once the treatment had been shown to be safe and effective. ACT UP was also looking over our shoulders, pushing for better access, more access and more drugs *now*.

There were treatments that either did not work, or had too many side effects to make them useful. Clinical trials and research were so important to ensure that we were doing no (or minimal) harm in our quest for better treatments. As an example, we were able to show that high-dose Vitamin C was ineffective in improving the immune system, and stopped many people spending dollars they did not have, desperately chasing treatments that charlatans promoted.

And then came 1996, protease inhibitors and combination antiretroviral therapy – they revolutionised outcomes for PLWHA. Hospitalisations plummeted, people were living longer. David Ho thought we could cure HIV in three years or turn it into a Chronic Manageable Disease. We quickly learnt that combination ARV therapy was not a cure and that chronic manageable disease came with quite a few unwanted side effects. But there are those who have travelled the journey from the mid-1980s to today. They have enrolled in the trials, they have been treated with the earlier toxic agents that gave them time, but also gave them body shape changes and other long-term toxicities. These are the people experiencing the ‘early ageing’ manifestations of HIV who need our support today.

The doctors were managing patients who had as much knowledge about HIV and

treatment as they did. Being knowledgeable and equipped to ask the hard questions about what was and wasn't being done for them became a hallmark of the consulting room. And what a great thing it was. It kept us on our toes, and ensured the best treatment for all. The partnership in the consulting room quickly progressed to a partnership in research. HIV-positive people became integral partners in decision-making about which studies should be pursued, what was important now, and they pushed us to push the boundaries.

We would not be where we are today without the integral partnerships formed between people living with HIV, affected communities, government and the health-care professions.

## **Bill Paterson**

### *Through my eyes*

I first heard about an epidemic among gay men from a small notice in a gay newspaper (called *Campaign*, I think). The notice, reported in the very early 1980s, warned of a phenomenon in Los Angeles of gay men presenting to hospital with atypical pneumonia and a rare unusual cancer. Within a short time, warnings were coming from the sexual health clinics about possible risks of promiscuity. I was living in Western Australia so felt quite removed from the whole issue.

In the next three years I was to travel to the United States and to London, where it was apparent something terrible was happening. Sex was associated with fear bordering on terror, worse in the United States but getting there in London.

I returned to Sydney in late 1984 and very soon after, my best friend was admitted to St Vincent's Hospital. At that time I also entered into a relationship with an HIV-positive man – safe-sex messaging was established so I wasn't too concerned about transmission – my partner was astounded that I could be so relaxed about his status.

By the beginning of 1985 I was in what was to become known as a serodiscordant relationship and working on the inpatient AIDS Unit at St Vincent's.

I didn't know it then but I was to become part of a model called peer-based service delivery. Gay men and lesbians and those who we would come to know as Queer coalesced to care for their peers. This was sometimes done through the paradigms of our professions such as nursing, social work, physiotherapy and others, and at other times frameworks were developed to enhance services such as Community Support Network and the Ankali Project. Peer-based service delivery of this nature was not just the same old stuff delivered by peers. The nature of what we were delivering was fundamentally different from our other professional work, informed by lived experience and tempered in the crucible of a rigid hospital setting.

I am now aware, though not at the time, that our experience in service delivery drove us to engage in systemic advocacy. In the microcosm of the hospital setting, we relentlessly drove an advocacy agenda on behalf of our patients. It included changing the ways that people living (but more often dying) were managed coming into and out of the hospital, the systems of management between departments and the prosecution of policy frameworks to support these changes. The transmutation of the personal to the political.

During those early years I was only vaguely aware of the greater social movements, the AIDS Coalition to Unleash Power (ACT UP), AIDS Council of NSW (ACON) and the emergence of the phenomenon, which I now know as the 'body positive'. The most moving demonstration of this was at the 6th International Conference on AIDS in San Francisco where, in front of 14,000 delegates, HIV-positive people moved to the front of the room to remind everyone there just what it was all about.

The year 1992 saw my departure from St Vincent's Hospital, the death of my partner and then the next partner and my own seroconversion. This heralded a new phase of engagement with the HIV phenomenon.

## **Elizabeth Reid**

### *The role of caring and living with the dying*

*In 1988 Elizabeth Reid gave the plenary address at the 'Living Well' Conference at Fairfield Hospital, Victoria. The conference brochure noted the conference was "organised by – and for – people with AIDS, ARC and HIV . . . and their lovers, partners, family and close friends". Reproduced below, are excerpts from her speech, 'Two Voices'. The speech highlights the important role of carers and caring in those early years and drew attention to the idea of finding a way to live positively with HIV, suggested a focus for research and, most importantly, spoke of the value of hearing all the voices that are part of the experience.*

"This speech is a plea for voices or, as Bill O'Loughlin phrased it in his speech at Hobart, a plea for stories. My husband's voice is stilled now and you can only hear his thoughts through me. By now, over 500 voices have been stilled. Many of their words may live on with their lovers and carers. These and the voices of the living need to be shared so that we can build up the tapestry called living with HIV . . .

"My hope was shattered by just one atomic sentence: 'My result was positive'. We were separated by half the world and by a crackly, echoing telephone line. He had been tested in Zaire where he was doing a couple of months work. I was in Australia. He was speaking obliquely from the public lounge of the guest house where he was staying, trying desperately to ensure that no one else could understand the import of



his words. Having lived with haemophilia all his life, he understood the need for very careful consideration before disclosure . . .

“Sadly our period of living with HIV was short, six months, before the dying began. But thank heavens we had made that transition to living for we were to learn that the living we had learnt can continue through the dying. We had learnt the skill of living whatever life was possible. For us, this was to be especially important for the virus soon began to impair Bill’s mind . . .

“The carer therefore lives in two worlds: one of the dying, the other of the present and future living, the pain for the now and the pain for the future . . .

“Diagnosis of HIV need not be a diagnosis of a terminal illness. Rather it is a diagnosis of a particular kind of life . . .

“We need more research that gives hope, studies of the living well, those infected whose lives are full and happy, the long-term survivors. People, in short, who have made the transition from diagnosis to living with HIV. We need to see these people in the medical literature as well as hear their own voice . . .”



Attendees at the third National Conference on HIV/AIDS in Hobart in August 1988 took to the stage to openly declare their positive status and protest the invisibility of the positive community.

This marked the first public time that a 'coming out' statement was made by people living with AIDS. It was considered a brave and significant moment for proclaiming the rights and the identity of the HIV-positive population in Australia, and it started a range of actions that would bring greater visibility to the HIV-positive agenda within the Australian response to AIDS.

PHOTO: TOM WORSNOP

# TALKABOUT

Newsletter of People Living With AIDS (N.S.W.)

People living with AIDS in NSW, the newsletter of the People Living With AIDS Inc. (NSW) is published twice a year in March and September. It is a free publication and is available to all members. It is a place of sharing, of support, of information, of news, of ideas, of stories, of experiences, of triumphs and challenges. It is a place where we can all speak for ourselves.

This year we are joined together by a great collection of the people who are living with AIDS and who are making a difference. All those who are reading this will receive a copy. It is a place where we can all speak for ourselves. It is a place where we can all speak for ourselves. It is a place where we can all speak for ourselves.



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# Talkabout

Newsletter of People Living With AIDS Inc. (NSW)

Where we speak for ourselves ISSN 1034-0566

**TEN YEARS INTO THE EPIDEMIC**

We mourned and reflected at the Candlelight Rally on May 20th (right, in Sydney 2,000 people attended).

We also take action

See inside:

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 and we learn how to survive  
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**DON'T FORGET TO FILL OUT OUR READERS' SURVEY p.15**

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# Talkabout

The Newsletter of People Living With HIV/AIDS Inc. NSW

Where We Speak for Ourselves



**Positive Speakers Bureau**


No. 75 April 1997

# Talkabout

The Newsletter of People Living With HIV/AIDS NSW Inc.

Where We Speak for Ourselves

**back to work**



**back to the future**

No. 95 March 1999

# Talkabout

The Newsletter of People Living With HIV/AIDS NSW Inc.

Where We Speak for Ourselves



**toxic ?**

The Magazine of People Living With HIV/AIDS NSW Inc.

No. 511 November 2000

# Talkabout

Where We Speak for Ourselves



you've come a long way

**baby**

WOMEN LIVING WITH HIV

# talkabout

Where we speak for ourselves



'disclosure'  
'communication'  
'sex + health'

PEOPLE LIVING WITH HIV/AIDS

'Disclosure would be less challenging if we all face up to discrimination about HIV.'

# talkabout

Where we speak for ourselves



**HIV treatment as HIV prevention**

A review by the evidence based prevention team

**Lasting Impact**

How a 2001 survey showed the impact of HIV treatment on the lives of people living with HIV

PEOPLE LIVING WITH HIV/AIDS

PositiveLivingNSW



November 1996



October 1997



May 1998



November 1998



January-February 2002



November-December 2002



December 2003-January 2004



December 2004-January 2005



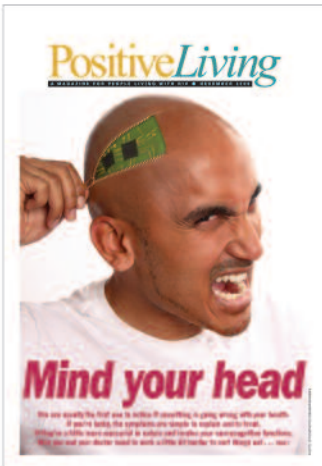
September 2005



December 2005-January 2006



April 2006



December 2009



September 2010



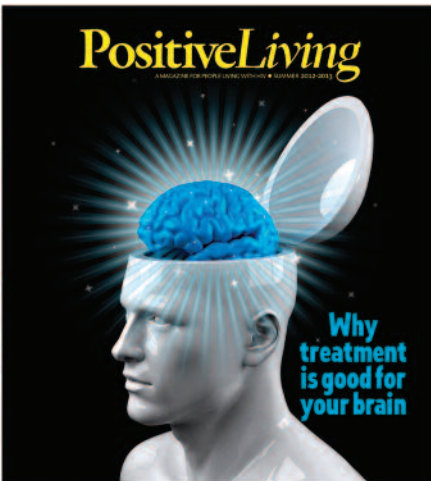
Autumn 2011



Spring 2011



Winter 2011



Summer 2012-2013



Summer 2013-2014

PositiveLiving 1996-2014

# Collaborations

1990-1995

*It was the time when the HIV epidemic raged.  
In the act of loving another man I could  
have killed him. From the mid-80s the dying  
had built up slowly and then, around 1990,  
it went BAM! – slammed into us – death after  
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wondered when it would be our turn  
to sicken and die.*

**Bill O’Loughlin**

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## INTRODUCTION

In this period, affected groups turned increasingly to governments to gain access to major financial support. At the same time, as governments became aware of the magnitude of the public health problem they were facing, they themselves turned increasingly to those groups and communities, both for more information that might curtail the spread of the disease, and also to utilise – and build on – the support networks already established there.

Collaborations expanded; there developed integral partnerships between groups such as PLWA, the affected communities, governments, and the health care professions. Everything that emerged came from a system of collaborative input from scientists, clinicians, communities, and public health and policy experts.

There were hurdles, one of the most important being early access to drugs that had the potential to save lives. The slow rate of drug releases became a major area of contestation. But the release of the Baume Report in 1991 led to improved access times, a brief respite in an ongoing battle. During this time, the role of zidovudine (AZT), then double-therapy didanosine (ddI) and zalcitabine (ddC) with AZT, extended periods of health reaching, what seemed incredible durations of survival, of eight years (a real improvement from the six months survival from AIDS in the 1980s).

Nothing remained stable, but adaptability, determination, and the ability to mobilise together for the benefit of people living with the infection, and people at risk of being infected, certainly made for challenging times. Sex was still in the picture, and adopting a positive attitude towards sexual expression was an important focus.

The National People Living with AIDS Coalition (NPLWAC) became incorporated in 1993 as the National Association of People living with AIDS (NAPWA), and began to operate in a more formal arrangement.

It was also an era of open, effective, in some cases controversial education, outreach and behaviour change messages targeting specific communities at risk. Zidovudine and good obstetric care accounted for a reduction in transmission to babies from infected mothers; Needle and Syringe Programs were available, if controversial; and Safe Sex Programs were supported in some but not all jurisdictions. Harm reduction and access to narcotic drug maintenance remained a battle for many services, and it has not yet been won in prisons.

Although gradual decriminalisation of sexual preference and improved access to 'normal' societal rights occurred throughout this period, it was far from equitable and very patchy across Australia.

**Mark Bloch**

## *Lives cruelly cut short*

This period was one of the toughest times being involved in HIV care. Many of those who became positive in the peak period of the mid-1980s were becoming sick and coming in with purple Kaposi's sarcoma (KS) lesions on their skin, often visible and spreading. People would put make-up on to try and hide the KS lesions on their face.

There was also a lot of PCP pneumonia, fevers, diarrhoea and wasting from mycobacterium avium complex (MAC), thrush, and blindness from cytomegalovirus (CMV) retinitis.

There was no combination therapy or highly active antiretroviral therapy (HAART) available yet. Zidovudine (AZT) was initially the only drug apart from Bactrim, used to prevent PCP and toxoplasmosis. AZT had to be taken every four hours, night and day, and patients had to set alarms to wake them up to take their meds. It wasn't very effective but that's all there was, and besides very common side effects of stomach upset and headaches, it often caused anaemia and muscle loss, especially in the butt.

When ddI was developed, there was anger at the slow approval of new drugs as people were dying from lack of treatment options – mass action by ACT UP to allow access to this drug, and their pressure also led to the change in rules that made it possible for people to import three months of unlicensed medication for personal use. I linked up with a buyers club in the United States and imported ddC for patients.

It was very painful to see friends and patients change from looking well to rapidly going downhill, wasting away. The HIV ward at St Vincent's Hospital, Sydney (17 South) was full and many sad funerals occurred. There were so many lives cruelly cut short so young. You'd go to Mardi Gras and at the party remember all the people you knew who weren't there anymore. Sometimes I saw someone who I thought I recognised on the dance floor; then realised it couldn't be them, because they were no longer around.

**Anne Mijch**

## *A time of transition*

Whilst it became clear only in retrospect, even at the time those living with HIV and AIDS, the clinical scientific and policy responders were aware of an emerging change in HIV. We realised that the rate of rise of new diagnoses seemed to be reversing (from an estimated 1500 new diagnoses annually to closer to 1100). Further, the proportion of individuals testing prior to a devastating illness was declining. New diagnoses in old populations (people born in, or travelling to, countries of high endemicity) were stable. In other groups (gay men, and infants born to women with HIV) new diagnoses were declining, and newly emergent populations (particularly people who inject drugs or newly transfused individuals) were not becoming infected.

This in large part corresponded to an era of open, effective, and in some sense controversial education, outreach and behaviour-change messages targeting specific communities at risk. Zidovudine and good obstetric care accounted for 25% reduction in transmission to babies from infected mothers. Needle and Syringe Programs were available, if controversial, and Safe Sex Programs were supported in some but not all jurisdictions. Harm reduction and access to narcotic maintenance remained a battle for many services, and it has not yet been won in prisons.

The palliative care era was over, but the effective chronic care phase was not yet established. Each and every emergent understanding or effective treatment intervention seemed to require its own battle to implement. Prophylaxis against *Pneumocystis carinii* pneumonia (PCP) when CD4 cells fell to 200 was debated on toxicity, and cost (even cost shifting between states and federal governments); battles to register the use of very effective inexpensive agents and to roll out easy availability were a beginning of the subsequent campaigns to access *Mycobacterium avium* complex (MAC) prevention, antiretroviral treatment (mono then double and then in the mid-1990s triple therapy). Real-time access to immune monitoring (initially a highly expensive cancer research tool) transitioning to a diagnostic and monitoring test at treatment sites was also a hard-fought innovation.

The results of successful lobbying, treatment access and new Model of Care (focusing on survival with HIV rather than dying from AIDS) were apparent quite quickly, as AIDS diagnoses stopped rising at the rate of the 1980s (when numbers diagnosed with AIDS annually in Australia rose by 50%) to stabilise at around 900 per year. What was clear was that this frightening number of sick people had lower rates of preventable but devastating PCP or bacterial pneumonias and septicemia and MAC, and more often less deadly Kaposi's sarcoma (albeit disfiguring but not so often rapidly progressing).

During this time the role of zidovudine then double-therapy ddI and ddC with zidovudine extended periods of health, reaching what seemed marvellous durations of survival of eight years (a real improvement from six months survival from AIDS in



the 1980s). Not so good now but worth fighting for as the community and clinicians certainly did with gusto.

Campaigns to reform registration of new treatments resulted in the Baume Report and changes, modification of pharmaceutical funding to provide access to highly expensive agents in the community (where PLWHA were) and to progressively modify care systems were slowly successful. These included: day care facilities, psychiatric care services, primary care by specialised high case-load general practitioners, obstetric care services of appropriate sensitivity and practices standards, community care, models recognising the value and impact of peer support, advocacy, prison services, and multicultural services. All of these evolved under a system of collaborative input from scientists, clinicians, community and public health and policy experts.

Nothing remained stable, but adaptability, determination and ability to mobilise together for the benefit of people living with HIV and people at risk of HIV infections made these times exciting, challenging and impactful years!

As people living with HIV infection survived longer, new understandings of the impact of uncontrolled illness on mental health emerged, and new understandings of HIV brain and nervous system interaction emerged. Research networks were strengthened with the Clinical Trials Network, and Australia was seen as an exemplar of HIV response.

Meanwhile, the third epidemic; that of societal response, moved on. The bigotry, judgemental and fearful responses of some meant they were blind to emerging changes to epidemiology, care, prevention and support. Legislative changes to criminalisation of HIV exposure and transmission were often determined by opinion rather than evidence. A number of vulnerable individuals were caught in vendettas and, sadly, some incarcerated, discriminated against, alienated and even driven to suicide.

Although gradual decriminalisation of sexual preference and improved access to usual societal rights (partner recognition, insurance, work, right to decide parenting, treatment and travel and immigration rights) occurred throughout this period, it was far from equitable and very patchy across Australia. Heroic efforts by legal and political champions commenced, but continuous progress even today remains a challenge. Discrimination in the workplace, especially by healthcare providers, is still problematic two decades later!

Helping agencies were approached; some often at the coal face were magnificent, providing hands-on support, advocacy, information and education. Others were notable as they turned their backs on those in need! Parents groups, volunteer organisations, social workers and nuns remain memorable contributors to the networks of care. Fundraising by cultural sectors and others (from individual school children to business philanthropists) brightened the environment.

By contrast, the pomposity and finger-pointing from others like shock-jocks, religious and political extremists and protagonists of 'cruelty as a solution', droned on from some quarters, drowned out by the chorus of the Fair Go approach of many.

People living with the infection were integral to all aspects of Australia's response. Evidence-based, committed to individual and community benefits, focused on the best outcome, not diverted unnecessarily by alternative agendas, this group exemplified what a cohesive committed and 'canny' group can achieve. They were well positioned to move as the next era of manageable HIV and the demise of AIDS and then Treatment as Prevention were to emerge over the next two decades.

## **Levinia Crooks**

### *We made a difference*

The early 1990s were a turbulent time for HIV in Australia and Sydney specifically. I was the first employee of NPLWAC, the predecessor organisation to NAPWA and at the same time President of the AIDS Council of NSW. In that period I also held a number of other paid and voluntary positions, including with the Bobby Goldsmith Foundation and Commonwealth Department of Health. I was writing a number of resources mainly for people living with HIV, their carers, volunteers and workers in the HIV sector.

It was also the period in the HIV epidemic in Australia, which had greatest direct impact on my friends and colleagues. The crisis was at its peak, and deaths were all too common. It was a time that etched memories on those of us who lived through it, which hopefully no one will ever experience again.

But strangely it was a period of great inspiration and incredible development. We were pushing new boundaries in the HIV sector; consumer participation was coming into its own and many in the health sector were looking to the HIV sector for models of participation.

At a personal level it was a devastating time. Perhaps the most challenging experiences I had were when close friends and loved ones experienced HIV-related dementia. This seemed so unkind, particularly for people who had been through extensive treatment for opportunistic infections only to experience a more debilitating ailment next. Dementia and the fear of it was a constant concern.

Throughout this period I was involved in treatment activism and by the time more effective treatments came onto the market in 1996, I think all of us felt we had actually contributed to making a difference.

**Bill O'Loughlin**

## *We were recognised as experts*

The period 1990 to 1995 seems such a long while ago, such a different world. Sometimes I have to help myself to accept that it really did happen. But, when I pause, it is simple and just in the background of my memories: fear, illness, death, sadness, terror, numbing grief, and resignation (oh, and some wild parties, and lots of strong friendship and intense laughter). It was the time when the HIV epidemic raged. In the act of loving another man I could have killed him. From the mid-80s the dying had built up slowly and then, around 1990, it went BAM! – slammed into us – death after death after death. We who were infected wondered when it would be our turn to sicken and die.

The names of the prominent dead appear in the historical records. I lived and worked in the Melbourne epidemic but played in Sydney and my mates there differed from those in Melbourne. The Sydney boys had been through those wonderful late '70s, early '80s that gave them that magnificent bold sense and confidence of themselves as gay men and community. Men such as Adam Marriot, Andrew Morgan, Dodge Traffic and his twin Andrew, and Terry Giblett took that flair into their AIDS activism. We in Melbourne were a bit plainer, perhaps more earnest, a tad dowdy compared to them (although once Adam copied me and bought a Hawaiian print shirt from Country Road. I was secretly flattered that I was about to inspire Oxford Street style, but it didn't take off . . .). They all died during those years.

Then there were the ordinary dead – those who passed quietly through our community. I remember when working at Victorian AIDS Council/Gay Men's Community Health Centre (VAC/GMHC) as a counsellor taking a call from a man who said he wasn't well and had become isolated at home. I persuaded him to come in and can still clearly recall our meeting. I recognised his face from the venues and, although I wasn't a doctor, I could see he was, quite literally, dying. I calmly settled him in a counselling room then got out to his sister in the waiting room to arrange getting him to hospital urgently. He died within a day or so. This was all just part of a day's work. I probably then went out for dinner. I forget his name.

I don't keep diaries and current internet searches don't help prompt my memories of the events and historical moments from that era. What follows are random recollections I carry with me, thus, inescapably, I figure in them, so excuse that. I won't write about treatment activism, which was a critical aspect of that period, as others will do so better than me. I failed high-school chemistry and to this day still can't recall the brand names on my bottles of ARVs. I would have been a poor treatments activist.

My simple overview of what happened for me during that era is that, as one of the initial staff at the VAC/GMHC, I was still working there as 1990 came around. I

worked with gay men, sex workers, injectors, nuns and priests, prisoners and prison officers, unionists, corporations, immigration lawyers, disability services and once, oddly, some aromatherapy saleswomen. Sometime in the early '90s I was appointed to join with Ross Duffin as another of the HIV community representatives on the Federal Government advisory body, The National Council on AIDS, and remained on it through most of the rest of the decade. Also in the early 1990s I began to work in Africa as we started to explore the epidemic in developing countries. By 1995 I was a self-employed consultant and soon to be President of the Australian Federation of AIDS Organisations. All the while I was waiting my turn to die.

The history of the Australian PLHIV movement has been documented but one event seems to have disappeared from the records. After the first PLHIV conference at Melbourne in November 1989, Terry Giblett organised another national gathering of people living with HIV at Sydney University a few months later, on the weekend before Mardi Gras 1990. I forget what the meeting covered but can remember sitting there in the glorious Sydney late summer sunshine and watching a strikingly handsome young man needing assistance to walk around because he had gone blind from some AIDS-related condition.

One outcome of the meeting was that Terry wanted the NSW PLHIV group to march in Mardi Gras. Three of us mates, including Peter Charlton, the first employee of PLWHA Victoria, had come up from Melbourne. As the parade assembled we joined Terry under a modest banner and formed a group of four. I remember another Melbourne man came along, and then, somewhere along Oxford Street, an enthusiastic scantily clad young man jumped in from the sideline crowd and danced gaily beside us till the end of the parade. We didn't ask who he was nor why (I just assumed his party drugs had kicked in too early). Perhaps my memory isn't perfect and there were one or two others involved but certainly no more than that. What I do clearly recall is the knot in my gut as we walked the length of the route, a little bunch under the banner of People with HIV. It was momentous. We were being public for the first time. It was very hard to do. The crowd cheered us, but then I reckon they cheered every group.

When the floats were being assembled for the parade we were immediately in front of the large AIDS Council of NSW (ACON) and Ankali contingents and there, amongst them, were many people with HIV, including those soon to be prominent activists – and they didn't join our group. This is not a criticism of them but it is a significant reminder that, at the beginning of 1990, there was immense stigma about having HIV. Some five years after we had started the community response to HIV it was still too challenging for many people with HIV to be public about it. It reminds us of the processes we all had to go through, personally and communally, that gently allowed many of us to slowly gain the confidence to risk exposure, and face the shame, stigma and disease of having HIV.

The other reason why that event stays in my thoughts is because of its associations with Peter Charlton. It was historic to have him as the first employee of People Living with HIV/AIDS Victoria. It was also historic to then be with him as he died a

year later. To spend that final dreadful week non-stop day and night by his bedside, with his friends, many of us VAC staff, holding a bucket up for him as thick gloopy clots of blood oozed from his mouth, nose and backside because the KS had riddled his insides. This typifies what happened again and again – talented leaders of the HIV movement would appear, make extraordinary contributions, and then die. AIDS did wipe out many of those who were trailblazers, who were bold and courageous, who showed us what it meant to live a grand life as a gay man, because they were the ones out there exploring what it meant to be gay and, to put it frankly, putting their arses on the line – and thus got infected and died.

And so it was I made farewells to those I mentioned earlier – Adam’s face covered in grotesque KS lesions, Andrew remembered by a group of us setting a small handmade paper boat into Melbourne’s Yarra River at the same time as his memorial service in Sydney. Then there were all the Melbourne deaths. Being at Keith Harbour’s memorial service in Melbourne and sitting behind the parents of a young and lovely VAC colleague who would also soon die. Another whose funeral date we knew of in advance of his death, because he chose to die rather than suffer dreadfully. What of all the others? Many sadly are now mainly vague memories. Old mates could gather and reminisce and compose memories. But we don’t do that much.

These men are recorded here because of their role and contribution (and I am intentionally concentrating upon gay men. The impact of HIV on others and their response is another story). It has become common to refer to the distinctive features of the Australian response to HIV. Some now find that passé; some reckon it was over-exaggerated. I have no doubt that it was remarkable and ground-breaking. In particular I know this because, since early on, I have been fortunate to be exposed to the responses to HIV in many other countries.

In 1989 I went to the International AIDS Conference in Montreal and then on to a study tour of Boston, New York and San Francisco. I expected to learn much from those centres of the epidemic – and I learnt very little, if not nothing. I did see the spectacle of ACT UP take over the opening ceremony in Montreal with their intimidating and alienating New York style. But in visit after visit to American gay and HIV organisations and services, I was struck by the limitations of their understanding and organisational vision. Again and again I had to explain that the concepts I was mentioning were not impossible but were actual practice in Australia. Notions such as community engagement, empowerment and determination that formed the basis of our response with gay men and communities rather than their using ‘volunteers’ as another form of service provider; leadership, as in real leadership, by the community, who decided our policies and programs rather than their professional senior staff and a ‘board’ of prominent businesspeople, celebrities and medical experts; and the moralising around sex and transmission and the tone of their education and prevention messages. San Francisco HIV Educators spoke of the need to ‘give oral sex’ back to gay men because they were finding the absoluteness of their messages about safe-sex was unacceptable and created a gap between the

message and the recipient. Sex venues, in the cities that still allowed them, had blasting bright lights everywhere, no privacy, and monitors walking around with big sticks to ensure patrons only engaged in kissing and petting.

The years 1990 to 1995 saw the maturing of the Australian response. The partnership already formalised in the National HIV Strategy, and also evaluated as successful during that same period, saw us gay men and people with HIV on national and state HIV advisory bodies and respected for our knowledge of what was happening in the epidemic and what needed to be done. Our community organisations were funded. The social research was remarkable for linking and informing community, researchers and practice. Many government HIV bureaucrats understood the epidemic, often were proud of their role, and implemented their own projects. Our national conferences of people living with HIV challenged the implicit message in HIV education that we were those people that uninfected gay men need to be 'protected from' thus shifting the frameworks of HIV education and, also, drove awareness of the need for education for infected people and for our own organisations. Most remarkably, we, the HIV community, were recognised as 'experts' and the uniqueness of our experience, knowledge, capacities and wisdom was legitimised. We made mistakes but learnt from them. There were dreadful fights within the HIV movement and especially within and caused by some of the PLHIV groups. Enemies were made and grudges remain (why do they seem to outlive the good memories?) but still it was an extraordinary period.

In 1991 I went to Africa to the first-ever continental and global workshop, conceived and led by the visionary Elizabeth Reid of United Nations Development Program, exploring the impact of HIV in developing countries. I had been invited to participate, given our experience in Australia. That workshop set in chain the chance to then work in many other countries, which, without reservation, allowed me to know that our Australian response to HIV – locating it within affected communities, giving them the capacity to lead their own response, and putting people with HIV at the centre of the response – was of universal benefit and application, and, at that stage, in its fullness of practice and application, was unique to Australia.

On my first day in Nairobi in 1991 I stood in the centre of town, watching people pass me by. I knew something that none of them knew. I had seen the research showing that something like, and I can't recall now the exact statistics, but something like 20 to 30% of the young adults around me were infected with HIV, and no one had told them. Their government had done nothing. The medical sector had done nothing. The World Health Organization and other United Nations agencies had done nothing. Within about five years one in four, or one in three, of those standing around me would begin to die – and I knew that and they didn't. We all know what happened . . . and, unnecessarily, continues to happen in far too many similar countries.

The year 1995 saw me in Cape Town for the International Conference of People Living with HIV. It was a shambles of an event relieved by the funkier nightclub I have ever been lost within, and a hotel pool whose bar served gin and tonics for a

dollar. One of the conference events was a memorial service at the Anglican Cathedral, so, as it was early evening, and the pool was closed and the nightclub had yet to open, we all trooped along. It wasn't an overtly religious occasion and it was a pleasant enough building to spend some time in. Then the priest leading the memorial told us that this was the cathedral of Bishop Desmond Tutu. He spoke quietly of the many times they had gathered in that building surrounded outside by police and soldiers and not knowing what would happen to them when they walked out the doors. He spoke of the years of fear and terror, of the despair they lived with, of imprisonment, banishment and murder, and of the power and might of their foe. Then he spoke about a miracle. He spoke of the miracle of apartheid collapsing when they had never believed things would change. He offered, to we people with HIV, his story as a form of hope and asked us to have faith in a miracle happening for us – not in some preachy, religious manner – but rather as something to hold on to, something to draw hope and inspiration from.

I sat there listening. I appreciated his sentiments. I thought it was a nice try but he was stretching things a bit much. I could see the link he was making but . . .

Then a year later came the Vancouver conference.

**Jill Sergeant**

## *Stories and authentic voices*

It is very life-affirming to recall that during the early '90s, in what were some of the hardest years of the HIV epidemic in Australia, there were still people thinking positively about sex.

At the time I was editor of *Talkabout*, the publication produced by People Living With AIDS NSW (now Positive Life NSW). At an editorial meeting in 1991, I remember Andrew Morgan, one of our editorial committee members, proposing the idea of doing an edition that championed HIV-positive people's right to have sex.

Andrew was a worker in ACON's HIV peer-support program, and an out-and-loud positive gay man. He was angry that positive people were being judged when it came to sex; that they felt they couldn't, or shouldn't, be having sex. This was at a time before the message of mutual responsibility had really taken hold.

So in May 1991, we produced what was certainly a first for Australia – and perhaps even the world – an edition of a peer publication for people with HIV focused entirely on sex and relationships. Positive men and women, gay and heterosexual, told their stories about sex and reclaimed their rights as sexual beings. It was illustrated with sexy but relatively sedate line drawings by Phillip McGrath.

We did it all again in 1993, only this time – in another first – the edition also featured black and white photos (including a raunchy centrefold), of openly HIV-

positive people nakedly, languidly, lasciviously wrapped around each other. The images were shot by community photographer Jamie Dunbar. Looking back, it's hard to remember that sex was so taboo for positive people. But *Talkabout* put it on the front page. We said it loud and we said it strong.

The positive sex concept was taken further with ACON's PositHIV Sex campaign (also driven by Andrew Morgan), which specifically targeted gay men. AIDS activist Bruce Brown was in the ACON photo shoot, and his photo featured on the cover of the *National AIDS Bulletin* in March 1994, to the consternation of the Commonwealth government.

*Talkabout*, which began in 1989, was badged as the publication for people with HIV 'Where we speak for ourselves'. I was editor of *Talkabout* from May 1990 until November 1998. While it wasn't always as much fun as the two sex editions, I think everyone involved felt the excitement of breaking new ground. The Positive Sex editions were not our only 'firsts'. We did editions devoted to issues for women, heterosexuals, people living in rural Australia, Aboriginal and Torres Strait Islander people, treatments, retirement, complementary therapies, a multicultural edition . . . the list goes on. All of this was based around communicating the lived experience of people with HIV.

Not being HIV-positive myself, I always saw my role as more of a facilitator than an editor. I facilitated the telling and sharing of stories, which in those early days were crucial. Real stories and authentic voices helped break down isolation and stigma for people with HIV.

I realised quickly that most people didn't want to write their stories for *Talkabout*, but almost everyone was willing to be interviewed. Everyone involved had full control over how they were represented – from reading over the edited interview transcript, to stipulating the level of confidentiality. People could even withdraw their consent for publication, right up until the time that each edition went to the printer – but nobody ever did.

People were interviewed about the specific theme we were covering, and we tried to include diverse voices in every edition. We didn't ask for a whole life story, just people's thoughts on a topic – such as sex. Or disclosure, work, pregnancy, diagnosis . . . and so on. Stories were matched to factual information, service profiles and resources. It was a formula, but it worked, probably because contributors were so honest and open in sharing their experience.

Of course, I didn't do all this alone. I had an amazing group of people supporting me, coming up with smart, topical ideas for content, connecting me with potential contributors, keeping me on track in my facilitating role – and even volunteering to pose nude for the sex edition.

There are too many people to name. Many are still around, and you can read their own thoughts on Australia's HIV history elsewhere in this publication. Others didn't make it this far.

There was Jacques Monroe who, with the inimitable Tony Carden, toured and reviewed the Northern Suburbs Crematorium – the *Talkabout* editorial committee



felt that we needed to have something to laugh at in every edition. For a couple of years we even had *Anguish in Bohemia*, a serialised soap opera modelled on Armistead Maupin's *Tales of the City*, which was collaboratively written by 'Dara Toad' (an acronym made up of the authors' initials). I remember one of the characters died from having a piano dropped on her; I don't think any of them died of AIDS. Petite, sassy, Amelia Tyler was one of the Anguish writers.

There was Vivienne Munro, who left the world with characteristic grace only the day before I started writing this article. Viv and Amelia were bold, passionate advocates for their fellow positive women at a time when few women felt able to disclose their status. Even now, I stand in awe of their courage; I don't think I would have been as brave, in their shoes.

There was the dynamic Rodney Junga. Rodney was never on the editorial committee, but he was an enthusiastic contributor to *Talkabout*, especially for the 'First Peoples' edition. Rodney helped me, and many others, understand the experience of Aboriginal and Torres Strait Islander people living with HIV.

There was Dodge Trafic (aka Don Carter) who was PLWA Coordinator when I started at *Talkabout*. A rainbow-mohawked geek biker, Don kept the organisation running, not only with his formidable admin skills, but also with his tough, astute thinking, his vision and diplomacy.

And Robert Ariss, who was my mentor and chief co-conspirator from the day he rang to offer me the job. He'd say, 'Hi gang', whenever he arrived in the office. That's where I get it from.

Robert's wisdom. Amelia's laugh. Jacques' sly wit and warmth. Dodge's latest gadget (he would have loved the 21st century). Viv's big heart. Rodney's generosity. And Andrew Morgan, who was the only person I've ever allowed to call me Jilly. All still vivid in my mind. It still hurts to write their names. Trailblazers all.

## **Claude Fabian**

### *Anti-discrimination campaign and positive retreats*

Following recommendations from the Australian National Council on AIDS (ANCA), the federal government decided to develop an Anti-Discrimination Campaign (ADC) that included national television, radio and print advertising as well as a significant supporting national public relations program. It was the first national campaign targeting HIV/AIDS discrimination, and arguably the first in the world. It was also unique at the time in that the people featured in the campaign were all 'real' people living with HIV, supported by their family, friends, work

colleagues and carers. It was first launched in January 1993 by then Minister for Health, Brian Howe. Due to its success and positive evaluation, it was re-launched in 1994 by the then Minister for Health, Dr Carmen Lawrence.

Due to the involvement of 'real' people in the campaign as well as the complexity and the sensitivity of the many issues relating to discrimination, ANCA asked for assistance from PLWHA NSW Inc. (now known as Positive Life NSW). A delegate was appointed to provide comprehensive support to all HIV-positive people involved in the various components of the campaign. I filled this position in the ADC after the original delegate became unwell. In this role I attended all significant campaign meetings, including those with the federal government, the advertising and public relations agencies that developed the campaign and with various other stakeholder organisations. As well as providing ongoing support to participants, I was also the key support on location for the filming of the advertisements and at the media training of participants.

The formative research undertaken before campaign development found that people were less likely to discriminate against people with HIV/AIDS if they knew someone with HIV/AIDS or could identify with them in some way. Therefore the campaign strategy was to depict the participants as someone's brother, son, workmate, partner, uncle, daughter, husband, child, etc, and to show them living their lives in these roles. The tag line was 'HIV doesn't discriminate, people do'.

The supporting public relations strategy built on the advertising by securing interviews with both mainstream and gay media that allowed participants to tell their own stories of how discrimination had personally affected their lives socially, professionally and economically and the impact it had had on their overall health and wellbeing. Importantly, it also gave participants an opportunity to talk about positive experiences. A media kit was distributed nationally to all media and included background information on the many ways HIV/AIDS discrimination impacted people's lives and what could be done to prevent it. It also provided information on positive steps that were being taken to combat discrimination in terms of legislation and policies and included a comprehensive list of spokespeople who were available to talk about HIV/AIDS discrimination from a variety of perspectives.

The ADC won a major prize at an international competition, the prize money \$10,000, was donated by the advertising company in equal shares to The Quilt Project and PLWHA NSW Inc.

### **Positive Retreats**

At the beginning of the 1990s only a couple of drugs were available in the treatment of HIV, which many people felt were not only toxic, but not particularly effective. Therapies such as acupuncture, massage and meditation, while not a cure, were being used by many as a way of dealing not only with the side effects of the treatments people were taking, but also as a way of managing stress, grief and loss, and physical discomfort.

My involvement in making the Positive Retreats Project a reality is something that I am particularly proud of and brings me immense joy. This project combined complementary therapies and peer support in a symbiotic relationship. I was passionate about both due to my personal experience. I was aware of the value of complementary therapies as I had been using them for many years to manage and enhance my own health and wellbeing. By the time the retreats started I was also very involved with peer-support programs generally, and the ACON Peer Support Project in particular. As none had been shown to be 'the magic bullet', complementary therapies were not taken very seriously at the time the project was established. Nonetheless we felt that they had a valuable part to play in the overall management of HIV, both on a therapeutic level and an emotional one.

An anonymous donor funded the first three retreats and an evaluation from these retreats informed a funding proposal to the NSW government, which attempted to access money remaining from funds quarantined to compensate people who had contracted HIV from contaminated blood. We requested approximately \$168,000 and were more than a little surprised when we received a one-off grant of \$400,000. The grant was to be managed by ACON as a joint project between PLWHA NSW Inc. (as Positive Life NSW was known then) and ACON. These funds were used to run the 18 Positive Retreats plus a couple of Women's Retreats and several in the Northern Rivers. More than 400 people benefited from the project, as well as many others from retreats organised by other groups and funded by the original grant.

The retreats were a five-day residential program that gave positive gay men the opportunity to experience complementary therapies and create social networks. They provided individuals with a space and time, not only to look at possible therapies that might help their overall management of HIV, but also to connect, learn and enjoy the company of other positive people. The emphasis was on complementary therapies not on 'alternative therapies'. At no time did the project or its associated facilitators and practitioners suggest that people stop following the advice of their individual doctors or stop taking their medication. The first 12 retreats were held at 'Kyabra', a property in the Southern Highlands about 90 minutes from Sydney. Some of the options provided included: acupuncture, homoeopathy, peer support activities, different forms of massage, reiki, horse riding, art-as-therapy (facilitated by Kathy Triffitt), various types of meditation, yoga, bush walking and a process called 'Cutting the Ties that Bind' (facilitated by Susan Lytton-Hitchins). There was also ample time to just relax, think and enjoy nature and some good company. Through these activities and many informal one-on-one sessions, participants learned a great deal and many got to work through much grief and loss and unresolved issues. As participants were often dealing with years of accumulated grief and loss, discussion of many emotional issues was an integral part of some formal activities. A fully trained chef catered for all dietary needs and food preferences. The chef always got the best comments from retreat participants. Importantly, the chef also conducted cooking demonstrations and discussed the importance of nutrition and food preparation in managing health and wellbeing.

After the first 12 retreats 'Kyabra' was sold, and then with the introduction of new HIV treatments, needs and expectations changed.

One thing that came out of the retreats for me was some books that are a record of people's lives. I read them on occasions, particularly at times when my world seems less than wonderful, when I have felt less willing to keep going, when I've wondered why I am still alive and so many friends and people I've known are not. They've continued to provide me with what my friends Susan, Olga and I had as a central theme of the Positive Retreats . . . *hope*.

The retreats owe a lot to a number of committed individuals, the various therapists and a small number of trained peer support facilitators such as Larry Wellings and John Trigg who made up the backbone of the organising structure both prior to and at the retreats.

**Paul van Reyk**

## *Necessary and strategic collaborations*

Collaboration is one of the factors frequently identified as critical to the success of the Australian response to HIV/AIDS. Generally what is meant is the collaboration across a range of responses between governments (both federal and state), medical professionals, researchers (medical, epidemiological and social) and the affected communities. Specific events or programs are put forward as examples, among them the June 17, 1983 public meeting in Paddington Town Hall in Sydney – organised by the recently formed AIDS Action Committee (AAC) – which kick-started the collaboration between the emerging HIV/AIDS medical specialists and the gay community, and the establishment of the National Advisory Committee on AIDS in November 1984, with representation from government, the medical profession and the affected communities.

I want here to focus attention on the collaboration within and across the affected communities. I want to try to unpack why collaboration was needed in the past and how collaboration worked as both a reflection on that past and as a sort of operational manual for when collaborations are needed in future.

### **Needful collaboration for survival**

The first feature of the early collaborations within the gay community and across the affected communities more generally is that they were necessary for physical and social survival. As Ross Duffin, AIDS activist and later Treatments Information Officer with ACON, puts it: "In the early confusing years of '84 to '86, fear made us come together in ways that would never have happened otherwise." Bill Whittaker, Executive Director of ACON in its first years, is more blunt: "Our friends were

dying and that tends to focus your mind.”

Coming together was made easier because of shared histories between the gay community, sex workers and intravenous drug users. ‘We were all people who often were on the outer of society, we were fighting for our right to exist, we had all experienced punitive legislative sanctions against us’, Julie Bates, sex-worker activist with the Australian Prostitutes Collective at the time, points out. Some part of this history was joint action on homosexual and sex work law reform, which had been happening since the early 1970s, and, in the case of homosexual law reform, had accelerated after the arrests of hundreds of people at the end of the 1978 Mardi Gras night march. That event itself inevitably was a collaboration. “We crossed so many areas anyway; there were already connections and cross membership; there were gay men who were drug users, there were gay men who were sex workers,” says Bates. These collaborations around law reform led to “a whole set of personal relationships and networks that underpinned the collaborations in the early years of AIDS,” adds Duffin.

But what was needed was the spark to fire the collaboration. Arguably that was the demonstration organised by the Gay Solidarity Group (GSG) against the May 1983 call from the NSW Blood Transfusion Service (BTS) for homosexual men not to donate blood for fear of contamination of the blood supply. Within a month, the two main ongoing collaborative processes in NSW were established to forestall further direct community action: the AAC, which brought together the main law reform activist organisations – GSG and Gay Rights Lobby – and existing gay community counselling services and church groups; and the NSW government AIDS Consultative Committee with gay community representation.

The cross-gay community collaboration continued with the establishment of the AIDS Council of NSW (ACON) in January 1984, which brought together the AAC and the organisations that had emerged from the gay community in the past year, providing direct care, emotional support and material assistance to people with HIV/AIDS – Community Support Network, the Bobby Goldsmith Foundation, the Gay Counselling Service.

At the national level, collaboration across the affected communities was formalised through the establishment of the Australian Federation of AIDS Organisations (AFAO) in November 1985, bringing together the state AIDS Councils and national peak organisations.

The success of these collaborations in no small part was due to the lobbying expertise and political networking built by the gay communities across Australia who had spent the last dozen years engaged in campaigning for homosexual law reform, which had resulted in reform in South Australia (1972), the ACT (1976), Victoria (1980) and was to be achieved, despite AIDS hysteria, in the Northern Territory in 1983 and NSW in 1984. This in turn built on the experience of many key individuals in a range of other activist areas including: law reform, student politics, the anti-Vietnam War movement, trade unionism and environmentalism. Again, the personal relationships and networks formed in these activisms were mobilised first in

law reform and then in HIV/AIDS. Law reform campaigns had also built the lobbying credibility of the gay communities with successive governments, and shown their capacity for the mobilisation of large numbers of gay men and their allies in public demonstrations, making the communities a force to be reckoned with.

These collaborations, says Bates, “were essential in bringing together all of the skills we needed to set up the infrastructure and platforms from which to respond, to lobby, to look for funding” in the years that followed.

### **Strategic collaboration on treatment access**

While public demonstrations continued for law reform and against NSW police raids on the Club 80 sex-on-premises venue in January and February of 1983, the May BTS demonstration was the last public HIV/AIDS activism until the beginning of treatments activism in November 1987. In the intervening years, the much-lauded collaborations between governments, medical professionals and the affected communities by and large worked to develop the effective prevention and care regimes for which Australia has been internationally recognised.

All of that changed when the first antiretroviral treatments began to be trialed and approved. The system for drug approval in Australia at the time was extremely cautious, a carry-over from that developed in the wake of the adverse effects of thalidomide. “In the United States drugs were getting approved on limited data; they had expanded access,” says Duffin, “we had none of that. The drug approval system in Australia was based on the principle that all drugs could be thalidomide and so let’s let people overseas be the guinea pigs and we’ll approve them when we know they are safe. Our average delay in approval was something like six years, which meant that, for example, ddI became available in the United States in 1991 and if we stuck to that average we wouldn’t have seen any ddI in Australia till 1997.”

“Those of us working in activism at the time,” says Bill Whittaker, then Executive Director of ACON, “thought that while AFAO, ACON and VAC [the Victorian AIDS Council] were doing what they could to get clinical trials in Australia it would at times take fairly extreme activism. We had the dilemma at ACON that if we were to take the kind of action needed, our funding could be cut and that would impact on our services to the very people we were fighting for.” Whittaker had attended the International AIDS Conference in Montreal in 1988 at which the US activist organisation AIDS Coalition to Unleash Power (ACT UP) had demonstrated and later attended ACT UP meetings in New York. Back in Australia “I became convinced that an ACT UP style organisation would be extremely useful to do extreme activism and then the mainstream organisations could come in and do the negotiations with government around resolving the problems. Sort of a tag team approach.”

Whittaker canvassed this with PLWHAs within and outside ACON, and in April 1990 ACT UP Sydney was formed. ACT UP held its first action later that month, targeting the Australian Drug Evaluation Committee (ADEC) for failing to approve wider access to AZT. In August, AZT was approved for people with less than 500 T-cells.

This was in every way a different collaboration to what had been established before. For a start, the public face of the relationship between ACON and ACT UP was not one of open, friendly collaboration. “It wouldn’t have been successful if it looked like collaboration,” says Whittaker. “The very point was that it should not look like that.” But the flow of information between the two organisations was constant, with ACT UP informing ACON of upcoming actions and ACON then being in a position to prepare a more moderate position to take to the negotiating table. “This [the extent of the collaboration] is stuff that nobody knows about unless you were inside of it. On the surface of it, ACT UP and ACON had almost nothing to do with each other in the public sphere,” says ACT UP member Lyle Chan. “On the other hand,” says Don Baxter, who followed Whittaker as Executive Director, “I’m quite sure some of the people in NSW Health would have known not so much exactly what was going on but certainly how [treatment activism and the ACON/ACT UP relationship] was being managed and were supportive of it being managed carefully that way.”

Collaboration didn’t stop challenge and criticism between the two but this also was rarely public. “I think there was an assumption on both sides that there would be a back channel,” says Baxter, “and that we could criticise one another but we wouldn’t go to war or we would try to avoid going to war.” Chan says, “There were skirmishes along the way, but we didn’t lose sight of the fact that we had one job to accomplish and that was to end the crisis.” Both sides acknowledged the benefit for ACON in having an outside check and spur to keep ACON responsive and accountable to the community it represented and worked for. “Some of the relations did get problematic,” says Whittaker, “activism cannot always be controlled. But the good of this outweighed the bad.”

There were benefits to ACON too, from ACT UP’s link to the international network of ACT UP groups. This became particularly useful with the establishment of the Buyers’ Club. One of these Clubs had been established in New York through the Gay Men’s Health Crisis service, to satisfy the demand for PLWHA for access to promising treatments that were either not being trialled or were in trials with limited places and restrictive eligibility criteria. Individual PLWHA in Australia had been in direct contact with the US Clubs but the demand in the US alone was becoming difficult for the Clubs to supply. Baxter hired Chan to set up a more formal, albeit illegal, Buyers’ Club to operate from within ACON. It was Chan’s credentials as a long-standing member of ACT UP in the US prior to coming to Australia that re-opened the channel to existing Clubs and enabled Chan to develop his own relationship directly with the Clubs’ suppliers.

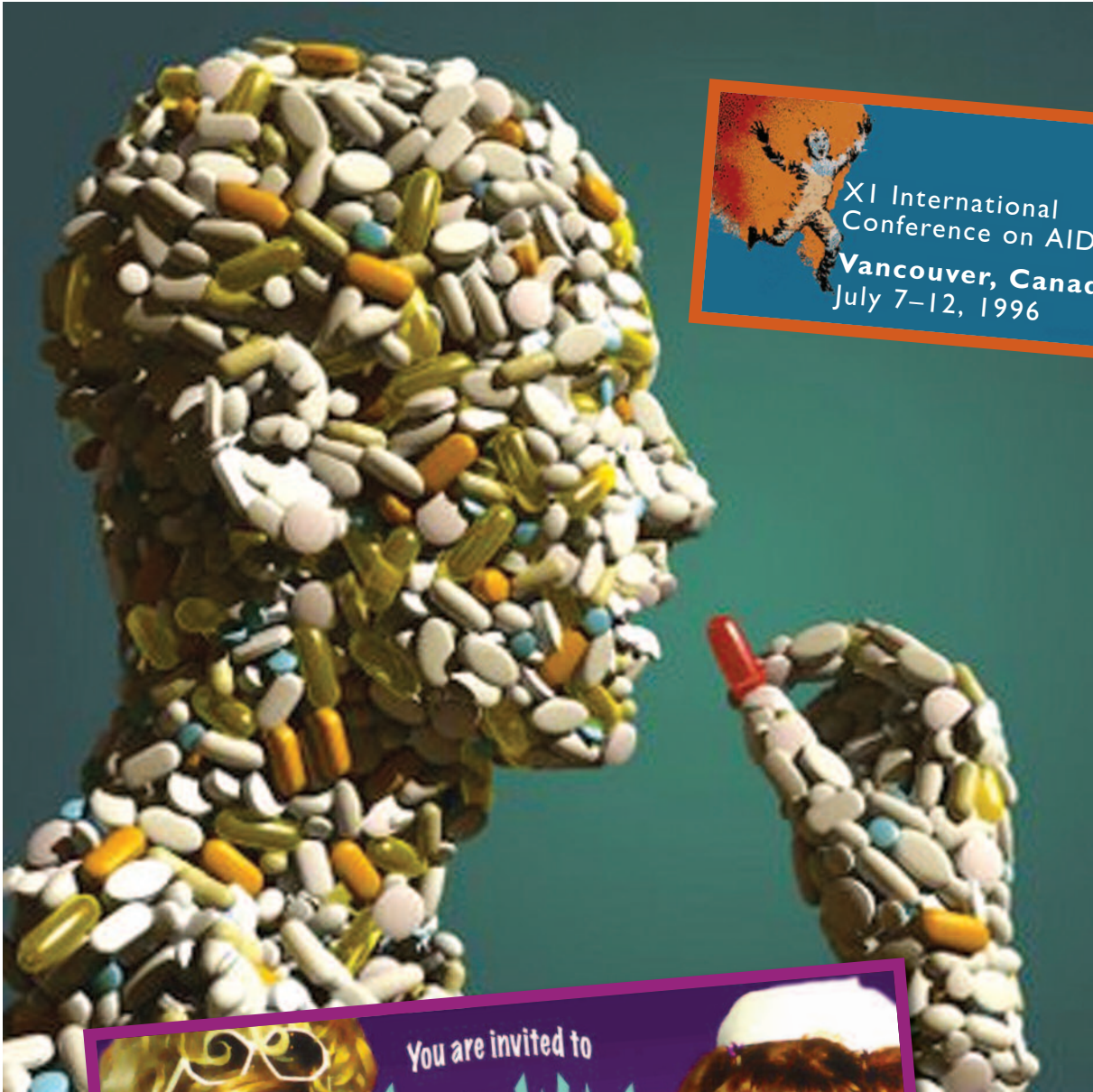
In March 1991, Brian Howe, the Commonwealth Minister for Health, engaged former Senator Peter Baume to conduct a review of the pharmaceutical drug approval process in Australia. This was the second inquiry in two years. The culmination of the collaboration between ACON and ACT UP was in their joint work on these inquiries, with ACON providing the formal input but always informed by discussions with ACT UP.

In July 1991, *A Question of Balance*, the report of the Baume inquiry, recommended sweeping reforms to the Australian drug approval system. This became known as the Baume report.

ACT UP NSW ceased in late 1993. “After ddC was proved to be of marginal benefit,” says Chan, “we all looked up the pipeline and realised that the pipeline was empty so it was no longer about getting government regulators to cut the red tape because there was nothing to release. So the only solution was to go back earlier and earlier up the pipeline and work with scientists at earlier stages, what do they have in test tubes that hadn’t even reached animal trials yet. The stuff that ACT UP was good at was getting hundreds of people onto the streets and chanting one message, but there was no more, one message. The issues were so complex you couldn’t fit them on a placard, not on a t-shirt, not in a sound bite, so the role in unblocking the approval process came to an end.”







XI International  
Conference on AIDS  
**Vancouver, Canada**  
July 7-12, 1996

You are invited to

# CHIN WAG

a "Chat Show"  
all about HIV Treatments  
and Healthy HIV Living

HOSTED BY  
**VANESSA WAGNER**  
AND  
**NURSE NANCY**

Two women are featured in the advertisement. On the left is Vanessa Wagner, a drag queen with blonde hair, wearing a purple patterned top and large sunglasses. On the right is Nurse Nancy, a woman with brown hair and glasses, wearing a white nurse's uniform and a white cap. Both are holding microphones.

# Anti-Retro Spectro

1996-1999

*In the annals of AIDS, 1996 will always be the ‘protease moment’ – the year that the advent of effective treatment for HIV was announced, framed in a new but soon to be very familiar terminology: protease inhibitors in combination therapy.*

**Geoff Honnor**

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## INTRODUCTION

In the February 1996 Mardi Gras Parade, Sydney, the AIDS entry was a 50-metre long, spot-lit red ribbon, carried by those affected by the virus. It spoke volumes, a sad remembrance of things past – but in a few months a new future was to emerge.

One of the most challenging aspects to handle about the epidemic had been its sheer intractability, but in July, 1996, at the XI International Conference, Vancouver, the news about new combination therapy ‘went round like wildfire’; it was almost like manna from heaven.

There was extensive uptake of HAART [highly active anti-retroviral therapy] once it became available – it was ‘the protease moment’. With the arrival of that antiretroviral ‘cocktail’ of drugs came hope, and the possibility that HIV no longer had to be a death sentence, although this was not immediately obvious at the time – there had been other ‘false moments’ before.

The benefits of the new combination therapy drugs soon became apparent – suddenly people seemingly on their deathbeds had energy again, had an appetite again and they put on weight, they became stronger, became more confident and outgoing, and re-established their lives in the community. And they even had a sex drive again!

People could begin planning their lives again. It was a time when the focus shifted from dying to living, although it wasn’t very clear at that point how dramatically the death rate from AIDS in Australia was falling, though it was, even as people continued to die. By the time of the 11th Annual Australasian Society for HIV Medicine Conference, held in 1999, the topics being discussed were adherence, side effects, lipodystrophy, treatments breaks, and the possibilities of a return to work.

In the context of rapid change and diffuse responses to that change, in this period HIV-positive people were lucky to have a developing focal point for the treatments response in Australia. This was led by the AIDS Treatment Project of Australia – and an extra-ordinary collection of people, not all of whom were HIV-positive, made sure this initiative was successful. Initially located within PLWHA NSW, the project moved to NAPWA and provided a focus for important national treatment education and treatments work that the new era required.

People living with HIV continued to play a vital part in the response as new and effective forms of HIV leadership continued to emerge. Many HIV-positive people over this time continued to work hard, holding on to some vision of future potential. Their special efforts in this time of change should never be underestimated.

NAPWA also secured ongoing core funding through national government programs and clever work from a number of key HIV-positive community advocates had achieved this. Perhaps this work was not visible to those who were outside of the situation. However, this work ensured that a structure was in place for national HIV-positive advocacy efforts into the future. Leadership for this had come from within the HIV-positive organisations.

The nature of the HIV-positive community changed, too, with less interest in advocating for such issues as voluntary euthanasia, and more interest in dealing with this, perhaps, now-manageable, but still highly problematic infection. There was a reduced need for crisis services such as home nursing care, and more need for ongoing support for general health issues, such as oral health, mental wellbeing, and access to allied health providers.

**Darren Russell**

## *The benefits of the new drugs*

Our world changed in 1996, and for the better. The antiretroviral ‘cocktail’ of drugs arrived, and with these new drugs came hope and a realisation that HIV no longer had to be a death sentence. I had been working for six years in the HIV field before then, and we watched so many (mainly) young and middle-aged men die in awful, prolonged ways. As a doctor, prescribing these new, life-saving drugs was an exercise in hope – and our hopes had been so cruelly dashed so many times in the previous ten years.

The benefits of the new drugs became apparent within weeks – thin, wasted, exhausted men and women suddenly had energy again, had an appetite again, and even had a sex drive again! Their ‘vital force’ was re-energised and they put on weight, became stronger, became more confident and outgoing, and re-established their lives in the community. As a clinician it was wonderful and inspiring to see. No one who witnessed it was not moved by stories of people becoming alive and brimming with hope. I recall one man, covered in purplish Kaposi’s sarcoma lesions, who had made his will and was preparing to die. Within two months his Kaposi’s lesions had all but vanished and he was planning his life again.

Nowadays we have antiretrovirals that can be taken as a highly potent single pill a day with virtually no side effects – almost inconceivable in the ’90s. The pioneers who commenced antiretroviral therapy 15 years ago paid a price in side effects, including lipodystrophy, but were gloriously alive! I would not have been able to continue working in such a bleak field if the world had not changed for my patients and for me in 1996. The world went from grey to technicolour in a matter of months. Many of the people from that era who were patients are still alive, and I keep in touch with some of them to this day.

The nature of the HIV-positive community changed, too, with less interest in advocating for such issues as voluntary euthanasia, and more interest in dealing with this now-manageable, but still highly problematic infection. The focus switched from dying, to living . . . This was also a change for the better.

**Michael Hurley**

## *We were rocking and reeling*

To understand the changes that occurred from 1996 onwards, some background is necessary. I just want to recall what was happening in the epidemic in the mid-1990s. Many gay men, lesbians and their non-gay friends in inner-city communities were reeling from years of rising deaths, frequent funerals, and friendship networks disappearing. At the same time, many gay men were creating new sexual possibilities.

In 1994, Sue Kippax and Gary Dowsett of the National Centre for HIV Social Research asked me to give the plenary presentation at their annual conference in July. My friend Robert Martin died about two weeks before the conference and I spoke at his funeral. Before Robert, there was Ken 'Joe' McClelland (1992), and before Joe there was Ken Charnock (1991). In the conference presentation I noted that Robert was the eighth person I knew who had died since October the year before. Amongst others who died that year were Robert Ariss, Tim Carrigan, Stephen Cummins and Stephen Kirby. It was the year AIDS deaths peaked in Australia at 764 people.

I spoke at the plenary about grief, loss, anger, sex, and what it was like being gay at that time. Perhaps more surprisingly I used the film *Four Weddings and A Funeral* to frame much of my presentation. I said that the film:

contains one of the most profound representations of one gay man grieving the loss of another that I have ever seen. And then I think about how that representation of a gay man's grief is used to signify the importance of love, a love in which the specifics of gayness disappear.

In the presentation I mentioned a remark made by Andrew Morgan that the hardest thing to handle about the epidemic was its sheer relentlessness. Afterwards he thanked me for my paper and said it would probably take him the rest of the afternoon to emotionally recover. He wasn't being critical. I would have known if he was. He was simply ruefully drawing my attention to the effects on him of what I'd said. I took from what he said that if you take an audience into the pain, you have some responsibility to take them out again. After being a barman at the Oxford Hotel at 19, Andrew drove the expansion of the HIV support project at ACON and was one of the people involved in the dark satirical humour of the samizdat street publication, *The Daily Plague*.

In 1995 the number of deaths dropped to 666. Ninety-four percent of those who died in 1995 were male. Up until then, about 90% of those who had died were gay men.

The number of new diagnoses of AIDS also peaked in 1994 at 909 and then fell to

648 in 1995. Most people living with the infection, at least in Sydney, enrolled in clinical trials of new highly active antiretroviral treatments (HAART).

That year, I was Writer in the Community for several months at the AIDS Council of NSW. I ran writing workshops attended by HIV-positive and negative people. One of the participants, an HIV-positive man, David H. wrote:

'If you suck cocks, everyone will know you are a faggot because your teeth will rot.' Half my lifetime ago this extraordinary piece of advice had been the last legally sane thing my mother – for I still called her that then – ever said to me. I am wondering, as I have so many times since my diagnosis, if this, like so many other things she had said to me, hadn't wound up being true on one level or another . . . And do I now, actually feel better because this poor old crazy woman, who for the last twenty years had dressed in layer upon layer of mismatched polyester (after once being beautiful and stylish) has died before me? Yes, I do.

David's mix of steely anger, mental toughness, kindness, macabre humour and reflectiveness has stayed with me until now, almost twenty years later, as one of the signs of the times. David died thirteen years later in 2008. Along with HIV he had Hepatitis C and emphysema. One of his friends, a woman, wrote online:

I never knew him before he was ill, so I missed the years when he was a drop-dead gorgeous male model, a Berkeley activist, a caterer in the film industry. I got the more contemplative David, the one who loved literary fiction and loved to talk about it, who painted prolifically . . . who could talk and talk and talk . . . He had a distinctive voice. I can't believe I won't hear that voice again, that laugh, that wit, that American-style heavy-duty swearing . . . Life was hard and he told you about it but he never stopped being interesting. He never stopped being David H. Until the other day.

This time the specifics of a gay life emerged, rang true and peeled his name.

In February 1996, at the launch during Mardi Gras of my book *A Guide to Gay and Lesbian Writing in Australia*, I was seated for an hour after the speeches, signing copies and speaking with each person in the queue as they reached me. One of the men from the writing groups was next in the queue. He leaned forward as I wrote and quietly told me he had since sero-converted. We were on the mezzanine in the State Theatre in all its eclectic golden glory, surrounded by perhaps hundreds of people. There was not a lot I could say. I was immersed in an epidemic of HIV and AIDS. In hindsight, it was probably the last moment an early diagnosis automatically meant a high risk of death. That man is still alive.

The success of HAART was reported and hailed at the Vancouver AIDS conference in July, 1996. The news went round Australia like wildfire and there was extensive uptake of these new treatments as soon as they became available.

During 1995 and 1996 I reconnected with Ross Duffin who was then an



Education Officer at the Australian Federation of AIDS Organisations and part of the Gay Education Strategies Project (GES) team that was producing HIV education resources nationally for HIV-positive and -negative gay men. Ross invited me to be an External Member of the Campaign Working Group for GES. For eighteen months at those meetings I met and worked with men from all over the country who were responsible for HIV education in state and territory AIDS Councils. It became a peer group for me and I am friends with several of them still. One of them was Darryl O'Donnell.

From our point of view what we saw was a community living gay and positioning HIV within that wider frame. At the Vancouver conference, Gary Dowsett and David McInnes called this, post-AIDS.<sup>1</sup> A lot of gay men were moving on, not by forgetting or denying but by creatively responding to being alive, both long-term survivors and HIV-negative alike. Paul Kinder also spoke at Vancouver of ACON's new educational position on 'negotiated safety' – HIV-negative regular partners, not using condoms, and negotiating agreements about sex outside the relationship.<sup>2</sup> GES took the lead from what the research was telling us, what the community was doing and saying,<sup>3</sup> and we began to create new educational and research agendas that imagined a future.

Ross argued in 1996 that 'gay men have adopted a set of strategies to minimise HIV transmission rather than eliminate it' and went on to say: 'we've also tried to grapple with a risk assessment or risk minimisation framework for safe sex guidelines'.<sup>4</sup>

We were rocking, but at the same time, I, like many another, was also reeling. Despite that, there were things to be done.

Eric Rofes' book *Reviving The Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* appeared in 1996 and Ross invited him to speak at the first national lesbian gay transgender and bisexual health conference in October in Sydney. In the book Eric had asked,

Is an unambivalent commitment to survival possible in the face of a continuing cycle of infection, illness, deformity and death? . . . Is it desirable for gay men facing a future filled with suffering and loss to embrace survival above all else?

I liked his willingness to ask hard questions and own the ambiguities and ambivalences when it came to sex, hectic living, mourning, infection and prevention. We knew about risk, but scientific knowledge doesn't automatically determine how one lives. You can sense now that those questions were written pre-HAART. Eric remedied that in 1998 with *Dry Bones Breathe: Gay Men Creating Post-AIDS Identities and Cultures*. There he distinguished between AIDS as a disease syndrome and AIDS as a socio-cultural event, and this identified the widening gap between gay men's lived experience of the epidemic and the ways that this was often represented negatively in the United States by community organisations as they insisted on condoms every time.

I still have a hard copy of the paper I gave at the Biopsychosocial Aspects of AIDS Conference the following year, 1997, in Melbourne. It was titled '15 Notes on Hope' and an edited version was reprinted later in the *Sydney Star Observer*. It was a description of the varieties of hope that were emerging as the new treatments began working. The hard copy is a mix of printed and handwritten text and contains much crossing out and last-minute edits. One crossed-out part recounted a remark I had made at an educators' conference a week before about how some of us so wanted the epidemic to be over that we were in danger of declaring it over by an act of will. That desire for an ending, I had said, fuels hope, false hope. Darryl had commented, "Michael, that's the most depressing thing I have heard at this conference." My heart sank when I heard this, but, he went on, "It has to be said." Darryl later went on to lead the NSW Health Department's response to HIV for many years.

Now I would construct the 'false hope' differently. I may not have meant anything more than wanting the dying to stop but I suspect it was also about wanting the virus to go away.

What we had, I said cautiously in 1997, was a 'breathing space'. Marcus O'Donnell, then editor of the national gay magazine *Outrage* and later the *Sydney Star Observer*, insisted to me in conversation, "Michael, the epidemic as we have known it is over." I agreed, as long as we kept 'as we have known it' clearly in view. Ross Duffin and I spoke constantly at the time and agreed the social and psychological effects of the epidemic on us and others would be with us for the rest of our lives. The dying was slowing but many of the living were bruised.

It wasn't very clear at that point how dramatically the death rate from AIDS in Australia was falling, though it was, even as people continued to die. By the time of the 11th Annual Australasian Society for HIV Medicine Conference, held in 1999, the topics being discussed were adherence, side effects, lipodystrophy, treatment breaks, return to work and the over responsabilising of people living with HIV in prevention. Unprotected sex was increasing, much of it more or less safe (negotiated safety, strategic positioning, sero-sorting), some of it not. My own mood and thinking oscillated between grief, optimism and the pleasures of sexual distraction. I knew too many people whose bodies had been ravaged by illness and whose treatment experience was too multi-sided for their issues to be relegated to minor problems. For all that, however, they were alive, pleased to be so, and most still are today.

Some Indigenous gay men challenged what they saw as a white perspective on the epidemic. Chris Lawrence wrote:

Aboriginal and Torres Strait Islander Communities are a long way from nearing a post-AIDS perspective . . . many of the white educators are not grasping our issues . . . The economics, social and health issues and political climate are high indicators of HIV infections for Aboriginal and Torres Strait Islander peoples.<sup>5</sup>

In the 1997 paper I identified three different narratives of hope. The first narrative involved a passionate yet stoic refusal of despair: 'a commitment to communal

survival in the face of those who have died. This hope produced the quilt, the candlelight rallies, the reading of names.’

At about this time, Andrew Sullivan from the USA wrote *When plagues end: notes on the twilight of an epidemic*. In it, he said:

Perhaps this is why many of us find it so hard to accept that this ordeal as a whole may be over. Because it means that we may be required to relent from our clenching against the future and remember – and give meaning to – the past.

The future in Sullivan’s remark was open not closed. It’s a beginning I said, not an ending. I called that at the time a second narrative, ‘hope triumphant’. In terms of death and dying in a country where most HIV-positive people had access to and accessed treatments, it was. Between 1995 and the early 2000s, the number of both AIDS diagnoses and AIDS deaths dropped by well over 90%. We didn’t know that’s how the promise of life would play out in detail at the time. It was a multi-strand narrative.

Alan Brotherton, a former NAPWA president, suggested that the new treatments had given people living with HIV “a renewed confidence in the present rather than a certain sense of futures”. He spoke of “hope and optimism in the face of great uncertainty”. This was narrative three: ‘improvised optimism’. It was characterised by the uncertainties of an unknown future, even as many people’s health improved dramatically.

Marcus, Ross and Alan were HIV-positive. Darryl and I were HIV-negative. We worked and socialised together. What mattered was that we heard each other and worked out what to do.

We lived with all three narratives at once, often bouncing around between them, panting for breath, smiling, unclenching, but others were still dying: Neil Sanderson (1995), Peter Blazey (1997), Bill Phillips (2000) and Gerald Lawrence (2000).

In the 1996 Mardi Gras Parade, the AIDS remembrance float was a 50-metre long, spot-lit, red ribbon. It was simple, elegant, elegiac, timely.

In the 1997 parade each colour of the rainbow was used to symbolise ways of living in the epidemic. It was the longest entry in the parade, involved hundreds of people, and red was but one of the colours. It was alive, visually messy, and positioned the epidemic within a wider sense of how gay life was being and could be lived.

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## Darryl O'Donnell

### *Four years. It might have been a lifetime*

1996 to 1999. Four years. It might have been a lifetime. As 1996 opened, I was living in Perth, doing my first real job. Well, actually it was my second. My first had been as National Coordinator of NAPWA a few years earlier, working with Mark Counter in Brisbane, before I moved and took the job with me to Melbourne, where I worked with Geoffrey Harrison. NAPWA was very mobile then. A staff complement of one part-time worker, earning \$21,000 per year (pro rata of course). I thought it was a princely sum.

For my first full-time job, I crossed the Nullabor, heading west to our farthest-flung AIDS Council. My full-time job was made up of two halves: I was non-gay-identifying homosexually active men's project officer one half of the time, and positive education officer the other half. Neither role seems appropriate in retrospect, but it seemed to make sense at the time.

In 1996, treatments are dawning. Today we know it as a turning point. The end of the beginning. Today, we imagine that the new treatments arrived with a bang and life changed. That the future changed and it was good. That's true, but only in part. We didn't know that then. We didn't know that life would stay changed. I don't remember when I noticed fewer pages of death notices in our newspapers. It must have been just before 1996. But I do know that it took me a long time to realise what the new treatments meant. To trust their promise. We immediately saw the benefits, for some. People who were supposed to die but who didn't. People who had prepared themselves and those around them carefully. They were as surprised as anyone. Not dead yet, but often broke and unemployed and bewildered. What the hell was happening? The predictability of life and death in an epidemic was becoming unpredictable.

By the end of this period – 1999 – I still feared that the treatments would fail. Many were still sick. Treatments had failed us before, and hoping that the horror had passed was still too great a leap to take. Life was different, and the difference was good. But we didn't know that it would stick.

But back to Perth. 1996. It was exciting. We put out a new campaign each week in the local gay press. When anger boiled at France's nuclear testing at Mururoa Atoll,

we ran a picture of Jacques Chirac with the unmistakable message: ‘Get Fucked’, in tiny letters above, we wrote something like “Use a condom when you . . .”. It was a time before government approval of education campaigns. Perhaps approvals would need the advent of email. At the Western Australian AIDS Council (WAAC), we shared a computer. I think it had email. We needed a manager’s approval to call long-distance. Perth was far-flung.

But the best campaign, the one I continue to be most proud of, was our One Community campaign. Its premise summed up the aspirations of the moment: Positive + Negative = One. Its straplines were ‘Are you negative towards positives?’ and ‘Are you positive towards negatives?’ The equation – the campaign’s visual device – was powerful. For a time, you saw it everywhere. People wore the t-shirts, and you didn’t know who was positive and who wasn’t. Perhaps it didn’t matter. It was a time of community building and healing. AFAO picked up the campaign and ran it nationally. ACON, famous for running its own race, surprised us all by picking it up too! But they changed the slogan to One Community, Many Diversities. They couldn’t help themselves.

By August 1996, I was in love. Six months long-distance – six months too long, so I crossed the Nullabor again, returning to Melbourne. For a time I worked for now-forgotten People Living with HIV/AIDS and their Carers Unit at the National Centre in HIV Social Research (NCHSR) at La Trobe. Yes, NCHSR, the Sydney institution, had a Melbourne outpost! For the Sydney lot, it may as well have been Perth. We launched the first national HIV Futures survey and achieved a sample of more than one in ten Australians with HIV. An extraordinary achievement that would continue to be replicated in Futures surveys to come. Its simple premise: make the research work for people with HIV. We committed to reporting back to every community where we could achieve even a small sample size. Positive people’s organisations around the country drove the recruitment. Participants endured the long survey and then passed copies to their friends. Community mobilisation in motion.

I was Secretary of Victorian AIDS Council/Gay Men’s Health Centre (VAC/GMHC) and later a staff member. I say worked, but it was more like ‘lived’. The politics of the time were intense. At VAC/GMHC, I ran a forum – probably Australia’s first – on the criminalisation of HIV. Victoria has always been odd on this issue – an embarrassing trailblazer and over-achiever in its prosecutions. There’s never been a public health benefit to it, but that’s not what drives it. What drives it in Victoria remains a bit of a puzzle. And there seemed to be no victory for either the accused or the defence. What was it all for? More happily, we would succeed at the Victorian Civil and Administrative Tribunal when a man was banned from playing football for having HIV. The fear of HIV and of contagion was still real. But the politics of HIV got the better of me in Melbourne, and I got it wrong. We moved to Sydney.

It’s 1999 and that’s how I partied. In April I became the President of the Australian Federation of AIDS Organisations (AFAO). Michael Wooldridge was

Minister for Health and the Federation was in reasonable shape – nothing more than its usual shambles and politics. AFAO was planning for its future – and surprisingly, at the centre of its strategic planning was something that mattered. Not always the case for a strategic planning exercise. AFAO was grappling with the problem of its national members – NAPWA in particular – being financially dependent on it. To that time, funds for NAPWA were disbursed to it via AFAO. The question: if we truly believed that an independent voice for people with HIV mattered, were we willing to sacrifice funds for it? When there's not much cash, you don't like to give it up. Would we give it up? Did we really believe in the principles of the National HIV Strategy? Did we really believe in self-determination? We did. I put the motion. The Federation voted. NAPWA was unshackled and a new era began.

I had gone to Sydney single-mindedly determined to work for the lauded and esteemed AIDS/Infectious Diseases Branch at the NSW Department of Health. A funny thing to say, but we should acknowledge great bureaucracy where we see it. When I got that job, I put on my wall the Perry Ellis campaign I'd carried with me since the early '90s. Its slogan: 'The AIDS Crisis isn't over for anyone until it's over for everyone'. On my pinboard, I placed a postcard from the One Community campaign. They stayed there another fourteen years.

**Kath Albury**

## *Chin Wag: treatments education, cabaret, collaboration*

I have been co-hosting Chin Wag (and its predecessor, Vanessa Wagner's *Wheel of Misfortune*) since the late 1990s. Although I'm an academic, I'm not a medical researcher, nor a social scientist – the character of Nurse Nancy was developed as an (affectionate) parody of the ubiquitous clipboard-wielding social researchers who haunted Sydney dance parties in the 1990s. Nurse Nancy's high-femme medico drag complemented Vanessa's hirsute-politico drag, and we translated our friendship into a happy co-hosting relationship. As a negative person, I am deeply grateful for the insights offered by my friendship with Tobin Saunders (whose sidekick is Vanessa Wagner), and this collaboration with NAPWHA.

The nature of our collaboration has shifted since the mid-1990s. Our first sessions focused on managing the intensity of side effects associated with HIV treatment, and the complexity of drug regimes. Much of the comedy in these sessions was strongly interwoven with a sense of empathy and shared care in managing the indignities of treatments: the sequinovic squirts were a favourite topic in the late '90s and early

noughties. As I noted in a very early reflection on these sessions, Vanessa and Nurse Nancy's performance of the more shameful and shaming aspects of living with HIV treatments was akin to 'showbiz homeopathy' – a mild dose of poison mixed with absurdity. As Sydney researcher Kane Race put it, *Wheel of Misfortune* used “camp comedic styles to deflate the promises of commercialised medicine and bring them back down to earth, where real people take treatments and live with their unpredictable and frequently messy effects.” (Race 2009:110)

Happily, the time came when our audiences asked us to ease up on the poo jokes. HIV treatments were easier to take, and we were entering the era of 'undetectable viral loads'. *Wheel of Misfortune* was reborn as Chin Wag, a chat show focused on 'living well' with HIV. The humour in Chin Wag tends to focus not so much on the indignities of drug side effects, but the indignities of sexual desire and practice. In accordance with Michael Warner's definition of queer sexual ethics, the baseline assumption in any Chin Wag is that “if sex is an indignity, we're all in it together” (Warner 1999:36). Our audiences for Chin Wags have been very diverse, but by and large, they agree.

I haven't kept a diary (though I wish I had), but some events stand out. Since 1997, we've visited every capital city (some more than twice), and several large regional centres. One audience in a regional capital seemed to be exclusively made up of local health and welfare service providers. Chin Wag was the first opportunity many of them had to hear the breadth of experiences of their positive clients, who were generous, but blunt in their assessment of some of the local services (including the requirement to collect their HIV medication from a very public small town hospital dispensary). At one event in Western Australia, we met a mother accompanying her newly diagnosed son to his first poz event. We had been secretly anxious that she might be put off by some of the more vulgar parts of our show, but she told us that the humour had made it easier to absorb the factual information, which would have been 'too frightening' without it. Since 2009 or so, the standard Chin Wag is primarily made up of positive gay men aged approximately forty to sixty – not only the 'classic' demographic for HIV in Australia, but coincidentally, the classic drag show audience.

Chin Wag may be a chat show, but it is also a queer drag cabaret. As Shane Vogel puts it in his study of queer cabaret artists Kiki and Herb, cabaret fosters what queer theorists Lauren Berlant and Michael Warner dubbed 'criminal intimacies'. These are “relations and narratives that are only recognized as intimate in queer culture” and that provide “a context for witnessing intense and personal affect while elaborating a public world of belonging and transformation” (in Vogel 2008:47). Queer audiences seem to immediately recognise, and engage with, the combination of intense personal disclosure and public transformation offered by Tobin/Vanessa. Chin Wag's audiences know Tobin/Vanessa as the person who came out as positive on the way into the *Celebrity Big Brother* house, and while they value the advice of the expert Chin Wag panels, they resonate with Vanessa's accounts of her lived experience as a sexually active HIV-positive gay man. Obviously, they love the drag eye-candy, too.

Last year we presented the first Chin Wag to an exclusively poz het audience, and we were interested to see how the overtly queer format of Chin Wag would translate. While the response to the drag-cabaret format – and associated vulgarity – was uniformly joyous, the response to the practical information was deeply moving. Positive heterosexuals, particularly positive women, may not be confronted with homophobia, but they experience staggering discrimination as a result of their HIV status. We heard appalling stories of discrimination, including non-consensual disclosure of sero-status by medical professionals in a major regional city. One couple wept as they recounted their treatment by neo-natal staff. We haven't heard these kinds of stories from gay men for at least a decade, but they appeared to be common for positive heterosexuals.

As Vanessa/Tobin puts it, Chin Wag is an event for people 'living with and affected by acronyms'. From HIV, to HAART to Hep C, it recognises that there is more to living well with HIV than blood counts and adherence to treatments. At its heart, the event celebrates not just poz people's health and wellbeing, but their rights to humour, smut, playfulness and a full expression of positive sexuality. While Tobin/Vanessa's wit and silliness are the backbone of Chin Wag, it would not be the event it is without the guiding hand of Brent Beadle and his NAPHWA/Treataware colleagues. In the words of a 2002 evaluator, Chin Wag is "part educative intervention, part peer support, and part good night out. Few forums are able to obtain success against such indices." I really can't say it any better than that.

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### **Tobin Saunders**

## *A rollercoaster ride*

I have lived with HIV since 1991 and let me tell you . . . what a rollercoaster the last 23 years has been! It's been a veritable Luna Park; one minute frightened like hell clattering through the Ghost Train, the next minute clinging to one of the many nauseating, spinning or up and down rides, adding a frisson of excitement and a temporary stomach adjust, finally disgorged and disorientated I flop in to a Tunnel of Love swan boat for a mini-respite before re-entering the fray.



I remember performing as a 'Life Boat Boy' at an AIDS fundraiser in Adelaide gay club Mars Bar, my very first act of charitable HIV/AIDS activism. I was in my graduate year at dance school and a green twig when it came to sexual health and negotiating the emerging epidemic. The year was 1989. It was only two years later that I was in need of my own life boat boy, not struggling but feeling adrift in the gentle riptide of AIDS, destination Death Island! As the utter catatonic shock subsided I decided it was better to swim than sink and so began the biggest, most enduring and amazing 'swim' of my life.

HIV was part of my DNA, my performing cellular structure too! I was a self-employed, out-there diseased activist with nothing to lose and a lot to fear. My work as a contractor meant working alongside the big HIV/AIDS organisations (like a colourful pilot fish) where I started evolving as one of the 'faces' of HIV. At about the same time NAPWA Chin Wags were kicking off I came out as HIV-positive on live national television whilst being interviewed by the lovely Gretel Killeen, prior to lockdown in the *Big Brother* house. It doesn't get louder than that!

With my sidekick Vanessa Wagner I have probably hosted or performed at more than 400 paid and charity gigs, mostly dedicated to the lives of people living with HIV and being a beacon of public pride and hope to those at my other shows. HIV has been a central theme in 'our' lives, yet we live in an open relationship where neither dominates! I have always hoped to upturn the old 'ignorance is bliss' paradigm with a hard-to-ignore, easy-to-digest walking, talking lesson in life!

Now, where's the fairy floss, I deserve a reward!

**Andrew Kirk**

## *The long beginning to the end*

For most of us who had acquired HIV in the early stage of the pandemic, the mid-1990s were years of paradoxical uncertainty: utter despair that time had run out and fervent hope that new combination therapies would save us.

It was into this world that I entered HIV/AIDS advocacy as a board member of PLWHA (NSW) and later as President of NAPWA. I was convinced that the new advances in treatment would mean HIV's effective end as a death sentence. At the time, I had not thought through the manifold ramifications of survival, including the debilitating stigma and discrimination. Rumination on this would come years later.

It was 1996 and I had begun my first triple treatment. The impact was immediate and extraordinary. My body felt transformed as an enormous amount of energy was restored. Symptoms gradually resolved and tests confirmed that the virus – population previously in the billions – was laid to waste, scattered and hiding in reservoir cells. The dream that I had wished for, for so many years, had arrived.

Up until this point in the crisis, no single approach had an edge on routing HIV. Complementary therapies boasted an impressive following, but their results were not able to be independently verified and relied heavily upon unscientific anecdotes and word of mouth. The scientific approach to the problem had very rocky beginnings, with the earliest treatments causing considerable side effects and in some cases death. None of the drugs, individually, was able to outwit HIV and so the retrovirus quickly resisted all attempts to control its reproduction.

Fortunately, the collective brain work of scientists meant that we were able to combine new drugs, such as protease inhibitors, to prevent the virus from replicating – and it worked!

Combination therapies quickly established themselves as the frontline HIV treatment, and governments funded the treatments and support. Rapidly, people living with HIV and AIDS took up the new drugs, which in most cases saved our lives.

The politics in the HIV advocacy space were somewhat more complicated, because of a fear that the new combinations would prove more toxic than the experimentation wrought upon us in the '80s. Many had bad stories to tell, including facial wasting from high-dose AZT, body fat redistribution (lipodystrophy was to become a big turn-off side effect), premature ageing and psychological disturbances from some medications. It was rational to be fearful of medical science, but when the good results began filtering in, the public argument was definitively won in favour of the scientific breakthroughs. Complementary therapies were soon relegated to the sidelines, and over the years have completely fallen out of favour as a definitive treatment for HIV.

My own personal crusade was a hypothesis, derived from the promising 1996 results on the use of AZT to prevent mother-to-child transmission. I hypothesised that lowering viral load through combination therapy would also result in HIV-positive people being less infectious.

This was due to the use of more modern drugs that meant 98.8% of all children born to mothers who had HIV would be HIV-free. A closer look showed that no transmissions occurred at all with a viral load of less than 1000.

A corollary of the new paradigm included selling difficult messages about the importance of condom use when the threat of the Grim Reaper was no longer a shopping trolley stopper. This posed a very sticky problem; how to persuade gay men to continue to use condoms in an era that heralded the end of HIV?

My recollection of the time is that there was nervous unease in HIV circles about condom use with the advent of new treatments. I was struck by the reticence of a minority in the positive community to wholeheartedly champion treatment uptake in the interests of both people living with the retrovirus and the public health considerations of a less infectious HIV-positive population. I do not know if that reticence was attributable to an understandable fear of the unknown, or a fear that if people were on treatment they would stop using condoms as their primary method of safe sex. Was it a fear that HIV/AIDS would lose its prime driver for the safe-sex

message – that is fear itself? I advocated that we had to accept that we were working in a new environment and needed to adapt by embracing the new treatments with fierce alacrity. The world would never see HIV/AIDS the same again and condom use was probably going to fall away regardless. Chemical prophylaxis would need to be added to our armoury of safe-sex defences. Alas, these ideas were for the select few at the time.

However, the adopted solution of the HIV sector was pretty simple – no change of direction: broadcast promotion of latex and narrowcast messaging aimed at people with HIV, who knew their status, to (rather obtusely) weigh their sexual behavioural ‘risks’. I look back and conclude that this was a failed First World War strategy of static trench warfare with a serious lack of concern about attrition (of young gay men in particular). There was no targeted approach by the partnership to even attempt to win the war. They were strategically in a stalemate and not planning a checkmate. Under that scenario HIV would win over time, as more and more people would be living with the disease.

The National Association of People Living with HIV/AIDS (NAPWHA) itself focused practical efforts during this period on getting factual information to positive men and women about the treatment options available. There was tight engagement with the clinical profession and the drug companies to ensure that the information provided was timely and accurate. Some may say that we were unpaid advocates for the drug companies, but I would retort that although unpaid, we remained the advocates for people living with HIV/AIDS and our needs overruled drug company interests on most occasions. Earlier years’ arguments with the companies over open-label compassionate access had been won and the companies were forced to invest upfront, albeit on the promise of long-term returns. Certainly no one at NAPWHA was looking out for drug company interests, rather they were allies in the fight and they brought big guns to the battle.

Even though we had the tools and resources to do something significant about stopping HIV transmission, implementation of this goal had failed in the later 1990s.

The partnership had many valuable aspects. However, one of its major weaknesses was that a collection of ‘equal’ voices often meant that, as the situation on the ground changed – as was the case with new treatments – there was no single point of leadership to drive a new course.

So as the fear of dying from HIV receded, much of the momentum that spurred the early days of the pandemic dissipated. I left the sector somewhat disillusioned with the lack of vision for what might have been.

**Alan Brotherton**

## *Life after Vancouver*

In 1996, I gave a paper at the XI International AIDS Conference, held in Vancouver. It was about the effective use of narrative to engage audiences with stories of positive people, but it could have been about anything, really. In the context of that conference, at least for those of us in developed countries with access to healthcare, there was only one finding that really counted.

After the crushing disappointment of the Concorde trial, and the peak in deaths through the early 1990s, early evidence of the sustained effectiveness of combination therapy was news everyone wanted to hear. I got to the key session early and obtained a premium seat on the floor in the corridor just outside the doors of the already packed room.

It wasn't, in truth, new news – I was taking a triple combination at the time, as I recall. But it was a very public confirmation that we'd turned a corner, and it was worth sticking to the adherence schedule and putting up with side effects for what looked like a long-term gain.

I was President of NAPWA at that time, and we'd already started engaging positive people around their health promotion needs, through the Positive Information and Education (PIE) project. People around the country shared their concerns and issues. While news of emerging combination therapies and their effectiveness was already in circulation, people appeared preoccupied with a range of other issues – disclosure, prevention, health maintenance and so on.

Nonetheless, treatments education was on the agenda. Travelling the country in 1997 to promote the NAPWA/AFAO 'HIV Tests and Treatments – New and Improved!' resource I was taken aback by some reactions. Looking back over this period, the response to what we now know was game-changing good news, seems like a chaotic mix of disbelief, optimism, cynicism, elation and even fear. At a stall on Oxford Street, I was told by a few people that the promise of new treatments was empty. "I took AZT and it didn't work, it's all rubbish," said one. A group called Iris (the Virus) was established. The group's main message seemed to be that treatments were poison and learning to love and live with one's virus was the way to go. This wasn't only an Australian phenomenon – ACT UP Golden Gate and a group in the UK were also ardent spruikers of a 'gay men's genocide/poisoning' narrative in relation to treatments. Peter Blazey, a prominent journalist, also railed against the evils of Western medicine in the pages of the community press.

I guess many people remained cynical and wary after the 'failure' of single-agent therapies, which was conclusively demonstrated at the 1993 Berlin conference. Maybe the gap between peak deaths (in Sydney around 1994 and 1995) and the good news was too short for many people to recover from the anger, grief and loss of the early '90s. There was a lot of passion, a lot of tensions around positive

‘ownerships’ of AIDS Council programs, and everyone was emotionally invested in the meaning of treatments, one way or the other.

At the other end of the scale, some treatments optimists had little time for the social dimensions of new treatments. Ross Duffin and I gave a session at an AFAO meeting where we suggested service providers needed to plan for helping get people back in the workforce, recover from the disabilities and wounds of years of illness, and find a way back into life in the absence of their previous social networks. Some days later, a prominent community journalist accused us, in an article in the *Sydney Star Observer*, of being in love with death and the epidemic.

Given what everyone had just come through in the preceding years, we shouldn’t be surprised at this mix of reactions. The promise of combination therapy was delivered on, for Australians at least, and newer and better drugs spilled out of the pipeline. But that wasn’t necessarily visible from the vantage point of 1996. Just as now, it was a time of speculation. By 1999, however, there were enough stories – and clear evidence – of lives clutched back from gloomy prognoses and being lived with joy and vigour that most people accepted the promise was being fulfilled.

## **Andrew Little**

### *A personal perspective*

A period of great change – 1996 of course being the turning point that effective combination therapy became widely available. Like many others, I was lucky enough that the treatments arrived in the nick of time. I experienced my own dramatic Lazarus effect.

Working at NAPWA provided a safe space for me whilst recovering from the impact of HIV. I began at first as a volunteer, helping Steve McIntyre to coordinate the Sixth National PLWHA Conference in Sydney in November 1996.

The irony of the timing at the conference of the launch of the booklet *A Guide to Retirement* (part of the Access series produced by NAPWA) was not lost on anyone, being only a couple of months after the momentous Vancouver Conference and the announcement of the new treatments’ effectiveness.

One of the pieces of work I undertook, and which I was most proud of, was helping to develop a workshop with Russell Westacott (with whom I job-shared the NAPWA Communications Officer role), a Financial Planning and Workforce Issues for PLWHA workshop for healthcare workers. This began the avalanche of a variety of Back to Work programs here in Australia, led by the extraordinary Sarah Yallop, and which I was to go on to develop into a major program while working at the UK Coalition of People living with HIV.

One of the fundamental things that occurred with the onset of combination

therapy – besides the onset of a multitude of side effects – was the need for people living with HIV and AIDS to shift their attitude towards medication. We needed to shift from taking medication to make us better, to taking the treatment to keep us well. This became a major focus of many of the support groups run as part of the Peer Treatment support groups that I co-facilitated with Larry Wellings at the AIDS Council of NSW. People needed to adjust their lifestyle to accommodate the treatment and to recognise that they required an ongoing commitment with very high levels of compliance.

During those two years, NAPWA was small but influential, with a small secretariat (Russell and I job-sharing) later expanded by the addition of Ken Irvine on a back to work job placement. The Board of NAPWA, however, was extremely active, with Board members taking on portfolios – areas of responsibility. Some of the names of those extraordinary individuals spring to mind: Alan Brotherton and Ian Rankin ably leading the charge as President; Mark Reid from Western Australia serving as Vice President; Ian Grubb focused on international liaison and development; Bev Greet taking on the mantle of positive women; Neville Fazula and Rodney Junga focused on Indigenous matters; David Menadue as ever taking an active role; Phillip Medcalf representing NSW. NAPWA worked very closely with Jo Watson and Bill Whittaker from PLWHA NSW on all things treatment. We also worked very closely with the multi-talented policy team at AFAO, including Geoffrey Fish, Chris Ward, Michael Hurley and Susie Maclean.

It was a heady time as access to, and compliance with, treatment took a major focus, and we witnessed the emergence of the possibility of a future for people with HIV.

Always underpinning the work of NAPWA was the driving force of ensuring that positive people were talked to and included in policy development and that positive people spoke for themselves.

I was privileged to have had the opportunity to work for NAPWA and to work alongside some extraordinary individuals.

After I left to explore my future, NAPWA changed dramatically under the awesome leadership of Jo Watson – but that is another epic story.

**Geoff Honnor**

## *HIV from the Protease Moment to the New Millennium*

In the annals of AIDS, 1996 will always be the protease moment – the year that the advent of effective treatment for HIV was announced, framed in a new but soon to be very familiar terminology: protease inhibitors in combination therapy.

Protease inhibitors are now a pretty unremarkable part of the HIV treatment scenery. Just one of a number of therapeutic agents whose combined action against different stages of the HIV replication process can dramatically lower viral load and halt disease progression in its tracks.

But in 1996, fifteen, relentless, frustrating and terrifying years after the US Centers for Disease Control first reported a strange cancer as a common factor in presentations of seriously ill gay men in New York and San Francisco, it was a bit like discovering the Holy Grail – except better.

To provide some context, three years earlier, the Global AIDS Conference had taken place in Berlin amidst sepulchral gloom and despondency. Epidemic fires in South Africa were seemingly turning into a pandemic blaze across the sub-Saharan continent, and the findings of the Concorde study into AZT – the sole agent, which, to that point, looked as if it might have offered an effective antiviral impact – were profoundly disappointing. Any benefit was short-lived and at higher doses, toxicity rendered any notion of ‘benefit’ cruelly ironic.

Of course, AZT also is now part of the treatment scenery, its benefit later realised and amplified in the combination therapy approach announced at the next World AIDS Conference, held in Vancouver in July 1996.

From dark, old world shadows in Berlin to the pristine freshness of a booming multicultural Pacific Rim metropolis. A perfect allegorical setting for what was to follow.

In the excitement of the moment, some dared to imagine that combination therapy also represented victory over HIV, but the persistence of the virus – even when driven well below levels able to be detected by blood testing assays – soon leavened over-enthusiasm.

At the opening plenary, Donna Shalala, President Bill Clinton’s Secretary for Health and Human Services, delivered an address – or rather, re-delivered a speech given to a Women’s Health Conference in Beijing a few months earlier – which was notable for highlighting the growing numbers of women acquiring HIV and their specific vulnerability to transmission. It’s also notable for the transparency with which artful avoidance of any specific acknowledgement of the needs of other marginalised high-risk populations – sex workers, drug users, gay and men who have sex with men – is achieved.

Afterwards, an American colleague, in mock outrage at people complaining that Secretary Shalala had contrived to avoid any mention of gay men (no mean feat given around a quarter million American gay men had died from AIDS by that point) said, “Of course she mentioned us. It was the coded bit where she said, ‘Citizens! Keep your pants on and don’t do drugs.’ You could hear citizens’ zippers closing right across the auditorium.”

In Australia, where expanded access to the new therapy via clinical trials was well under way by 1996, the results from Vancouver had been anticipated. The Lazarus effect had begun its transformative work, at first sporadically amidst the continuing obituaries of those for whom the Protease Moment had come too late, then with greater frequency. People not seen for a long time re-emerged, albeit in many cases, increasingly altered in appearance by often quite severe lipodystrophy.

It was a manifestation of mitochondrial toxicity, a fat-stripping, side effect testament to the chemoprophylaxis power of the early combination therapy regimens, which Australian researchers were central to identifying. The condition was exacerbated in some instances by the post-Vancouver Hit Hard, Hit Early approach, which many American and some Australian clinicians championed; others did not.

In some ways, an evidence-based response to the realisation that, far from the ‘traditional’ view of a dormant or HIV latency period post-primary infection, disease progression – and concomitant immune system damage – was continuous from sero-conversion, Hit Hard, Hit Early was also testament to beliefs around the as-yet-untapped full power and benefit within the new treatment paradigm.

The hypothesis that hitting the virus earlier, with as much therapeutic power as might be used, is a well-founded one, and it is in fact galvanising the response to HIV in our own time. The difference is that we have access to a much wider range of far-more-effective therapeutic options about which we know vastly more in terms of both benefits and limitations than was the case in the late 1990s.

In some instances, lives were saved; in others, toxicity and pill burden offered more blight than benefit and eventually the ‘first do no harm’ principle of physician practice in conjunction with increased knowledge about the limitations of what might be achieved therapeutically led to a more conservative approach to prescribing, with the memory of ‘treatment as toxicity’ an enduring legacy – and a barrier to treatment uptake ever since.

In some ways the Hit Hard, Hit Early debate was a late-1990s adaptation of the contestation of approach syndrome that has always characterised the response to HIV. For instance, the Berlin conference was the high-water mark of the natural or complementary approach led by the HEAL movement versus the allopathic approach characterised at Berlin by the failure of AZT. Three years later all was reversed with the focus on ensuring that the benefits of the new treatments were made available to all. HEAL had vanished from the scene.

The process of defining ‘the’ appropriate HIV response in the aftermath of Vancouver was contested across the spectrum.



Was service provision constructed as first-line crisis response an adequate programmatic framing in an era where crisis was morphing into chronic manageable illness? What was ‘wellness’ in HIV for people whose lives had been totally disrupted, and was it reasonable to anticipate they simply get up and march forward regardless? Should we have pulled the plug earlier on the somewhat casual approach to defining Category 4 stage AIDS (the then HIV eligibility precursor to DSP access) that prevailed in some quarters? Were we in fact, with the best of intentions, consigning some people to a kind of limbo from which return to perceptions of ‘normal life’ would be nigh impossible?

In the end, the Howard government, which had taken office in Canberra a few months prior to the Vancouver conference, made that decision for us and over-corrected in doing so, to the extent that an HIV diagnosis alone had become insufficient grounds for Disability Support Pension access by 2000, and increasingly it seemed, as reviews became more frequent, insufficiently ‘worthy via suffering’ grounds for remaining on it.

At the same time, Commonwealth funding in support of the 4th National Strategy response to HIV, then in development, would decline in real terms as it was stretched to include responses to an increasing range of blood-borne viruses and sexually transmissible infections other than HIV in an era where the increasing tendency was to view HIV as contained if not over.

At a 1998 Australian Federation of AIDS Organisations’ workshop to identify appropriate responses to changing times, there was significant service provider pushback against the notion that the times were changing all that much. Treatment wasn’t working for everyone, and anyway no one could tell how long it would keep working for anyone. “You might all fall off the cliff in a couple of years’ time,” was one participant’s cheery contribution.

There was indeed – mixed in with genuine concern about an uncertain future – a degree of provider irritation at being expected to change familiar program models that worked effectively – at least from a provider perspective – as well as anxiety about issues associated with HIV that not even the Protease Moment could resolve – continuing frailty and illness, particularly in those whose long HIV journeys had commenced well before the post-Vancouver era; also stigma and discrimination, the marginalisation and economic disadvantage inherent in difference, the punitive criminalisation of HIV transmission laws in a number of jurisdictions and the rapid loss of transparent HIV community engagement and linkage, as people increasingly ceased contact with organisations that seemed as redolent of a time they’d put behind them as they were irrelevant to what lay ahead.

One response to this phenomenon was simply to redefine program delivery in terms of the issues arising from the narrow frame of reference encompassing the usually small numbers of people who did remain in touch. NAPWA chose a different, more innovative approach.

As the 1990s drew to a close, the PLWHA (NSW) treatments project – long the cornerstone of the Australian HIV community-based health and treatments response

– transferred from state-based to national peak positioning, providing NAPWA with a solid foundation from which to reinvigorate, if not reinvent, the notion of PLHIV community-based response both nationally and also in the eastern seaboard states in particular, where all three NAPWA member organisations would embark on their own processes of reinvention that continue to reshape and redevelop the increasingly dynamic engagement on which their continued viability is totally dependent.

In searching for an appropriate descriptor for the late 1990s, I considered the famous line that William Wordsworth wrote of the French Revolution, “bliss was it in that dawn to be alive but to be young was very heaven.” He was young and Paris in 1791 was still of course a long way from the blood of the revolutionary scaffold and the Committee of Public Safety’s descent into a Reign of Terror, but it’s a little too romantic . . . Maybe, as is often the case, the immortal opening lines of *A Tale of Two Cities* provide a more elegant fit, and Dickens of course was writing about the French Revolution as well, albeit with the benefit of much greater hindsight. ‘It was the best of times, it was the worst of times’. A fervent amen to that.

**Jo Watson**

## *How a national treatments response emerged*

The year 1996 is the year remembered now as the confirmation of the success of HAART, but at the time it was a time of hope managed, and there was not yet the notion that the treatment story could lead to an immediate fix.

In reality, the Australian treatments advocacy work was still maintained with a relentless mix of negotiations and activism to ensure wide access, as well as an ongoing race to secure the next pipeline news and delivery to Australia.

In 1996 I was the research officer at PLWHA (NSW) and specifically assigned to support the NSW Treatments Working Group (TWG), which was made up of heavy hitters such as Bill Whittaker, Andrew Kirk, Rolf Petherbridge, Les Szaraz, Peter Canavan, Cassy Workman, Mark Kelly and Margaret Duckett. It was a group that really was the powerhouse behind Australian treatments policy and activism with the pharmaceutical industry and the government. This was the group responsible for the 1997 campaign Hit Hard, Hit Early, which was not shy about asking Sydneysiders “Do you want to be around to see Cathy win at the Sydney Olympics in 2000?”

The 1996 *Time* Magazine Person of the Year was David Ho, for “helping lift a death sentence – for a few years at least.”

Bill Whittaker and I had conceived the idea of the AIDS Treatment Project

Australia (ATPA) as a model of the Project Inform work then operating in San Francisco, and we started with some roadshow forums and information lines from the NSW organisation. We funded it through money directly from industry and developed a whole program of work around social education and outreach around the state. We had a steering group, which included people such as Trish Bullen, Virginia Furner and Sarah Huffam.

The transfer of the ATPA from PLWHA (NSW) to NAPWA in mid-1998 meant that Brent Beadle and I landed in the Wentworth Avenue NAPWHA office, housed within a room within AFAO, to a space inhabited then by one part-time admin officer (Ken Irvine), and both Andrew Little and then Geoff Honnor contributing through a Communications Officer role that was coming to the end of its term.

Andrew Kirk was then NAPWA President, and Geoff Honnor was the ATPA Convenor, and we were tasked with supporting NAPWA to deliver an elevated level of national treatments advocacy information and education. Many at the time believed NAPWA was not going to survive without a new direction and function, and this move was meant to test whether a shot in the arm could bring focus and meaning. The 7th National Conference for People with HIV/AIDS was held in November 1998, and 270 participants informed a number of recommendations, which were taken into the process of setting strategic directions that was under way. With the explosion of new scientific information and new treatments in the mid to late 1990s – the unpredicted challenges of treatment adherence, treatment-related toxicities – the need for accurate, consumer-friendly and independent treatment information was never greater.

By the end of 1998, Andrew Kirk stepped down to move into even more political spheres, and was replaced by Peter Canavan as NAPWA President. My period of transfer between national tasks as ATPA Coordinator and NAPWA Coordinator was already in motion. John Rule acted as a coordinator in between periods as well, and also oversaw the development of the new NAPWA Strategic Plan during 1999/2000.

Over those years the work of Honnor, Kirk, Canavan, Beadle, David Menadue, John Daye, Bill Whittaker and I were to overlap, align, disrupt and be debated by many, even amongst ourselves. Nevertheless, the one uniting theme was that we had all truly nailed our colours to the mast as treatments advocates and/or educators.

It was a period of emotional investment – investment that would galvanise the PLHIV community response to determine and pronounce their ownership over what treatments meant and how to engage with that. I often thought that the very word ‘treatment’ was the Shiboloth of the period, used to mark how you understood each other, the rest of the response, the successes, advances ahead, and how to determine the deficits and challenges still to be fought.

While we were invariably described as treatment optimists, zealots (amongst other terms) in fact I think the nuances were not as simple. In truth, the underlying drive was to focus on what would give people the best outcome not just in terms of their lab results, but in terms of their capacity to pull back from the brink, and feel that lives could have more options.

This period saw access programs that were providing drugs for AIDS Dementia Complex as a matter of emergency, even while others in so-called ‘advanced stages of disease’ were waiting for salvage therapy. We were running roadshows promoting access programs while waiting for regulatory processes, and also supporting large studies to capture as much information as possible on the as yet unknown manifestations of the next phase of longer-term side effect issues and toxicities. We were headed into the new phase of what it meant to be living longer with the first generation of drugs that would buy time, but with heavy burdens on already frail bodies.

Treatments was at once personal and political, and I would find myself in a room talking to groups about how to camouflage the flavour of a particular drug by coating your mouth with peanut butter and then I would demonstrate swallowing the liquid (as it was then); then in another room hosting one-on-one sessions where every second question was not about the how, or which pill, but how much time would taking the drugs buy a person in reality?

It was a new impetus, not just in an individual life sense, but also in the very essence of how the PLHIV sector response could determine itself by clearly demanding what it wanted, how much faster, or better it wanted it, and if there were impacts – what was acceptable. NAPWA endorsed the ATPA to take on another national roadshow in 1999, following the success of the pilot treatments roadshow it had run in 1997.

These series of travelling HIV treatment information sessions, known as Roadshows, were held in rural towns and urban centres across Australia. They were a unique approach to treatments education, which had not before existed in Australia. The aim of these was to bring important, accurate and up-to-date HIV treatment information and discussion of health management issues for people living with HIV, and service and health care workers in the community. Initially there was a need, which was not met by other HIV sector organisations – and the roadshows really hit the target.

The assumption underlying the strategy was that effective information delivery from a credible and accessible source would influence treatment behaviour with the aim to either correct or reinforce health knowledge. The objectives were to provide PLHIV with the most recent information on HIV treatment options and to inform some of the most recent understandings of pertinent issues of the moment.

I remember 1999 as also the year when Michael Hurley was based at AFAO as a researcher in residence and researching then current practices in Treatments Education. His work with a number of community players of the time highlighted how much work was done across peer support, information and positive education domains under the notion of ‘treatments’ focus. This work was important because it brought out in the open that there was not a coherent national set of practices or even consistent messages, but that in fact it was the treatment officers and PLHIV activists who were actually the hands-on supports for translating activism wins into life impacts. It motivated us to be more dogged with the work of leading the

treatments advocacy successes into the implementation and promotion of treatment uptake and experience for people across the country.

By 1999, the membership of AFAO put motions to the floor of their Annual General Meeting, which agreed to affirm the centrality of HIV-positive people in the response to HIV. In 2000 this was followed up through action including the transfer to NAPWA of specific projects – the national Treatments Officers Network (TON), the national Treatments Policy group, and the transition of the publication *Positive Living* to being a publication managed by NAPWA.

NAPWA had also negotiated with the Commonwealth Department of Health to evolve from an auspiced project of AFAO to a separate organisation responsible for its own resources and projects. Part of that transition included recruitment for a full-time Executive Officer to replace the national coordinator position, and which continued my ongoing work within the organisation that lasted until mid-2014 – a full innings of 16 years.

NAPWA put efforts into access issues, and clinical research commitments and drug pipeline forecasts, and the focus was strongly centred on treatments and promotion of same. There was an investment in being expert and being strong advocates at all levels and internationally. This also meant advocating amongst the community sector, which continued to contest what post AIDS meant, and how to understand community engagement and leadership across the various tribes.

In our work strong bonds were forged with individuals within the clinical research and pharma sectors. These partnerships and friendships burgeoned into support for NAPWA and its member organisations by way of collaborations within our programs, in our advocacy agendas being met, and in time and funds provided to the body positive initiatives. There were some hard scraps along the way, fought out in forums and across tables and in the media. We danced across alliances that sometimes shifted according to the issues but we had many wins and we had envious looks from international colleagues working amongst larger populations, or more fragmented community structures.

Since 1998, further diverse activities and initiatives carried out by the ATPA, which later morphed into the Treataware project, were Local Community HIV Treatment forums, Short Courses in HIV Medicine, Social Educator Training, facilitating the Treatments Officers Network (now the Treataware Outreach Network), advocacy around scientific research, clinical trials and special access schemes, and factsheets for PLHIV.

Of course, NAPWA was much more than treatments advocacy, and surged ahead from 2000 with newfound Commonwealth funding agreements and projects under an HIV Living banner, as well as delivering biennial conferences, and other agendas, but there was always work progressing to reach the next new paradigm of treating, towards a cure, or towards a better way of improving access to treatments and care. Fast forward to 2013 – when Poz Action was described and launched in a NAPWHA symposium at the 2013 ASHM Conference, and where we participated in several other sessions devoted to clinical management or experience.

There is so much more that could be covered – but there are other sources and other perspectives. The following quote from Japanese writer Haruki Murakami seems particularly apt:

Writing from memory like this, I often feel a pang of dread. What if I've forgotten the most important thing? What if somewhere inside me there is a dark limbo where all the truly important memories are heaped and slowly turning into mud?

The dying finally slowed, and the response continued with new focus because there was the next era to reach. The treatments response would continue as we saw the growing PLHIV population create another chapter to tell.

# Declaration of Rights

## FOR PEOPLE LIVING WITH HIV/AIDS

### Life • Love • Participation

The National Association of People Living with HIV/AIDS (NAPWA) is Australia's peak non-government advocacy organisation representing PLWHA community based groups from each of Australia's States and Territories.

**W**ORLDWIDE, approximately 40 million people live with the human immunodeficiency virus (HIV), which causes AIDS. Half of all adults living with HIV/AIDS are female and in sub-Saharan Africa, the most affected region, the figure is nearly 60 per cent<sup>1</sup>. Twenty million people have died from AIDS since the first cases were identified in 1981. More than 14 million children have become AIDS orphans, and despite antiretroviral therapy that has significantly reduced AIDS-related deaths, the HIV population has expanded alarmingly, increasing by more than 50 per cent since 1991<sup>2</sup>.

The need to find effective ways to deal with the transmission of HIV, in all nations, rich and poor, is now greater than it has ever been. And with more people living with HIV than at any time in our past, the need to protect their health and human rights is also greater than it has ever been.

Human rights are fundamental to the response to HIV, for three reasons: *ethical*, because all human beings have a right to health, to life and all other human rights; *legal*, to implement the International Declaration on Human Rights and the many other international and national laws and guidelines on human rights, and for *pragmatic* reasons, because it is beyond doubt that a human rights based response, which empowers our whole community to avoid infection, and which treats those with HIV with respect and inclusion and aims to properly manage their health, is significantly more effective in reducing the spread of HIV than a response of silence, discrimination or exclusion<sup>3</sup>.

The Rights we now declare uphold not only the rights of those with HIV and AIDS, but are made for the greater good of our community in their promotion of its ethical and physical health. These Rights implement the self-evident precepts, embraced in international law, ethics and basic common sense, that no one human is more human than another, that no one human being has more worth than another, and that all human beings have equal human rights.

These Rights are declared to improve the quality of our *Life* and the *Life* of the community at large. They are centred in *Love*, as this is the ultimate foundation of all human rights. They will be carried out through our *Participation* in all aspects of the consultative and decision making processes in relation to them.

These Rights are firmly anchored within existing human rights laws and guidelines, and adopt, in large measure, the *International Guidelines on HIV/AIDS and Human Rights* of the United Nations Commissioner for Human Rights (ONHCR) and the *Joint United Nations Program on HIV/AIDS* (UNAIDS), revised in 2002 after extensive worldwide consultations and chaired by eminent Australian jurist, Mr Justice Michael Kirby<sup>4</sup>.

We, the peoples in Australia living with, and affected by HIV/AIDS, through our National and State representative bodies, CONFIRM our Right to Life, Health and the other Rights enshrined in the *Universal Declaration of Human Rights*, and DECLARE, for ourselves and for the good of our Society in general, our RIGHTS as follows:

**1 (Full Rights)** The full complement of human rights under international law, those most relevant to HIV/AIDS -including the Right to:

- life
- participate fully in public and cultural life, including freedom to practice spiritual and cultural beliefs
- share in scientific advancement and its benefits
- freedom of movement
- freedom of association
- marry, form relationships and have a family
- a reasonable standard of living
- be free from torture and cruel, inhuman or degrading treatment or punishment.
- liberty and security of person
- the highest standards of physical and mental health
- non-discrimination, equal protection and equality before the law
- freedom of opinion and expression
- privacy and confidentiality
- work
- equal access to education
- social security, assistance and welfare
- seek asylum

**2 (Co-ordinated Response)** The Right to a coordinated and effective response from all levels of government in Australia to the HIV/AIDS pandemic.

**3 (No Discrimination)** The Right to live free from harmful discrimination or stigma which in any way relates to our positive HIV status, and to be treated with respect and dignity.

**4 (Sex)** The Right, as consenting adults, to a full and satisfying sex life.

**5 (Participation)** The Right to:

- participate at every level of consultation, decision making and implementation regarding HIV/AIDS advice, policy, laws, treatments, funding, research, education, resourcing and financing, and all other matters relevant to the HIV/AIDS response;
- be represented in the governance of all organisations that are involved with HIV/AIDS or which provide any service in that regard; and
- form autonomous, self-governing organisations of people living with HIV/AIDS and for those organisations to be consulted and listened to in all levels of HIV/AIDS decision making.

**6 (Testing)** The Right to confidential and comprehensive pre- and post-test counselling and to give informed consent. The Right to HIV testing and monitoring without coercion. This includes an enabling environment for the upholding of privacy and the protection of confidentiality.

**7 (Treatment)** The Right to the highest quality and standards of specialist medical treatments of our choice. The Right to refuse treatments if we so choose.

**8 (Care)** The Right to any quality and specialist medical care, palliative care and support services suitable and acceptable to the individual including:

- the Right to life-saving and life-prolonging health care;
- the Right to have our psycho-social needs addressed as well as our biomedical needs, and in particular, the Right to quality and specialist psychological and mental health services;
- the Right to make fully informed and voluntary decisions about our participation in clinical trials, to access quality care regardless of our agreement or refusal to participate in HIV/AIDS research;
- and in each case we have these Rights without regard to our ability to pay or the absence or type of health insurance and coverage.

**9 (Medications)** The Right to access HIV/AIDS medications and treatments as and when we need them, and regardless of our capacity to pay. This includes the Right, protected through legislation, to access and advocate for new and emerging medications, as clinically necessary and through emergency access measures.

**10 (Family and Relationships)** The Right to marry, to form and maintain family and partnership arrangements, and care arrangements as we choose, including:

- the Right of HIV positive women and HIV positive men to have children and to make fully informed decisions in that regard;
- the Right to adopt children, and to maintain custody of our own children; and
- the Right to require that Australian Governments protect and promote these Rights in the legal system and create supportive and enabling environments for women, men, children and the family and the partnership arrangements we have described herein.

**11 (Housing)** The Right to acceptable standards of housing, including the Right for people with life-threatening HIV/AIDS to have priority access to public housing.

**12 (Education)** The Right to education, at all levels within the community, unrestricted on the basis of HIV status.

**13 (Prisoners)** The Right to community standard health and treatments for those with HIV/AIDS in custodial settings. The Right to health for those in custody. This includes the Right to access, treatment prevention technologies, condoms, clean needles and the like free of charge.

**14 (Injecting Drug Users)** The same Right to health as any other Australian. Access to programmes which protect the health of people who inject drugs and reduce HIV transmission (such as needle syringe programmes, substitution and rehabilitation therapies) are a human right. Laws must be enacted by Australian Governments to protect that right and in so doing the public health of the community.

**15 (Indigenous)** The same Right to health as any non-indigenous Australian, and the same Right to the same standards of health as any non-indigenous Australian, delivered in a culturally appropriate way, which reflect the differing and particular needs of indigenous Australians.

**16 (Multicultural)** The Right to receive all information and services, and to attain all of the Rights which we now declare, provided in a culturally acceptable manner and spoken and written in the language of their choice, and through an interpreter if necessary.

**17 (International)** The Right to require that all governments, organisations, corporations and other bodies in Australia share their knowledge and experience regarding HIV/AIDS issues and promote and protect our Rights at the national and international level. This includes the fulfilment of Australian international commitments through specific HIV/AIDS programs and in the programs of all groups involved in the Australian international HIV/AIDS response.

**18 (Freedom of Movement)** The Right of people living with HIV/AIDS to freedom of international movement and migration privilege, as accorded any other individuals. This also includes the Right to seek asylum and not be refused on the basis of their HIV status.

**19 (Death)** The Right to die with dignity and in the manner the individual chooses.

**20 (Implementation)** The Right to secure, through policy and legislation, protection in both the public and private sectors for those with HIV/AIDS. This should be achieved through enforceable codes of conduct and professional practice.

**21 (Accountability and Enforcement)** The Right to require that Australian Governments enact and adopt monitoring and enforcement mechanisms to implement our Rights, with appropriate penalties where that is not done, together with affordable and effective administrative and civil remedies to enable and ensure our Rights are appropriately enforced. The Right to require Australian Governments to review, enact and reform legislation to protect and promote each of our Rights which we now declare.

*Declared* by people in Australia living with HIV/AIDS, through their National, State and Territory representative bodies at the Tenth Biennial NAPWA Conference, Adelaide, South Australia on Friday November 18, 2005.

<sup>1</sup> United Nations Population Fund, International Conference on Population and Development, Program of Action, September 1994 <sup>2</sup> UNAIDS 2004 Report on the Global AIDS Epidemic, July 2004. <sup>3</sup> Dr Peter Piot, UNAIDS Executive Director, Speech to the 59th Session of the UNHCR, Geneva, 19 March 2003; see also Ralf Jürgens, Human Rights for People Living with HIV/AIDS, Partnership to fight HIV/AIDS in Europe and Central Asia, Dublin, 24 February 2004, with numerous references. <sup>4</sup> UNAIDS and UNHCR, HIV/AIDS International Guidelines on HIV/AIDS and Human Rights 1998.

The Australian HIV Observational Database Temporary Residents Access Study (ATRAS)

UNSW napwa national association of people living with hiv/aids

### Conduits & Continuity Bridging the Gaps for HIV Support

**NEW NILES ANTONY**  
The new Niles Antony is a young man who has been living with HIV for several years. He is a member of the National Association of People Living With HIV/AIDS (NAPWA) and is involved in various community activities. He is a strong advocate for HIV support and is currently working on a project to improve the lives of people living with HIV.

**TREATWARE OUTREACH NETWORK**  
The Treatware Outreach Network is a national network of HIV support services. It provides a range of services including counseling, support groups, and access to HIV testing. The network is made up of over 100 organizations across Australia and is committed to providing high-quality, evidence-based HIV support services to all people living with HIV.

**IN PINK**  
The In Pink campaign is a national awareness campaign for HIV. It aims to reduce the stigma associated with HIV and to encourage people to get tested for HIV. The campaign features a pink ribbon and the slogan 'In Pink, We're Stronger'.

**NANA BRUCE**  
Nana Bruce is a young woman who has been living with HIV for several years. She is a member of the National Association of People Living With HIV/AIDS (NAPWA) and is involved in various community activities. She is a strong advocate for HIV support and is currently working on a project to improve the lives of people living with HIV.

**LAUREN**  
Lauren is a young woman who has been living with HIV for several years. She is a member of the National Association of People Living With HIV/AIDS (NAPWA) and is involved in various community activities. She is a strong advocate for HIV support and is currently working on a project to improve the lives of people living with HIV.

**WILLIE**  
Willie is a young man who has been living with HIV for several years. He is a member of the National Association of People Living With HIV/AIDS (NAPWA) and is involved in various community activities. He is a strong advocate for HIV support and is currently working on a project to improve the lives of people living with HIV.

**THE WAIT IS OVER**  
The Wait is Over campaign is a national awareness campaign for HIV. It aims to reduce the stigma associated with HIV and to encourage people to get tested for HIV. The campaign features a white ribbon and the slogan 'The Wait is Over'.

**GETTING THE BEST HIV CARE**  
Getting the Best HIV Care is a national awareness campaign for HIV. It aims to reduce the stigma associated with HIV and to encourage people to get tested for HIV. The campaign features a green ribbon and the slogan 'Getting the Best HIV Care'.

pozhet events

mixed events  
women's days  
african women's days

Getting the best HIV care

A CAMPAIGN FOR THE NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS

An end to stigma

The stigma of HIV is something we can live without. And both your body and your mind will thank you for it.

We need to hear from all areas of people about what is needed to be positive.

Help you can work to overcome. Log on to [www.hivstigma.net.au](http://www.hivstigma.net.au) and complete the online survey.

This research is being conducted by the National Association of People Living With HIV/AIDS and the National Centre in HIV Social Research. It is the first step in a program of activities aimed at putting an end to the stigma of HIV.

If you're living with HIV, start a treatment conversation with your doctor.

THE WAIT IS OVER

IF YOU HAVE HIV YOU CAN NOW CHOOSE TO TREAT EARLIER.

TREAT EARLY. STAY HEALTHY. PROTECT YOUR PARTNERS, TOO.

SPECIAL REPORT

# benchmarks towards a better place

HIV Living Unit  
December 2007

NAPWA National Association of People Living With HIV/AIDS

The Art of Living PROCEEDINGS OF THE 9th NAPWA BIENNIAL CONFERENCE

HILTON HOTEL, CAIRNS QUEENSLAND  
OCTOBER 27-29, 2003

"The addition to be alive..."

napwa

national association of people living with hiv/aids

napwa

national association of people living with hiv/aids

NAPWA MONOGRAPH 2009

The Criminalisation of HIV Transmission in Australia: Legality, Morality and Reality

napwa



# Meaningful Solutions: The Turning Point

2000-2014

*NAPWA was very conscious of, and wanted to be about, working with and for all people with HIV. It was during this time that a new national HIV-positive women's network was established . . . in 2003, the Indigenous network was established. And NAPWA also did important work in Papua New Guinea and in East Timor . . . The NAPWA board, staff and volunteers also worked tirelessly in occasionally fractious but ultimately incredibly productive partnership with clinical researchers and doctors. We had input into research priorities, the design of clinical studies, and helped shape the delivery of primary care, integrating the perspective of people living with HIV into these models in a unique way that has happily had influence in other areas of health and illness.*

**Kirsty Machon**

## IN THIS SECTION

**Edwina Wright** *They sang out loud*

**Graham Brown** *Harnessing community mobilisation*

**Dermot Ryan** *Having a life, in our words*

**Lisa Bastion** *But things are different in Western Australia!*

**Peter Watts** *Advancing the cause of better treatment outcomes*

**Glenn Flanagan** *HIV-positive people central  
to campaign developments*

**Paul Kidd** *Hobart 2005, HIV-positive people making  
another big impact*

**Peter Canavan** *What good advocacy can achieve*

**Cameron Cox** *Sex workers fighting battles against stigma*

**Robert Mitchell** *NAPWHA responding to a changing epidemic*

**PATSIN** *We are here, right cross Australia*

**Neil McKellar-Stewart** *From Alice Springs to  
Northern New South Wales*

**Tim Leach** *Partnership work with Igat Hope in Papua New Guinea*

**Bill Whittaker** *Drug approval and clinical trials systems*

**Kirsty Machon** *Health and treatments policy work at NAPWA*

**Adrian Ogier** *Improving treatment knowledge of  
HIV-positive people*

**Max Niggl** *Positive speakers, the human face of HIV*

**Katherine Leane** *Journeying with NAPWHA*

## INTRODUCTION

From 1996 onwards, people with HIV were living longer and living well, so this period of HIV health and treatments could be called 'the proving ground', following the previous 'testing ground' era. By 2000, effective triple-combination drugs had now been in use for some years. First-generation drugs such as AZT, 3TC, ddC and ddI were still in use, combined with Protease Inhibitors (PIs). Sensibly, trials were considered not to show their true benefit until longer-term use 'in the real world'. The experience with combination HIV treatments reinforced this point.

These first-generation HIV combination treatments had seen the advent of another era – the lipodystrophy era – marked by body fat redistribution, metabolic and lipid disorders; so people living with HIV were also now dealing with a new symptom – drug side effects, both short-term and longer-term. There were also the goals of improving CD4 counts using Interleukin-2 within the very large international ESPRIT and SILCAAT trials, which disappointingly were a failure in the long run, as was reported in 2009.

There was now a need to develop meaningful solutions in an ever-changing context, which included funding changes in the Howard years. So maintaining a partnership across community organisations, people living with the infection, health services, public health officials, law enforcement, political parties and activists, researchers and clinicians was not an easy task; and it was tested time and again.

Once again, adaptability in a rapidly changing context was at the forefront of NAPWHA's approach, when its member bodies voted to endorse changes to the Rules of the Association and a new model of governance. The new structure was to allow an enhancement to the NAPWHA representation of the diversity of HIV-positive lives and issues that existed within the Australian HIV epidemic.

As part of its concerns, NAPWHA made a written submission to the National Inquiry on Employment and Disability, which was examining the barriers faced by people with disabilities in seeking work, and issues for employers in recruiting, retaining or fully utilising employees with disabilities. Thus in June 2008, NAPWHA welcomed Australia's ratification of the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

Other issues that NAPWHA raised concerns about were stigma – psychological research on stigma had generated a great deal of evidence about the impact of HIV-related stigma on the physical health and psychological wellbeing of people living with HIV/AIDS. Also, NAPWHA had expressed its interest in, and concerns about, the issues of assessments for migration to Australia for HIV-positive people, and how this was dealt with.

Another major issue was the increasing number of criminal prosecutions of people living with HIV relating to HIV transmission. NAPWHA has been at the forefront of drawing attention to the fact that this stands outside of good public health practice, goes against partnership intentions of successive national strategies and is in fact a contrast to internationally endorsed recommendations about the role of law in HIV prevention.

While for many, being diagnosed with HIV during this period may not have been experienced as such a life-threatening event, sero-conversion still involved a period of intense, challenging and sometimes contradictory emotions. All kinds of support were still required; and one of these was support to continue life in a sex-positive way, and so AFAO and NAPWA worked together, providing information and advice for people with HIV in an affirming way through *HIV Positive Gay Sex*, a booklet for gay men and their partners, celebrating their rights to continue to have satisfying sex lives and intimate relationships. The need to bring people living with HIV back into the social and work arenas saw a range of programs introduced.

A series of conferences, organised by NAPWA in the first half of the decade, reflected the concerns of people living with HIV at the time, such as: How to continue to speak out and be heard? How to live artfully now that futures were opening up? What would be our place? So, in Melbourne in 2001 it was *Positive Voices*; in Cairns in 2003, *The Art of Living*; and in Adelaide in 2005 it was *Our Place, Your Place . . . In the Bigger Picture*.

In the bigger picture, NAPWA's advocacy for PLHIV continued; and NAPWA took this role seriously through a number of other initiatives such as conducting the first-ever National HIV Leadership Retreat held in July 2008. In late 2011, NAPWA changed its name to NAPWHA, to reflect, among other things, that the incidence of AIDS had significantly declined and HIV was now seen as the condition that was relevant for PLHIV in Australia.

**Edwina Wright**

## *They sang out loud*

People's footsteps trek in and out of medical clinics and hospital outpatients all over the world, every day. And it's likely that it is the people who sweep and wash the clinics' floors during the early evenings who best understand that a community has come and gone during the day. For in front of them, a doctor sees a person, not a community. And current best practice is for a doctor to attend to their patient as an individual and personalise their care as much as possible – thereby elevating them above the throng, making them stand out, clearing the airwaves so as to hear them, *non sotto voce*. This approach also strengthens the doctor's sense of being able to do something for the patient. Hence if this approach makes the patient feel at ease, equally it does so for the doctor.

And it's here that doctors can become lost and deaf, losing track of where and how that individual lives their lives when they turn on their heels, and go back out through the clinic door. When I was a first-year registrar at Fairfield Hospital, in Melbourne in 1990, I was astonished at how erudite and forward and purposeful were the Australian members of ACT UP! Nothing in my medical career had prepared me for it. They sang out loud, the song of their community. A song that all my patients had been silently singing as I assiduously personalised them and attended to their needs. But this artificial division between an individual and their community is as useful as straightening a broken bone and forgetting to put the plaster on. If I did not understand the world to which they returned, my treatments would ultimately fail, trodden on by the pacing boots of stigma, unfairness, ignorance (scientific included), lack of power and cruelty. And I had to learn that song very quickly, because (a) the song was about a world I had not experienced and (b) people were dying and needed to be understood, wholly. And people will always be dying and needing to be understood, wholly.

There is so much in medicine that one can simply never learn, but understanding how important the community's role is in providing the context and guidance on how to care for people living with HIV has been one of the most critical lessons in medicine for me. And it's been a lesson learned from a song I have very much come to love.

**Graham Brown**

## *Harnessing community mobilisation*

Meaningful solutions: the turning point is an apt term for the 2000 to 2014 period. The role of people living with HIV has always needed to be strong in the Australian response to HIV, and this period gave us many opportunities to show this. It was a period of new hope but also mixed with disinvestment and political neglect. In many ways it could be argued as a time of opportunities rescued.

I have been fortunate to be able to be open about my HIV status throughout this period. However, I did not see myself as speaking for PLHIV but bringing an HIV-positive perspective along with my other professional and personal experiences. I was one of many in the mix and was privileged to see the advocacy and leadership of PLHIV in full flight.

I recently co-authored an article identifying the learnings that broader health promotion and public health projects can take from the Australian response to HIV.<sup>1</sup> These learnings, I use as headings below, they provide a useful way to highlight the participation and leadership of PLHIV that I have seen throughout the Australian HIV response.

Australia's community response to HIV drew on the emerging frameworks of health promotion and empowerment; however, it was in the context of a community-led crisis response. It began as a mobilisation response in bars, lounge rooms and backrooms. As the response has grown and evolved, people living with HIV have maintained a central role; not just mobilising and advocating but as active partners in the response. Australia was fortunate during this period to have PLHIV organisations that could synthesise evidence from epidemiological, social and behavioural research along with the collective lived experience of HIV and the community response. This was coupled with the capacity to take bold steps when evidence was limited, and resist simplistic answers, ideology or discrimination being substituted for evidence.

### **Learning: Commit to social, political and structural approaches**

Since the beginning of the epidemic, community mobilisation in HIV was not only about changes in behaviour – it was also about changing laws and policies, improving health services, ensuring participation in quality research, ensuring a human rights-based response, and directly challenging prejudice, ideology and dogma that prevents effective health promotion. It is in these areas that the expertise and experience of PLHIV has been critical – not just achieving these changes but in many cases over this period maintaining these vulnerable wins.

**Learning: Build and use evidence from multiple sources to continuously adapt and evolve**

When HIV rates in Australia started increasing in early 2000s – but inconsistently across the country – it was unclear how and why these differences were happening. In the mid-2000s – for the first time in some years – the HIV partnership drew together and undertook an exhaustive examination of the epidemiological, social and behavioural research, policies, testing and treatment, and health promotion strategies and structures in order to understand what was happening in Australia and the state-based differences.<sup>2,3</sup> We saw the voice and perspective of PLHIV throughout the partnership loud and clear – not only from PLHIV organisations but also in other community organisations and in research. The debates were hard and perspectives clashed. However, the early years’ investment in challenging stigma across the partnership, and the commitment to the Greater Involvement of PLHIV (GIPA), meant that strong, thoughtful and articulate PLHIV voices were present and integral to this response. What the analysis found and what happened next is well documented elsewhere.<sup>1</sup> However, it was an example that evidence is critical – but it will not speak for itself or automatically translate into policy and practice without mobilised communities demanding and forming solutions. We are seeing this mobilisation again in response to the new opportunities and challenges we face today.

**Learning: Sustain participation, investment and leadership across the partnership**

The Australian HIV response has shown that sustained community-driven interventions working across multiple social, political, economic, behavioural and health service levels, operating within enabling social and legal environments, are the most likely to reduce the transmission and impact of HIV. However, maintaining a partnership across community organisations, people living with HIV, health services, public health, law enforcement, political parties and activists, researchers and clinicians is not easy and has been tested time and again. We have seen that the roles and contributions across our partnership are different and constantly evolving – but all important to achieve and sustain changes for our communities. When one part of our partnership is not able to fulfil its role, all our partners are affected.

In closing, people living with HIV have been a full and central partner in achieving policy reform; reorientation of health services; research investment; adaptations to new treatment and prevention science; challenging personal, social and structural level stigma, prejudice and discrimination; and boldness in the face of sensitivities and legalities around sex, sexuality and drug use. The Australian experience has shown that for HIV-positive people to have a strong, effective and central voice we need a strong, effective and resourced community sector for all affected communities. People living with HIV need allies and our allies need us.

## NOTES

- 1 Brown G, O'Donnell D, Crooks L, Lake R. 'Mobilisation, politics, investment and constantly adapting: Lessons from the Australian health promotion response to HIV'. *Health Promotion Journal of Australia*. 2014;25:35-41
- 2 Fairley C, Grulich A, Imrie J, Pitts M. Introductory Editorial: the analysis of a natural experiment in HIV control. *Sex Health*. 2008 Jun;5(2):89
- 3 NSW Department of Health. *Consensus Statement – A Think Tank: Why are HIV Notifications Flat in NSW 1998-2006?* NSW government, Available at <http://www.health.nsw.gov.au/sexualhealth/Documents/HIV-consensus-statement.pdf>, 2007.

## Dermot Ryan

### *Having a life, in our words*

It's our stories that make a difference to the lives around us, both of the people we know and those we don't.

In the early 2000s, staff in the AFAO NAPWA Education Team started a conversation about the differences for people diagnosed with HIV in the post-Highly Active Antiretroviral Therapy (HAART) era compared to those in the decades before. At the centre of these conversations was the need for HIV-positive voices to inform the narrative. 'In our words' was an important principle informing the way we practised health promotion. Based on a number of interviews undertaken with HIV-positive people diagnosed in both the pre and post HAART era, the *Having a Life* resource, started to take shape.

Informed by interviews, conducted during 2002 by Jill Sergeant and also by earlier work undertaken by Ross Duffin as a part of the Gay Education Strategies project, a natural structure for the resource started to materialise. What emerged was a rich description of the varied lived experiences of HIV-positive people. Positive people who participated in the development of the resource shared their insights into an 'HIV-positive' identity; coping with diagnosis; how to disclose and what to do when someone does it for you; looking after your health; dealing with treatments; the place of employment/family/lovers/partners and friends; the experiences of grief and loss; the joys of children and babies; as well as aspirations for the future.

The final result was a resource that gave priority to the voices and experiences of the people who had not just navigated and survived HIV, but who have learned to thrive again and were willing to generously share their collective experiences in the knowledge it would assist others.



**Lisa Bastion**

## *But things are different in Western Australia!*

There is often a wry smile passed between people at national meetings when a delegate from Western Australia (WA) inevitably states, “But things are different in WA!”

WA occupies the entire western third of Australia and has a land mass of 2,529,875 square kilometres. The state has a population of approximately 2.5 million people and 92% of the state’s population lives in the south-west corner of the state. The majority of the state is sparsely populated. Perth, the capital city, is one of the most isolated cities in the world. Providing equitable and accessible prevention, testing, and treatment and support services for at-risk or HIV-positive people living throughout WA is challenging.

HIV notifications in WA have been out of step with the Australian HIV epidemiology for the past six to eight years. The annual number of HIV notifications in WA more than doubled during the last decade, to 121 cases in 2012. From 2008 to 2012, heterosexual contact was the most common category (54%), followed by men who have sex with men (40%). This trend was not observed nationally. The increase in HIV notifications in WA was mostly attributed to the rise in the number of overseas-acquired HIV infections in people born overseas.

The character of the HIV-positive population has changed. The HIV notification data told that story. Clinicians have talked about the special needs and barriers to accessing treatment among overseas-born HIV-positive people. But the HIV data failed to tell the government what to do about the challenges faced by service providers, or how to reach and form partnerships with new and emerging populations and service providers.

The role and voice of the HIV-affected community has never been more important in WA because of the diversity of the HIV-positive population and the size of WA. New HIV prevention and education services have been embedded in community-based organisations that have not traditionally provided HIV or sexual health education and prevention services.

Safe disclosure of HIV status, and the fear and experience of stigma and discrimination is further complicated by migration status for many people. HIV status can threaten the pursuit of residency of people otherwise gainfully employed in WA. Community-based organisations and clinical services are vital in facilitating the narrative and context of people’s lives within the WA HIV response.

We all continue to learn from the changing partnership and lived experience of HIV-positive people in WA.

**Peter Watts**

## *Advancing the cause of better treatment outcomes*

I may rather call this period of HIV health and treatments ‘the proving ground’. By 2000, effective triple-combination drugs had now been in use for some years. First-generation drugs such as AZT, 3TC, ddC and ddI were still in use, combined with protease inhibitors or non-nucleoside reverse transcriptase inhibitors. Trials were (and still are) considered not to show their true benefit until longer-term use in the real world (outside of trials). The experience with combination HIV treatments reinforced this point. These first-generation HIV combination treatments saw the advent of another era – the lipodystrophy era – marked by body fat redistribution, metabolic and lipid disorders. PLHIV were also now dealing with a new symptom – drug side effects, short term and longer term.

In the absence of a cure for HIV, it was initially thought we could ‘treat our way out of HIV’ – this strategy was eventually considered futile due to HIV ‘seeding’ of the viral reservoirs (where ARV treatment could not reach). Thus the need to treat HIV life-long, using current therapies, but in order to mitigate life-long exposure to HIV treatment side effects, researchers turned their attention to Treatment Interruption studies. Many formulas were tried, both CD4 count-guided treatment breaks and time-guided breaks (e.g., week on week off, so-called WOWO study). In all cases virus re-emerged from the reservoirs, albeit somewhat more drug sensitive. The largest of these studies was the SMART study, which included a number of Australian sites, and which cycled people on (below 250 CD4s) and off (above 350 CD4s) treatment, compared to people who continually stayed on treatment. The result was internationally well known – i.e., the SMART study was not so smart after all, as the trial was halted due to increased deaths and morbidity off treatment. From there on, the benefits of HIV treatment were proven to outweigh the risks.

Not until the advent of better, less toxic, more tolerable second-generation HIV drugs and new drug classes, was lipodystrophy easier to overcome. Many counter-therapies were tried and researched in Australia (and internationally), but all failed or offered limited success, such as rosiglitazone, leptin, etc. The best, although a cosmetic correction rather than therapeutic reversal, for facial lipoatrophy was Newfill (now called Sculptra). This injectable cosmetic facial filler remains available today, and is funded in Australia for PLHIV to access, after long policy and advocacy work from NAPWHA in this period to ensure its availability and subsidised affordability. It is particularly useful for those living long-term with HIV who have not been able to reverse the effects of their former drug therapies, which drove the development of lipodystrophy. Australian researchers were leaders in the field of lipodystrophy – ‘The Lipodystrophy Case Definition’, by Adam Carr and others, was

published in *The Lancet* 2003 to help improve clinical assessment of its prevalence, risk factors, pathogenesis, prevention and treatment. Fortunately, the latest HIV drugs contribute far less to this syndrome, and older treatments have slipped from the foreground of the Australian treatment guidelines for this reason – and for reasons of better efficacy and higher resistance barriers among newer drugs and simpler combinations.

Lipodystrophy in this period also had great social impact for those living with HIV. It was difficult to conceal and therefore imparted a level of unwanted disclosure that created further difficulties for the community of PLHIV, bringing about a level of discrimination through ‘sero-divide’ within the gay community in particular.

Prevention of lipodystrophy was a mainstay in this period, assisted greatly by the arrival of newer second-generation drugs, which were less toxic to the mitochondria (thought to be a causal mechanism of lipodystrophy). Along with new drugs and classes, also came ‘the lifestyle era’ of HIV – one in which much education and campaigning was developed nationally and within states and territories. Proper diet, exercise and quitting smoking became the new catch-phrases of these campaigns (e.g., the Queensland Positively Quitting project and campaign). Not only was muscle fitness and improved lifestyles (including quitting smoking) thought to combat (at least mask) lipodystrophy effects, these approaches were also given new emphasis in this present period for managing other HIV co-morbidities such as bone health and cardiovascular health, particularly as people now can be expected to live a long life on HIV treatment. Thus quality of life gained from healthy lifestyle has been the great focus of the last decade in HIV health promotion.

We also recall the goals of improving CD4 counts in this period using Interleukin-2 (IL-2) within the very large international ESPRIT and SILCAAT trials, which disappointingly were a failure in the long run. The work of this period in Australia meant assisting many people involved in these trials at Australian sites, particularly in overcoming the harsh side effects of this treatment. IL-2 was deemed to offer no additional benefits over existing ARV therapies.

But have the newer more effective next-generation treatments done their job – are they ideal yet? Changes in pill count and dose frequency have been the great hurdle since 1996. In 2014, HIV treatment can be as simple as one pill once a day (single-tablet regimens); but for many – especially those who have been on treatment long term – it can still be as complex as four or five pills per day, and side effects are still not ideal. Advancing the cause of better and newer treatment outcomes remains the focus until a cure and vaccine exists, along with the Australia-wide goals of reducing new infections using current behavioural and biological prevention efforts.

### **Australia's HIV Treatment Timeline 2000-2014**

- 2000 Efavirenz (EFV)  
Abacavir (ABC)
- 2001 Trizivir (ABC/3TC/AZT)
- 2002 Kaletra (LPV/r) soft capsule twice daily dosing  
Note: 2006 change to tablet (ME-Meltrex) formulation  
Amprenavir  
Note: 2004/2005 change to fosAmprenavir formulation  
Tenofovir (TDF)
- 2004 Atazanavir  
Fuzeon (T20)
- 2005 Kivexa (ABC/3TC)  
Emtricitabine (FTC)
- 2006 Truvada (TDF/FTC)
- 2007 Tipranavir (TPV)  
Darunavir (DRV)
- 2008 Raltegravir (RAL)
- 2009 Etravirine (ETV)
- 2010 Atripla (TDF/FTC/EFV)  
Maraviroc (MVC)
- 2012 Nevirapine XR (once daily)  
Ralpivirine (RPV)  
Eviplera (TDF/FTC/RPV)
- 2014 Dolutegravir (DTG)  
Stribild (TDF/FTC/ELV/COBI)

### **Glenn Flanagan**

## *HIV-positive people central to campaign developments*

From 2000 to 2003 many positive people who had earlier retired were thinking about returning to work. Many were worried about the risks involved, felt unconfident about their skills or what would happen if they became unwell. Computers had also transformed many workplaces, just after some had left the workforce. We ran a project at PLWHA NSW called Positive Decisions, which gave people with HIV a safe space to explore being back in a workplace, learn new skills and build networks and confidence. Many community organisations came on-board with us to offer positive people placements and a chance to take a new risky, but

very hopeful step in life. A number of people found a pathway to meaningful work and occupation with the support of an organisation of positive people responding creatively to the changes of the epidemic.

### **Survival**

Poverty and the impact of health on quality of life were also significant challenges for people with HIV after 2000. Many of us are living well and living longer, working and having lives that we could only have dreamed about a few years earlier. Some of us, however, are living longer in material poverty, impaired health and struggling with loneliness and with memories of loss and grief. Survivors are due respect, understanding and support, and the work of NAPWHA's Care and Support Portfolio played an important role in this period to ensure those of us who are vulnerable are not forgotten, and appropriate supports are in place. This advocacy work should not be forgotten.

### **Invisibility**

This was also a time when people talked about HIV-positive people becoming more invisible in the broader community. Maybe that's understandable – many of us experienced our lives and our futures being given back to us. An HIV diagnosis no longer seemed to be a death sentence, and many felt we could manage it as just a part of our lives. The need to talk about it to the others in our lives became less urgent for many of us.

### **Health promotion**

At the same time as people talked about the increased invisibility of HIV-positive people, HIV-positive organisations became much more active in health promotion and education. There was an amazing increase in energy, creativity, ideas and arguments at this time, which for me feels around 2002-2007. Positive organisations shifted focus and resources. The contribution of HIV-positive people to HIV prevention was recognised as central. None of this came without debate and controversies. There were arguments about whether positive organisations should even be in this space. But like earlier challenges in the epidemic, we just did it and people with incredible skills worked on many impressive campaigns that involved HIV-positive people at every stage of their development.

**Paul Kidd**

## *Hobart 2005, HIV-positive people making another big impact*

First published in *Positive Living* October-November 2005

The annual conference of the Australasian Society for HIV Medicine (ASHM) was held in Hobart, Tasmania on 24-27 August 2005.

Bringing together clinicians, medical scientists, social researchers and community representatives, this annual conference is Australia's de facto national AIDS conference. While it may not boast the cutting-edge science, celebrities and hoopla of an international event, its capacity to bring current issues home to an Australian context makes it a key part of the calendar.

This is the first time that the ASHM Conference has been held in Hobart but, as NAPWHA President Gabe McCarthy noted in the opening session, the city was the host of one of the landmark events in Australia's HIV/AIDS history – 1988's Third National AIDS Conference.

On the last day of that historic conference, a group of positive people took to the stage and publicly announced that they were HIV-positive and would no longer remain invisible. This brave and extraordinary step, following several days of sometimes bitter and acrimonious debate, is widely seen as the birth of Australia's PLWHA movement.

It was fitting, then, that in Hobart in 2005, people living with HIV/AIDS made perhaps their biggest impact yet on the ASHM conference, with a variety of presentations focusing on research, health promotion and the lived experience of people living with HIV/AIDS.

Named in honour of a former president of NAPWHA, the Phillip Medcalf Memorial Symposium was a highlight of the conference.

NAPWHA treatments spokesperson John Daye gave an enlightening presentation on salvage therapy, reporting back from a workshop convened by NAPWHA's Treatments Policy Group.

A key issue here is the difficulty in defining just what 'salvage therapy' is. "There is no moment when drugs stop working," he said, "and no magic spell to recite when they do."

Outlining the various strategies being used by clinicians, Daye spoke of the tendency towards "buying time" for people with limited treatment options and the challenges that creates for them. There is a need to think strategically, and to strengthen relationships between positive people, treatment advocates, industry and the researchers, he said.

A presentation from Kathy Petoumenos on the Australian HIV Observational Database looked at the causes of death among people living with HIV/AIDS in

Australia. While deaths from AIDS-related causes have declined among HIV-positive people in Australia since the advent of HAART, positive people are at higher risk than the general population from non-AIDS-related causes.

Of the 105 deaths recorded in the database between 1999 and March 2004, 42 (40 percent) were from HIV-related causes, 55 (52 percent) were non-HIV-related and 8 were unknown. Major non-HIV-related causes of death included cancers, cardiovascular disease and liver failure, and were more common in people with advanced HIV disease.

Stephen Gallagher of ACON gave a thoughtful presentation on levels of HIV treatments literacy among people with HIV/AIDS. Looking at enquiries from positive people to ACON's treatments information service and issues raised at 'Genesis' workshops for people recently diagnosed with HIV, Gallagher identified several areas where misconceptions seem to be occurring.

While it's to be expected that recently diagnosed people will have difficulty assimilating a broad range of treatments information, Gallagher also noted that many people diagnosed less recently need to be updated on more recent developments – much of their knowledge is out of date by 5-10 years, he said.

Brent Allan of the Victorian AIDS Council looked at the changing role of Positive Living Centres, and presented the results of a 'Snapshot Survey' of the Melbourne PLC. Positive Living Centres are "not so much buildings but spaces," Allan said, and outlined the ways in which these services support people with HIV, especially those with complex needs.

A similar theme was picked up by John Hall, also of the Victorian AIDS Council, in a poster presentation on housing and HIV. Hall noted that as many as 20 percent of the Melbourne PLC's membership had inadequate, transitional or otherwise unsuitable housing. Hall presented a number of case studies outlining the negative consequences of inappropriate housing.

Echoing Stephen Gallagher's call to "not forget the small stuff," Hall's presentation called for a 'back-to-basics' approach to health management for positive people.

NAPWHA President Gabe McCarthy presented an oral poster, which canvassed the concerns of positive women about antenatal testing for HIV. Traditionally, HIV testing for pregnant women has been guided by a risk assessment, but more recently there have been calls for a switch to routine testing of all pregnant women. McCarthy argued that the complexity of the issue means that positive women must be consulted before any change of policy.

The issue of organ transplants for people with HIV/AIDS was discussed in a lively debate. While in the past people with HIV had been excluded from consideration for organ transplants, with improving HIV treatments this is now changing.

Francesca Torriani of the University of California argued that having HIV should not prevent people from receiving organ transplants, and outlined the increasing need for these. End-stage liver disease is now the biggest killer of people with HIV/AIDS in the US, where a large proportion of the HIV-infected population is

also infected with hepatitis C.

In Australia, by 2015 about 20,000 people will have hep C-related cirrhosis and about 10 percent of these will need liver transplants, she said. Evidence from the US has shown that people with HIV respond well to transplants, with comparable survival rates to their HIV-negative counterparts. "There's no reason not to transplant into HIV patients if their HIV infection is well controlled," she said.

Ed Gane, director of the New Zealand Liver Transplant Unit at Auckland Hospital, presented the opposing argument. Decisions about transplantation should be made on the basis of the best-possible utilisation of available resources, he said. While kidney transplants to positive people had generally good outcomes, he pointed out that in HIV/HCV coinfecting patients, hepatitis C becomes much more aggressive following liver transplantation. The focus should be on hep C treatment, not transplants, he argued.

Marina van Leewuen of the National Centre in HIV Epidemiology and Clinical Research presented some preliminary data from a study looking at the prevalence of anal cancers in homosexual men. These cancers are quite rare but occur about twice as often in gay men compared with the general population. The aim of the study is to determine the rates of anal squamous intraepithelial lesions (ASIL), a precursor to anal cancer that can be detected via pap smears. The study will enrol 200 HIV-negative and 125 HIV-positive gay men.

The preliminary results, based on a subset of the data, found that the prevalence of ASIL was significantly higher among HIV-positive men (62 percent versus 28 percent). While these results are obviously of concern, they don't necessarily mean higher rates of anal cancer in positive gay men. The natural history of this disease is still not well understood and part of the objective of this study is to understand better the link between ASIL and anal cancer and the usefulness of smear tests as a diagnostic tool.

In a satellite forum entitled 'Drilling into the data', researchers from the Australian Research Centre in Sex, Health and Society discussed some new analyses of the data from the Futures 4 survey conducted two years ago. Marian Pitts looked at the impact of growing older on people living with HIV/AIDS. The majority of Futures respondents over 50 years old have at least one other major health condition besides HIV, she said. They typically have fewer treatment options and access HIV and non-HIV services less, and may have fewer sources of social and emotional support.

A session entitled 'HIV Research – Community Perspectives' generated a great deal of energetic discussion. John Rule from NAPWHA presented a thought-provoking paper looking at the relationship between the HIV community and the research sector. Kirsty Machon, also from NAPWHA, took the same theme a step further, asking how we can define the value of research and arguing that better research, not more of the same, is needed.

Bill Whittaker and Jo Watson presented an outline of a major discussion paper, developed by NAPWHA, which examines the impact of increasing complexity on HIV treatment, care, research and prevention. The paper argues that it is time to



rethink the model of HIV care in Australia to better serve the needs of positive people and support the clinicians who care for them.

With so much serious discussion, a NAPWHA-sponsored 'hypothetical' at the end of the second day brought much-needed comic relief. Entitled 'Future Shock', the scenario took a panel of medicos, researchers and positive people ten years into the future, to the year 2015. Advances in genetic modification had delivered a most unusual new HIV treatment, the panel was told – one that could be sexually transmitted.

The panel were taken out of their comfort zones and asked to consider how governments, researchers and pharmaceutical companies might grapple with such a frightening, yet captivating idea.

From 1988, when HIV-positive Australians first stepped into the public eye and demanded their voices be heard, to 2005, when we play key roles in Australia's HIV response, and forward into the disturbing but intriguing new world of 2105. Not bad for a few days in Hobart.

**Peter Canavan**

## *What good advocacy can achieve*

*Peter Canavan was the guest speaker at the Consumer Health Forums' Continuing Consumer Representatives Training workshop in May 2003. Peter spoke about the success of the HIV/AIDS consumer advocacy movement and what has been effective in the HIV/AIDS community sector response. This is the text of that talk.*

I have been asked to speak to reflect on some of the success of the HIV/AIDS consumer advocacy movement, and to share some thoughts on the elements of this approach that I believe are common to all consumer advocacy.

I want to start with a particular notion that sometimes gets called 'centrality of HIV people', but which really just means HIV-positive people being seen as crucial to the decisions that will affect our health and our lives: in policy, in research, and in the doctor's surgery.

Early in the epidemic, people with HIV coined the phrase 'talk with us, not about us'. There had been a lot of 'talking about'. In the media, people talked about us as either dying, 'innocent victims', or potential threats and dangers to public health and morality. At scientific conferences, people talked about us as a puzzling set of diseases and infections, but also as a kind of career move – solve 'positive people', and you might get the Nobel prize.

After a while, positive people, sick of being talked about, decided to intervene with an unambiguous message: these are our lives, our bodies, and our choices. So talk to us as if we matter. We are the reason you are here. In many ways, this approach has been the enduring hallmark of our response as HIV-positive advocates.

That it should be we, the people living with HIV and AIDS, who, where possible, represent ourselves, and speak for ourselves to government, in clinical research, or around any other table where significant decisions affecting our lives and health are likely to be taken.

From this approach, a consumer health movement would be born. It would be difficult, but exhilarating. The approach was radical. People with HIV formed support groups, and then action groups, and then activist groups, and insisted on being heard: in policy decisions, health planning, drug access, and trial design.

Having a central role in the planning and delivery of a national response to HIV/AIDS, the People Living With HIV/AIDS (PLWHA) movement has been well placed not only to advocate for better health rights for individual positive people, but to ensure public health funds and resources have been allocated in ways that are appropriate, focused and accountable.

At the beginning of the 1990s, it was people with HIV who, frustrated at the very lengthy delays in getting access to new and experimental treatments, were instrumental in bringing about the Baume Report, which radically altered the drug approval system, and led to the much more expedient availability of new and unapproved drugs. The HIV-positive community and our doctors also pioneered the use of Special Access Schemes, to allow people to access drugs not yet approved for marketing in Australia, as they made their way through the drug approval process.

More recently, positive people have been involved in all sorts of aspects of HIV health delivery, from prevention campaigns and information, through to working with pharmaceutical companies and lobbying the PBS to reach agreements about the costs of new treatments and get them listed on the PBS.

All of this didn't just 'happen'. It was a model without a real precedent in any other health area. It was also driven by some of the following, important environmental factors, which all came together in the formation of a new approach to health advocacy.

### **The strength of community-based political activism and lobbying**

HIV/AIDS disproportionately affects gay men in Australia, and continues to do so. In the 1980s and early 1990s, this was a community that saw itself particularly under threat, but which was also galvanised and mobilised politically – as a result of the direct struggles of the gay and lesbian liberation movement. During the late 1980s and early 1990s – a particularly harrowing time, with a great deal of loss and death – the community was able to focus this anger into the specific, highly political and extremely visible direct actions of the AIDS Coalition To Unleash Power (ACT UP). ACT UP used the media, public art, political demonstrations, and even civil disobedience to force issues such as access to treatments, public hospital underfunding, and the need to reform and speed up drug approval times into the spotlight.

### **The development of strategic networks**

The HIV-positive community worked tirelessly to convince government, clinical researchers, and industry that HIV-positive people not only could, but morally should, play a key role in decisions affecting their own health. Partnerships were formed. At first these were tentative and nervous. There was some mutual suspicion, and a sense of being off 'familiar' turf. Over time, however, the parties began to understand each others' unique perspectives, and to see the value of partnership between all those with a stake in the outcomes.

Recently, the deputy director of the National Centre in HIV Epidemiology and Clinical Research observed that the relationship between the clinicians, the research community, and HIV-positive people and their advocates, had grown stronger. It was based on mutual respect, not just tokenism. Positive people, he said, could answer the one question that researchers – understandably excited by the possibilities of science and new breakthroughs – often found hardest to focus on: Will this research be relevant to positive people? How will it affect real lives?

More recently, HIV-positive advocates have also developed important relationships with the pharmaceutical industry. It's often considered somehow uncomfortable to engage with industry, as they are so easily painted as 'the bad guys', or 'evil profiteers'. But drug companies and consumers do have mutual interests, in making drugs which work, and which can be used in the community in realistic ways. The more they know about the realities of people living with the diseases, which they may only see as a few statistics or a list of symptoms, the better the outcome for drug access, and for better-designed drugs.

### **The nature of the disease and the stigma of the epidemic in the broader community's mind**

HIV presented huge public health challenges and required large amounts of resourcing in prevention, education, treatment and in care and support. Not many people know that one of the most costly parts of the HIV prevention approach is needle and syringe exchange programs, but they are also widely acknowledged as the reason why Australia has such low HIV infection rates in non-gay communities.

But stigma, discrimination and misunderstanding were rampant in the early years of the epidemic. Community attitudes – including myths about HIV transmission and risk – created a genuine sense of crisis among positive people, who often felt they could not disclose their HIV-positive status for fear of losing jobs, families and friendships. This had to be dealt with because governments realised that these fears could potentially threaten the goal of a measured and informed public education strategy. 'Partnership' became the name of the approach. All stakeholders needed to collaborate, or be left behind from a coordinated delivery of interventions. 'Partners' included positive people, governments at all levels, scientists, doctors, health care workers: anyone, in other words, directly affected by, or affecting, the epidemic.

### **Individual responses**

This might all sound more organised than it actually was. The reality is that all this was carried in practice by a relatively small number of individuals, who saw a need to develop an organisational response that was identified as belonging to HIV-positive people, not the service providers, or the clinics.

This was not to take away the importance or need for such players, but to emphasise again the importance of a perspective coming directly from positive people ourselves – so that we could say clearly what we believed to be policy or treatment priorities.

As many of you would be aware, it is one thing to identify the need for a health consumer group, quite another to develop an organisational structure, which is resourced and effective, in a sustainable way.

When the organisation is one that is committed to a governance structure represented by the people living with illness or disease, it brings its own set of obvious challenges, which need to be effectively planned and accounted for.

### **What has been effective in the HIV/AIDS community sector response**

#### *Skills building*

The HIV/AIDS community sector, and others in the ‘partnership’, such as clinicians and industry, have invested heavily in the development of a sound base of community skills. Communities have worked in clinical research and trial design; been trained as public speakers and peer educators, or educators in schools. The sector has also developed sound skills in policy writing, workshop facilitation, and adult education, including the development and provision of resources and educational material specifically targeted to community and peer needs.

More recently, NAPWA has engaged in some specific training work for its members. Through its policy team, NAPWA has provided training packages for people representing the HIV community on the National Centre in HIV Epidemiology and Clinical Research, and developed a ‘demonstration project’ on research into practice, involving PLWHA South Australia, local SA service providers, and social researchers.

#### *Consumer representation*

PLWHA organisations have insisted on the importance and relevance of designated consumer positions on advisory committees, in clinical and social research, and in government policy. Although recruiting for, training, and maintaining these positions can at times be a hard ask, it is widely accepted by all those in the HIV partnership that a well informed consumer perspective adds substantive authority to an effective response. These partnerships are not always perfect, and the various points of view are often very different, but they have been extremely effective.

#### *Respect and ongoing liaison with primary health care providers (e.g. GPs), and other medical bodies*

Through organisations such as the Australasian Society for HIV Medicine, PLWHA

organisations have sought to develop strong relationships with health care workers dealing with HIV. Together, we have developed training and development packages for community, and participated in education programs for doctors and industry. PLWHA organisations and representatives routinely speak at HIV medical conferences, report back on international conferences, and provide advice on the development of consumer friendly patient information. Clinicians and health care providers sit on advisory groups for community based organisations, provide technical and medical advice for resources and educational material, and contribute to community publications, conferences or other meetings.

#### *A commitment to 'having a life', not just 'living with'*

The PLWHA movement has always been committed to the idea of living with HIV in ways that are not dominated or overwhelmed by the practicalities of managing HIV – that is, to encouraging life and living beyond doctors' surgeries, hospitals, or the requirements of welfare. The PLWHA community sector has seen this holistic approach as absolutely fundamental to the needs of positive people in the real, changing, and sometimes, uncertain environment in which our lives are lived.

#### *The media*

HIV advocates have always believed it is important that our issues maintain a profile in the media. This is not just about the public visibility of individual positive people, but is a real way of ensuring that the political issues affecting positive peoples' lives, and indeed, the lives of others who use the health care system, remain in the public spotlight. This has been particularly relevant to consumer groups over the last year, with the ongoing struggle to maintain a fair, accessible and equitable pharmaceutical benefits scheme. The PLWHA community has provided support for and worked with other consumer groups to develop a cohesive approach on this common issue.

#### *Government*

Working with government can be challenging, but effective relations with government are, to put it bluntly, indispensable to community activism. At organisational levels, and amongst individuals, positive people have been able to develop networks with government agencies, funders and bureaucracies, which have proved helpful to both parties. Government has had the opportunity to hear first-hand how the lives of positive people are affected by policy decisions taken in the abstract, and the public health benefits of a well-informed, well-educated group of health consumers. Positive groups and advocates have been able to secure more appropriate public health outcomes, and support for our work as educators, in policy development and as advocates.

#### *The human element*

The most consistent theme running across all these areas is the absolute importance of the physical presence of individuals affected by HIV, reminding everyone from

laboratory scientists to health economists or epidemiologists of the very real human dimension of this condition. The 13,000 people with HIV are not just numbers on a graph, that pink or purple bit on an epidemiological pie chart, the sum total of their CD4 count of viral load, or a collective headache for the architects of the Pharmaceutical Benefits Scheme. They are 13,000 individual lives lived, with the complications and ramifications of HIV infection. Humanising HIV, through the media, and in the halls of political or industrial power, remains one of the most important elements of a meaningful and sustainable health response—and is one that can be easily and effectively adopted in other health settings.

### *Adapting the model*

These features of a response can be platforms with which to build collaborative networks and partnerships, and position a health consumer group for profiling the issues of priority for attention to the broader groups of stakeholders and funding bodies. They will be able to be articulated through programs of activities and projects. This includes the identification of the issues that reach more broadly across the whole of society, and which need recognition and support because of the impact of illness beyond immediate families and the individual experience.

In the current climate, with commitment to a universal health care system being substantively undermined and questioned, it is more important than ever for health consumers to stand up, and be prepared to say: this is my body, my life, and my taxes. We need to collectively let politicians and policymakers know that Australians do value an equitable, meaningful health care system, and that we will fight against any attempts to introduce a two-tiered health care system by stealth.

### **Conclusion**

The voices of advocacy can be diverse and far reaching, but no matter the specific focus in the health response, it is the passion of human rights and empowerment, and the fight for an equitable and supported place in the allocation of public services and resources that demands that all Australians be given that place. We need none of us accept that these principles of universal access cannot be transferable to any Australian.

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<https://www.chf.org.au/pdfs/ahc/ahc-2003-1-because-its-personal.pdf>

**Cameron Cox**

## *Sex workers fighting battles against stigma*

Sex workers living with HIV carry both the stigma of being sex workers and the stigma of being HIV-positive. These two stigmas when combined have a multiplier effect, which in totality far exceeds the sum of the two parts.

This stigma is backed up in Australia by laws that either criminalise sex work (or aspects of it), that criminalise sex workers who have HIV or that require unnecessary disclosure of HIV status in sexual situations.

As a result of stigma and discrimination, most sex workers living with HIV have kept both their HIV status and their sex work identities completely secret. This has meant that their accessing of services available to people living with HIV and to those services available to sex workers has often been minimal or none at all. When services are accessed this is often done using one identity only; the other being kept secret.

Sex workers who have attempted to come out as HIV-positive, or have accessed services as HIV-positive sex workers, have invariably encountered hostility and in some cases threats of, or actual physical violence.

In the period from 2000 to 2014 two major developments occurred for sex workers living with HIV.

First: an organisation that represents sex workers took the very public and courageous step of acknowledging the existence of HIV-positive sex workers. Scarlet Alliance, Australian Sex Worker Association commissioned an assessment of the needs of HIV-positive sex workers. This research project was peer-led, conducted and managed by sex workers who were living with HIV.

Second: there was a marked increase in the number of prosecutions for alleged transmission of HIV. A number of these received considerable publicity, bringing them both to public attention and the attention of sex workers living with HIV.

For HIV-positive sex workers, the case that was the most concerning was that of a male sex worker in the ACT in 2008 who was jailed for working whilst HIV-positive.

HIV-positive sex workers were already aware of the NSW case of a sex worker, who had previously publicly admitted to being a sex worker living with HIV. This had resulted in an absolutely awful situation of blazing publicity and public outrage, and resulted in her detention under public health legislation for most of the 16 remaining years of her life.

The ACT case had also attracted sensationalist media attention, and even though no evidence was ever presented that any HIV transmission or even any unprotected sex had occurred, the sex worker was jailed for simply being HIV-positive whilst engaging in sex work.

This, and a number of less-reported cases in other states, were seen by sex workers as proof that though much had changed for HIV-positive people as a whole, attitudes and responses to sex workers who had HIV remained hostile at best. The criminalisation of sex work, of people living with HIV, and of sex workers living with HIV make up the fundamental core of this stigma and discrimination and as such must be challenged.

Many sex workers still feel we are back at the beginning of the HIV epidemic, fighting battles against stigma, prejudice, discrimination and unjust and unworkable laws.

A current theme in HIV prevention is ‘no one left behind’. Ironic, for sex workers – and in particular HIV-positive sex workers – as they feel almost completely left behind. Even more ironic, as sex workers we were amongst the earliest adopters of safe-sex practice; and this fact made a significant difference in the history of the HIV epidemic.

**Robert Mitchell**

## *NAPWHA responding to a changing epidemic*

This year marks my 21st anniversary of becoming infected with HIV; as a young gay man I was well aware of AIDS but didn't fully comprehend how it would affect me personally. Soon after I was diagnosed, I was approached to become involved in my local AIDS Council. This was the start of my ongoing involvement in the community response to HIV. Over that time my involvement has changed and shifted as has the epidemic and community organisations' response to it.

I would like to reflect on the shifts and changes as they shape organisations and affect the role and responsibilities that they have. The central unifying point over time is the commitment of people to contribute to a greater cause and to try and effect positive change that improves the lives of others.

How this occurs has to a great degree been shaped by the epidemiology of the disease at any given time. Other factors that shape our actions have been the environment in which individuals and organisations work.

I have been fortunate to see and participate in the response at many levels. Back in the late eighties and early nineties I saw how a few well-placed individual bureaucrats effectively shaped the structure of the HIV response in Australia. They understood the threat that AIDS posed at that time and that only a comprehensive response would be effective. The partnership approach developed.

This was a time when there was no effective treatment, and people were dying of



AIDS. The gay community was most impacted by this unknown infection and the focus was on trying to keep people alive as long as possible. The community response was to establish AIDS Councils to care and support those with AIDS and educate the gay community about the risks and the importance of safe sex. AIDS Councils worked within the structure of the partnership, whilst at the same time often radical activists, individually and collectively, railed against the systems that were seen as unresponsive to the needs of people with AIDS. There was often a symbiotic element to the relationship in order to effect change.

When I joined the AIDS Council a mixture of people were involved, ranging from well-intentioned individuals whose involvement was driven by the need to help people with AIDS, through to representatives of the gay community fighting for change and equal rights for the gay community. This often resulted in tensions around the focus of work and programs.

The turn of the century marked the start of my involvement in national representative organisations, firstly with the Australian Federation of AIDS Organisations as a state-based representative. The twice-yearly general meetings of the organisation were a very casual and relaxed affair. Indeed, when I arrived early for my first meeting there was no one at the venue, staff arrived about five minutes before it was due to start and the actual meeting commenced about an hour later. To me this was a time of respite in the response, the urgency had receded from the response and there was a great deal of discussion about how to shift services from purely care and support to a more empowering model of support for positive people to resume living normally with a long-term illness. The prevention agenda was still firmly fixed on safe-sex messages but this was when I became aware of what were the early stages of combination prevention. It was an eye opener when sero-sorting was discussed as a prevention tool. This was the point at which I realised that HIV-positive people needed to be more central to the response.

At that time, NAPWA was a small organisation operating in back of the AFAO office in Wentworth Street, Sydney. My first involvement with the national organisation was attending a conference in Melbourne, staying at a university college. I remember most of all the diversity of people and the opportunity to meet and talk with other HIV-positive people. There was an experienced group of extraordinarily passionate HIV-positive people who were central to the organisation, many of whom had been involved since the start of the epidemic. The rest of the participants were like me, inexperienced and there to meet other HIV-positive people and have an opportunity to discuss issues that directly affected each of us.

The policy work of NAPWA at that time was driven by these HIV-positive people identifying areas of interest and concern and working together in groups with each area a portfolio. Those portfolios were: Care and Support; Education; Health and Treatments; Indigenous; International; Women; and Legal. Each of the six-monthly meetings of the membership of NAPWA would focus on discussing and progressing the work of those portfolios. Every two years at the biennial NAPWA conference the broader positive population had a chance to gather and network and to influence

the direction of the work of NAPWA.

Through the early years of the new millennium as the lives of HIV-positive people changed with the advent of better treatments, the work of NAPWA similarly followed these shifts. People became more focused on living with a chronic manageable condition and re-engaging with the workforce and less reliant on support services. This was a challenging time to identify how best NAPWA could undertake advocacy work.

In 2007 the portfolios were changed to become Networks (Health Promotion and Education, HIV Living Today, Health Treatment and Research, Positive Aboriginal and Torres Strait Islander Network (PATSIIN), and the Women's Network) and the Secretariat launched Treataware as a program to focus on providing treatment and clinical trials information. Another shift was to stop the biennial conferences and focus on developing the skills of HIV-positive people to become leaders in their own advocacy. The major event was a retreat weekend aimed at building the leadership skills of those attending.

By 2009, NAPWA's efforts to change its advocacy style came to fruition with the organisation finally achieving representation on the Commonwealth Health Ministers Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections. The advocacy agenda of the organisation was now focused on treatment and co-morbidities, ageing and HIV, stigma and discrimination, all of which reflected the changing concerns of HIV-positive people.

In 2011, NAPWA was part of the Australian Delegation to the United Nations Special Session on HIV/AIDS. This was a critical achievement as Australia was the co-sponsor of the session and joint negotiator for achieving the political declaration arising from this session. The most significant statement from this declaration, agreed by all nations around the world, was the need for HIV-positive people to be central to all aspects of the response to HIV. It was also a landmark statement in naming specifically those communities most affected. A significant achievement for the year was the implementation of the Australian Temporary Resident Access Scheme (ATRAS) study, which aimed at addressing the long-term problem of providing treatment to people not eligible for Medicare-subsidised drugs.

The name change for NAPWHA in 2011 reflected the fact that occurrence of AIDS had significantly decreased in Australia and that the unifying issue was HIV. Australia was named to host the 2014 International AIDS Conference and NAPWHA was endorsed by the Australian HIV community sector as the country community partner. NAPWHA has led the efforts to adopt a set of targets to reduce HIV transmission and support treatments uptake in Australia. These targets reflect those which were negotiated at the United Nations in 2011.

Over the previous few years there had been a shift in the way in which policy and advocacy was carried out in the organisation and whilst the support of the organisation's secretariat has always been important, there was a need to more efficiently harness the strength of our member organisations. From this realisation came Poz Action, the operational leadership from across NAPWHA working

together to develop and implement policy areas that are common across the membership and giving our member organisations a more direct involvement in advocacy at the national level.

## **PATSIN**

# *We are here, right across Australia*

*All I can dream for is that Aboriginal people deserve and get a better life.*

*We are here, right across Australia.*

*Let us support one another by yarning through our journey.*

**Ian Saunders**

The virus may not discriminate on the grounds of race, colour or gender, but cultural and economic differences can mean that Aboriginal and Torres Strait Islander people – and their communities – experience the HIV epidemic in markedly different ways to other Australians. While the number of Indigenous Australians infected with HIV remains relatively low, these communities have faced the real risk of a worsening epidemic.

Cultural differences can create major obstacles, both to Indigenous people and to service providers and advocacy groups. “There are so many different culture clashes that we deal with, especially language,” Michelle Tobin has explained. “One community can speak one type of language, another can speak the same, but the meanings are different.” Cultural taboos around gender relations can have a major impact. Education materials that might be culturally appropriate in Western society can often cause offence in Indigenous communities. A poster depicting male and female genitals, for example, will isolate the female section of the community, “because they’re not allowed to look at it or deal with it,” likewise, “dealing with doctors or health workers of the opposite gender can create barriers”.

Even the most basic healthcare information needs to take account of the differences, Clyde Dubois points out. “It’s okay to say, ‘take your medication if you’re HIV-positive’, ‘eat healthy’ and stuff like that, but when you’re in a remote community . . . you don’t have fresh vegetables.” Poverty, too, creates major obstacles to positive Indigenous people. Many remote Aboriginal communities have almost ‘third world’ living standards, and it’s important to deal with underlying problems such as alcoholism and sexual abuse. Additionally, studies of HIV treatments and side effects take too little account of racial differences, with Indigenous people sometimes experiencing different treatment side effects to other people.

There are important differences in the makeup of the epidemic among Indigenous people, too. In contrast to the wider community, where the majority of HIV-positive people are urban gay men, HIV is more likely to affect Aboriginal and

Torres Strait Islander women, heterosexuals, younger people and those living in rural and remote areas as well as gay men and sistergirls.

### **IPN+ formed**

In the NAPWA structure during the 1990s there had always been an Indigenous spokesperson position and/or a portfolio of activities, and there had always been a network of Indigenous people across Australia who knew something about each other and their HIV status since communities started to deal with the impact of HIV.

In June 2003, the Indigenous Positive Network (IPN+) was formalised to provide support to Indigenous positive people, to advocate on their behalf, and to provide them with the skills they would need to speak out within their own communities. Clyde DuBois and Michelle Tobin were elected as co-convenors. The years 2001 to 2003 had been a particularly challenging time for Indigenous people, though. New infections from heterosexual transmission exceeded those from male-male sex for the first time. Injecting drug use also made up a larger share of HIV infections among Indigenous people. The formalised network wanted to respond to these and other concerns.

“To be taken seriously . . . it’s better to come from someone Aboriginal people see as one of their own, from their own community,” Clyde explained. “We’re there to help empower and facilitate the growth of those individuals to go back into their own community to do that.” With many Indigenous people reluctant to seek mainstream health services, Michelle said it was important that advocacy and support services are also targeted appropriately. “It’s really important to actually have a voice for Aboriginal people.” If that support comes from within the Indigenous community, there was a greater likelihood positive Indigenous people will respond to it. One area where IPN+ believed it could make a big difference was in increasing the levels of general health literacy and understanding medical information, particularly with regard to treatments and their side effects. “One of the harder things we’ve come across is actually getting Indigenous people to come in and be tested, regardless of whether it is for HIV or another STD, even among those who do agree to be tested, many will not return for test results or treatment,” said Michelle.

By going into Indigenous communities as Indigenous positive people, IPN+ hoped to improve acceptance of the usefulness of HIV treatment. The network recruited a ‘core membership’ of 13 Indigenous positive people who ratified the network’s terms of reference. At the National Association of People Living with HIV/AIDS (NAPWA) conference in Cairns in October 2003, the group was endorsed as an associate member. As a young organisation, IPN+ was still finding its feet and developing its own capacity, but that didn’t stop the network from having big plans for the future. The network hoped to establish local groups in different parts of the country, and to work on a broad program involving policy development, advocacy with various levels of government, education and peer support.

### **PATSIN forms**

Neville Fazulla, a network member, reported to the NAPWA Special General Meeting in April 2006, that, by a special resolution, IPN+ had renamed itself the Positive Aboriginal and Torres Strait Islander Network or PATSIN. PATSIN would continue to be unique in that it would be made up entirely of Aboriginal and Torres Strait Islander people living with HIV, and seek to do its work through a consensus-oriented process, meaning that discussion and debate continue until everybody is satisfied with a result, not just the majority. By incorporating its perspective into the work of NAPWHA, PATSIN would provide the opportunity for HIV-positive Aboriginal and Torres Strait Islander people to advocate for change at a national level. PATSIN would also give its members the opportunity to network across their diverse communities; to identify best practice in health promotion; and to encourage the promotion of safe sex, safe needle use, HIV testing and early treatment.

Perhaps most crucial of all, PATSIN would provide culturally appropriate peer support to Aboriginal and Torres Strait Islander people with HIV. PATSIN would be committed to peer-based support as it provides a voice to advance the rights and dignity of Indigenous people living with HIV. And PATSIN was to have members in most states and territories in Australia. Regular teleconferences and face-to-face meetings provide an opportunity to come together and discuss issues relevant to the network and to the Aboriginal and Torres Strait Islander positive population in general.

In 2013, a PATSIN logo was designed by Indigenous artist Arone Meeks. Arone creates paintings, sculptures and prints that express a passion for country, spirituality, sexuality and politics. He described the logo as signifying “a safe place to yarn, and a special place where members could support each other, inclusive of any of our mob that were living with HIV. Therefore having a voice and a say in what was happening with future issues . . . The male image is to the right of the Rainbow Serpent (our creator) and to the left is a female image. The central serpent shape also carries designs of creation and the virus that some carry . . . The overall colours of the logo are that of both the Aboriginal and Torres Strait Islander flags.”

Spokerspersons and convenors have been: Rodney Junga-Williams (deceased), Neville Fazulla, Clyde DuBois, Michelle Tobin, Wilo Muwadda, Dennis Martin (deceased), Bev Greet, Terrilee Simpson and Ian Saunders.

Edited from *Positive Living*, April-June 2004; Ian Saunders 'PATSIN: The Positive Aboriginal and Torres Strait Islander Network' *HIV Australia* Vol. 11 No. 3 October 2013 and the NAPWHA Annual Report 2013-2014

**Neil McKellar-Stewart**

## *From Alice Springs to Northern New South Wales*

My narrative starts in Alice Springs in the spring of 2003, when I arrived on the first stage of a 'grand tour' around Australia, having just resigned from a far-too-familiar and comfortable public service position in Brisbane. Alice at that time had a resident population of around 20,000 people; of these, around 16% were Aboriginal or Torres Strait Islander people. It was a place of sharp and hard contrasts in its people as well as its jaggy flinty ranges. The mural in the Gap Hotel, made famous in the film *Priscilla Queen of the Desert*, had long been covered over but there was a visible, if somewhat muted, camp community of gay and lesbian people. Some of whom would meet for parties at the Gap Hotel: we all knew one another socially if not in the biblical sense. To be HIV-positive was not something that was disclosed unless it was to the most trusted of friends. Clinical care, however, was at that time world class, with an experienced HIV clinician and well-qualified locums doing sessional work. It was there that my regimen was switched from first-generation protease inhibitors to a combination with far less metabolic disturbance. My HIV medication still had significant side effects, most commonly diarrhoea and nausea, and were dosed three times a day with four pills. Still, I got into a routine and my adherence was pretty good; certainly maintaining virological control was possible. I'm not sure how many other PLHIV resided in Alice, but I certainly didn't meet any. This was probably a common feature of life as an HIV-positive person in regional Australia at that time. It is very much still the situation in many parts of regional Australia.

Overt stigma and discrimination could be expected from some of the more belligerent non-indigenous locals (and tourists), but in a small community such as Alice anxiety about unwanted disclosure came not from the wider community but from within the gay, lesbian, bisexual and transgender community, within which personal information could be unwittingly disclosed and become the topic of rumour and innuendo. So it was prudent to keep one's own counsel. The lure of desert landscapes and working with custodians of the world's oldest culture captivated me and my travelling companion, and we settled into life in Alice, if somewhat in cultural shock.

After working for a time in Alice with Aboriginal people in a number of human services organisations, we secured employment in a small community of 200 Aboriginal people in the desert to the north of the Maralinga test area in north-west SA. This was to be home for three years. When we moved there, concerned city-based friends questioned the wisdom of such a venture: social isolation; reduced access to primary, let alone specialist, medical care; the remoteness (500 km from

Alice); the harsh natural environment and the possibility of infectious disease. No doubt someone moving away from the HIV care available in a capital city to a small rural community might have occasioned similar concerns. However, it was not the case: I have never felt so alive and robust as out there in the desert, and quarterly clinic visits were only five hours away (and provided an opportunity to party and to engage once again in a cultural context that was more familiar, and undoubtedly less confronting). When it came time to leave I did so with very mixed emotions, and certainly resolved not to move back to Brisbane.

The Northern Rivers region beckoned: in this part of rural NSW, there was a queer presence in the earliest rock, lifestyle and alternative festivals, which began in 1967; however, it was the Nimbin Aquarius Festival in 1973 that provided the catalyst for a nascent gay and lesbian community. Within ten years, gay men were firmly rooted in the Northern Rivers with an ethos of care for community and for the natural environment. This protected space was not immune from the trauma and devastation wrought on gay communities by the AIDS epidemic in the eastern seaboard capitals in the '80s. Passionate and organised advocacy on the part of the positive community and their friends saw ACON opening its Northern Rivers office in 1989. A local community board oversaw the management of the branch. Together with ACON Northern Rivers staff, a large number of GLBT community members were involved in helping support gay men across the region living with HIV/AIDS. At the time, HIV was restricted almost entirely to gay men and there was no treatment in sight. People who required HIV clinical care routinely had to travel to either Brisbane or Sydney to receive specialised care.

Further community advocacy saw the awarding of state government funding for the establishment in April 1990 of a specialised sexual health service providing HIV clinical care. The medical care for PLHIV through what was then known as SHAIDS (Sexual Health and AIDS Service) continues to this day. In 1994 there were approximately 100 gay men with HIV. The numbers of gay men with HIV rapidly increased throughout the '90s as the widespread community and personal suffering in the eastern capital cities led many positive gay men to relocate to the Northern Rivers (Nimbin, Lismore, Mullumbimby, Byron) and rural properties in the surrounding villages, seeking a place to escape the ineluctable progress of this virus. Twenty years later there are now about 400. The relocation of patients from a high-caseload general practice in Sydney during this time, together with growing numbers of gay men requiring HIV clinical care, saw the establishment of a branch of Holdsworth House general practice in Byron Bay in 2005.

It was into this well-served community that I arrived in May 2006. The earlier 2000s were a period when there was considerable uncertainty about HIV treatment: dosing requirements, particularly for the early protease inhibitors, were exacting on patients with large pill burdens, three-times daily dosing and numerous, sometimes severe, side effects. Zidovudine (AZT) was to remain a part of recommended first-line treatment in the US ARV guidelines (largely adopted in Australia) until 2008. Indinavir, saquinavir and didanosine (ddI) all were routinely recommended for

treatment-naïve patients. Because of failed monotherapy and dual therapy initiated before 1996, many patients had complex ARV exposure histories and acquired drug resistance. People were living with lipodystrophy and other side effects. Adherence with multiple side effects was challenging for some. The Strategies for Management of Anti-Retroviral Therapies (SMART) clinical trial had commenced in 2002 and many PLHIV hoped it would alleviate the burden of treatment side effects (it didn't, but treatments have so improved that the ongoing side effects for which SMART was designed to address have long since dissipated). In this regional area alternative and natural therapies were touted as easy panaceas in many areas of health care, not least of all HIV.

Throughout this period the nature of services provided to PLHIV have fundamentally changed, with reduced need for crisis services such as home nursing care, and more need for ongoing support for general health issues, such as oral health, mental wellbeing and access to allied health providers. When I first arrived, the legacy of the worst years of the HIV epidemic, were still very evident: people were dealing with previous opportunistic infections such as toxoplasmosis and PCP, and acquired insults such as lipoatrophy and other metabolic consequences of their early treatments. Now issues cluster around ageing, social isolation and emerging chronic medical issues. These are not unique to PLHIV in regional areas, but living regionally does provide additional challenges: access to medical specialists and some diagnostic and monitoring services is more limited, and the logistics of accessing services are more challenging. Some people who have lived through the earlier years of the epidemic face ongoing health challenges and issues around living on reduced incomes in a region where some living costs (including transport) are high.

In 2000, considerable uncertainty prevailed about the future for people living with HIV: Would HIV treatments provide enduring protection from HIV disease progress? Would other, acute health issues emerge as HIV treatments continued? and Was this 'treatments era' merely a period of stasis before further decline? That has turned around: no longer do treatments workshops focus on side effects and alternative therapies, but rather managing general health and taking sensible steps to prevent HIV and age-associated health issues.

This period has been one of exciting change personally: a sojourn in the desert culminating in a settled and productive employment in regional NSW and ongoing good health with highly effective treatments.



**Tim Leach**

## *Partnership work with Igat Hope in Papua New Guinea*

NAPWHA has been conducting work in Papua New Guinea (PNG) for over a decade and has worked in other countries as well, including Timor Leste. It has a model of international development that has been documented, applied and reviewed.

This has been the part of NAPWHA that I have worked most closely, and I have observed or been a part of much of NAPWHA's work in PNG, although not the earliest phases. The very earliest connections between PLHIV in PNG and Australia's community response were the result of Australian HIV activists building links with HIV-positive people from PNG. NAPWHA was a critical support in establishing Igat Hope, the national organisation for PLHIV in PNG, and the two organisations have worked in partnership ever since.

NAPWHA's work has been conducted by lots of different people – some brought their lived experiences as HIV-positive peers and as members of the HIV-positive movement in Australia, some brought technical skills in medicine or research, some (like me) brought their experiences as development practitioners, others brought combinations of these things. All up, the list of those engaged in NAPWHA's work includes Robert Baldwin, Kenn Basham, Brent Beadle, Peter Canavan, Bev Greet, Barry Horwood, Robert Langdon, Suzanne Lau-Gooey, Gabe McCarthy, Lou McCallum, Jenny McDonald, Anne Mijch, Wilo Muwadda, Max Niggel, Simon O'Connor, Susan Paxton, Elizabeth Reid, John Rock, Andrew Timmins, John Trigg, Jo Watson, and myself. John Rule has played a particularly significant role in NAPWHA's work in PNG, firstly as Manager of HIV Living and International Projects around the time NAPWHA began to expand its HIV-related regional development work and then later as the Deputy Director of NAPWHA.

Other than through AusAID-funded work in PNG, NAPWHA has also continued in partnership with the Collaboration for Health in Papua New Guinea to build in-country healthcare capacity. Ten years of collaborative activities have seen NAPWHA assisting in: the development of positive spaces and representative groups of PLHIV in PNG; the active involvement of PLHIV in policy responses in-country; and the development of strategic relationships with other organisations responding to the HIV epidemic in PNG.

It's interesting that these comments appear in the section on turning points. In PNG the turning point seems not to have yet been reached. ARVs are free in PNG and, officially at least, there is access to ARVs in most parts of the country. But PLHIV still die in PNG with confounding frequency. Igat Hope has lost two of its own employees in the last year, from a workforce of just six.

I attended a very interesting forum in Port Moresby in May 2014. Convened by UNAIDS, it brought together funders, donors, government and other major players in the HIV response, along with over 70 PLHIV, sex workers and men who have sex with men (or, as they prefer to be described, men of diverse sexualities). The community contingent had been organised by Igat Hope. In a well-coordinated presentation, the community representatives spoke of their experiences of the HIV response in PNG – the stories painted a pretty grim picture. They described a lack of hospital beds, chronic doctor and nurse shortages, stock-outs, grossly inadequate counselling services, discriminatory healthcare workers, appalling levels of adherence (based partly on the complete lack of adherence support services), community persecution and, for men of diverse sexualities and sex workers, criminal prosecution.

The forum could not have happened without Igat Hope. Everyone in PNG is theoretically committed to engaging affected communities/key populations, but these communities need to organise themselves, and to have some capacity to consult and speak on behalf of a constituency. Igat Hope has this and, as the forum showcased, is able to use it.

It is commonplace to bemoan the advocacy capacity of the community response in PNG. It is weaker than it should be, but I thought the forum was a very fine demonstration of advocacy in a country with too few examples.

NAPWHA has taken a candid look at its work with Igat Hope. It funded its own process of reflection that identified many significant achievements, and illuminated some mistakes along the way. Igat Hope would not have survived without NAPWHA and I don't think that PNG would be able to work towards its own turning point without Igat Hope.

I think NAPWHA has shown remarkable perseverance, flexibility, creativity and an admirable preparedness to reflect on its work, even if that produces some challenging results. NAPWHA has a story to tell about development partnerships, and that other development agencies should be interested in hearing it.

**Bill Whittaker**

## *Drug approval and clinical trials systems*

First published as *Bringing Australia's drug approval and clinical trials systems into the 21st century* in *HIV Australia* Vol. 7 No. 1 April 2009

At a community HIV treatment information night held in Sydney recently, I reminded the audience that HIV antiviral treatments don't just miraculously arrive on the pharmacy shelves for people to use – and that a lot of work is done by HIV community advocates to help make this happen, a fact that is increasingly less well understood, it seems.

Of course such unawareness is hardly the fault of that audience, or the wider community for that matter. We in HIV community groups do a pretty poor job of promoting the work we do, mainly because we have neither the time nor funding to do it. Ironically, advances in HIV treatment and care resulting in dramatic improvements in life expectancy have actually increased the complexity of policy and program work we have to do. For example, there is a lot of work going on to move away from outmoded, crisis-driven models of service delivery to new models capable of providing efficient, high-quality care for HIV-positive people over decades – rather than for the much shortened life expectancy that was the norm until quite recently. Much of this work involves engaging with mainstream health services to ensure that quality HIV care is integrated into these services wherever possible.

But the cornerstone of health service delivery for HIV-positive Australians will remain prompt access to the best treatments and diagnostic tests, supporting our health professionals working in HIV, and ongoing scientific research to inform best practice. So today and for the foreseeable future the core business of the National Association of People living with HIV/AIDS (NAPWA) is about ensuring these benchmarks are met.

A particularly important part of this work is getting access to clinical trials and compassionate access programs of new HIV drugs, especially to provide options for HIV-positive people who are failing treatment. This means establishing relationships with scientists and pharmaceutical companies, both in Australia and overseas, and taking a strategic approach to this work, given the large number of researchers and pharmaceutical players now involved in the HIV field.

NAPWA's work also involves monitoring the clinical trials approval system, the Australian regulatory systems for approving new drugs and funding them through the Pharmaceutical Benefits Scheme. If there are bottlenecks or problems, we try to be proactive in helping to sort them out.

All this work is complex, sometimes tedious, but essential. I strongly believe our commitment and capacity to do this work is based on the example set by a group of remarkable HIV activists, who, in the early 1990s, 'took on' the Australian clinical trials and drug approval system and achieved substantial reforms, which today

benefit all Australians.

So what led to these reforms? Well, for decades Australian health consumers and doctors were disadvantaged by a byzantine regulatory system for approving new clinical trials and for evaluating new drugs. This resulted in long delays in making new drugs available and a growing reputation internationally that Australia was not an attractive place to do clinical research.

HIV activists were not the first to attempt change. More than a dozen reviews, inquiries, etc, had been set up over the years. None succeeded. A small group of entrenched bureaucrats and others, playing on public fears about drug safety and predictions that the sky would fall in if anything changed, masterfully resisted all attempts at reform.

However, in the early 1990s the HIV epidemic brought matters to a head because it became very clear that unless things changed Australia would become a backwater for HIV research and new HIV treatments would take years to become approved. With a mounting toll of illness and death from HIV/AIDS, HIV activists became absolutely determined to force reform *on* the system.

Hours of work went into understanding the complexities of the clinical trials and regulatory systems. Alliances with doctors and scientists were forged, as well as with sympathetic politicians and health officials. Public demonstrations led by HIV organisations including the activist group ACT UP gained public attention and support for reform. Other disease groups supported the call for change.

At the end of the day, change is unlikely to come unless there is political will to do it. We were very fortunate to have had Brian Howe as Commonwealth Minister for Health in the early 1990s. Brian listened and against a great deal of advice from entrenched sections of the health bureaucracy, agreed to a full and independent review of the clinical trials and drug evaluation systems. I was fortunate to be asked to join the review task force chaired by Professor Peter McDonald, which gave me the opportunity to further advance the reform agenda of the HIV community sector.

The review recommended sweeping changes to simplify the clinical trials approval system in Australia. These were immediately adopted by the Australian government.

The review made other recommendations, including that education initiatives be funded to empower people with HIV to be fully involved in decision-making about their health. Today, this might seem a perfectly normal thing to do, but even just 15 years ago it was considered a radical departure from the 'doctor knows best' mantra so many Australians accepted. The first national HIV treatment information project was set up at ACON as a result of the review with funding from the Commonwealth.

The other major recommendation made by the task force was that Australia should accept evaluations of new drugs done by credible overseas regulatory authorities, rather than 'reinventing the wheel' and doing these evaluations all over again. This was seen as perhaps too radical, so another review was set up to consider that idea and to work out how a number of other reform measures recommended by the McDonald review would be implemented.

Despite some disquiet in our ranks, the community sector accepted this second review. Firstly, because we were reassured by Brian Howe that it was a genuine process, not one to obfuscate, and secondly because he was appointing former Liberal Senator and Health Minister Peter Baume to conduct the review. Peter was a brilliant choice and he produced an outstanding report with far-reaching recommendations, all of which were endorsed by Brian Howe and the Australian government.

Today, Australia is widely regarded as an attractive site to conduct research, not only because of our outstanding doctors and scientists, but also because the clinical trials system is now viewed as efficient and effective, with a good balance between safety, ethics and accountability issues. The contribution of the HIV community sector in helping to build this model has been substantial.

I began this article by mentioning a recent community HIV treatment update in Sydney and how participating in that event reminded me that we should do more to tell people with HIV and affected communities about the work we do. We should also remind people that HIV activism is still needed and that they should think about getting involved in community-based organisations.

Activism has achieved a lot in the fight against HIV, and has also assisted other disease responses. However, the work is never finished. Difficulties will emerge and glitches happen. It's also important that the effectiveness of health and research systems are challenged from time to time to ensure their continuing relevance and excellence.

I often think about Thomas Jefferson's quote that eternal vigilance is the price of liberty. In the context of living with HIV, I like to paraphrase that by saying that activism is the price of keeping ahead of diseases such as HIV and of keeping ourselves and our communities healthy and dynamic. It's a good reason to remain involved in activism and to encourage others to join in.

**Kirsty Machon**

## *Health and treatments policy work at NAPWA*

I remember an HIV-positive friend telling me once that of all the HIV 'campaigns' directed at him as a gay man living with HIV, some were effective and others memorable, but only one ever made him happy. This was a NAPWA campaign called Everyday Pleasures, and my friend kept the different postcards from it on his fridge. Everyday Pleasures – let's call it a thought bubble rather than a 'campaign' – was relatively straightforward and inexpensive, and based on a very simple idea. We

wanted to show images of, and tell stories about, the thousand everyday reasons that from moment to moment give pleasure and joy to existence: pleasures that might be as simple as a walk, a chance sexual encounter, a cup of tea, a son or a daughter, or a ripe peach eaten standing under a sunlit wall in a strange country.

Everyday Pleasures was not really ‘about’ anything more than that. But it was what it was *not* about that was important. The materials and stories and messages were *not* about managing illness or side effects; they were *not* about doctors or about headaches; they were *not* about understanding the science of proteins or protease. Most importantly, they were *not* about protecting someone else from HIV, or HIV-positive people protecting themselves from so-called ‘super-infection’ (an idea that had gained attention in the early 2000s, with the widespread uptake of antivirals, and the widespread muttering, not entirely without basis but largely without compelling evidence, about the potential of super-resistant HIV to wreak death on a major scale again).

Ordinary pleasure was, in the context of HIV at this time, an explicit political statement. If resistance was on people’s minds, it was also resistance of a political form: how to live in some equilibrium with a virus that not only controlled one’s health and interfered with one’s business, but also invited control from others – from doctors and scientists, from lawmakers, or even from family and friends. If ‘barebacking’ and ‘superHIV’ were somewhat anxiously linked in the minds of many HIV-positive people, it was in part because they were very definitely linked in the minds of others: in the minds of doctors and lawyers, and gay men, and even in the minds of health policymakers in governments around the country, exquisitely tuned as they are to the smallest hint of future epidemiological catastrophe.

I worked at NAPWA as its health and treatments policy analyst between 2000 and 2006. We were a small team, but energetic, and the energy, I think, stemmed from a particular source: that we all, in some ways, shared a political sensibility, and our work was at its core, political. I don’t mean either the trite, tribal left-and-right politics that seems to characterise ‘working in politics’ lately, or a *Game-of-Thrones* kind of thrill where the chase and the intrigue is all and the end is abstract. I mean that it was a genuine pleasure, and a real privilege, to work somewhere where you didn’t have to either suspend, sideline, or actively suppress your beliefs, values or ethics, because they were always manifest in the work we did and the reasons we did it, and the outcomes people were fighting for collectively – for people living with HIV and AIDS, yes, but with a broader picture in mind too. As well as working with a wide range of HIV service providers, healthcare workers, policymakers and educators, we also did a lot of work with other health consumer groups who were, in the end, interested in the same thing: a fair and humane and decent healthcare system, which did not thrive on fear and ignorance and the unquestioned power of science and medicine, and where pharmaceutical companies did not have free rein to set the price on hope, or indeed, on life.

The politics of HIV had always been founded, necessarily, on a very insistent kind of realism. It had to be so, given a virus bound so inextricably to corporeal things –

to bodies and to sex, to birth and to babies, to blood and to pleasure. And bound up also in the political and the politicised: with religion and with politics; with sexism and with racism; with homophobia and with misogyny; and not least of all, with capital itself.

What I always thought NAPWA was really about was the idea that people might have a better life, if not free from HIV, then at least good and rich and full of everyday and maybe some extraordinary joys too. If living wasn't to be dying, then NAPWA's work had to be political and real. ACT UP had put it, in a phrase never since bettered, that 'silence equals death', meaning that you can't tackle a virus such as HIV without telling the truth about it. But even by the early years of this century, more than 20 years after GRID first made its mysterious, ominous appearance in the news pages, there was plenty to do with HIV that was still not talked about well, or at all.

I remember, for example, once dedicating the front page of *Positive Living* to a groundbreaking social study of the often-forgotten lives of straight men living with HIV, only to be castigated with an annoyed protest letter complaining that since straight men were "such a small part" of the epidemic, putting them on the front page of *Positive Living* could only be explained as the editor "being political". Which, in fact, and very definitely, I was.

NAPWA was very conscious of, and wanted to be about, working with and for all people with HIV. It was during this time that a new national HIV-positive women's network was established, thanks to the energy of women such as Amelia McLoughlin, Katherine Leane, and Gabe McCarthy (sadly since passed away). In 2003, the Indigenous network was established. And NAPWA also did important work in Papua New Guinea and in East Timor, helping nascent, fragile networks of local people living with HIV to take form.

The NAPWA board, staff and volunteers also worked tirelessly in occasionally fractious but ultimately incredibly productive partnership with clinical researchers and doctors. We had input into research priorities, the design of clinical studies, and helped shape the delivery of primary care, integrating the perspective of people living with HIV into these models in a unique way that has happily had influence in other areas of health and illness. This was an approach that had been pioneered back in the days of ACT UP, but by this time, it had really taken on a life. An idea that had once been regarded sceptically – that people living with HIV (or any health condition for that matter) could make health outcomes better by contributing their insights to the whole process of research, clinical management and care – had gained acceptance and respect. In that sense, the advent of HIV had proved a real 'game-changer'. There are surely few hardline Thomases who would now doubt that people who live with a health problem have deep and intimate knowledge of it that simply can't be gained from a cell culture dish.

I was proud of many of the things NAPWA did, and thinking back, it is surprising to me how much was actually going on, and what was achieved. NAPWA has always packed a great punch for its relatively small staff and board. This small but hard-working organisation was founded on, and ran with, the knowledge that HIV cannot

be anything other than political. I believe NAPWA's work has genuinely shifted thinking, and more significantly, practice: among all sorts of people – from doctors in Australia to clinical researchers overseas; and from individual politicians to pharmaceutical companies. But mostly I hope it has helped change the thinking of the many HIV-positive people who have been involved, and even those who never have. Because HIV is real and it is personal. And lives matter, not in spite of or because of this virus or that health condition, but because there are a thousand everyday, ordinary reasons to live them.

**Adrian Ogier**

## *Improving treatment knowledge of HIV-positive people*

This is an edited version of an invited presentation given to the Cancer Drugs Alliance Forum on 26–27 March 2014.

Much of the work we do at NAPWHA is about treatment. Not just improving access to it but improving the treatment knowledge of HIV-positive people in Australia. We are unapologetically pro-treatment at NAPWHA. Our website, magazine and social media are peppered with stories of exciting new treatments on the horizon . . . of trials you can join . . . how the different classes of drugs work, and the tales of people who are treating their HIV and living well besides. We believe HIV is better controlled than uncontrolled.

But there hasn't always been this option. When AIDS arrived on our doorstep 30 years ago, we had nothing to treat it with. All we had was a major personal, social and public health crisis. What happened very early on was quite astounding.

AIDS had hit a community emerging fresh from already fighting another human rights battle. So, many of our community were already equipped for action. We consolidated. We adopted a bipartisan approach. This community action, together with health sector and later government support, helped lessen some of the personal burden.

But things were pretty desperate. Well before the advent of triple-combination therapy in 1996 and HIV became a manageable disease, we had AZT. It was highly toxic in high doses and pretty ineffective on its own.

We got proactive. Well before the Baume Report streamlined drug approvals in Australia, we had set up our own version of Dallas Buyers' Clubs and were importing d4T, the drug *du jour*, from the USA. Things improved with the Baume Report in the early nineties. This ultimately removed the need for Australia to go through the same trial process if the drug had already met acceptable international



standards. But we were tough. In the beginning, access programs were very strictly controlled. They had to be. Only those with the most advanced HIV qualified for those early trials. But later trials meant compassionate access schemes to catch any overflow.

We tried never to play the exceptionalism card and worked with other health consumer groups such as the Consumer Health Forum, so our advocacy work would impact on all communities living with a chronic condition. Our advocates had to be skilled up, to become forces to be reckoned with. They needed to hold their ground. They had to put in the work and they had to care about it. Not surprisingly, many of these advocates were and continue to be people living with HIV.

We had to be sophisticated and smart with the pharmaceutical industry (not unlike the smartness with which HIV invades a human T-cell). We secured positions on their advisory boards. No access programs ran until we signed off on them. We helped companies push drugs through the regulatory process. We helped determine who the drug would best treat and argued about cost. Was it reasonable? Was it really worth losing time waiting to resubmit? We never said 'this drug at any cost'.

We researched. When a drug called adefovir came along in the late 1990s we decided not to support it, copping flak at the time but we were redeemed when the US Food and Drug Administration refused to approve it because of its toxicity profile, and the company eventually dropped it. For a drug to get through it had to be superior or at least not inferior to one we had already. We looked for better immune response. One that knocked viral loads faster or improved T-cell recovery. Are toxicity levels less? Is it more tolerable? Does it work for longer? Does this drug work better in combination with that one?

Nowadays, it's hard to find better drugs than we have already. So we're looking at new paradigms. Drugs that are differently acting. Better doses. Longer acting that will require less dosing, maybe even a monthly injectable.

In 1997 we supported one pharma company with the approval process for a drug called Doxil. Doxil was a treatment for Kaposi's sarcoma, an AIDS-defining cancer not uncommon at the time. As part of the process NAPWHA agreed to conduct a series of qualitative interviews with the very people Doxil would help in the months before their death. It was an emotional exercise. But we found out what they wanted. And that they all wanted different things. To some, extending their life however short, was all-important and putting up with side effects secondary. For others, quality of life was paramount. Not all would benefit from Doxil. Not all wanted it.

Doxil got approved. Not solely because of this qualitative research but it certainly helped.

As a consumer advocacy group we have learned a number of things:

- It takes time. HIV has been around in Australia for more than 30 years.
- It takes hard work and nous. Educate and nurture those who are passionate.
- You must play on a number of levels with a variety of players.
- Amalgamate. Act from a central position. Speak with one voice.

**Max Niggli**

## *Positive speakers, the human face of HIV*

Like most HIV-positive Speakers Bureau, Victoria's Bureau developed in response to the HIV and AIDS hysteria, fear and prejudice in the late 1980s and early 1990s, when HIV-positive people articulated the need to inform the community about the facts of HIV transmission, prevention strategies and how HIV and/or AIDS has impacted on their lives.

Since the advent of more effective treatments, many PLHIV have become members of the Positive Speakers Bureau (PSB), to give something back to the community and to have a say in how they are treated as patients and consumers of health care, and that empowerment continues to encourage our speakers to speak out. Long-term evaluation on the impact of HIV-positive speakers on healthcare workers show that there is a significant change in attitudes towards PLHIV after a speaker has delivered their presentation. Audience members comment on the honesty and the bravery of speakers, and gain a new understanding of PLHIV as patients. With more speakers able to address greater audience numbers and the increased public visibility of PLHIV, we create a continuum of understanding about the care and treatment needs of PLHIV. Organisations' staff and volunteers are then better placed to work around aspects of discrimination and stigma that currently exist and how to best meet the specific needs of PLHIV.

Living Positive Victoria strives to educate and inform PLHIV, the wider community and promote a positive image of PLHIV. In the 2012-2013 financial year, members of the Living Positive Victoria Positive Speakers Bureau have spoken to more than 10,500 people about their experiences of living with HIV and or AIDS.

The Victorian Bureau's success is the result of long-term strategies, multiple interagency collaborations, extensive promotion and very hard work on behalf of all speakers who have developed the Bureau since its inception in 1989-1990. There have been hiccups when there has been little speaker support or training in the past but the fact remains that PLHIV speakers have contributed enormously to the success of the Australian HIV response.

Speakers become the human face of HIV and provide a personal narrative about living with the virus, to help reduce myths and discrimination. HIV and AIDS stigma and discrimination (while illegal) is still widespread and is often so subtle that some are not even conscious of how they discriminate against PLHIV. It is only when they meet and listen to a PLHIV speaker that they become aware of and seek to modify their behaviour.

Speakers deliver key health promotion messages on STI prevention, education, harm reduction and safer sexual behaviour for the youth of Victoria. Homophobia, sexuality, social justice and equity of access to health care are also discussion points. In the past, many speakers have come to the Bureau with little self-confidence after

successive bouts of illness, often marginalised because of low income or lack of government support. Increasingly, many trainees are now living well with HIV and have a strong desire to be open about their HIV status and to educate the community. The Bureau's core fundamentals are to inform and educate our speakers using community development principles and peer education. The Positive Speakers Bureau program is peer and mentor based to facilitate the sharing of knowledge and specifically targeted capacity-building and training.

A recent initiative, the Living Positive Victoria's Senior Voices Project provides an education and capacity development service to the community and aged-care service sector across Victoria. We recruit, train and support a highly skilled team of older (50 years plus) PLHIV speakers to address the issues of HIV and ageing and co-morbidities, by involving PLHIV from diverse backgrounds in the response against perceived stereotypes, stigma and discrimination facing PLHIV in aged-care services. The project provides high-quality training of older HIV-positive people to become public speakers, education around HIV-related issues (including sexuality, sexual health and HIV treatments and ageing issues) to aged-care facilities, staff and other aged-care services, and provides social and educational networks for older people living with HIV. With the overwhelming support from key stakeholders in the HIV and aged-care sector across the country, we are looking forward to the Senior Voices Project encouraging older PLHIV to come out and speak about what it means to age well with HIV.

One of the hallmarks of the PSBs around Australia is the mentoring and partnership between interstate PSB Coordinators and speakers. The sense of belonging to a peer group and the many resultant enduring friendships unite us in a common purpose. The ability of each state to tailor their Bureaus to their speakers' requirements results in a unique programs in each state, and across the country.

**Katherine Leane**

## *Journeying with NAPWHA*

During the late '80s, community fear and ignorance about HIV/AIDS was rife and being labelled as a part of two stigmatised minority populations – being a woman and an injecting drug user – was not a good place to be. In what I now refer to as my denial decade, I spent ten years – as the famous Eagles song goes “you're afraid it's all been wasted time” – isolated and vulnerable. I sat and waited for the Grim Reaper to come knocking at my door.

In October 1987, when I was first diagnosed HIV-positive and pregnant, I buried many of my dreams and hopes. Sadly, at times, I struggle to erase many negative memories from this decade, especially around grief and loss. I was a young mother

with an active four-year-old, looking forward to our happy future, but instead I was being advised to terminate a pregnancy and not disclose my HIV status. I recall this being one of the saddest times of my life, as my dream of having many children and a large family vanished forever.

In June 1988, when I fell pregnant again, I made the choice to continue this pregnancy, juggling my belief it was meant to be, but still keeping a burdensome secret, dealing with guilt and thinking I was the only HIV-positive and pregnant woman in Australia. Looking back now, I was incredibly fortunate to have my unborn infant under the expert care of Professor Peter McDonald. Throughout my last trimester I was given access to a new trial drug called AZT. I think the dose was 600mg either four or six times a day. In February 1989, my beautiful baby daughter was born by caesarian, perfect, happy and healthy. Although we endured a gruelling wait for more than two years of endless blood tests and more secrets, finally she was declared HIV-negative.

It was late in 1998 that I attended my first HIV-positive people's national event. The idea of openly participating in a National HIV/AIDS Conference being held near Sydney's iconic Kings Cross and co-facilitated by NAPWA, the national peak body that represented people living with HIV, was a highlight. Looking back now, I consider this was a huge turning point in both my personal and professional life.

My attendance was the result of a joint sponsorship from both NAPWA and PLWHA (SA). I was an active member of PLWHA (SA) Positive Speakers' Bureau (PSB) and an ordinary board member. Here I was to encounter my first taste of political HIV advocacy and lobbying and peer networking and it felt like this was a place where I could belong, contribute and not feel judged as a woman and mother who was living with HIV and a person who also injected drugs. On reflection, I can cite my attendance at that NAPWA conference as a milestone for me personally in my uninvited journey with HIV. Being introduced to the organisation NAPWA and the national arena after a decade of denial and isolation, I was inspired by my HIV-positive peers and especially their generosity in sharing knowledge, information and skills. I recall being in awe of their collective expertise and clearly remember deciding this was a place where I wanted to contribute and could belong without judgement.

In my journey with NAPWA I have been fortunate to meet women such as Amelia McLoughlin, Viv Munro, Kim Davies and Bev Greet. I was inspired by these strong women who were not hiding their HIV status and who became empowering role models to other positive women. When I met Amelia McLoughlin, she held the position of Convenor of NAPWA Women's Portfolio and her capacity to speak out, share her views, and challenge prejudices towards women living with HIV was powerful. Amelia and Viv were the first women's peer support officers at the ACON Women and Families Project along with another worker, Angela Stewart. I held a similar position at the HIV Women's Program in SA so we connected easily and Amelia inducted me into the NAPWA family.

Back in South Australia, as a new board member I was nominated to be a

NAPWA state representative. In this role, from around 1999 or the year 2000, I began attending the NAPWA Special General Meetings and Annual General Meetings. This opportunity provided me with a sound background for learning about HIV firsthand at a local, state and national level, and the opportunity to highlight the issues relevant to women and families living with or affected by HIV. I attended teleconferences, workshops, roundtables, forums and training and more training. I learnt about the principles of the Greater Involvement of People living with HIV/AIDS and the Meaningful Involvement of People living with HIV/AIDS and the underlying foundation behind 'nothing for us without us'. There were opportunities to learn and hear all about the other NAPWA portfolios such as HIV treatments, Legal, Education and Prevention, International and Women. In South Australia, I was employed part-time as the HIV women's peer support worker, which involved working one-on-one with women living with HIV. I observed that due to the huge stigma attached to living with HIV, especially for women, their children and families, that, in Australia, women were almost an invisible minority.

However, I saw firsthand that at NAPWA both the staff and members treated all minority groups with respect and dignity, including but not limited to hemophiliacs, sex workers, people who inject drugs, men who have sex with men, people who have been incarcerated and women from many diverse walks of life. They walked the walk and talked the talk when it came to human rights, dignity and self-determination. After NAPWA meetings I would always return to Adelaide with an overload of interesting information and a respect for the passion demonstrated by all the staff of our national organisation.

I was lucky to observe the leadership style of Peter Canavan when he was NAPWA President. Peter travelled to meet the other members in their home domain and developed a working knowledge of the positive organisations and politics in each state or territory. With his hands-on approach to leadership, Peter consulted and networked widely. He spoke of the centrality of HIV-positive people and we felt a strong connectedness across a diverse group of people from many different backgrounds. I believe under his leadership, along with the insightful work of the Executive Officer, Jo Watson, NAPWA became a recognised national leader and advocate for all PLHIV.

Whilst a state representative, I was under the leadership of NAPWA President, Philip Medcalf, and his leadership was important. As a smaller state, with his support, we finally felt a sense of belonging to our national organisation, having our small but unique experience considered in the overall national HIV landscape. Philip facilitated the opening of many partnership doors. He was proactive in linking with all the membership and developed a genuine inclusive approach and respect for input from the smaller states and territories such as South Australia, Western Australia and Tasmania. When Philip died, it was an incredibly hard time for all at NAPWA; the staff and Board had to manage through a difficult time.

In the mid-2000s other key women came through as state representatives: Diane from Western Australia; Mandi from the ACT; Gabe McCarthy, Lara and Kim from

Queensland; Susan from Victoria. And in the Indigenous portfolio were Bev and Michelle. Back in SA, where I was now Vice President of PLWHA (SA) we introduced a NAPWA report as a regular agenda item to broaden our national understanding and links. Our then-President in SA was Rodney Junga-Williams who was also a key part of NAPWA's Indigenous portfolio.

Also around the mid-2000s, NAPWA, through the activities of the HIV Living Unit, assisted us at PLWHA (SA). We were supported both financially and with skills-building to create a demonstration project that gave PLWHA (SA) the capacity to undertake an in-depth Strategic Directions Plan.

Gabe McCarthy became the first woman president of NAPWA and working together as the board and staff, we held some amazing conferences. Held on a biennial basis, I can recall Melbourne, Cairns and the final one, the tenth, in Adelaide in 2005 titled 'My Place, your place: in the Bigger Picture'. In Adelaide there were about 200 delegates and here we launched the NAPWA Declaration of Rights. The national conferences were a huge amount of work but they enabled HIV-positive people to hear firsthand information and be active participants in their national organisation.

Having successfully nominated for the NAPWA board, I remained a part of this dynamic team for nine years. I also chaired the women's network, which originally Gabe and I co-chaired until her sudden and sad passing. Our official title became the National Network of Women Living with HIV and we have built a strong network of 14 members in 2014. To promote our network and increase its profile we have a clear workplan and advise the Board of issues relevant to women living with HIV. We strongly support and encourage women to nominate for the Board. So far we have developed our own logo, information flyer, banner, and introduction letter explaining our work and terms of reference. Our operational name is Femfatales.

In my duties as chair, I have been keen to build up the women's network membership and to have representatives from all Australian states and territories. And by 2014, we have almost reached that goal. As network chair, I have had the opportunity to visit many places. As a NAPWA board director, I joined the National World AIDS Day Reference Group. One year, I spent a week in the Northern Territory and spoke at a World AIDS Day (WAD) breakfast with a focus on women; another year I spoke at Tasmania's WAD event.

Another highlight was when NAPWA facilitated a Leadership Weekend to attract and inspire emerging national leaders. That weekend we met and shared our experiences of leadership in our own contexts, and we also had the benefit of hearing from people such as Bill Whittaker, who had displayed great leadership in the past. Wilo Muwadda was also impressive in speaking about leadership and Indigenous communities. I heard about many diverse leadership styles and approaches from Michael Hurley. I came away with a valuable lesson about good leadership and learnt that few of us set out to become leaders. I learnt that empathy and intuition will inspire others. While I was on the Board, NAPWA implemented its Strategic Plan 2009-2012, which prioritised building national leadership,

partnerships and networks within the diverse membership and strengthening NAPWA's governance role across Australia. At this time the NAPWA president was Robert Mitchell, who had a thoughtful, calm and insightful approach to all his duties. This was supported by the gradual transition from portfolios to networks, with an allocation of more resources and a dedicated secretariat to support the infrastructure changes.

I value all my time and learning experiences with NAPWHA. Along with other members, I supported the name change to NAPWHA in 2011. I have seen the reputation and impact of NAPWHA go through many phases. The organisation has shown outstanding leadership in responding to the issue of HIV criminalisation, furthering the treatments agenda for PLHIV, and now engaging clearly in HIV prevention efforts. I consider the continued success due to the passion and commitment of all involved, especially board, staff and members. Within an enabling environment this results in the empowerment of those who live with HIV every day.

*In 2000, considerable uncertainty prevailed about the future for people living with HIV: would HIV treatments provide enduring protection from HIV disease progress, would other, acute health issues emerge as HIV treatments continued, and was this 'treatments era' merely a period of stasis before further decline? That has turned around.*

**Neil McKellar-Stewart**





# Voices of PLHIV: *the commitment continues*

2014 onwards

*Thirty years on from the discovery of HIV, we can be immensely proud and excited by what has been achieved – but there is still much to be done . . .*

*One thing has remained constant; one thing that continues to distinguish the global response to HIV from any other disease response, and that is the central role played by people living with HIV. Now – just as 30 years ago – this role remains as important as ever.*

**Sharon Lewin**

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## INTRODUCTION

We are witnessing a transformational period in the 30-year global fight against HIV. New scientific advances in preventing and treating HIV allow for a dramatic reduction in new HIV infections, in HIV-related illnesses and associated deaths. Antiretroviral treatments are getting better and cheaper, and there is an expanding suite of prevention options available. More people with HIV are living longer and living well. For the first time in the history of the HIV epidemic, the prospect of achieving an 'AIDS-free generation' can be envisioned. But this goal will not be reached without a concerted effort, and many questions remain as to how this can be achieved.

The concept of a 'cure' for HIV, not so long ago considered a pipe-dream, is now being re-conceptualised. From the discovery of the HIV virus in 1984 onwards, the search for a cure has gone on and this has been a shared quest between scientists, doctors, activists and people living with HIV.

While there are opportunities and optimism, major challenges remain. There are human rights issues and health policy challenges; one critical challenge is tackling stigma. Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic. Stigma is a problem because it compromises the human rights of people with HIV, affecting their health and wellbeing as well as their social identities and relationships. It also undermines the ability of health-promotion programs to access the people who are most in need.

Another human rights concern is for people with HIV who enter Australia on a Temporary Resident Visa; they are ineligible for Medicare Services and Pharmaceutical Benefits Scheme subsidised medicines. Yet most of these people will later go on to become residents and receive Medicare eligibility, so this initial ineligibility is both illogical and undermines the notion of universal access to treatment for PLHIV in Australia.

There continues to be a responsibility to others outside Australia. Such projects as the Collaboration for Health in Papua New Guinea, where NAPWHA has been a key partner, represents that work.

Australia played a leading role in the design and adoption of the 2011 UN Political Declaration on HIV/AIDS. Especially the efforts of the NAPWHA President, Robert Mitchell and the NAPWHA Special Representative, Bill Whittaker, assisted, as part of the Australian delegation, in negotiating the Declaration. The Declaration committed to achieving dramatic reductions in the worldwide transmission of HIV, to significantly increase the number of HIV-positive people on treatment, and to eliminate all forms of stigma and discrimination against people living with HIV, by 2015.

The UN Declaration recognised that eliminating the transmission of HIV requires a dramatic up-scaling of prevention programs, both in terms of treatment as prevention, and education with at-risk populations. Yet despite willingness on the part of the PLHIV community, clinicians and researchers to fully utilise the potential biotechnology and the proven education programs, what we see is a disinvestment in the HIV response and a lack of leadership, particularly from Australian governments. The 2014 federal

budget has signalled that the Commonwealth plans to strip \$8.5 billion from Australian health care. This will have a direct flow-on effect to people with HIV. The introduction of a \$7 co-payment to see the GP, the prospect of charges to attend public hospital emergency departments, and a \$5 increase in PBS co-payment fees for medicines, will all impact negatively on the ability of people with HIV to access the health care they need and to maintain an undetectable viral load. All of this works to negate the purpose of the UN Declaration.

Over the last two years, NAPWHA, concerned about many issues currently being faced by PLHIV, called together the operational leadership of member organisations of the association to reinvigorate the HIV-positive led response. Out of this ongoing effort, the Poz Action program of activities has taken shape. The aim is to develop strategies to better coordinate and share resources and expertise and to drive a policy and program agenda that addresses health policy challenges, human rights for people with HIV, and reduced HIV-associated stigma and discrimination. Priority issues include: delivering a coordinated national response to criminalisation of HIV in Australia, delivering national leadership in health policy and treatments and, maintaining the centrality of people with HIV in all aspects of the HIV response including HIV prevention. People living with HIV have always maintained their advocacy and leadership efforts. Currently it requires government at a Commonwealth level, to also maintain active leadership in this area and play a role in resourcing and reinvigorating the HIV partnership response.

The HIV response in Australia has historically been a partnership between government, clinicians, researchers and non-government organisations and affected communities. It is internationally accepted that the meaningful involvement of people living with HIV in program and policy development, implementation and evaluation, improves the relevance, acceptability and effectiveness of the HIV response. That people with HIV in Australia in 2014 are able to live with some degree of dignity, maintain and improve their health and wellbeing, and make choices that have a beneficial impact on their own life and that of their partners and family is testament to the quality of past advocacy by PLHIV. It is essential that beyond 2014 the voices of PLHIV are still heard and that organisations like NAPWHA continue to represent the lived experience.

There has to be respect for all voices of people living with HIV; indeed, this lived experience, when successfully tapped, gives voice to the reality of PLHIV and is vital to the ongoing development of effective prevention, treatment and clinical and social care responses, in Australia and overseas. In these challenging times, NAPWHA will continue in the role that it has played for over a quarter of a century, to be the national voice of people living with HIV.

**Michael Kirby**

## *Speaking out and demanding action*

Just at the moment when gay, lesbian, bisexual and transgender people were beginning to secure a few political, legal and social successes in Australia, a frightening epidemic arrived to dash our hopes. Like many who were around in those days, I lost wonderful friends whom I still miss and grieve for. Don't let anyone tell you that time heals all wounds. It does not always happen that way.

Apart from grief, I feel anger at the shock and fear that HIV suddenly introduced into lives that had already been traumatised by hostility. Hostility from families, churches, media, politicians, schools, judges and the rest. John Rule, whose work for NAPWHA I honour, recently gave a candlelight memorial address that expressed exactly my feelings of anger, bewilderment and loss at that time. What would our lives have been like if those who died were still around? Why have we accepted the silences around our own experience and denied our own pain? What relationships would we have had, growing older? Why did this happen? Above all, why did it happen, when it did, to us?<sup>1</sup>

It is natural for humans to try to find a silver lining. But the silver bullets still elude us: a cure, and a safe and effective vaccine. Still, the power of medical science has made a huge difference. Only the ignorant, and wicked minds of the stigmatisers remain, languishing with their medieval demons. You know whom I am referring to. Museveni of Uganda. Putin of Russia. A couple of Popes and bishops we could name. The haters in our own sunny land.

For all that, from the very start of the epidemic a few good things happened to partially address the unexpected ill fortune:

- The appointment of Jonathan Mann to head the Global Programme on AIDS of the World Health Organization. From the very first day, he insisted on the active participation of people living with HIV. Not only spoken about. Or spoken to. Speaking out. Insisting on scientific and social progress;
- People, including myself, began stumbling out of the darkness to which we had been consigned by other people's phobias. We began to speak up. In the 1980s, I did so and I thank my partner Johan van Vloten, and organisations such as Ankali and many HIV-positive people for teaching me and rescuing me from that dark place the Americans name the 'closet';
- In the hothouse of Australia's divided politics, we found two giants (Blewett and Baume), who, working with PHIV, gays, lesbians, bisexuals, transgender (and other citizens) devised a national strategy that tapped the resources of an increasingly assertive community. And Australia gave leadership to the world; and

- The horrible epidemic propelled the world into rare acts of solidarity. Joint United Nations Programme on HIV/AIDS. United Nations Development Program. President's Emergency Plan for AIDS Relief and the Global Fund. Millions of lives saved and restored. These were exceptional acts of generosity. In the Pacific, Australia has been in the lead. And the voices of PLHIVs have helped to keep it so.

I refuse to say there has been a silver lining. Too much pain and anger for that. But at least we have reduced the darkness. We must continue to do so. We must go on trying to understand what this great affliction is teaching us about our world, our country and ourselves.

#### NOTE

1 John Rule, *What Candles May Be Held to Speed Them All?* AIDS Candelight Memorial Address, 18 May 2014, Surry Hills, Sydney

**Dennis Altman**

## *PLHIV have led a partnership response*

In the early years of the epidemic Noreine Kaleeba, the remarkable woman who helped found The AIDS Community Organisation in Uganda, told me of going to San Francisco, and recognising in the Castro the same sense of communal loss and grief she had experienced in her own villages.

When we look back over thirty years, gay men of my generation, as well as families of people with haemophilia, face a major hollowing out of our lives as so many of our peers are no longer here. Many of the founders of the Positive movement came out of the gay movement, but gay liberation was an expression of joy and hope; the PLWA movement emerged at a time when most people who were diagnosed with HIV faced death.

I had the privilege of being a friend of one of the founders of the PLWA movement, Michael Callen, who at one point dragged me with him through a seedy New York sex establishment where he was trying to explain safe-sex messages. Michael came to Australia in 1986, and helped inspire people here to assert themselves as advocates rather than victims.

For almost three decades, people living with HIV in Australia have led a partnership response to the epidemic, sometimes fragile and volatile, but on balance one that has consistently been a world leader in both prevention and treatment. The most encouraging sign as we move into a new period of the epidemic is the emergence of a young generation of HIV activists, mainly but not always positive, who are redefining the nature of activism itself.

**Bill Whittaker**

## *Transforming Australia's HIV prevention and treatment efforts*

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### **Introduction**

We are witnessing a transformational period in the 30-year global fight against AIDS. New scientific advances in preventing and treating HIV have given us the knowledge and the means to make dramatic reductions in new HIV infections, HIV-related illnesses and deaths. For the first time in the history of the HIV epidemic, the prospect of achieving an 'AIDS-free generation' is being envisioned.

This goal will not be reached without a concerted effort by every country. We need to put aside the weariness, complacency and unwillingness to change that pervades aspects of the global HIV response. We need to invest fully and wisely in HIV treatment and prevention, even though the global economic climate is difficult and is impacting on national budgets and health spending. Every day that we delay makes the task harder and results in thousands of new HIV infections, adding in turn to individual, societal and economic burdens.

How the world reacts to the unprecedented opportunity we have to change the course of the HIV epidemic will affect the lives of many millions of people around the world. More than ever, we need strong leadership and community resolve so we make the right decisions in this exciting but challenging time.

### **The HIV treatment and prevention revolution**

The impact of antiretroviral (ARV) drugs in halting disease progression and prolonging life is being demonstrated all over the world. Today's ARV treatments are effective and generally well tolerated. Major improvements have been made in reducing pill burdens, and once-daily single-tablet combinations of different ARV drugs are available. Adherence to treatment and ARV drug resistance remain a challenge, but many millions of people are successfully taking ARV treatment, with manifest benefits for their health and wellbeing.

Since 2009, there has been a clear shift in HIV clinical management from deferring ARV treatment to starting ARV treatment earlier, based on the rationale that early ARV treatment delivers both individual and public health benefits. This approach is supported by large observational studies<sup>1-3</sup> that have found a clinical benefit in treating earlier. Other studies looking at the life expectancy of HIV-positive people have found that taking ARV therapy (ART) to maintain a high CD4

count will probably translate into a mortality benefit.<sup>4,5</sup> The treatment as prevention approach is supported by two ground-breaking clinical studies (HPTN 052<sup>6</sup> and iPrEx<sup>7</sup>), which show the powerful effect of ART in reducing HIV transmission.

Although the benefits of ART are uncontested, the question of when to start ART in patients with less advanced HIV disease (e.g., for people with a CD4 count above 500cells/mm<sup>3</sup>) has not been answered definitively by randomised studies, and remains a focus of research and debate.<sup>8</sup> Certainly, some studies<sup>9</sup> have not found any clinical advantage in starting ART with a CD4 count above 500cells/mm<sup>3</sup>, but none have found any previously unidentified increased risk due to long-term ART use either.<sup>10,11</sup>

Some argue that more research is needed on the optimum point to start HIV treatment. Other concerns about early treatment include the cost of the medication, the possibility of developing long-term treatment related side-effects and toxicities, the possibility of developing early resistance to HIV treatments and the fact that treatment is a lifelong commitment that some patients may not be ready to make.

However, in light of available evidence and expert opinion, a growing number of clinicians now recommend that their patients start ARV treatment as early as possible, based on the following considerations:

- Untreated HIV infection may have detrimental effects at all stages of infection.
- Later treatment may not repair the damage associated with viral replication and immune activation during early stages of infection.
- Earlier treatment may reduce the added risk for HIV-positive patients of developing health problems like cardiovascular, liver and kidney diseases, cognitive effects and cancers.<sup>12</sup>
- Treatment has the important added benefit of helping prevent HIV transmission.

The executive director of the United Nations Joint Program on HIV/AIDS (UNAIDS), Michel Sidibe, has noted that the added benefit from ART in preventing HIV transmissions means we can now think about the role of ART in a new way, not just to save lives of those infected but to prevent HIV infection in the first place – making the step from averting illness in individuals to dramatically slowing the epidemic in populations.<sup>13</sup>

### **2011 United Nations Political Declaration on HIV/AIDS**

It was in an environment of increasing optimism about scientific advances in HIV that United Nations (UN) members gathered in New York in 2011 to consider a draft UN Declaration on HIV, designed to provide a new policy, program and funding framework for future global efforts.

However, this optimism was tempered by the reality that getting agreement on a



new declaration would not be easy, given that bold and perhaps contentious measures were needed to capitalise fully on HIV treatment and prevention advances. Furthermore, there was concern that funding to implement the declaration would be a challenge, given that health spending was already under considerable pressure from a global financial crisis.

Weeks of negotiations took place in the lead-up to the UN meeting in New York. Some UN members argued it would be best to adopt a short declaration to re-endorse the actions contained in two earlier declarations on HIV (in 2001 and 2006).<sup>14,15</sup> The argument here was that progress could be lost if negotiations broke down in what was seen as a difficult global environment. On the other hand, a short declaration would not have been able to adequately address the strategy, policy and funding changes needed to reverse the pace of the global HIV epidemic. Also, a large number of commitments, targets and timelines made in the 2001 and 2006 declarations had either passed or were no longer relevant.

In the end, the argument for adopting a forward looking, comprehensive declaration prevailed and the draft declaration was endorsed unanimously by the UN General Assembly.

The centrepiece of the 2011 UN Political Declaration on HIV/AIDS (UNPD)<sup>16</sup> are bold new HIV prevention and treatment targets for the global community to reach by 2015.

These global targets include reducing sexual transmission of HIV by 50%, reducing HIV transmissions through injecting drug use by 50% and eliminating mother-to-child HIV transmissions – all by 2015. The UNPD also sets a target of having 15 million people living with HIV in low- and middle- income countries on ART by 2015 as part of the goal of providing universal access to HIV treatment for all in need.

To achieve these targets, the UNPD calls on all countries to make major strategy and program adjustments. These include: (a) widely promoting HIV testing; (b) scaling up prevention and treatment programs and ensuring they are targeted at populations at highest risk; (c) implementing harm-reduction policies and programs; (d) ensuring wide availability of condoms and sterile injecting equipment; (e) deploying new biomedical prevention interventions as soon as they are available; (f) promoting male circumcision in certain contexts; and (g) mobilising communities, particularly through exploiting new technologies for communication, such as social media, mobile phones and the internet.

The UNPD also commits countries to fight HIV-related stigma and discrimination, and create enabling legal, social and policy frameworks to help maximise prevention and treatment uptake, especially among populations at highest risk of HIV infection.

Other important commitments in the UNPD include achieving better coordination and monitoring of HIV programs, measures to help strengthen health systems and a call for all countries (not just donor countries) to assume greater ownership and funding of their HIV responses.

All countries promised to update their national HIV strategies and financing plans by 2012 to reflect scientific advances and the UNPD's targets and commitments; particularly the commitment to ensure that HIV programs and funding are reoriented to reaching key populations at the highest risk of HIV, and to remedy unacceptably low levels of treatment and prevention coverage among these populations.

Possibly the most remarkable outcome of the UNPD was that for the first time in the history of the General Assembly, men who have sex with men (MSM), injecting drug users (IDUs) and sex workers were named in a UN declaration. Previous attempts to do this in the 2001 and 2006 declarations on HIV were blocked by countries who refused to allow these populations to be named and instead insisted they be referred to euphemistically as 'vulnerable groups'. This refusal to acknowledge and name key populations at higher risk to HIV has arguably cost many new HIV infections and lives as it can render them invisible. It has hindered HIV prevention efforts and misdirected millions of dollars to target populations at a low risk of HIV, instead of directing it where it would have a greater impact.<sup>17</sup>

This decision to name these three populations has set an important precedent for future resolutions of the UN, beyond just the issue of HIV itself.

Finally, it should be noted that Australia played a pivotal role in gaining agreement of UN member states to the UNPD through the efforts of Australia's UN Ambassador, Gary Quinlan, who co-chaired the negotiation process. Consequently, Australia is expected to show leadership in implementing the declaration's commitments domestically, as well as championing its implementation regionally and internationally. Australia's progress in doing so is discussed later in this paper.

### **Regional progress: responding to the 2011 UNPD and HIV prevention and treatment advances**

The UNPD commits all countries to update their national HIV strategies and financing plans by the end of 2012 to align with the agreed targets and commitments of the declaration.

As part of monitoring UNPD implementation, UNAIDS publishes progress reports, which are provided to it by UN member states. A review of these countries' progress reports<sup>18,19</sup> was undertaken for the purpose of comparing Australia's progress in implementing the UNPD with that of eight other Asia-Pacific countries. This review also looked at how these countries were responding in their national HIV plans to the major advances in HIV prevention and treatment referred to earlier in this paper.

This review provided a mixed picture of progress. In their progress reports to UNAIDS, some of these eight countries have reported on the specific prevention and treatment targets of the UNPD. However, this information is mainly statistical in nature and does not report on the actual policy and program actions that countries will need to put in place to reach the UNPD targets and respond to advances in HIV prevention and treatment.

All countries were asked by UNAIDS to report if they had followed up on their 2011 UNPD commitments, and if their national HIV strategy and national HIV budget had been revised accordingly. Of the eight countries examined for this paper, all except Papua New Guinea answered 'yes' to both questions. However, the extent of these strategic and budgetary revisions varied considerably, and the current Cambodian, Indonesian, Laotian, Malaysian and Singaporean national HIV strategies do not appear to have been updated in any significant way to reflect UNPD commitments, or HIV prevention and treatment advances. Papua New Guinea reports that it has not yet followed up on 2011 UNPD commitments or revised its national HIV strategy and budget accordingly.<sup>20</sup>

Thailand announced a new HIV strategy in June 2012,<sup>21</sup> aligning with the UNPD and including a target to reduce new HIV infections by two-thirds by 2015, which exceeds the UNPD global target. Key Thai stakeholders met in August 2012 to discuss the strategic use of ART in Thailand's HIV response. It is reported that a consensus was reached that Thailand's goal should be to achieve a 'test and treat' policy and program approach, whereby all HIV-positive people are offered ART, irrespective of CD4 count.<sup>22</sup>

Vietnam released a new national strategy on HIV/AIDS in 2012,<sup>23</sup> which aligns Vietnam's HIV response with the UNPD and its targets and commitments. The strategy describes policy and program measures that will be taken to implement the strategy.

Australia's most recent UNPD progress report to UNAIDS<sup>18,19</sup> states that an update to the national HIV strategy is being considered in light of new developments in treatment and prevention, and also in relation to the UNPD commitments, with the aim of intensifying efforts to eliminate HIV. Two years post the UNPD, Australia's HIV strategy is yet to be updated.

### **Australia's progress: responding to the 2011 UNPD and to HIV prevention and treatment advances**

Over the past 15 years, HIV-related illness and AIDS-related deaths in Australia have plummeted, with many HIV-positive people now living full lives and enjoying good health.

Australia is fortunate to have many advantages to support its largely successful HIV response, including: an excellent health system; a proven record in delivering high quality HIV prevention and treatment services; a strong community based response to HIV; an impressive record in HIV research; an effective partnership of governments, people with HIV, affected communities, and medical and scientific expertise.

Australia's pragmatic programs and policies, including strong support for harm reduction, have helped Australia achieve virtual elimination of HIV transmission among IDUs and sex workers. Although there are concerning risk factors for HIV infection among Indigenous Australians, rates of HIV infection remain low and comparable with those in the general population. So at present, Australia's HIV

epidemic remains largely contained to the population in which HIV first emerged in Australia, MSM.

However, some seem to take the relative stability of Australia's HIV response for granted, ignoring continuing rises in new HIV infections and the fact that we have not been able to reduce HIV infection rates over the past several years (the number of new HIV diagnoses is 1000 plus annually, which is an unacceptably high figure).

There are worrying trends, including a decrease in HIV testing rates<sup>24</sup> and an increase in unprotected anal intercourse among MSM.<sup>24</sup> Also of concern are data suggesting a significant proportion of people with HIV and their clinicians are delaying the initiation of ART past the point where initiation is strongly recommended in ART guidelines, adding to the complexity of care and the risk of poorer outcomes.<sup>25</sup>

A recent estimate by the Kirby Institute found that ART uptake by HIV-positive Australians may be only around 50%,<sup>26</sup> putting Australia in a league with low treatment figures seen in poorly performing parts of the United States and Europe.

These are worrying developments. However, if we deploy scientific advances in HIV prevention and treatment to the greatest effect, we have an opportunity not only to address areas of difficulty in Australia's HIV response, but to achieve much more. Indeed, with its advantages, Australia could be among the first countries to achieve virtual elimination of HIV transmission and, in doing so, lead the world by example.

### **National HIV/AIDS strategy, and state or territory HIV strategic plans**

Australia's current 6th National HIV strategy (2010–2013)<sup>27</sup> is fine on principles, but scant on specific policy and program actions and funding information. The strategy's implementation has been slow and frustrating. The strategy is now significantly out of date because it does not reflect the major scientific advances in HIV treatment and prevention referred to earlier in this paper, most of which came after the current strategy was written. The strategy does not address Australia's commitments under the UNPD either.

Over the past two years, leading HIV organisations including the National Association of People with HIV Australia, the Australian Federation of AIDS Organisations and the AIDS Council of NSW have been calling for action<sup>25,28,29</sup> to revitalise Australia's HIV response in light of the challenges described above and to meet its obligations under the 2011 UNPD.

In late 2011, Commonwealth, state and territory health officials; the Federal Health Minister's HIV advisory committee; and community HIV organisations met and agreed in principle that new national HIV prevention and treatment targets should be adopted, using the targets in the 2011 UNPD as a baseline. However, after this initial enthusiasm, getting governmental agreement on the details stalled for over 18 months.

Finally, in a welcome development, the Standing Council on Health, which comprises the health ministers from the Commonwealth, states and territories, recently endorsed a set of national HIV prevention and treatment targets,<sup>30</sup> which

align with those set under the 2011 UNPD. These Australian targets are:

- reduce sexual transmission of HIV by 50% by 2015;
- sustain the low general population rates of HIV in Aboriginal and Torres Strait Islander people and communities;
- sustain the virtual elimination of HIV among sex workers;
- sustain the virtual elimination of HIV among IDUs;
- sustain the virtual elimination of mother-to-child HIV transmission;
- increase treatment uptake by people with HIV to 90% by 2015; and
- Maintain effective prevention programs targeting sex workers and IDUs.

This endorsement of new targets for Australia's HIV response by all Australian health ministers – based on scientific advances in HIV and UNPD commitments – should provide important guidance to the states/territories and the Commonwealth governments to update their HIV strategic plans and programs.

Work is now underway to draft a new national HIV strategy. It remains to be seen whether the content and scope of this new national strategy meets Australia's UN obligations and responds meaningfully to the opportunities provided by scientific advances in HIV prevention and treatment. After years of relative drift at the national level, it will be particularly important for the Commonwealth government to articulate clearly what its role will be under a new national strategy and how it will work to support state and territory governments and community, medical and scientific partners.

### **New South Wales adopts a new HIV strategy**

NSW is the state most affected by HIV in Australia. The need to respond to scientific advances in HIV and to address rises in HIV infections and low rates of ART uptake, prompted the NSW government to develop a new state HIV strategy,<sup>31</sup> which was launched on 1 December 2012 with strong community endorsement.<sup>32,33</sup>

The NSW HIV Strategy is believed to be the first anywhere to set a timeline to achieve the virtual elimination of HIV transmission in the state (by 2020). Other targets in the NSW Strategy include sustaining the virtual elimination of HIV among sex workers and IDUs, reducing the sexual transmission of HIV among MSM by 60% by 2015 and having 90% of HIV-positive people on ART by 2015.

NSW is the only Australian jurisdiction so far to release a comprehensive new HIV strategy that reflects the key targets and actions called for in the UNPD.

### **The Melbourne Declaration 'Action on HIV'**

Growing concern over Australia's delay in responding to scientific advances in HIV treatment and prevention and to its commitments under the 2011 UNPD led to the development of the Melbourne Declaration on HIV (MDH).<sup>34</sup> The MDH was formally launched at the Australasian Society for HIV Medicine Conference in October 2012 and received wide media coverage.

The MDH is unprecedented in the Australian response to HIV. Never before had all the key clinical, community and research organisations in the Australian HIV response felt compelled to join together to draft and issue a public call for action to revitalise Australia's HIV response. As well as leading HIV organisations, over 500 individuals signed the declaration.

The MDH calls for urgent action to meet Australia's commitments under the 2011 UNPD. The MDH also calls for prompt action by the Commonwealth government to work with the states and territories to remove barriers to HIV prevention and treatment uptake in Australia, including by achieving the following:

- making rapid HIV testing widely accessible in clinical and community settings;
- investigating options for making self-testing rapid HIV test kits available;
- removing barriers preventing the initiation of ART at CD4 cell counts above 500 cells/mm<sup>3</sup>;
- removing financial barriers to treatment uptake, including burdensome pharmacy dispensing fees;
- making HIV pre-exposure prophylaxis available;
- establishing programs to make ART available to people who are not eligible for Medicare cover; and
- mobilising and informing people with HIV infection and those at high risk about new advances in HIV prevention and treatment.

Even though releasing declarations has become something of a regular feature of national and international HIV conferences, their impact is often limited because of the challenge of getting wide agreement from many stakeholders, and accommodating cultural and other differences among potential signatories. Consequently, such declarations can be too broad or too complex and call for actions that are not well prioritised or are impractical or disputed.

In order to maximise the impact of the MDH, the decision was taken to keep it short and limited to a small number of actions that were clear and achievable in the short-term and that represented the essential elements of a revitalised HIV response in Australia. Obviously, achieving consensus on such a document is likely to be easier in Australia than in some other countries or in some other forums.

The long-term impact of the MDH remains to be seen. However, since its release, key HIV organisations have used the declaration as a focal point for advocacy around the country. Arguably, this has helped focus advocacy efforts and encouraged HIV organisations to work together more effectively.

### **Conclusion**

The XX International AIDS Conference to be held in Melbourne in 2014 will see Australia's HIV response put under the spotlight. There is still time for action and leadership so we can tell a story not just about Australia's past achievements but also what this nation will do in the future to help end HIV and AIDS.

There is no doubt that Australia has shown great leadership and innovation in HIV prevention, treatment and research over the past 30 years. It is time for this nation to do so again. Australia should be setting an example to help other countries realise the promise of the 2011 UNPD to achieve an AIDS-free generation. We can also learn lessons from progress being made in other countries in the Asia-Pacific region that may not have all Australia's advantages but who are making concerted efforts to meet their obligations under the UNPD.

Australia must not let slip the opportunity to help revolutionise the global fight against HIV by acting on the UNPD and the transformational scientific advances in HIV prevention and treatment available.

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**Michelle Tobin**

## *Sharing an Aboriginal woman's story*

I am a mother of two beautiful daughters and three gorgeous granddaughters. I lost my husband back in 1992 to the AIDS virus. I am also a descendant of the Stolen Generation, and lost my family due to ignorance – like so many of us. I was diagnosed with HIV back in 1990. Fortunately, now, I have a wonderful man and my positive friends are my extended family. I am the only Aboriginal woman who participates in the speakers' bureau run by Positive Life NSW.

My motivation to get involved in the HIV sector was twofold, I wanted to prevent the stigma and discrimination that my daughters and I had endured, and I wanted to educate young people about the importance of safer sex and protecting themselves. I had a world of information that was inside of me – and I needed to share that.

I have spent many years advocating and educating our communities. In doing this I have been supported by many peers, and have received training from organisations to become an advocate in the field of HIV. Being a public advocate I needed some training to be able to deliver my story, this began with the Positive Speakers' Bureau (Vic), delivering our stories of living with HIV to secondary school students in Victoria; I continue to do this on the Central Coast of NSW.

I had my first trip overseas to an International HIV Conference in Chang Mai in 1997. Upon returning, there were not many services set up for women living with HIV, let alone for an Aboriginal woman, so to make a change I decided to join Positive Women (Vic). This was a political arena I was not really prepared for. I did not realise how hard it was to be heard, especially when you're a minority within a minority. During my ten plus years on the board of Positive Women (Vic), I was the Chair for a number of years, and was asked to attend the 2003 NAPWA Conference in Cairns. This was the first time I felt I was not alone, and I was introduced to four Aboriginal and Torres Strait Islander positive people from around the country. Upon meeting this group I was thrust into becoming the female convenor of IPN+, alongside Clyde DuBois, who was the male convenor.

IPN+ was still finding its feet and developing its own capacity, but that did not stop us from having big plans for the future. The network hoped to establish local groups in different parts of the country, and to work on a broad program involving policy development, advocacy with various levels of government, education and peer support. With the support of NAPWA, especially Jo Watson and Scott Lockhart, we had the ability to take the next stage and that was for IPN+ to develop a wider membership base, involving Indigenous people from across Australia.

By the next NAPWA Conference in Adelaide in 2005, we had built the core membership. The 2005 Conference was themed 'Our place, your place . . . in the bigger picture'. We held a musical performance by Tim Bishop and Sam Barsah to continue promoting the Indigenous network. During the conference we gathered for

social functions, including a welcome reception and community barbecue, and delegates met up with old friends and forged new networks. The conference also saw the launch of the revised version of NAPWA's landmark Declaration of Rights for People Living with HIV/AIDS. As delegates departed for the airport, we remembered the words with which Rodney Junga-Williams welcomed us to Adelaide: "I want you to know that you're all warriors and you simply being here – how brave that is." It was also at this point where our members stood up before our peers/delegates and made a commitment to everyone that we were here, and here we were to stay. It was a proud moment – being able to be open about our status and being committed to our Mob and the HIV epidemic.

To promote PATSIN to our broader communities we needed to start thinking about resources and fundraising. With the assistance of NAPWA, in 2006 we were able to have an official launch of our CD, *Two Songs for Healing*. This project had been made possible with the support of Oz Showbiz Cares/Equity Fights AIDS and all the 'Deadly' artists who have contributed to this project.

In the past we have seen education in our communities on many levels because of our commitment to giving a lived-experience perspective to Aboriginal and Torres Strait Islander communities across Australia, and we continue to do so, although there have been times when our network has struggled with its membership, due to other commitments or unforeseen circumstances. Sadly dedicated members of our network have passed away.

At the Anwernekenhe 5 Conference held in Cairns in 2011, we were able to rebuild our membership and look at what resources we needed to promote PATSIN's work. Our most recent work has been about the continuation of promoting PATSIN to the whole of the community, being a brochure, a banner/poster and T-shirts.

During this time, I was also fortunate enough to join the Women's Network, working on such resources as Treat Yourself Right, Common Threads, making posters, Femfatales T-shirts, the most recently a brochure about us. Importantly, work has been done on the female condom, allowing women to protect themselves. My need to be within these groups is that I have lived with this virus for almost 20 years and I have been given so much over the years, and it was time to give back and to help those within the broader community.

**Jesse Hooper**

## *I thought I was pretty resilient . . .*

I reflect on those who came before us. Those who fought for the rights that people living with HIV (PLHIV) have today. I reflect on those who lived openly with their status to better the lives of PLHIV today. Most importantly, I respect those who came before me. I consider myself incredibly lucky, and I am eternally grateful for those who came and went before me, because they are my heroes in the fight against stigma and discrimination. Without their selflessness, courage and passion I would not be doing the work I am doing today.

Arguably, there is no stronger way of delivering a message, of getting a point across than through a story. I am a passionate believer that through sharing the lived experience of living with HIV we will ultimately be taking HIV out of the closet and humanising it. I feel that the more we humanise HIV the less stigma and discrimination we will face. This is the reason why I have chosen to live openly with HIV, and why I am a supporter of any project that allows the HIV-positive community to share our unique and powerful stories.

So let me share a brief piece of my story with you.

I was diagnosed in mid-2009 at the age of 21. I think I dealt with it okay in the beginning. I told friends and family relatively quickly. I think most people in my life knew within a matter of months. I wear my heart on my sleeve and I'm not afraid to face things head on. HIV was no different. I'm not suggesting I wasn't devastated by the news – of course I was. Whilst it was pretty hard in the beginning, I decided relatively quickly that I wasn't going to be defeated by HIV. I was going to use HIV as an opportunity to make a difference, that I would live openly, and take HIV out of the closet – no longer did it need to be a dark secret, or something to feel ashamed of. I felt that this was especially important within my age demographic.

Having grown up a very independent person, I thought that I was pretty resilient and was used to dealing with life's challenges on my own. I did, however, become involved with Queensland Positive People (QPP) and the Queensland Positive Speakers Bureau (QPSB) early in 2011. I initially came into contact with QPP in support of a friend who had just been diagnosed. Given I was still new to the world of HIV, I thought we could attend the recently diagnosed workshop together. Instantly I felt so connected to the organisation and thought that QPP was the best thing since sliced bread. Just being able to share my story with people who could relate to what it was like to be HIV-positive was an amazing and empowering experience. I remember saying to my friend after our first engagement with the organisation that if I were to develop a new career path, supporting the positive community was what I wanted to do.

In June 2011, I was appointed as the Youth Representative of the Australian Delegation to the High Level Meeting on HIV/AIDS at the United Nations

Headquarters in New York City. This presented me with an amazing opportunity to represent young people living with HIV in Australia. I was able to meet like-minded young people from around the world, who shared the same passion I have for addressing the stigma and discrimination still so prevalent in our communities. I came back to Australia more passionate and more inspired than ever before. As a result of this meeting, I was asked to attend a meeting of the Ministerial Advisory Committee on Blood-Borne Viruses and Sexually Transmissible Infections. These experiences not only inspired me with a newfound passion and desire to make a difference, but it empowered me to run for and be elected to the QPP Board of Directors at the end of 2011. I sat on the Board of Directors for a year and a half before I resigned to accept an operational role within the organisation.

My first experience of publicly sharing my story came in *Positive . . . is that good?*, a collection of thirteen stories written by HIV-positive gay men in Queensland. Despite all of the stories being written by gay men, there is still clear diversity across the pages. This highlights that HIV is a personal journey and that no two journeys living with HIV are the same. The stories were also shared through the gay press here in Queensland.

Following this, I participated in a couple of short documentary-style films, *I Never Chose This* and *Infectious Personalities*. Both of these films provide information about HIV as well as demonstrating HIV stigma and discrimination, backed up by the lived experience of PLHIV. If you are interested in seeing them, they are available through the QPP website and Vimeo page. I also recently participated in another public awareness campaign with the HIV Foundation Queensland (HIVFQ). This project is currently being finalised; however, it will be widely available when released. I have every faith in the production team that this will be an amazing resource with a diverse range of stories and experiences.

Whilst I have done some very public work talking openly about my journey living with HIV, I think the most rewarding things I have experienced have been since being appointed to the position of Peer Support and Communications Officer with QPP in 2013. Working with clients has had the most profound and positive impact for me personally. Being able to support PLHIV, whether that is someone going through a diagnosis or someone who has been living long term with HIV. Giving people the information and the tools they need for their journeys gives me the best feeling, and is something I am incredibly proud to be able to offer the community.

The first major project I worked on since being employed with QPP is the ‘Talking About HIV’ campaign, which was launched in December 2013. I wanted to support other PLHIV in sharing their stories in whatever capacity they feel comfortable to do so. I was fortunate enough to find a diverse group of people who were either living with HIV, or HIV had had an impact on their lives. ‘Talking About HIV’ is a series of short films addressing the lived experiences of people with and affected by HIV. It is a starting point to initiate conversations about HIV with family and friends. Too often we hear that people choose not to test because of the fear of receiving a positive result. This demonstrates the importance of humanising

HIV. Removing the fear of testing, and removing the fear of a positive result. Knowledge is power, and that is no different for knowing your HIV status.

All of this demonstrates to me the fundamental meaning of MIPA (the Meaningful Involvement of People living with HIV). As a young person living with HIV, I was supported and empowered to be involved in conversations that affected me as a young person living with HIV. Now that I sit in an operational role in the sector, I want to pay this forward, and hopefully empower other people to come forward and share their stories.

**Cipri Martinez**

## *Our future includes social justice*

This year marks a turning point where I have lived more years with HIV than not. In July, I turn 42, and it is interesting to reflect upon the meaningfulness of my engagement after living with HIV for 21 years and what lies ahead for the next 21 years.

I attended my first support group in 1994. It was an important first step to self-discovery and self-development, where I could share with others in similar circumstances the shock and terror of living with a fatal disease such as HIV. Back then the prognosis was just five years. Individuals who had already lived this long were walking inspiration and provided desperately needed hope in the face of a medical establishment, which as yet had no answer to treat or cure HIV. Many of us were determined to grow from this experience and to leave a legacy of contribution and love where possible.

Becoming an activist during a moment of crisis was for me relatively easy; after all my life depended upon it and I had nothing left to lose. Why wouldn't I share the journey with my brothers and sisters who, like me, struggled to make sense of life and create meaning and love. Issues were easy to identify, such as: Where was our cure? Where was the research to solve this crisis? Why can't we access drug trials that might save our life? We were all unified in our determination that all of us deserved to live with dignity, without fear and discrimination, and when our time came to die with dignity too.

Fast forward to 2014 and with my head towards the sky and my arms open and palms out, I am so grateful to so many people. We are now in a time and place where it is possible to have a normal life expectancy, normal sexual relations and, if you choose, a normal life, although some of us will still choose an extraordinary life too. So why become an activist today? What is there to be passionate about? Where is the crisis? The greatest challenge today is perhaps to extend what is now a possible reality for the privileged few and extend it to the honoured many.

In Australia there remain population pockets that do not have access to affordable medication, including individuals who are Medicare ineligible. Perhaps they are a non-resident studying in Australia, or someone who has come to work in Australia on a 457 Visa. When one of us is denied the right to live (by being denied access to medication), we are all made poorer for it; the human spirit cannot reconcile the discrepancy. There is no equivocation; we are responsible for the humanity or inhumanity we create or that through lack of action is created.

The mission for many of us is not only to live and love for as long as possible, but to stop the HIV epidemic so that no one would ever again go through the unnecessary hardship experienced by so many. The time for intellectual debate on what prevention method should be used is over. We now have the knowledge and understanding that combination prevention (behavioural, biomedical and structural) tailored to the individual and their context is the most efficient, effective and empowering way forward. Communities and individuals need to be empowered to make as informed and resourceful choices as our combined and cooperative efforts can create. In this way we have the greatest likelihood of stopping the HIV epidemic everywhere.

Activism for cure research is also a top-order priority. When in 2009 Timothy Brown, the Berlin Patient, was cautiously declared cured of HIV, an important mind shift occurred globally. Suddenly what was once a theoretical dream for many became manifest in an individual. Since then, we have had a welcomed reinvigoration in cure research. Rethinking how we organise and collaborate on cure research in 2014 is very different to what was occurring in the early 1980s when the HIV epidemic first began. The capacity to share and exchange knowledge and resources has multiplied.

Much of the cure research to date has been narrowly focused on a mono cure, where one strategy attempts to solve the HIV cure conundrum. However, it appears that intuitively the answer is already before us. Like combination HIV medication and combination prevention, could combination cure strategies finally deliver an end to the HIV epidemic? Before we reach this position, organisational systems on how trials are conducted and costed may need to change. As will patents, so that sharing and building on each other's research knowledge can happen efficiently and effectively. There is so much to do yet, and given the ongoing cost to humanity, a sense of determined urgency remains.

So it is that I remain passionate for social justice. HIV treatment, prevention and cure cannot emerge without the combined efforts of individuals, communities, organisations, medical practitioners and researchers, and, most importantly people with HIV. I encourage you to participate both locally and globally; we all deserve to live in a society co-created by the best of our humanity.

**John Rule**

## *What candles may be held to speed them all?*

AIDS candlelight rallies have been an integral part of Sydney's honouring and remembering of those who have died of the infection that devastated our communities for so many years.

Each year in Australia, as throughout the Western world, candlelight memorials are held in remembrance of people who have died from AIDS. These memorials – in the past, often solemn and silent processions followed by a vigil – are accompanied by a public reading of the names of people who have died from AIDS. In Australia, the first candlelight memorial was held in 1985 when two men, Phil Carswell and Tom Carter, stood silently with lit candles in a Melbourne city square. From this, the event grew in magnitude and scope to the point where, 10 years later, the estimated attendance at candlelight memorials across the country had grown into the tens of thousands. Such AIDS memorials then also functioned as a ritual of remembrance, akin in many ways to collective funeral rites.

Throughout the 1980s, the gay community was enduring the illness and loss of large numbers of its members, yet there was a void of institutional recognition of this. The establishment of these AIDS memorials then served an important purpose. The stigma surrounding HIV/AIDS meant there was no formal recognition of HIV/AIDS as a 'national tragedy', nor would there be moves to commemorate formally those who had died from the virus in a manner that often occurs following events such as natural disasters or wars. So it is a tradition worth continuing, in some form or other, worth not allowing to lapse, or become an offhand exercise. When we attend an AIDS candlelight rally, we are commemorating that past, those lost lives and lost opportunities. We are mourning, memorialising and remembering, and this is good work we are doing. It is good work for those who have died and whose memories we are sustaining. It is good work for ourselves here-and-now, and letting some things 'settle-and-be-how-they-must-be'. It's good work for those in the future. This memorialising is, I think, sustaining of a future for others.

I have been part of the large gatherings of remembrance at AIDS candlelight vigils in the past. I have been amongst the candles that have moved from the Fountain in Kings Cross to Green Park, where vigils were set up near the hospice, where friends were dying. I have been part of the long stream of people carrying candles walking silently down Oxford Street along College Street and into the Domain, where many names were read out and many candles set up on tables, creating beautiful tableaux for those who had died. I have been part of the smaller gatherings in the corner of Hyde Park where a stage was set up and names were read, and we paid our tribute to those who had died.



I came to Sydney from country NSW in 1978, the year of the first Mardi Gras, I wasn't in that one, but by 1979 I was part of a crowd who dropped into the Beresford Hotel, which had opened and catered for men who were part of a developing culture of identifiable gay men in inner-Sydney. There were other social and sexual spaces and believe me I haunted all of them! But between the beers and the picking up, there was a bit of conversation at that pub, sometimes of a local political nature, and an opportunity to collect local gay newsletters. In that milieu, and when I took to Sydney University studies full time in the 1980s, I found traces of the gay liberation movement, with which I quickly identified. I was also empowered by reading books at that time, such as Dennis Altman's *Homosexual: oppression and liberation*, and an excellent but now forgotten book by David Fernbach, *The Spiral Path: A Gay Contribution to Human Survival*. I was part of a vivid time of imagining what our social futures could be. Then, living in Surry Hills, I became part of an incredible energy that was emerging at that time around gay rights and gay law reform; gays openly participating in social, community and political structures. I wish I could convey how open with possibilities that time felt. Not just for me alone, but for the social structures in which we lived and which we felt we were active in shaping. But then AIDS came along and I think this sense of possibility was taken away. We then had to live in crisis mode, through a war of sorts.

I have a feeling of having been through a war. But it is hard to describe. Looking out at the ravages of the First European World War, the young gay poet Wilfred Owen wrote *Anthem for a Doomed Youth*. There is a line in the poem that I have used for my title; I need to give you a piece of the poem so you get the line in context. Owen is writing about the loss of his generation:

What passing-bells for those who die as cattle?  
only the monstrous anger of the guns.  
Only the stuttering rifles' rapid rattle  
Can patter out their hasty orisons.  
No mockeries now for them; no prayers nor bells;  
Nor any voice of mourning save the choirs –  
The shrill, demented choirs of wailing shells;  
And bugles calling for them from sad shires.  
What candles may be held to speed them all?

What an appropriate question, as we hold our own candlelight rallies. What candles may be held to speed them all?

What candles may we hold to speed all those whom we remember, those who have died of AIDS and as a result of HIV over the last thirty years? Our lovers and friends fell by the wayside. Particularly, in those early years, they died around us, it was like a war. Not figuratively – but literally. There are those still standing, like me; we all went through that war.

In 1918, Wilfred Owen, who wrote that poem, wrote a letter to his mother saying:

“I confess I bring on what few war dreams I now have, entirely by willingly considering war of an evening. I do so because I have my duty to perform toward war.”

In a similar way, I want to remember my memories not for my sake alone, but because I believe there is a real utility in that for the present, a duty to perform. A utility for people other than me; I cannot help but make the connection that until the trauma of the experience of HIV hitting the gay community through those years is genuinely felt and recognised, we will have great difficulty moving through the present moment, in which one task is clearly to dispel fear and stigma about this disease called HIV. To understand this thing for what it is. It's a disease. A virus, not a crime. We have to live with it, personally, I feel I have to co-exist with it; and we have to realistically envision the potential that this virus can be managed.

In Jacques le Goff's book *Memory: an Anthology*, he says of the evolution of societies in the second half of the twentieth century that “collective memory is one of the huge forces at play . . . amongst those who wield power and those who are subject to it”. Are we, collectively, forgetting the trauma that occurred when HIV and AIDS came into our midst and ripped apart a burgeoning and liberating expression of sexuality and love? Are we at risk of forgetting the liberated future we were imagining?

We lost so many beautiful young men, old men and some women who were in their prime. Whilst we as a gay community lost those young men, their loss was also a bewildering experience for their mothers, fathers and siblings, for their immediate families – and I don't think we have understood that impact yet either.

Hopefully though, there will never be the loss here again as we experienced through the HIV epidemic in the 1980s and 1990s. We have moved in the epidemic from palliative care to chronic health care, to viable health management. And with the current treatments for HIV management available there is the potential to reduce and eradicate HIV transmission. There could be a future of hope, a future we owe to those who went before their time.

So my question, slightly different to Owen's version: What candles may we hold to speed them all?

**Daniel Brace**

## *Linking the past with the present*

I was 28 years old when I was diagnosed, and like every inquisitive young gay man in Australia, had a broad understanding of the relationship between the gay community and the early AIDS epidemic. But this history was, in reality, ancient history; it did not have any relevance in my life, until right then when I realised that in becoming HIV-positive, this little thing was much, much bigger than just me. Still, that

understanding was embryonic and unformed.

Trying to come to terms with my situation and reaching out through my networks was met with mixed success. While most reactions were supportive and caring, some were not. Even from within the community of PLHIV. This was a shock. I had a picture of a gay community united against HIV, but that was, in fact, completely fictional.

Over time, my understanding and appreciation deepened for these real people and their achievements. I understood how linked the rights of gay and marginalised peoples are with the rights of all human beings. How those stories are the rich oral history to be remembered and celebrated. Now I feel connected to a much larger, more vibrant and diverse community with a history that I can own. It's not the community I imagined; it's more, it is the worldwide community of PLHIV.

It's a community that still has its challenges, but it's one deeply grounded in a shared past and striding into the future, striving to become stronger and more inclusive. For many newly diagnosed, including me, this transition from being outside of the community to being an active member was not intuitive or easy. In fact, while it seemed to me to have happened by accident, it was because of the persistence, encouragement and investment of other PLHIV and our closest friends and supporters that it happened.

Being a new community member can be daunting. The oldest, and in some cases strongest, links of our networks were forged in the dark days of the AIDS epidemic. Those bonds are still strong, as is the sense of community responsibility born of that time towards our new community members, and all the efforts undertaken to protect them.

But these chains have been broken for a while now, crudely divided by the introduction of antiretroviral therapies. The difference has been described as generational, but perhaps more accurately should be talked about as attitudinal. New attitudes to medication, a post-AIDS political environment in Australian society, the hetero-normative leanings of mainstream gay culture, are all underpinned by incredible scientific and medical advances and the decriminalisation of homosexuality, which for many has become a distant memory.

But these are far from halcyon days. In this environment, we face a weakening of our unified front and our political bargaining power. Those people with post-ART attitudes seem to be more likely to be disconnected from membership-based organisations, even though they are very happy to openly disclose their HIV status in 'private' Facebook pages with hundreds of strangers. In such settings, the danger is they are in fact virtually isolated. Even so, this is an expression of community; and as these groups grow, so do the real affections and affiliations of their inhabitants.

The traditional structures of PLHIV-led organisations, mainly membership based, are our safety net. They are real and able to channel support and resources to meet our needs: peer support, programs to build individual confidence and resilience, and the ability to shout loudly on our behalf when we are unable to find our voice. I say this because I have turned to these structures and the people in them in my

hour of need, and they have not been found wanting. That's when the penny dropped for me. These organisations are absolutely necessary to keep our community together, strong and healthy. As a PLHIV who has been invested in and invests in our community-based organisation, I am evidence of the love and care of PLHIV for each other demonstrated through the programs and services offered by PLHIV-led organisations.

For young and recently diagnosed, being linked in and investing the time to get to know those people in our community who hold this precious history and are its living memory, should not be an act of lip-service, but should be in serious recognition that as a united community looking to the future, we must honour the past. Then there are those who effectively link the past with the present, those who are genuinely tying our community together by active encouragement and engagement with future leaders and individuals who are new to the community. This means challenging both sides of the fence, without knowing the impact or response. These should be, and in many cases they are, our current leaders.

Through my eyes, our role as post-ART diagnosed peoples is even more central and vital to ensure that, even when the virus has been defeated, our community of former-PLHIV and our supporters, continues to be together, strong, nurturing, and a force for positive change in the world.

**Sean Slavin**

## *Understanding and responding to HIV stigma*

### **Background**

Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic. Stigma is a problem because it compromises the human rights of people with HIV, affecting their health and wellbeing as well as their social identities and relationships. In the current era of effective treatment, the stigma attached to the virus arguably represents a more persistent problem than the virus itself. In individuals it can lead to depression and isolation and in communities it can hamper prevention efforts because it serves to deepen the divide between HIV-positive and negative people.

Over the three decades of the epidemic there have been many attempts internationally to understand and combat HIV stigma, with mixed success. Despite all this effort, the characteristics of stigma can often appear hazy. Perhaps akin to the experience of being stigmatised, it is not always easy to pin down a perpetrator or identify a particular act. This uncertainty is mirrored in the social science literature

about various health-related stigmas. Both experiences and ideas about what stigma is can vary from one person to the next and a number of different analytic approaches may be used to try and study it.

### **The NAPWA HIV Stigma Audit**

From 2008 onwards, NAPWA members began to focus on building a project to understand the impact of stigma on HIV-positive people. In 2010, in my role as manager of research programs at NAPWA, I developed this project aiming to: generate an evidence base for combating HIV-related stigma so as to improve health outcomes for PLHIV and support ongoing prevention efforts; build awareness about stigma and social research among PLHIV using a participatory model of research; and translate the research findings into practical and useful recommendations for community-based HIV/AIDS organisations, policymakers, government advisory groups and relevant health services. NAPWA collaborated with the Centre for Social Research in Health at the University of NSW on the project, and I worked with Dr Loren Brener and Prof John de Wit to conduct a survey and a number of face-to-face interviews with people living with HIV.

The online survey was completed by 697 Australians with HIV. Roughly 85% of respondents identified as gay men and this is broadly representative of the Australian epidemic. People's year of diagnosis varied from 1981 to 2011 with the average being 1999. Four-fifths of the sample was on treatment and the average year of commencement was 2002. About one-third said they had noticeable symptoms of HIV. Two-thirds said their quality of life was good or very good, and a little over half said they were satisfied or very satisfied with their health.

When measuring stigma we used an internationally respected standard set of scales that asked about self-perceptions, beliefs about others people's attitudes towards HIV, and experiences of stigmatising actions. A series of statements were presented and respondents were asked whether and to what extent they agreed or disagreed. For example, 34% of respondents agreed that "I feel guilty because I have HIV"; 77% agreed that "Telling someone I have HIV is risky"; 42% agreed with "I work hard to keep my HIV a secret"; and 40% agreed with "most people think that a person with HIV is disgusting".

By analysing responses to a series of these questions we arrived at an overall indication of the level of stigma experienced by Australian PLHIV, which we describe as moderate. Stigma was a common experience among respondents but for most it was not overwhelming or debilitating. There was variation though, in the extent to which people coped well with stigma, and this ability to bounce back or not take it personally was part of resilience. Not surprisingly, more resilient people tended to have less experience of stigma and this correlated with good self-esteem, satisfaction with health, good quality of life and good social support. Those people who experienced greater levels of stigma were more likely to be single, have lower levels of education, report noticeable symptoms of HIV and experience stress, depression or anxiety.

We were also interested in finding out about the areas of life where stigma occurred. Given recent health promotion efforts to increase the proportion of people with HIV who take treatment, experiences in this area were of interest. We found a significant proportion reporting some form of treatment-related stigma. For example: 42% agreed with the statement “If I go to an HIV clinic I am concerned that someone might see me”; 47% agreed with “I avoid taking my meds in public”; 64% agreed with “I am concerned that if I have physical changes from HIV meds people will know I’m HIV+”; and 61% agreed with “I worry that side effects can make my status apparent”. These findings may reflect outdated views about treatments as many current medications have few or very mild side effects. This suggests further work for treatment advocates and prescribers to inform PLHIV about current technologies.

We also asked respondents to tell us where and to whom they had disclosed their status. The highest levels of disclosure tended to be in more intimate areas of life – sex, family and friends – as well as healthcare settings. There was less disclosure in more public areas of life – work, housing and community. Unfortunately, this pattern of disclosure mirrored the presence of stigma. So when asked where stigma arises, by far the most common response was in relation to sexual partners, community and the media. Given that about 85% of the sample were gay men and said they identified with the gay community, this suggests there is still significant work to do with gay men to address stigma. This finding also presents a challenge to the logical yet seemingly incorrect conclusion that greater knowledge about HIV (as might be expected among gay men) does not necessarily lead to less stigma.

While the research found evidence of widespread and persistent stigma, it also found many PLHIV who managed to reduce the impact of any stigma and ‘get on with their lives’. This ‘getting on with things’, often involved managing identity and controlling the contexts in which disclosure occurred.

### **PLHIV organisations responding to stigma**

The NAPWHA *HIV Stigma Audit: Community Report* was released in 2012. The research findings provide evidence to support a new approach to HIV stigma. Many previous anti-stigma programs have focused on the perpetrators of stigma, attempting to provide information and experiences of real people with HIV in an attempt to change attitudes and break down prejudice. Such approaches are arguably intensive and uncertain to succeed. The concept of resilience suggests a different approach that focuses on people with HIV. Such an approach aims to build their skills to both manage exposure to potential stigma and reduce its impact when it does occur, by ‘bouncing back’ or not taking it to heart.

In the past two years Living Positive Victoria has pursued a new approach to stigma by developing an innovative social media-based campaign called ENUF, which profiles and promotes resilient HIV-positive champions backed by a social media movement. Living Positive Victoria has also partnered with NAPWHA and ACON to implement a program of the Ontario AIDS Network called the Positive

Leadership Development Institute. Adapted for the local context, initial Melbourne-run pilots of peer-led training workshops for emerging HIV-positive leaders are proving successful. The hope is that attendees will go on to develop and lead their own programs of resilience-building as well as model resilient behaviour in their own communities. Other PLHIV organisations throughout Australia have re-adjusted their campaigns by emphasising resilience strategies.

The challenge presented by HIV stigma is ongoing. We mustn't give up on trying to change stigmatising attitudes, but it is time to adopt a smarter, more targeted approach. Working to develop the skills and resilience of people with HIV will likely lead to less experience of stigma and also that experience will be less severe. More resilient people with HIV will also be healthier, enjoy better quality of life and be more active members of the community.

**Lance Feeney**

## *Effecting change gave me courage*

This is the story of a Sydney gay man's exploration of gayness and the world. It is also about experiencing HIV infection personally and about the impact of the epidemic on peers. It's about how those experiences eventually led me to become an advocate for people with HIV in Australia. Advocacy by HIV-positive people is a role I see as even more essential into the future.

I wasn't very interested in politics or activism when I was a young man in the 1970s. I was too busy having lots of sex with lots of men. It was through those men and their diverse lives that I started to work out who I was, and what my place was in the world. Sydney in the '70s was a cool place to explore sexuality. After Whitlam came to power, Australia seemed to grow up and change for the better. The conservatism of the 1950s and 1960s melted away in a flurry of sexual and drug experimentation, and a new more liberal morality was the result. I was spending time with a guy I'd met at Sydney University, and we shacked up together in a run-down semi in East Balmain. There was lots of dope smoking, music and adventures in beats and gay bars in Kings Cross and Oxford Street. Guys were experimenting, and bisexuality seemed to be everywhere.

In the late 1970s, I found myself travelling through Europe and ending up in the United Kingdom. They were wild times in London – for a gay man it was 'going off'. Not only in Earls Court and Hampstead Heath but I also made it to the Mineshaft in New York, and the Argos Bar in Amsterdam.

I'm not sure where I contracted HIV. There had been fisting parties and lots of drugs along the way. In late 1979, I remember feeling very unwell and struggling to walk up the hill to my lodgings. I consulted a local GP in Swansea who did a range

of tests and told me I had an unspecified viral infection. I left the UK in 1980 and returned to Sydney via New York and San Francisco. I got a job as a barman at the Beresford Hotel in Surry Hills. It was fun, the money was okay and there were lots of hot men around. Life was good.

In 1981, I opened my studio in Surry Hills, taking commissions as a stained glass designer and glass painter. Sydney was buzzing in the early 1980s. Bars such as the Signal and Barracks were jumping, and some smart gay-dudes who were cashed-up were running private dance/fuck parties. Along the way I met a guy at the beat at Wentworth Park and we started seeing one another. After a while we drifted apart and the next time I saw him, he wasn't looking well. He had lost weight and the body beautiful was gone. The next thing I knew he was going to Switzerland for some type of cancer treatment. That was 1982. At about the same time my friend Kevin arrived home from London. He was admitted to St Vincent's Hospital with pneumonia. A bit earlier in 1981/2, Sydney started to hear reports of guys getting sick in New York, San Francisco and London with strange cancers and pneumonias. People speculated that it was caused by lifestyle – too many drugs, sex and amyl nitrate. Now it was happening in Sydney. I remember thinking that if it was infectious that I most likely had it. How could I have not been infected after what I'd been up to!

The reports from San Francisco and London became more worrying. I got a call that Kevin was dying and I made the trip out to his parents' home in Western Sydney. I spent about 15 minutes with him. He was close to death and I'd never experienced anything like it before – the laboured breathing, the look of death in his eyes, his abject suffering. His parents were in a dazed haze of disbelief. Shock, I suppose. He died the next day. I don't remember the funeral. I think I was 'de-gayng' his house in Paddington and also in shock. It was to be the first of many more deaths and funerals.

A week before Sleaze Ball in 1984, I decided to go for a test and find out if I had it; no one knew what 'it' was. At that time they were measuring CD4 cell counts. A week later I went back to Taylor Square Private Clinic to get the results. All I remember is the doctor telling me I had 210 CD4 cells. When I asked him what that meant, he said, "well, we don't know very much about the disease yet, but you've probably got about a 95% chance of contracting a serious life-threatening condition within the next two years." Stunned, I left the surgery and went home to process what I'd been told. My boyfriend at the time wasn't very supportive. His attitude was "you'll be okay, get over it" and that attitude marked a turning point in our relationship. In the meantime, people we both knew were getting sick. Some were hospitalised. I remember sitting on the cliffs at Bondi thinking this might be the last time I did a Sleaze Ball.

We were scared and started cleaning up our acts. I cut down on the party drugs and worked hard at the gym. The Sydney Gay Sports Association and the Sydney Gay Front Runners started up. I joined a gay volleyball team and played competition every Wednesday night. I was trying to stay as healthy as possible. In



1986, our team went to the Gay Games in San Francisco. I stayed with an old friend on 18th Street near the Castro. He'd been a friend since our days working together as barmen at the Beresford. One of the guys sharing the apartment began to become unwell. He was a big strapping lad from New Zealand and worked at the local gay gym as a personal trainer. I remember him drinking diluted hydrogen peroxide because some 'shonk' had told him it would help. It didn't! He died some months later.

The telltale signs of AIDS were visible all over the Castro. The locals organised fundraising movie nights in the Castro Theatre to help guys in need. There were men begging on the corner of 18th Street and Castro. It was horrible. Some had Kaposi sarcoma's lesions on their faces and hands and were painfully thin. They squatted on the pavement with hand-scrawled signs saying 'please help me'. After the Games we tried to party on but it seemed hollow and insensitive. I stayed for a couple of months and then heard that one of my mates had taken a turn for the worst and flew home. I arrived at Sydney Airport early in the morning. The customs officer decided to dismantle and inspect my luggage. She took what seemed like hours to go through the contents. By the time I got home I heard that my friend had just died. He'd hung on waiting to say goodbye, but in the end couldn't hold on any longer. I was distraught. Some of us made the trek to Millthorpe in Central NSW where he'd grown up. The funeral was a joyless affair. Ironically, the year before he died he had been working as a barman at the Albury Hotel. When the signs of AIDS finally appeared, the licensee decided he wasn't a good look and was bad for business; he was asked to go. I remember sticking pins in an effigy of that owner for some time after.

The period from 1987 to 1991 was a blur. Commissions, commissions and more commissions! I moved to a bigger studio in Leichhardt. Friends and acquaintances continued to weaken, then sicken and die. My best mate committed suicide. On one side of the funeral chapel were the Italian family and on the other his ungodly and dissolute gay mates. It was a toxic environment. A queen at the back of the chapel yelled out in a highpitched and emotionally thin voice, "If you don't turn that fucking hideous music off, I'll scream." We huddled in the rain as they carried the coffin to the hearse. Nobody spoke.

About this time, AZT monotherapy came onto the scene, but my sense was that there was limited or no benefit. I declined to take it. Increasingly I was being kept alive by prophylaxis drugs. Bactrim for toxoplasmosis and PCP, Fluconazole for fungal infections, Valtrex for herpes zoster and fortnightly injections of Deca Durabolin for wasting syndrome. I had a CD4 count of less than 10 and was constantly dealing with CMV in the gut. There were weeks in bed with lung and throat infections. In 1991, I took my doctors' advice, stopped work and went onto the Disability Support Pension (DSP). Retreating to my home in suburban Sydney, I spent a lot of time alone gardening and helping others come to terms with the inevitable course of the disease. I visited friends and watched the inexorable decline in the health of my friends. One of those friends was my mate from 18th Street in

San Francisco. By then, all the guys in the house had died of AIDS and he returned to Sydney. He stayed for a while but his health deteriorated and I remember farewelling him when he flew back to the UK. We both knew it would be the last time we saw one another. It was a horrible time and now I have difficulty remembering much of that period in any detail. I think I wiped it from my memory in an unconscious attempt to maintain some semblance of sanity.

In 1995/6, the early protease inhibitors became available via compassionate access. My first combo was AZT, 3TC and saquinavir. It worked, but the side effects were intolerable. They switched the AZT to D4T. Within six months I started to notice tingling and numbness in my feet and hands. Within a year I couldn't run to catch a bus. I hung in there hoping the drugs would improve. In 1998 they changed my regime to ddI, hydroxyl urea and indinavir. On my 50th birthday, after weeks of gut problems, I was hospitalised with pancreatitis. The treatment was nil by mouth and shots of pethidine and maxolon every four hours. When I was discharged from hospital I weighed 54kg and needed a wheelchair. I had cheated death and it was time for something new.

The road back to health was a slow one. But, within a few months I was working again on a major commission. It was an act of love and I knew it was the last major commission I'd do. When it was finished, I walked away from that chapter in my life knowing that there was nothing more that I wanted to prove. But I did start searching for something more meaningful to do. I wanted to be with my own tribe, with gay men and with people with HIV. It was about then that I met Geoff Honnor. He encouraged me to find a new doctor and I went back onto salvage therapy. My goal was to go back to work when my CD4 got to 200 and within a couple of years it did.

In 2001, ACON was looking for someone to take care of the Positive Living Centre (PLC) in Surry Hills while it recruited a manager. Many of the HIV-positive men who came to the PLC were much like me. They had stopped work due to HIV-related illness and were getting the DSP. Many were angry, disillusioned and depressed about how their lives had turned out, and they were trying to get by as best they could and make sense of the madness. I enjoyed their company and decided to apply for the position of manager. Surprised at my appointment, I turned my energies to making the PLC a safe and welcoming place for all people with HIV. Those early days were a challenge for clients and staff alike. The police were regularly called to break up fights and help deal with men who were out of control. Eventually, though, there was a change for the better. We started running re-skilling courses on how to use computers, on writing, arts and crafts, on cooking and food preparation, and in skilling-up for administrative jobs. There was a peer weekend workshop called Genesis for newly diagnosed men and also quarterly social nights. And on Fridays a social lunch when 50 to 60 guys would eat together and catch up with friends. Visits by the police became rare, and more and more people started coming to the PLC.

In 2006 it was time for a new challenge. I started writing HIV-related content for the ACON website and for HIV-related health promotion campaigns. A new

Medicare-rebated dental scheme for people with chronic disease also began around this time. Understanding the potential, we encouraged people with HIV to get a referral and start the process of reconstructive dental treatment. Over the next few years that scheme changed the lives of many HIV-positive gay men. By restoring mouths and allowing them to re-engage in employment and regain social confidence and prosperity, the scheme was arguably the most beneficial health intervention after combination antiretroviral therapy. Witnessing the transformation in people's lives, made me increasingly aware of the power of public policy to change the lives of people with HIV for the better. It seems like such a simple thing to ensure that people have better teeth, mouths, oral hygiene and oral care but it was an important part of restoring people to overall general health and wellbeing.

In 2008, Positive Life NSW created a new systemic advocacy position and I was appointed. The role was to identify barriers to service access and develop joint strategies to deliver better outcomes for people with HIV. It was a dream job, the only funded role in Australia. I had never written a formal submission or a briefing document, let alone provided evidence to a government inquiry. But there were courses where I could learn the skills, and I had mentors providing advice. And effecting some positive change for people with HIV gave me courage. I felt like I had landed.

I've been in that role for six years and during that time, it has changed and grown. We've improved access and affordability of HIV medication, changed the way the Department of Forensic Medicine treats the bodies of people infected with HIV and hepatitis C, and gained access to life insurance products for people with HIV in Australia, something that was denied them for 15 years. We have helped to improve HIV-positive people's acceptance and understanding of the benefits of modern HIV treatment and played a role in reducing HIV transmission in NSW, and we've partnered with the HIV/AIDS Legal Centre on a range of projects to help people with HIV better understand their rights and responsibilities.

There are many more issues that will need to be worked through in the coming years. Appropriate and non-discriminatory services for people who are ageing with HIV; measures to help people with depression and neurocognitive impairment maintain health and wellbeing; drug and alcohol issues; and assistance for those who are living in poverty and struggling to afford the health care and accommodation they need. Over the last decade we've witnessed an increasing move towards a more medical model of HIV management and care. The challenge for people with HIV will be to step up and remain central and vital in the planning of all future service delivery and public policy. That is if we are to avoid an ongoing disinvestment in the HIV service sector. The danger is that as HIV becomes more normalised, people with HIV will disengage and become passive recipients of services and the public policies that shape them. That would be a reversal in the involvement of people with HIV in the Australian epidemic and I have no intention of accepting that reality. Many of my mates may be dead from AIDS, but their impact on me lives on.

**Jane Costello**

## *The right to participate in decision-making that affects our lives*

When asked to reflect on ‘Voices of PLHIV – the commitment continues (2014+)’, it is important to firstly recognise and acknowledge all of those who came before and are no longer with us, because so many of the achievements and milestones we have reached today as people living with HIV can be directly attributed to their sheer courage and determination in the face of adversity. I was reminded of the importance of history at a recent Candlelight Memorial Vigil, and how our shared history informs so much of our common future.

I was diagnosed with HIV some twenty years ago, immediately after my husband received his positive diagnosis. He was so ashamed and felt such guilt that he would not let me tell anyone of our joint diagnoses, and therein followed the longest ten years of my life, a life constructed around secrecy and lies. I created an entirely fabricated world in which we, for all intents and purposes, led a normal life. But it was problematic also, I wasn’t able to tell my family at the time, a decision I regret to this day. I also missed not being able to confide in other friends, and I realise that this decision made me put off dealing with my diagnosis, confronting the everyday reality of it, and its long-term implications. I didn’t deal with these until later.

‘Later’ occurred a decade on when our marriage ended, and I was then free to tell others of my status. Opening up to good friends was incredibly cathartic, but also very difficult as I had effectively lied to them for that period of time. There was also the issue that they would reject me because of the stigma, ignorance and prejudice that unfortunately still exists around HIV and people living with HIV. I am fortunate that family and close friends I disclosed to have been hugely supportive, and this I believe, led to my gradual acknowledgement and acceptance of HIV in my life, although I would be the first to say while it is a part of me, it certainly doesn’t define me.

However, having lived a life where I effectively avoided HIV or anything to do with it, I progressively started to become more engaged with the HIV community as a whole, and have been privileged to meet some extraordinary individuals who share my journey. One of the reasons I decided to become involved was the desire to give something back. I think the writer Isabel Allende sums it up best when she says “the whole point of being alive is being part of a chain, of a community, and what you do for others is what matters.” I had spent the best part of the previous ten years since my diagnosis existing, not truly living, and had waited for my husband who had been diagnosed in the very late stages with two AIDS-defining illnesses to die, and effectively put my life on hold. When he didn’t die, thanks in part to the advances in HIV medication, I was forced to re-examine my own existence.

I realised that my identity as a woman living with HIV placed me in a unique position as a peer to support and advocate for others. I trained as a positive speaker because I wanted to raise awareness around the lived experience of HIV in the wider community. In Australia women living with HIV are regarded somewhat as a minority within a minority, but it is important that our perspectives are valued and given due consideration in the HIV response. This led me to become a member of the NAPWHA National Network of Women Living with HIV (Femfatales), a group of quite remarkable women from varied backgrounds and with different stories, but all united in the goal of ensuring positive women's voices are heard and their needs reflected at the national level in the design and implementation of policies and programs.

My other reason for becoming more engaged with the HIV community was around the area of human rights. People living with HIV are entitled to the same rights as everyone else, and the protection and realisation of these human rights has been recognised to be essential to an effective public health response to HIV. These HIV-related human rights include “the right to life; the right to liberty and security of the person; the right to the highest attainable standard of mental and physical health; the right to non-discrimination, equal protection and equality before the law; the right to freedom of movement; the right to seek and enjoy asylum; the right to privacy; the right to freedom of expression and opinion and the right to freely receive and impart information; the right to freedom of association; the right to marry and found a family; the right to work; the right to equal access to education; the right to an adequate standard of living; the right to social security, assistance and welfare; the right to share in scientific advancement and its benefits; the right to participate in public and cultural life; and the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.” For people living with HIV this also encompasses the right to be free of stigmatisation and discrimination with concerns around privacy, gender equity, sexuality, access to medication and appropriate services, travel and employment restrictions, amongst others.

People living with HIV have a right to self-determination and participation in decision-making processes that affect their lives, and a successful rights-based response to HIV prevention requires the involvement of all people living with HIV. My decision to join the Boards of both Positive Life NSW and NAPWHA was grounded in a human-rights framework and the centrality of the positive voice in all that we do. If Australia is to achieve the UN Political Declaration on HIV and AIDS target of reducing the sexual transmission of HIV by 50% and the WHO Millennium Development Goal of halting and beginning the reverse of the spread of HIV/AIDS by 2015 we must include and respect the voices of all people living with HIV.

In my roles with the Positive Life NSW and NAPWHA Boards I have sought to highlight the diverse range of people living with HIV and in particular the unique challenges facing women and heterosexuals around the epidemic. The principles of GIPA (Greater Involvement of People Living with HIV and AIDS) and MIPA (the

Meaningful Involvement of People Living with HIV and Affected Communities) are core to this work.

In recognition of this, NAPWHA and NAPWHA member organisations, including Positive Life NSW, have developed Poz Action, a campaign that effectively recognises and takes ownership of all the often unrecognised work we undertake collectively on behalf of the body positive. Through our membership in NAPWHA as the peak body and through each individual state and territory organisation representing people living with HIV in Australia we achieve a lot – we lobby governments and change policy, improve and streamline access to treatment and services, educate and provide peer support, and aim to improve the health and lives of all people living with HIV.

As people living with HIV we have led the advances of the past thirty years of the HIV epidemic. Our challenge for 2014 and beyond is to continue to build on our achievements and successes, honour and respect the past, and to continue to advocate around issues that affect all people living with HIV. To quote Winston Churchill, “success is not final, failure is not fatal: it is the courage to continue that counts.”

**Barbara Luisi**

## *What culturally and linguistically diverse communities need*

The Multicultural HIV and Hepatitis Service (MHAHS) began as a 12-month project in 1991 to address what were considered to be the short-term HIV-related information needs of culturally and linguistically diverse (CALD) communities in NSW.

However, it soon became apparent that the antiviral drugs available at the time were unable to stem the increasing toll of HIV and AIDS, and CALD communities were not immune to this reality. Indeed, it became clear that this group was facing the same rates of HIV/AIDS and AIDS-related deaths as the general community, but without the same knowledge, understanding or access to services. In addition, these gaps were overlaid with language barriers, cultural misunderstandings of health and illness, and the realities of the migrant experience. For so many reasons it is difficult for people from CALD communities to be open about being HIV-positive.

To meet these challenges, the MHAHS adopted a unique service delivery model comprising three key dimensions. First, the adoption of a health promotion approach enabled the delivery of culturally appropriate, targeted education to enhance the HIV-related knowledge of the affected communities. Second, the provision of a bilingual/bicultural clinical support program that relied on a unique

system of matching clients to co-workers to provide nuanced and respectful psychosocial support to those affected by HIV/AIDS. Third, all of this was made possible by the use of highly trained bilingual community members who comprise the Service's pool of co-workers. It was through their contribution that the MHAHS was able to effectively engage with the affected communities.

The stigma that was experienced by the general community in the early days of the HIV epidemic is still a reality for a vast number of CALD groups. Whilst there may be some cultural issues that contribute to this, they are compounded by the fact that CALD community knowledge and attitudes have not kept pace with the developments in HIV treatment that today are delivering better health outcomes.

In addition, CALD clients continue to experience a number of barriers to accessing appropriate services, often because of the inherent complexities of the system. Shifts in policy often mean these barriers become even greater and harder to overcome. Eligibility for Medicare and access to some publicly funded services are cases in point.

In recent years there have been key shifts in the HIV landscape that have engendered a sense of optimism and renewal in the sector. The core work of the MHAHS continues to focus on engaging with new and emerging communities to enhance their knowledge of HIV, providing culturally appropriate support to CALD community members and facilitating access to the broad range of services that have contributed to the NSW HIV response.

**Bill Whittaker**

## *Ethics and issues in cure research: an HIV-positive perspective*

This is a speech made at the 2010 Conference of the Australasian Society for HIV Medicine, held in Sydney.

From the discovery of the HIV virus in 1984 onwards, we have in fact been searching for a cure for over 30 years – and this has been a shared quest between scientists, doctors, activists and people with HIV.

When the first antiretroviral drug, AZT, became available in the late 1980s, there was hope that the drug might not only treat AIDS, but might actually eradicate the HIV virus. This of course was a fleeting hope, but the limitations of AZT and some of the early antiretrovirals caused scientists to go back to the drawing board to learn more about the basic science of HIV, and to work on developing better-tolerated and more potent drugs. This was slow, difficult but absolutely necessary work, running over several years – perhaps the darkest years of the epidemic as so many of our

friends and loved ones got sick and died.

But by the mid-1990s, this investment in basic science research began to pay off and there was great excitement from new research showing the benefit of combining antiretroviral drugs to treat HIV, along with the development of protease inhibitor drugs and new tests for measuring drug resistance and viral load. This again raised the prospect of curing HIV infection by eliminating it from the body. However, this excitement was short-lived following the discovery that HIV is able to hide in cellular reservoirs even after years of continued antiretroviral treatment. Nevertheless, these improvements in antiretroviral drugs and better monitoring tests led to dramatic falls in sickness and death over the next decade.

Today – after 30 long years – we actually have the scientific knowledge and potent, well-tolerated treatments to give us the opportunity to revolutionise treatment and prevention of HIV. We haven't yet achieved a cure, but we have made enormous progress. So much so that the prospect of an AIDS-free generation is for the first time being widely contemplated.

This 30-year journey of scientific discovery and prevention and treatment advances, setbacks and progress, has also been accompanied by many policy and ethical challenges, here in Australia and around the world. I can hardly begin to do this topic justice in the short time I have today. But from an activist's point of view, we have had to learn a lot about ethics – and often learn quickly – particularly for the first 20 years of the epidemic when so many people were sick and dying. This does tend to focus the mind.

So when we talk about ethics and the cure, this is by no means a blank canvas for activists and affected communities . . . we have the collective experience of lessons learned over many years. So I do want to make the point that Australia is well placed to meet the ethical and policy challenges that will inevitably come up in cure research, difficult though they may be at times. The foundations are there.

And these foundations come from a long partnership between community and HIV researchers. Yes, the journey has been bumpy at times – there have been disagreements, sometimes very strong ones, on ethical issues. These have included inclusion and exclusion criteria for studies; the use of placebos in clinical trials; the issue of ongoing access to experimental agents after a trial has finished; and differing views on what constitutes clinical equipoise.

Australia has a longstanding reputation as a good place to do HIV-related research in a collaborative way, with strong community involvement, and based on strong ethical standards. Along the road, we've also taken time to reform Australia's clinical trial and drug approval system, to make Australia an attractive place to do research.

Today, it is the rule, not the exception that Australian researchers will approach community activists about proposed new research and will involve them in the planning of studies. Ethical questions are usually resolved at an early stage – and indeed representatives from organisations like NAPWA will often be involved in the design of clinical trials, the preparation of protocols, informed consent documents and information to try and make sure that prospective research participants are fully



aware of studies and what they are being asked to do. I cannot recall any recent examples where differences over study design and ethical considerations have not been able to be resolved.

An excellent example of this cooperation is NAPWA's involvement in the START study and the Vorinostat study. We were approached by the investigators very early on in the piece to be a part of the planning of these studies, including addressing ethical questions. We joined researchers in community forums designed to provide information to the public about these studies, and we had input into protocol and informed consent development.

For the international multi-centre START study, NAPWA participates in the INSIGHT research collaboration, which manages the study. There has been a particular effort to skill up community advocates from less-developed countries through INSIGHT.

For the Vorinostat study – an important piece of cure research that Sharon Lewin has mentioned – is a good case study of the research partnership coming together early on to discuss a proposed study and related ethical issues. NAPWA sits on the steering committee for the Vorinostat study, as well as the Data and Safety Monitoring Board. I think it is fair to say that both researchers and activists have benefited from this partnership and it is a benchmark for the organisation and conduct of HIV research in Australia, be it for the cure, or otherwise.

All countries will benefit if there is a strong global framework for advancing cure research, including to promote sound ethical principles.

On that theme, last year the United Nations adopted a bold new global plan for HIV aimed at ending the HIV epidemic – the 2011 United Nations Political Declaration on HIV/AIDS. Under this Declaration, all countries have committed to accelerating investment in HIV-related research, and there is a specific commitment to expand cure research. Countries have also committed to building a conducive environment for HIV research and ensuring it is based on the highest ethical standards.

I have no doubt that Australia's researchers, with strong community support, will make formidable contributions to accelerating HIV research and promoting sound ethical foundations for it. However, as with the other important commitments made by Australia under the 2011 UN Declaration, we have not heard anything yet from the Australian government about how it is going to meet Australia's commitment to accelerate investment in cure research and foster sound ethical standards.

Cure-related HIV research will obviously benefit from strong scientific leadership at the global level. On this theme, it is great to see the International AIDS Society actively championing cure-related HIV research. Under the leadership of the current president, Françoise Barré-Sinoussi, Steve Deeks, who has been our guest at this conference, and our own Sharon Lewin, the IAS has built a sound organisational platform to take cure research forward. The IAS' Global Scientific Strategy – Towards a Cure was launched in July. As part of this strategy, the IAS has set up various working groups on particular cure topics, with an impressive line-up of scientists, clinicians and community members involved.

In terms of ethical issues, the IAS has set up a Special Working Group on Ethical Guidance for HIV Cure studies. NAPWA is hoping to join this group and we hope to both benefit from being on it and contribute our experience to its work. This working group is an excellent way of addressing ethical issues that are likely to arise as cure research goes forward.

I don't have the time nor do I think it is useful for me to go into a lot of detail about possible ethical questions that may come up as cure-related research progresses – I have reasonable confidence that ethical issues can be addressed appropriately if we use the structures that are being set up by the IAS, as well as the ones we already have in Australia. However, it would be remiss if I did not put on the record some of the issues that have confronted HIV research over the past 30 years – be it cure or otherwise – and which will likely come up again as cure research unfolds.

First and foremost, there is the issue of gaining the informed consent of research participants. This is the linchpin in deciding the ethics of a clinical study. And the informed consent process has its limitations – and critics.

We will continue to struggle over the informed consent process – and this is good. By its very nature, it needs to be challenging. However, it's obviously more than just getting a participant's name on a piece of paper – ideally, informed consent is based on researchers and community advocates talking directly to potential participants, and to their communities, so that the direction of research is explained and support for research encouraged.

Another ethical issue for cure research is the reality that we now have very effective treatments for HIV – with many people keeping well and expecting to live an almost normal lifespan, especially if they treat early. Cure research will have a particular focus on involving people who are well – as it is these people who are more likely to give us the answers about whether or not a particular research focus works or not. Keeping the risk and benefit balance is arguably more challenging in people who are well than in those who are sick.

Cure research will also involve people not infected with HIV. This is not new of course, as for example with early-stage antiretroviral drug studies where HIV-negative volunteers are sought. Very experimental drugs and tests will likely be part of future cure research and will need HIV-negative volunteers – so there may also be complex ethical issues involving HIV-negative people as well.

Some have argued that the search for a cure could concentrate scientific effort, funding and focus too narrowly – and at the expense of other research priorities. Certainly, this could be the case if research focused on just one “silver bullet” that somehow transformed people infected with HIV into healthy HIV-negative individuals. But it is clear from the complexities of HIV infection and its impact on people infected that this is highly unlikely.

Cure research is not some niche activity. The reality is that cure research can and I am sure will benefit virtually all other aspects of HIV-related research – and vice versa. Such are the complexities of a cure and what needs to be done to achieve a

complete, let alone a functional cure. And continuing to develop better antiretroviral treatments, to better treat the co-morbidities associated with HIV infection, to better understand the individual, community and societal impacts of the epidemic – can all contribute to the goal of a cure.

Ensuring wide community support for the quest for a cure means we have to effectively communicate what exactly we mean by a cure – the possibilities and the limitations. There is confusion about what a cure means not only in the wider community, but among people with HIV themselves and communities at high risk. In explaining what a cure could look like, we should point out that the cure will need to be cost effective – but also that the current cost of scaling up treatment for all people with HIV will be enormous, particularly as for every person starting HIV treatment two are newly infected. A valid argument can be made that it would be unethical to focus just on developing treatments for life-long therapy, not to mention the long-term cumulative costs of providing such treatment. Also, a cure would essentially stop transmission of HIV to those uninfected – a tremendous advance.

In my final comments, I want to recognise the amazing contributions of the many AIDS activists who fought for research and for reform of red-tape preventing it. So many are dead, but I feel they are celebrating the fact that we are on the path of a cure, difficult though that path may be.

We should also recognise the thousands of people around the world and here in Australia who through their participation in research have got us to this point of contemplating an AIDS-free generation and a cure. Often this has not been easy because of the demands of particular studies, or side effects of experimental treatments and dosages, and in the knowledge that no individual benefit may be gained from participating in research.

Here are a couple of quotes I came across in researching the paper, which I think exemplifies the commitment of research volunteers over the past three decades:

*“The benefits I have in my life today are because people took risks. Sometimes you do things because you know that it’s going to be a part of helping other people.”*

*Philip, HIV+ research volunteer*

*“I can’t tell you how many people I’ve enrolled in studies over the years, who enrolled knowing full well that they were taking some risks, knowing full well that they would derive no benefit and knowing full well that they might be dead before any conclusion was drawn from the study.”*

*Dr Jacob Lalezari, San Francisco*

I feel very confident that this willingness to contribute to research remains strong. Indeed, an attitudinal survey of over 2100 HIV-positive people conducted by my friends at Project Inform in the USA found a high degree of willingness on the part of people with HIV to enrol in studies for purely altruistic reasons, and that even recently diagnosed individuals were willing to do so – more than 80% of those

surveyed expressed a willingness to participate.

For nearly 30 years, altruism in Australia has been very strong for HIV research. We have punched well above our weight in research participation – something we should be proud of. Will this continue now that so many people are well? I think it will. I think people will volunteer, even in the knowledge that cure research is very unlikely to benefit them directly.

This only adds to our obligation to very carefully address the ethics of cure research – and to never take this altruism for granted.

Finally, in the growing interest about a cure, we must not lose focus on the fact that we already have the means to end AIDS in many parts of the world – including here in Australia – by applying the scientific knowledge, the power of treatment to prevent disease progression and the power of behavioural and biomedical interventions to prevent new HIV infections. So obviously the pursuit of a cure should run in parallel with urgent global action to achieve the AIDS-free generation that more and more leaders, policymakers, activists, doctors and scientists are committing to.

But every step towards a cure can only help us accelerate progress and to improve the capacity we already have to reach that AIDS-free generation we all want. So in the exciting pursuit of ending AIDS and finding a cure, may a thousand research flowers bloom!

**Peter Fenoglio**

## *Cure? What Cure?*

Over the last few years I have become more aware of the impact of HIV-related stigma within the dynamics of social, family and community groups, and individuals in the groups. The significance of this impact is partly an outcome of an association with the possibility of a cure for HIV. In recent years much has been talked about a cure for HIV.

A recent study from the Johns Hopkins University in Baltimore in October 2013, found that the amount of potentially active HIV that lurks in infected immune system cells could be up to 60 times as large as previously observed. Thus, finding a medical cure is quite daunting. After 30 years of the epidemic and for the pre-ART long-term survivors, as well as being told HIV is not a death sentence but a chronic manageable condition, hope for a medical cure, I believe, is waning. We need to put this approach to a cure aside and let the scientific community continue their quest, but stop giving hope to those with the virus. From my understanding, a medical cure is a long way off. By a medical cure I refer to a vaccine or the destruction of existing HIV in the body.

Dr Robert Gallo, Director of the Institute of Human Virology at the University of Maryland, School of Medicine believes the cure for HIV will be a functional cure. He said, "I believe the field is close to a functional cure for AIDS, but not a virological cure, or total elimination of HIV from the body." Gallo expressed this belief as an effective cure as recently as January 2014. A functional cure sounds credible. Encouraging more people to be tested and if found positive to go onto ART as soon as possible. Rapid testing has fostered an increase in testing, and the possibility of home-testing gives people another option for HIV testing and detecting HIV rates in Australia. These options suit particular circumstances, especially with hard-to-reach population groups, and could also encourage and allow people to test in the privacy of their own homes, potentially without concerns about their confidentiality. The concept of a functional cure also includes encouraging sero-discordant couples and high-risk individuals to use PrEP. Keep using condoms and keep up the position strategies for MSM. Several international studies have shown these tactics to be highly effective.

Having acknowledged a medical and a functional cure, I would argue that the most likely cure at this time will be established from a social cure. The eradication of HIV-related stigma will be that cure. HIV-related stigma usually impacts on behaviour and decision-making by groups and individuals in a negative way. To alter behaviour and decision-making, we need to eradicate HIV-related stigma. Achieving eradication will promote self-empowerment, giving individuals responsibility for their personal health care, and wanting to know their HIV status.

A functional cure is a real possibility, but will highly depend on the social cure. However, there are a number of road blocks to a social cure. The manifestations of HIV-related stigma, are the main impediments to initiating, and succeeding in HIV prevention. The impact of HIV-related stigma on social, family and community groups and individuals, and the possible resulting changes in cultural behaviour is of major significance in the journey to stop HIV. Manifestations such as isolation, protection, contamination, disclosure, avoidance, ostracism, exclusion, rejection, blaming, assumptions, difference and indifference have a significant impact on the lives of PLHIV, affecting confidence, self-esteem and quality of life.

Much of the sociological work on stigma by Erving Goffman, Joseph Schneider, and Peter Conrad presumes that a person learns the consequence of being stigmatised primarily through direct exposure to exclusion, rejection and disapproval from others and from the media. I concur with their opinion that the perception of stigma, of what others think of 'them' and 'their kind', and how these others might react to the HIV-related stigma manifestation of disclosure, provides the foundation on which HIV-related stigma is constructed. Furthermore, Deacon et al. maintain that stigma is a complex social process directly related to competition for power and linked into existing social systems of exclusion and dominance.

Isolating oneself from the broad community group and the social and family groups offers possible protection from likely stigma and discrimination. Experiencing isolation can give one a perception of protection. Many PLHIV keep

people and opinion out of their space to remain in a safe personal space.

HIV is embedded in a well-established tradition of constructing illness through images and narratives of fear and blame. Paul Farmer, who has written at length about this, maintains that, “From typhoid to tuberculosis and AIDS, blaming the victim is a recurrent theme in the history of epidemic disease”. In the essay, *AIDS and its Metaphors*, Susan Sontag examined the use of metaphors of ‘war’ and ‘invasion’ and maintains that these metaphors promote feelings of ‘mystery, fear and anger’. She also argues that the ‘pollution’ and ‘contamination’ metaphors used around HIV and AIDS promote the tendency to blame those seen as the most likely groups to acquire the virus.

James Walkup et al. maintain that inconsistency occurs because haemophiliacs and those with prenatal infection are seen as ‘innocent’ victims, while other groups, who are seen as promiscuous and unfaithful and who have unprotected sex or are intravenous drug users and are responsible for the transmission of HIV, are guilty and deserving of the consequences. However, the majority of PLHIV still desire not to be known and to remain ‘underground’ and anonymous. They don’t want to be identified as a member of the HIV-positive group.

It is now estimated that in Australia around one-quarter of PLHIV don’t know they have the virus, and we know through the work of NAPWHA and others on HIV criminalisation, that many don’t want to be tested for the fear of stigma and the possibility of criminalisation and criminal charges. These and other sub-factors have maintained the indifference not only in the broader community, but also in the groups that practise risky behaviour.

Over the last several years of involving myself in the HIV sector I have established a great deal of confidence with speaking about my status as a person living with HIV. I would argue that one of the major ways we can initiate a social cure through the eradication of HIV-related stigma is with greater leadership within the HIV sector. Leadership to address the manifestations of HIV-related stigma and more importantly leadership to break down the road blocks of negative men’s attitudes, community and cultural discrimination, criminalisation, confidentiality, and sensational media coverage. Liz Sayce maintains that we all should: “Stimulate open debate about different experiences of discrimination. Make inclusion happen because inclusion changes attitudes and behaviours. Most importantly, address power. Do not get seduced by the naive view that, ‘informing’ or ‘educating’ people will change their attitudes, let alone their behaviour. Why should it, unless you have carefully analysed their motivations?” Concurring with this, Deacon et al. maintain that prevention strategies should not only rely on education, but also “use legal measures and activism to challenge the power relationships that sustain stigma”.

Greater leadership within the HIV sector will foster stronger resilience within the PLHIV community. Resilience to confront the manifestations that sustain HIV-related stigma and allow a social cure to enact the functional cure.

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## Sharon Lewin

### *There is still much to be done*

Thirty years on from the discovery of HIV, we can be immensely proud and excited by what has been achieved – but there is still much to be done.

We know that with universal access to effective suppressive antiretroviral therapy (ART) and the dramatic impact ART has on HIV transmission, we could see the end of AIDS. However, this can never be achieved while stigma and discrimination prevents people from knowing their status or accessing treatment, while healthcare systems are unable to support people in long-term care, and while global funding remains insufficient to allow for continuous access to antiretrovirals.

In 2012, there were 9.7 million people living with HIV on treatment in low- and middle-income countries; however, under the new WHO treatment guidelines this represents only 32-37% of those who require treatment. By 2015, this figure must increase to, at least, the global target of 15 million.

Halting our progress is the fact that more than 80 countries across the world continue to criminalise people on the basis of sexual orientation. These laws and other punitive measures against people who use drugs and amongst sex workers prevent people accessing the services and programs that we know protect their health, and the health of their communities.

Even without punitive regimes, life-saving interventions remain difficult to implement. In Australia, we know 25% of people with HIV don't know their status and only 50% of those diagnosed receive treatment.

However, at this time, we also have good reason to be optimistic.

Antiretroviral treatments are getting better and cheaper, and more people with HIV are living well and living longer. There is an expanding suite of prevention options available – but many questions remain as to how best implement these discoveries. Operational research related to interventions such as pre-exposure prophylaxis and circumcision will be key for tailoring prevention programs to different countries and settings. Despite these options, ongoing investment in finding a safe and effective vaccine is still urgently needed.

The concept of a cure for HIV, not so long ago, was considered a dream but now, we have evidence that shows us what is possible. A functional cure – or a way to stop using antiretrovirals whilst still keeping the virus under control – may be closer than thought, at least for some. Certainly very early antiretroviral therapy can profoundly reduce the size of the viral reservoir but much work is still needed to understand and eventually eliminate long-term reservoirs that persist on ART.

Throughout the changes we have seen in the history of HIV, one thing has remained constant; one thing that continues to distinguish the global response to HIV from any other disease response, and that is the central role played by people living with HIV. Now – just as 30 years ago – this role remains as important as ever.

*The traditional structures of PLHIV-led organisations, mainly membership-based, are our safety net. They are real and able to channel support and resources to meet our needs: peer support, programs to build individual confidence and resilience, and the ability to shout loudly on our behalf when we are unable to find our voice . . . These organisations are absolutely necessary to keep our community together, strong and healthy.*

**Daniel Brace**





## ABOUT THE WRITERS

### **Kath Albury**

Kath is Senior Lecturer in the School of Arts and Media at the University of NSW. She has a PhD and her current research projects focus on young people's practices of digital self-representation (including sexting and selfies), and the role of user-generated media (including social networking platforms) in young people's formal and informal sexual learning. Kath is also a community educator and facilitator, and has worked with NAPWHA's Treataware project since 1996. She has also designed and delivered primary prevention/sexual ethics programs for the National Rugby League.

### **Dennis Altman**

Dennis is the author of thirteen books, most recently *The End of the Homosexual?* He has been President of the AIDS Society of Asia and the Pacific, and a member of the Governing Council of the International AIDS Society, and is currently a Professorial Fellow in Human Security at La Trobe University. He is a Member of the Order of Australia.

### **Lisa Bastion**

Lisa has been Manager of the Sexual Health and Blood-borne Virus Program at the WA Department of Health since 2005. During that time, WA has observed an increasingly complex and diverse HIV epidemiology. The Sexual Health and Blood-borne Virus Program is responsible for planning, coordinating and monitoring the public health response to HIV within WA.

### **Brent Beadle**

Brent has been responsible for organising HIV treatments and health forum events, including the popular Chin Wag chat show series, around Australia and the region. Over the last fifteen years, he has also

produced Treataware's Short Courses in HIV Medicine for Community Workers, Volunteers and the Pharmaceutical Industry and facilitated the Treataware Outreach Network (TON).

### **Mark Bloch**

Mark is director of Holdsworth House Medical Practice in Darlinghurst, Sydney and has been working in HIV since 1983.

### **Daniel Brace**

Daniel is a gay HIV-positive writer, thinker, musician and activist.

### **Alan Brotherton**

Alan's first public engagement around HIV entailed lying down with other ACT UP members in Pitt Street, Sydney in 1991. He subsequently took on more active roles and was Convenor of PLWHA NSW from 1992-1995, and President of NAPWA in 1996-1997.

### **Graham Brown**

Graham has been living with HIV since 1996. His experience in the Australian response to HIV includes senior roles at the WA AIDS Council (1995-2002), WA Centre for Health Promotion Research (2002-2010), and Australian Research Centre in Sex Health and Society (since 2011). Graham was also President of AFAO (2008-2011), and is a member of the Commonwealth Ministerial Advisory Committee on BBV and STI (since 2009). He holds a PhD.

### **Bill Bowtell**

Bill is a strategic policy adviser, with particular interest in national and international health policy structures and reform. He trained as a diplomat, with postings in Portugal, Papua New Guinea and Zimbabwe. As senior adviser to the Australian Health Minister, Bill played a significant role in the introduction of the

Medicare health insurance system in 1984. He was an architect of Australia's successful and well-regarded response to HIV/AIDS. Between 1994-1996, Bill was senior political adviser to the Prime Minister of Australia. He maintains a close interest in the potential impact of the HIV/AIDS epidemic, and the other communicable diseases, on the social, economic and political development of the Asia-Pacific region. He is an Officer of the Order of Australia.

#### **Peter Canavan**

Peter was a member of the TWG, which then transferred to NAPWA as the ATPA. He served as NAPWA Treatments spokesperson for a number of years prior to being NAPWA President from 1998-2001. Peter was honoured with life membership of NAPWA in recognition of his treatments advocacy work. He has also worked in paid positions for AFAO and NAPWA until late 2010.

#### **Jane Costello**

Jane is passionate about empowering and improving the lives of people living with HIV. She is currently President of Positive Life NSW, a Director on the NAPWHA Board, the Australia representative to the Asia Pacific Network of Positive People (APN+), and a member of the NAPWHA Women's Network. Jane has been involved in the HIV sector for a number of years as a facilitator, speaker, presenter and researcher. She holds a Masters in International Studies (MINTS) and is currently completing a PhD doctoral thesis.

#### **Cameron Cox**

Cameron started work as a street-based sex worker in Sydney shortly before the advent of HIV. He is the Male Sex Worker Representative at Scarlet Alliance, continues to do sex work and also works as an outreach officer for a health-based sex worker organisation.

#### **Levinia Crooks**

Levinia joined ASHM as CEO in November 1999. She has worked in the HIV sector since 1986 at which time she was conducting social research to inform the development of counselling and support services for people living with HIV. She has been involved in the community response to HIV in Australia and regionally and served as President of the AIDS Council of NSW and Bobby Goldsmith Foundation HIV/AIDS charity. She has also served on the Board of the Australian Federation of AIDS Organisations. Levinia holds a position as Adjunct Associate Professor, Public Health and Human Biosciences, La Trobe University. She is a Member of the Order of Australia.

#### **Ross Duffin**

Ross was on the first elected ACON committee, was ACON's first education manager and then worked in the HIV Support Project until the mid-1990s. He then helped establish the National Gay Education Strategies Project at AFAO.

#### **Claude Fabian**

Claude is an artist and activist. He has been making costume jewellery and mixed media art pieces for over 30 years. He has been a member of ACT UP Sydney, on the Boards of PLWHA NSW Inc., ACON, BGF and the SSO, he is a co-founding member of the NSW Positive Speakers' Bureau. He was one of the participants in Australia's first national HIV/AIDS anti-discrimination campaign. His other interests include photography, politics, history, reading, listening to music and art. Claude now lives in the Illawarra with his partner.

#### **Lance Feeney**

Lance has worked in the HIV NGO community sector since 2000. He managed the Positive Living Centre and HIV Health Promotion Teams for ACON before moving

to Positive Life NSW in 2008 to develop its new policy and advocacy project. Lance was a director on the board of HALC in Sydney between 2010-2013. He is currently a NAPWHA director.

### **Peter Fenoglio**

Peter's recent research focused on the impact of HIV-related stigma on cultural practice. He is a visual arts educator, HIV activist artist, and is involved in the PLHIV sector. Peter recently completed his PhD.

### **Glenn Flanagan**

Glenn, who was diagnosed HIV-positive in 1995, was a NAPWHA Board member (2003-2004), NAPWHA Education Portfolio convenor (2004-2006) and worked at Positive Life/PLWHA (NSW) from 2000-2009 in community development, peer education and publications. He currently works with refugees and asylum seekers at Companion House in Canberra.

### **Martyn French**

Martyn is a clinical immunologist with the Department of Clinical Immunology, Royal Perth Hospital and PathWest Laboratory Medicine. He is the Winthrop Professor in Clinical Immunology and Deputy Head, School of Pathology and Laboratory Medicine, University of Western Australia.

### **Beverley Greet**

Beverly has had HIV since 1984. She has one son and is the co-founder of Positive Women Vic Inc. and founding member of People living with AIDS (PLWHA), NAPWA, International Community of Women Living with HIV/AIDS (ICW) and the Global Network of People Living with HIV/AIDS. She is currently chairperson of Positive Women Victoria Inc. and a member of Femfatales. Beverley has a Medal of the Order of Australia.

### **Geoff Honnor**

Geoff is an HIV-positive gay man who has held a variety of paid and voluntary positions in the NSW and national HIV community-based response over the last couple of decades. Never one for half measures, in his most recent role as Director, HIV/Sexual Health at ACON, he decided to end HIV. It seems to be going better than might have been anticipated.

### **Jesse Hooper**

Jesse has been involved in the HIV sector for three years. He has represented HIV-positive youth at local, national and international levels. Jesse lives openly with HIV and is passionate about supporting people living with and affected by HIV. He is currently working at Queensland Positive People as the Peer Support and Communications Officer.

### **Jennifer Hoy**

Jennifer is an Infectious Diseases physician with over 30 years experience in HIV patient care and research, initially at Fairfield Infectious Diseases Hospital. She is the inaugural Professor Director of HIV Medicine at the Alfred Hospital and Monash University. Jennifer has spent many years researching improvements in antiretroviral therapy, managing the toxicity of earlier treatments and understanding the cause of the increasing occurrence of co-morbidities such as bone disease and heart disease.

### **Michael Hurley**

Michael is an Adjunct Associate Professor at the Australian Research Centre in Sex, Health and Society, La Trobe University where he was previously a Senior Research Fellow. He taught at the University of Technology Sydney, 1985-1998, and in TAFE in Melbourne 1978-1984. He was Writer in the Community at the AIDS Council of NSW in 1995; Researcher in Residence at the

Australian Federation of AIDS Organisations, 1999-2000; and, a member of the International Gay Men's Health Think Tank, 2001-2002. He has published widely on contemporary gay cultures; gay men, sex and HIV; and on gay and lesbian writing and publishing in Australia.

#### **Paul Kidd**

Paul was Editor of *Positive Living* 2002-2007, President of Living Positive Victoria 2009-2011, and is currently a Director of Hepatitis Victoria and Chair of the VAC/LPV HIV Legal Working Group.

#### **Susan Kippax**

Susan has a PhD in Social Psychology and is a Fellow of the Academy of the Social Sciences of Australia. She is Emeritus Professor in the Social Policy Research Centre, University of NSW, and was Director of the National Centre in HIV Social Research (1995-2007). She began her research into the social aspects of HIV in 1985.

#### **Michael Kirby**

Michael is a past Justice of the High Court of Australia (1996-2009) and has been a Commissioner of the WHO Global Commission on AIDS and Commissioner on the UNDP Global Commission on HIV and Human Rights since 2003. He is patron of the Kirby Institute, University of NSW. Michael is a Companion of the Order of Australia.

#### **Andrew Kirk**

Andrew has been living with HIV since early 1984. He has been an activist for drug treatments since the beginning of the pandemic. He worked on the staff of Senator Chris Puplick from 1984 onwards and strongly supported a bipartisan response to HIV/AIDS in Australia. Following the evidence of successful ART, he joined

PLWHA and NAPWA in the mid-1990s to promote the uptake of the new drug combination therapies. He is currently involved in the HIV sector through his work with the NSW government.

#### **Tim Leach**

Tim is a development practitioner who works a lot in PNG. For many years he has undertaken work on behalf of NAPWA with Igat Hope, PNG's positive people's organisation. He is a former Deputy Director of the Australian Federation of AIDS Organisations and has also worked for ACON, the NSW Anti-Discrimination Board and the Australian Human Rights Commission.

#### **Katherine Leane**

Katherine was an active NAPWA Board Director for seven years and currently chairs the NAPWA National Network of Women living with HIV. She is a passionate advocate for PLHIV, especially around sexual and reproductive health and human rights and rights of people who inject drugs. Katherine is Vice-President of Positive Life SA and has been on its Board for more than 15 years. She is a public speaker with Positive Life SA and Hepatitis SA and shares her personal experiences of living with both BBV as an education tool and to raise awareness. Katherine believes strong advocacy is important in the current culture where relentless funding cuts are occurring.

#### **Sharon Lewin**

Sharon is Professor and Head of the Department of Infectious Diseases, Alfred Hospital and Monash University; Co-head, Centre for Biomedical Research, Burnet Institute. She is also the co-chair of the International AIDS Conference 2014.

**Andrew Little**

Andrew graduated as a social worker and worked for the Department of Social Security until leaving on medical grounds in 1992. He survived his retirement, living long enough for the advent of combination therapy. Since then he has worked in the UK running a large back to work program for people living with HIV, before heading up a pan-London Disabled Peoples advocacy organisation. He returned to Australia with his partner in search of a better quality of life and now works for the National LGBTI Health Alliance. Andrew is a great fan of kayaking and long walks with his schnauzer.

**Barbara Luisi**

Barbara has worked in the health sector in NSW for the past 23 years in a range of roles across a number of areas including multicultural health, women's health and Aboriginal health. A strong focus on equity and access has been a core dimension of this work. Barbara been part of the management team at the MHAHS since 2004.

**Kirsty Machon**

Kirsty is a writer, health policy researcher and journalist and worked for NAPWA from 2001-2006. Her policy interest areas included HIV treatments, access, ethics in clinical research and reproductive issues for people living with HIV. Kirsty was the President of VAC/GMHC from November 2011 to November 2012. She is currently completing a PhD in the history of Darwinian concepts of common ancestry and their effects on scientific and philosophical attitudes about the treatment of animals.

**Cipri Martinez**

Cipri has been actively engaged in the Australian HIV response since his HIV diagnosis in 1993. Inspired by the existing

community response and HIV peer leadership in 1996 he was part of establishing a support group for young HIV-positive gay men and was elected Treasurer and Board member to People Living With HIV Western Australia. His passion for HIV prevention and peer support is shown through long-term involvement with the NAPWHA, the WA AIDS Council and the Australian Federation of AIDS Organisations amongst other Australian HIV sector agencies. Cipri is currently the Vice-President of NAPWHA and creative Founder of PositiveAdvocate.com. He defines success in life by a legacy of love.

**Neil McKellar-Stewart**

Neil is currently HIV Health Promotion Officer in ACON's Northern Rivers Office. He has been engaged in the PLHIV community since the late 1980s. Neil has formal qualifications in geochemistry, librarianship and more recently nutritional biochemistry. He has been a subject specialist librarian in university and TAFE libraries, has managed statistical collection areas in the Australian Bureau of Statistics, and has been involved with aboriginal community development in remote central Australia. He contributes enthusiastically to NAPWHA's Treataware Outreach (formerly Treatment Officers Network), is a member of NAPWHA's *Positive Living* Reference Group and is AFAO's representative on ASHM Sub-Committee for Guidance on HIV Management in Australia.

**David Menadue**

David has had HIV since 1984. He has been involved in HIV sector organisations since 1988, including Vice-President and Board member of the Victorian AIDS Council over many years, Vice-President of People living with HIV/AIDS Victoria, President of the NAPWHA, a Board member of the Consumer Health Forum and the Disability

Caucus of Australia. He was awarded an Order of Australia for services to community health in 1995 and is the author of an autobiography, *Positive*.

### **Anne Mijch**

Anne is an Infectious Diseases Physician, Speciality HIV Medicine, having trained at Prince Henry and Prince of Wales, Fairfield hospitals. In October 1984 along with Suzanne Crowe she established the first HIV/AIDS service in Victoria at Fairfield and worked there during the 1980s and 1990s. She was Director of Victorian HIV Service Fairfield Hospital (from 1996 until mid-1997) and then the Victorian HIV Service at the Alfred Hospital from 1997-2007. She is currently working as HIV Consultant in PNG, other Oceania nations, India, Myanmar, Thailand, Laos and other southeast Asian nations. Anne is an adjunct Professor at Monash University and Associate Professor, Burnet Institute for Medical Research. She has a Medal of the Order of Australia.

### **Robert Mitchell**

Robert Mitchell is a 44-year-old HIV-positive person living in Hobart, Tasmania. He is the current President of NAPWHA and has been involved with the organisation for the previous decade in various roles. He is currently a member of the Australian Commonwealth Health Minister's Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACBBVS) and was an Australian delegate to the 2011 United Nations General Assembly Special Session on AIDS. Robert has been involved in the community response to HIV in Australia since 1993, when he first joined the Board of the Tasmanian AIDS Council and has also been a Board Member of the Australian Federation of AIDS Organisations.

### **Max Niggl**

Max was diagnosed 27 years ago. He is currently the coordinator of the Victorian Positive Speakers' Bureau. Max considers his professional and personal development in the HIV community sector to have been his most rewarding experience. The work of PLHIV speakers inspires him to continue supporting their efforts to make a difference not only in Australia but globally as well.

### **Darryl O'Donnell**

Darryl has over 20 years' experience working in HIV community, research and public sector roles. During the 1990s he worked as National Coordinator of NAPWHA, with AIDS Councils in Queensland, Western Australia and Victoria and was later the National President of the Australia Federation of AIDS Organisations. From 1999 to 2013, he worked for the NSW government, where he was responsible for statewide HIV policy and program development. He has also led on many national HIV policy and program initiatives. Darryl is now the Executive Director of the NSW Mental Health Commission.

### **Bill O'Loughlin**

Bill was infected with HIV in 1982. In 1985 he trained as a home care volunteer and was a founding member of Australia's first independent PLHIV peer support group. One of the first staff at VAC/GMHC, he later became involved at national and global levels and still works as a consultant, mainly on HIV, in many countries. He is currently the President of Harm Reduction Victoria, the state drug user organisation.

### **Adrian Ogier**

Adrian has worked in and around the HIV community sector since he arrived in Sydney in the late 1980s. He has written things, designed stuff, run offices, organised events, performed, trained, talked,

managed and edited. He is currently resting in the Southern Highlands.

### **Bill Paterson**

Bill is an HIV-positive gay man; he has been HIV-positive since 1992. His role in the early HIV epidemic in Australia began in 1984 when his best friend was admitted to the newly formed inpatient AIDS Unit at St Vincent's Hospital, Sydney, causing him to join the staff as a Registered Nurse, become a Clinical Nurse Specialist and then the Nursing Unit Manager where he developed the Unit from 6 to 12 to 18 and eventually 24 beds in the period from 1985-1992.

### **Elizabeth Reid**

Elizabeth is an international development practitioner, with a special interest in HIV. She and her late husband Bill began living with the possibility that he was HIV-infected from 1983. They had been working in Zaire, Bill as the Director of the US Peace Corps, and she as a development practitioner. They were drawn, professionally, into the HIV epidemic when the first joint Belgium-US HIV mission came to Zaire in 1984. Bill's dying began on Valentine's Day 1986. They journeyed from the Mama Yemo Hospital in Kinshasa via the Institute of Tropical Medicine in Antwerp to Australia, first to Prince Henry Hospital in Sydney, then to Canberra. Bill died on the last day of winter 1986, under the loving care of the nurses and other staff at Woden Hospital. Elizabeth is an Officer of the Order of Australia.

### **Paul van Reyk**

Paul was Policy Officer with the AIDS Council of NSW from 1988-1991 and has continued his involvement with HIV/AIDS in his private consultancy work since then, most recently in PNG. He is working on a long-term project to document stories from the frontlines of the response to HIV/AIDS and presented a paper on St Vincent's Ward

17 South at the 2013 Homosexual Histories Conference.

### **John Rule**

John holds a Conjoint Associate Lecturer position with the School of Public Health and Community Medicine, Faculty of Medicine, University of NSW. He worked for more than ten years at NAPWHA and was the first HIV Living Policy Analyst appointed in 2001, the Manager of the HIV Living Unit and International Programs from 2004, and the first person appointed as a Deputy Director to the organisation in 2007. Now concentrating on publishing, his most recent effort is a book chapter about the 'politics of place', in *Studying Politics Today: Critical Approaches to Political Science*, published by Routledge. He has a PhD in education. He is a person living with HIV.

### **Darren Russell**

Darren is a sexual health physician and the Director of Sexual Health at Cairns Hospital. He started working with HIV-positive folk in Melbourne in 1990 in a large, inner-city medical practice and stayed in Melbourne until 2005 when he moved to Cairns. He is the current Chair of the HIV Foundation Queensland.

### **Dermot Ryan**

Dermot has a 20-year career in the community health and HIV sector. He reflects on *Having a Life*, which was published whilst he was Manager of the AFAO/NAPWA Education Team. He currently works as the Manager of Healthy Communities and Regional Services for ACON Health in NSW. He is regular contributor to the Australian HIV sector.

### **Ian Saunders**

Ian Saunders has been HIV-positive since 1992. He was diagnosed when he was 18. He has been the Convenor of the Positive



Aboriginal and Torres Strait Islander Network.

### **Tobin Saunders**

Tobin is an out, gay, HIV-positive freelance performer, writer, choreographer, dancer, actor, DJ and events coordinator/producer. Combining elements of contemporary dance, expressive movement, popular culture, social comment and satire, Tobin's work could be described as Pastiche. And Vanessa Wagner is one of Australia's most colourful and entertaining identities and a pre-eminent, publicly out HIV-positive peer activist and educator.

### **Jill Sergeant**

Jill has worked in the HIV sector since 1990, when she started out as Editor of *Talkabout*, the newsletter of People Living with HIV/AIDS NSW (now Positive Life). Jill is currently a Project Officer with the Policy and Communications Team of the Australian Federation of AIDS Organisations.

### **Sean Slavin**

Sean works in the Health Promotion Program at the Australian Federation of AIDS Organisations. He has worked in HIV social science research and community-based education and prevention for over 15 years. Sean's experience spans community-based organisations, including a period as the manager of research programs at NAPWHA, university research centres and government. He has a PhD and has conducted social research into various aspects of preventing HIV and living with HIV.

### **Michelle Tobin**

Michelle is a Yorta Yorta woman and is a descendant of the Stolen Generation. She has been advocating for the rights of people living with HIV for the past 20 years. Michelle has been a Convenor and member

of the Positive Aboriginal and Torres Strait Islander Network and a member of Femfatales, the National Network of HIV-positive Women.

### **Jo Watson**

Jo Watson was with NAPWHA during the years 1998-2014. She has taken great pride in working on the response to HIV within Australia for PLHIV and their organisations. She was a community representative on the Executive Committee of the International Network for Strategic Initiatives in Global HIV Trials (INSIGHT) from 2006-2010, and continued as the Australian representative on the Insight Community Advisory Board until 2014. She also continues as an investigator on the Australian HIV Observational Database Temporary Resident Access Study.

### **Peter Watts**

Peter is the Health Promotion and Treatments Officer working for Queensland's peak community-based HIV peer support and advocacy organisation Queensland Positive People (QPP). He has held this position with QPP since 2004, and formerly worked for the Queensland AIDS Council (QuAC) in a similar role from early 2001. Peter is also part of the national NAPWHA Treataware Outreach Network (TON), with the work of this group focused on community HIV treatment education, access and advocacy.

### **Bill Whittaker**

Bill is a special representative of NAPWHA and an advisory Board member of Pacific Friends of the Global Fund to Fight AIDS, TB and Malaria. He is one of the architects of Australia's response to AIDS and has worked in HIV advocacy, policy and strategy for more than 25 years. He participated in and contributed to the United Nations Special Sessions on HIV/AIDS in 2001, 2006

and 2011. Bill served as a commissioner on the UNAIDS High Level Commission on HIV Prevention. He has provided strategic advice in Australia and internationally, including for the World Health Organization, UNAIDS and the International AIDS Society. He is a former CEO of the AIDS Council of NSW, and President of the Australian Federation of AIDS Organisations. Bill chairs the NSW Ministry of Health's Implementation Committee for the NSW HIV Strategy 2012-2015. He is a Member of the Order of Australia.

### **Garry Wotherspoon**

Gary is a writer and historian, whose books include *Being Different: nine gay men remember*; *City of the Plain: history of a gay subculture*; and *Making a difference: A History of Positive Life NSW*. He was awarded Australia's Centenary of Federation Medal in 2002, for his work as an academic, researcher and human rights activist.

### **Edwina Wright**

Edwina is a clinician-researcher, Adjunct Lecturer and Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, and is the President of the Australasian Society for HIV Medicine.



The production of this book, including the NAPWHA history exhibition at the World AIDS Conference 2014 in Melbourne, has been supported by a grant from the Commonwealth Department of Health.



# *Through our eyes*

**Thirty years of people living with HIV responding  
to the HIV and AIDS epidemics in Australia**

From a time when people living with HIV were largely invisible, except as visibly sick and disfigured, to today when Poz Action and the representation and participation of people living with HIV is embedded in the Australian HIV response.

There are many stories, and many voices and the need to remember others now long silent. This book features a diverse range of writers, the majority of whom are HIV-positive. Other contributors have been working closely and steadfastly alongside HIV-positive people over many years.

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