

# HIV AUSTRALIA

A SPECIAL COLOUR EDITION

## Reflections: 25 years of HIV

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# HIV Australia

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## Editors

Abigail Groves (Policy)

Finn O'Keefe

## Contributing Editor

Jason Appleby (Treatments)

## Design + Production

Ascending Horse

## Correspondence

HIV Australia C/- AFAO, PO Box 51 Newtown NSW 2042 Australia

**Telephone** +61 2 9557 9399

**Facsimile** +61 2 9557 9867

**Email** editor@afao.org.au

**Website** www.afao.org.au

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Photo Ross Coffey

## AFAO's aims are to:

- Advocate on behalf of its members at the Federal level, thereby providing the HIV/AIDS community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV/AIDS;
- Develop and formulate policy on HIV/AIDS issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV/AIDS and its effects.

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AFAO is the peak non-government organisation representing Australia's community-based response to the epidemic of HIV/AIDS. AFAO's members are the state and territory AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Injecting and Illicit Drug Users League, Scarlet Alliance and the Anwernekenhe National Alliance.

## We want to hear what you think about

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C/- AFAO, PO Box 51, Newtown  
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# HIV AUSTRALIA

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HIV Australia welcomes suitable reports from interested authors. To submit an idea or report for consideration, email [editor@afao.org.au](mailto:editor@afao.org.au)



## HIV Australia: Now in full colour!

This special edition of *HIV Australia*: 'Reflections: 25 years of HIV' marks our debut as a full colour publication.

AFAO would like to acknowledge the artists, designers and photographers who, over 25 years, have contributed their creativity to our fight against HIV/AIDS. Archival material – such as this advertisement for the Black and White Ball on 26 November 1988 – is featured throughout this issue of *HIV Australia* with credits where known.

## Holy condom controversy

Cardinal George Pell, the Catholic Archbishop of Sydney, has supported the Pope's controversial stance rejecting condom distribution as an effective strategy to fight the global AIDS epidemic. "Condoms are encouraging promiscuity. They are encouraging irresponsibility," Pell stated in a recent television interview.

These comments echo sentiments recently expressed by Pope Benedict XVI, who claimed that condoms could make the AIDS crisis worse. During a visit to Cameroon in central Africa, Pope Benedict said that HIV/AIDS is "a tragedy that cannot be overcome by money alone, that cannot be overcome through the distribution of condoms, which can even increase the problem."

Despite this view being widely condemned by AIDS activists around the world, Pell has added to the controversy, stating that he supports the Pope's position. Pell cited evidence that the infection rate of HIV is much lower in the primarily Catholic nation of the Philippines than in Thailand, which he describes as being "awash with condoms." "There are condoms everywhere and the rate of infection is enormous. That's what the Pope is talking about."

Don Baxter from the Australian Federation of AIDS Organisations (AFAO) refutes this, stating that rates of HIV transmission in Thailand have, in fact, declined as a result of more widespread use of condoms by sex workers and the general population. He also warned that the Pope's comments could be easily misinterpreted within African communities, where it is common for both men and women to have concurrent sexual partners within a committed relationship. "Calls for not using condoms and being faithful

are heard by Africans to mean if they have regular partners, they don't need to wear condoms," Baxter said.

Cardinal Pell's statement has been rejected by other Australian religious leaders, including Phillip Jensen, the Anglican Dean of Sydney, who responded by saying "We don't oppose the use of condoms ... We have no problem with birth control that includes condoms."

Rebecca Hodes, of the Treatment Action Campaign in South Africa, said that if the Pope was serious about preventing new HIV infections he would focus on promoting wider access to condoms and spreading information about how best to use them. "Instead, his opposition to condoms conveys that religious dogma is more important to him than the lives of Africans," Hodes added.

More than two-thirds of the 32.9 million people living with HIV around the world live in sub-Saharan Africa. Three-quarters of all AIDS deaths in 2007 occurred in the region.

Baptised Catholics made up 17 percent of the African population in 2006, compared with 12 percent in 1978, the Vatican says. Africa is the fastest-growing region for the Roman Catholic Church, which competes with Islam and evangelical churches.

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## Health Minister announces new Commonwealth Government Advisory Committee on HIV, Hepatitis and STIs

Health Minister Nicola Roxon has announced the formation of a new advisory body on the national response to blood-borne viruses and sexually-transmissible infections.

The Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections is chaired by Professor Michael Kidd. Professor Kidd is joined by 14 members appointed as individuals on the basis of their expertise. Members include representatives from government, clinicians, researchers and the community.

The new Committee will advise the Government on a national framework to prevent and treat blood-borne viruses and sexually-transmissible infections. The committee will work with research, public health and community groups to develop a three year work plan. An action plan to prevent the spread of blood-borne viruses and sexually-transmissible infections (STIs) among Aboriginal and Torres Strait Islander people will also be developed.

The new Advisory Committee has been welcomed by AFAO.

"Minister Roxon has put together an excellent Committee to lead the revitalisation of Australia's HIV and hepatitis responses," said Dr Graham Brown, President of AFAO and a member of the new Committee.

"Professor Michael Kidd is a dynamic and highly engaged Chair and the membership of the Committee brings together talented people from many of the sectors key to a successful Partnership response for HIV and hepatitis C. Minister Roxon has charged the committee with developing and overseeing the new National Strategies for HIV, STI and hep C. She wants the Partnership approach restored and the increasing HIV infection rates reversed – and she has appointed the right people to advise her on how this can be achieved," said Dr Brown.

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## HIV transmission murder case: Canadian man found guilty

A Canadian man who is thought to have recklessly transmitted HIV to seven women, two of whom subsequently died, has made legal history by becoming the first person ever to be convicted of first-degree murder for sexual HIV transmission.

The trial, which lasted six months, concluded when a jury found Johnson Aziga, 52, guilty of two counts of first-degree murder, ten counts of aggravated sexual assault and one of attempted aggravated sexual assault.

Mr Aziga, who was born in Uganda, arrived in Canada as a refugee in 1990 and was diagnosed

HIV-positive in 1996. After the dissolution of his marriage in 1998, Mr Aziga dated several women. In October 2002, a woman diagnosed with HIV named Mr Aziga as a recent sexual contact. Since 1998, Canadian law has required people with HIV to disclose their status to sexual partners prior to sexual contact that may risk transmission. Mr Aziga was issued with a public health order requiring him to practice safer sex.

In March 2003, another woman also named Mr Aziga as a recent sexual contact. Mr Aziga was issued with a second public health order and police were informed. He was arrested at his home in August 2003 whilst having unprotected sex with a woman who has since tested HIV-positive and identified in court as Ms C.

The court heard evidence from all eleven complainants, seven of whom believed that Mr Aziga had infected them with HIV, including pre-recorded video and audio testimony from the two women who had since died. Both claimed that Mr Aziga had not disclosed his HIV status to them before having unprotected sex, and that they would not have had sex with him if he had.

The jury found Mr Aziga guilty of both murder charges and ten of the eleven aggravated sexual assault

charges, primarily because Canadian law essentially defines consensual sex without prior disclosure of HIV status as fraud. Mr Aziga will be sentenced on 7 May.

The case has reignited the criminalisation debate in Canada, which has prosecuted more HIV-positive individuals per capita for sexual HIV exposure or transmission than any other country in the world. Although Mr Aziga's double-murder trial is unique, almost 90 HIV-positive people have been prosecuted, and almost 70 convicted, of criminal HIV exposure or transmission in Canada since 1989.

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### **AIDS becomes China's top infectious killer**

Chinese officials say AIDS was the country's leading cause of death from infectious diseases last year. A report by China's Ministry of Health ranked AIDS above tuberculosis and rabies for the first time, saying it killed almost 7,000 people in the first nine months of 2008.

The Ministry says the total number of HIV cases in China is now more than 260,000, nearly double the figure published three years ago. It says more than 34,000 people have died of the disease in China so far.

United Nations figures estimate that 700,000 people in China were HIV-positive by the end of 2007. China also reported a 20 percent rise in syphilis cases last year, with a total of 257,474 cases, while gonorrhoea cases dropped by ten percent.

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### **Global HIV-related TB deaths are double previous estimates**

One out of every four deaths from tuberculosis (TB) are HIV-related, according to a new report from the World Health Organization (WHO).

Though rare in Australia, an estimated 1.4 million people with HIV developed TB during 2007. In the same year, 456,000 people with HIV died from TB, making it the leading cause of death among HIV-positive people worldwide. This is twice as many HIV-related TB deaths as had previously been estimated – although the WHO notes that the increase is mostly due to better methods for gathering data, rather than changes in the TB or HIV pandemics.

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The logo for HIV Australia, featuring the word "HIV" in large, bold, grey, sans-serif capital letters above the word "AUSTRALIA" in smaller, bold, grey, sans-serif capital letters. The letters have a slight 3D effect with shadows.

### **Got something to say?**

**Your views are important to the success of this publication.**

*HIV Australia* publishes letters and contributions from readers. If you want to respond to something you have read here, or have an idea for an article, please write to us at: [editor@afao.org.au](mailto:editor@afao.org.au)

# NEWS FROM THE ASIA PACIFIC

## AFAO welcomes changed priorities in new AusAID HIV Strategy

Foreign Affairs Minister Stephen Smith launched the new AusAID Strategy to tackle HIV in the Asia-Pacific region on World Health Day, 7 April. The new Strategy, titled *Intensifying the response: Halting the spread of HIV – Australia’s international development strategy for HIV*, aims to intensify and improve Australia’s response to HIV in the region.

Five million people in the Asia-Pacific region live with HIV. In Asia, HIV is the single largest cause of death from disease among people between the ages of 15 to 44 years. HIV prevalence reached 1.6 percent in rural Papua New Guinea in 2008 and 2.4 percent in the Indonesian provinces of Papua and West Papua in 2006.

The new Strategy has been welcomed by the Australian Federation of AIDS Organisations (AFAO). “The government’s new Strategy recognises that the rapidly escalating HIV infections among gay men and other men who have sex with men (MSM) in all major cities in Asia are becoming the major driver of expanding epidemics in the region,” said Don Baxter, AFAO’s Executive Director.

“We welcome the government’s recognition of this newly emerging priority and look forward to some rapid funding allocations to intervene in these emerging epidemics while they are still potentially controllable,” Baxter said.

Baxter said the epidemiological evidence has become very clear:

projections of new HIV infections, contained in the authoritative report prepared by the Commission on AIDS in Asia, demonstrate that sex between men in Asia will contribute more than 46 percent of new HIV infections in the region by 2020, unless programs and investment are substantially upgraded.

“Australia’s contribution to HIV funding and expertise in the Asia Pacific region over the last decade has been considerable – but investment in gay/MSM programs has been minimal,” Baxter said.

Baxter said AFAO welcomed the *Scoping study on MSM and HIV* which AusAID had already put in place, but said decisions on its recommendations need to be made rapidly, as “the virus is not sitting round waiting for us all to get our act together”.

In 2007, one in ten newly reported infections in Australia were originally diagnosed overseas. Many of these cases were diagnosed among travelers to south-east Asia.

## New Zealand HIV diagnoses in 2008 highest ever

The latest annual statistics report on HIV shows that 184 people were diagnosed with HIV in New Zealand last year, the highest number of diagnoses since the epidemic began.

“This is an alarming increase, which must motivate us all to look critically at the reasons why the rate of HIV infections continue to rise,” said Tariana Turia, Associate Minister for Health. Much of the 2008 increase has been due to the relatively high level of infection occurring amongst men who

have sex with men. Last year, about 70 percent of HIV infections that occurred in New Zealand were diagnosed amongst men having sex with other men.

Another worrying aspect of the report is the difference in testing patterns between European and Maori men. “There is a disproportionate rate of Maori and Pasifika men presenting as ‘late testers’ than European men,” said Mrs Turia. The rate for Maori ‘late testers’ was 40.6 percent; for Pacific 28.6 percent and for European 21.1 percent.

The annual statistics report also showed that most people who acquired the infection through heterosexual contact were infected overseas. “For infections that occur in New Zealand, compared to New Zealand European women, women of ‘other’ ethnic groups, Pasifika and Maori women also appear to be at greater risk when we analyse the rise in diagnosis rate,” said Mrs Turia.

The number of people diagnosed with HIV has fluctuated over the past four years: 2005 (183 people); 2006 (177); 2007 (156); and 2008 (184). Detailed information on these trends is available in the latest issue of *AIDS – New Zealand* newsletter published by the AIDS Epidemiology Group of the University of Otago.

The prevalence of HIV infection in New Zealand continues to be very low compared to other countries. From 1985 to 2008, some 3,000 people have been diagnosed with HIV in New Zealand.



**BEWARE  
SHARP  
ATTACK**



## Ita tells me to

Bridget Haire talks to Ita Buttrose

... But Ita is more than just a charmer, she is someone who delivers, and that is probably why she was plucked from the zenith of media stardom to play a leading role in the development of AIDS policy in the 1980s.

Of course you put on your best clothes to talk to Ita, no matter that it's a phone interview. Of course, when she doesn't answer, you imagine that you've been bumped for some glamorous powerbroker, consigning you to journalistic oblivion. Of course, when you answer your phone and find she's tracked you down through the byzantine network of office phone lines and she apologises with that famous lisp, you are charmed.

But Ita is more than just a charmer, she is someone who delivers, and that is probably why she was plucked from the zenith of media stardom to play a leading role in the development of AIDS policy in the 1980s.

"It was like being told your country needs you," she muses, recalling the night that Health Minister Neal Blewett called her out of the blue and asked to her to chair the National Advisory Committee on AIDS (NACAIDS). "I didn't hesitate".

It's a story that she's told before and one that she clearly relishes. As a single working mother – she was then editor-in-chief of *The Daily Telegraph* and *The Sunday Telegraph* and her children were

15 and 11 – it wasn't that she had time on her hands. AIDS struck a chord with Ita and she believed that she had the capacity to bring people along with the policy directions that Australia was to take.

"I think I was chosen because I was a good communicator, credible, someone people would believe," she said. "There was a lot of homophobia and fear and people were playing the blame game. Children with HIV/AIDS were shunted out of schools – I knew boys with haemophilia whose parents were petrified that their school would find out – it was such a terrible burden."

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Ita was able to use her celebrity to get people to listen and to talk, whilst performing that basic feat of empathy, putting oneself in other people's shoes.

"Speaking in churches, I'd say, would you love your child any less if your child was gay? And, how would a person with AIDS *feel*?" In an aside, she adds, "I spoke at the pulpit, you know – you don't expect these things to happen in your life."

These basic human messages were used to sell the idea of providing care for people with AIDS: pastoral care for those who sought it, and hospice care for the dying.

"The St Vincent's nuns were terrific – but elsewhere hospice care was difficult to come by. A lot of people didn't want to care for people with AIDS."

A lot of people also thought that HIV was transmitted by mosquitoes, shared crockery, swimming pools and so on, so dismantling these beliefs was a major task. Meanwhile, Ita had chummed up with Professor Ron Penny, who would teach her basic immunology and take her on visiting rounds in the AIDS ward.

Memories of the suffering and isolation that some people experienced still resonate.

"There was this boy, up on Ward 7, from the country. His father had wanted him to be a girl ... he came to town one day, he discovered the gay bars, and discovered that there were other men like him – it was a revelation. His father never knew he was gay, or infected ... and he subsequently died."

"And there was this Greek boy down in Melbourne ... he was so good looking, such a very handsome man ... and he said, 'No one touches me, no one hugs me.' It was so poignant, I held his hand. It was twenty odd years ago, but I still remember."



'STOP AIDS', reproduced from the *National AIDS Bulletin*, June 1988.

Another memory haunts for a different reason – the famous 'radical celibate' line.

"I wish I'd never said it! It haunts me to death!"

Ita explains that she'd mentioned 'radical celibacy' as a throw-away line in an interview, having just received some correspondence from an unnamed but apparently famous friend who asked her to consider the concept.

"That translated into a poster next Sunday: *'Ita tells: my life without sex'*" You see the poster and you think, what's that? You rush out and buy the paper and discovered that, because you're a radical celibate, you have a life without sex."

And the point was ... ?

"What I was trying to stress, because it was a point we were working on, was with sex you didn't know where the person you slept with had slept the night before ... you certainly should be using condoms."

Ita is reticent about political differences within NACAIDS, stating that the debates were robust, as they needed to be. She also states obliquely that doctors do think they know best and lay people are not meant to ask questions.

"When you are doing something as radical as we were doing and covering such ground – needle exchange, freely

available condoms – there always had to be a debate. It would be naive to think there wouldn't be a debate, and I think that's how you get the best possible outcome."

She is clear, though, that she did not support a push to ban Mardi Gras, which came not only from the religious right, but also from the then highly influential David Pennington. "I never had a problem with Mardi Gras ... it wasn't to do with saying, 'Go out and be careless'. It was about a celebration of saying that it's OK to be gay."

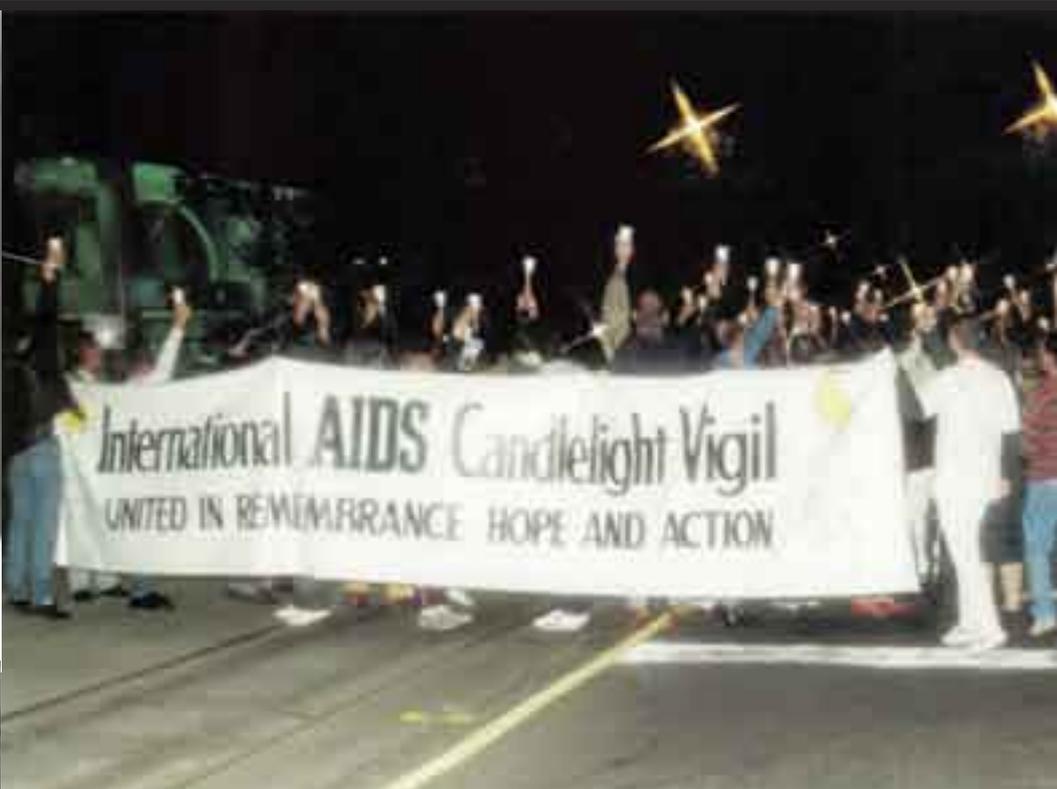
Ita knew that she was truly appreciated in the gay community when her earrings developed a cult following on the drag circuit.

"They kept taking my earrings! It was the 1980s, and they were big dangly ones. I lost them at Pokies, I lost them on Oxford Street – one pair were taken and auctioned by Gay Men's Health Crisis in New York. I finally said, Hey guys, I can't keep giving you my earrings, I'll have none left! But I can't tell you how many times I ended up going home without them."

**Bridget Haire is a Policy Officer at Family Planning Australia and former Policy Analyst at AFAO.**

# Reflections: 25 years of HIV

Clockwise from top left **Keith Harbour (OAM)**, former Vice President of AFAO; **International AIDS Candlelight Vigil**, reproduced from the *National AIDS Bulletin*, June 1991; **David Menadue** opens 'The Positive Living Centre' at Acland St, Victoria's first community centre for positive people, in 1993. Photo James McKenzie, reproduced from the *National AIDS Bulletin*, May 1993.



## When I first met AFAO ...

By **David Menadue**

I was elected to the AFAO Executive in the early nineties with an understanding that I would offer the perspective of an openly HIV-positive person.

I first met the Australian Federation of AIDS Organisations (AFAO) when it was just a young pup – six years old, I think (for the purposes of this article, let us call it the “puberty years”).

I was elected to the AFAO Executive in the early nineties, with an understanding that I would offer the perspective of an openly HIV-positive person. I think I had been cajoled to take the role by Keith Harbour from Melbourne, who had played a major role in the establishment of AFAO as a national peak for HIV organisations. Tragically, he was becoming ill and wanted to hand the “torch” over to other positive advocates. There were so few openly positive people in the sector at that stage, that anyone with a leaning

towards advocacy who thought they were able to handle the politics of the sector and put their hand up, usually got accepted.

Despite my somewhat hazy recollection of the time, I recall the Presidency of Bill Bowtell (formerly adviser to Health Minister Neil Blewett) and other Board members including Don Baxter, Dennis Altman and Anthony Smith, and the Executive

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# Reflections: 25 years of HIV

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Officer Leanne Joyce, all working out of a smallish office in Canberra.

Initially it was thought important that the Federation was based in Canberra, to get maximum access to politicians and key department personnel, but this issue was to be debated intensively in the mid-nineties, when the move to Sydney was to occur. Despite the fact that AFAO was still establishing its name with federal politicians and bureaucrats, it was clearly already a very credible and respected organisation by the time I got involved.

I had been Convener of People Living With HIV/AIDS (PLWHA) Victoria for two years, after receiving a baptism of fire liaising with the Melbourne media during my first months in the role. Our organisation, which was then a program of Victorian AIDS Council/ Gay Men's Health Centre (VAC/GMHC), had been trying to find a location for a Community Centre for PLWHA in Melbourne. When we finally found a suitable site in Caulfield, we were met with fierce opposition from local residents, so we held a press conference at the proposed site.

Almost all of the mainstream media – newspapers and TV channels – turned up to get what they knew would make a good story: local residents versus people with HIV/AIDS. Residents feared that we would ruin the amenity of the area, claiming we would host wild, noisy parties and throw needles over the fence! It was clear to us the residents' real concern was about protecting neighbourhood property values. Their response reflected ignorance and prejudice about a highly stigmatised disease. Although we generally got sensitive media coverage, we eventually lost the battle after local Councilors rejected our application for spurious reasons, such as parking concerns. Through this experience I



**When you say yes...**

**say yes to safe sex.**

Making the first move might be scary, but more guys than you think have sex with other guys. It's natural and if you're safe you'll have a great time.

And what's safe? Kissing, cuddling, licking, stroking, sucking, oral sex (avoid cum in the mouth) vaginal and anal sex with condoms and water-based lube \*

For more information on safe sex and discussion groups for young gay and bisexual men, call 483 6300 or 419 9934.

Produced by the Victorian AIDS Council 1992 \*Susan K Vogel



gained a media profile, whether I liked it or not. Along with Joan Golding (the parent of a gay man who had died from AIDS), I was called on many times afterwards as a spokesperson for PLWHA in the state.

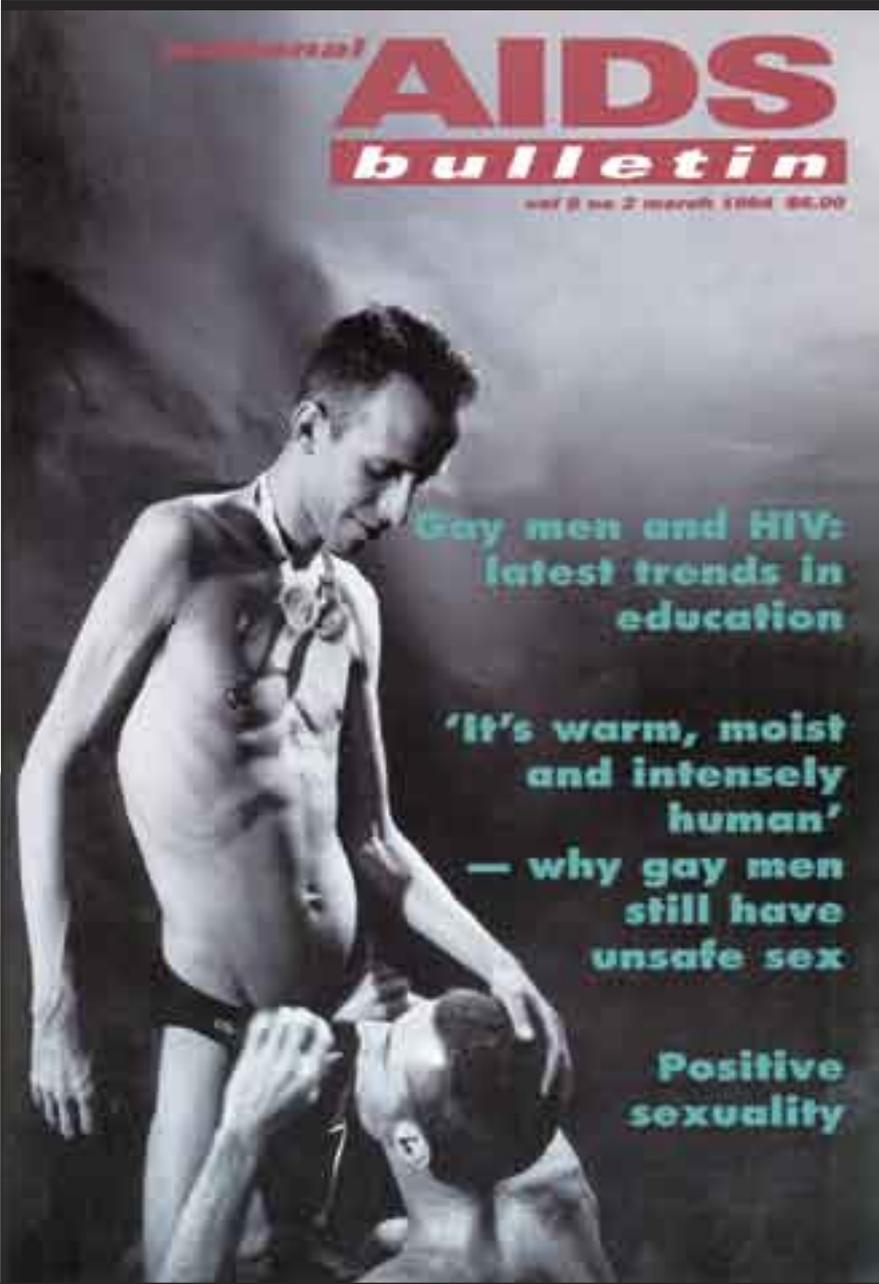
Other AIDS Councils and PLWHA groups were also dealing with almost daily instances of ignorance and discrimination. Hospitals and medical staff refused to treat HIV-positive patients; loony politicians and church leaders publically mouthed their ignorance and positive people were stigmatised by media perceptions of

people with AIDS. All of this was compounded by the Grim Reaper advertising campaign of 1987, which scared many people witless and prejudiced their attitudes to people with the virus.

I also remember considerable fuss around this time about the Victorian AIDS Council's HIV prevention campaign, which displayed a photograph of two young gay guys kissing. This incurred such wrath from the Victorian Health Minister Marie Tehan that she reduced the council's funding the following year.

Clockwise from opposite VAC/GMHC's 'Two Boys Kissing' Campaign; Bruce Brown and partner on the cover of the *National AIDS Bulletin*, March 1994; ABD President Steve Marks meets ACT UP, photo by Jamie Dunbar, reproduced from the *National AIDS Bulletin*, March 1991; an ACT UP demonstrator bound by red tape in Canberra, 1990, photo by Jamie Dunbar, reproduced from the *National AIDS Bulletin*, December 1993/January 1994.

# Reflections: 25 years of HIV



Venturing onto the national scene caused me some trepidation, but I generally found other committee members to be open to “newbies”, which helped me to find my feet in a whole new world of acronyms, Health Department officials, National Strategy negotiations and the occasional political stoush.

The principle of involving the community in the HIV response had been firmly established, largely due to the efforts of AFAO committee members. The organisation had learnt to deal with a range of recalcitrant

politicians, like Wilson Tuckey, Opposition Shadow Minister for Health who spoke to the 1988 National AIDS Conference in Hobart, arguing for a “remedicalisation” of AIDS and, by effect, marginalising the community’s involvement.

Community politics was a constant tightrope which AFAO, the state AIDS Councils and other national peaks, such as the fledgling National People Living with HIV/AIDS Coalition (NPLWAC), Scarlet Alliance and AIVL (Australian Intravenous League) all had to walk – trying to

keep good relations with the then Labor Government, while also listening to voices of protest from the HIV community, including from the more radical activist elements like ACT UP.

Issues like lack of access to AZT, and the government’s slow response in allowing regulation and importation of new drugs, lead to the famous ACT UP “D-Day” protest staged both inside and outside Parliament House, Canberra, in June 1991. ACT UP had played its role

*continues on page 37*

# Reflections: 25 years of HIV

Pictured left The front cover of the *HIV/AIDS and US MOB* booklet featuring artwork by Arone Raymonde Meeks and produced in 2005 by AFAO/NAPWA; Pictured right and opposite Artwork featured in the *HIV/AIDS and US MOB* booklet by Gary Dickinson.



## Implementing a vision: Towards a whole of community response to HIV/AIDS in the Aboriginal & Torres Strait Islander community

By Michael Costello and Colin Ross

*On Tuesday November 4, 2008, the inaugural Annual General Meeting of the Anwernekenhe Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA) took place in Alice Springs. The meeting was an historic moment, representing 14 years to the day (November 4, 1994) that the first Anwernekenhe conference concluded at Hamilton Downs, just outside of Alice Springs.*

*The first Anwernekenhe conference was in itself an historic event, bringing together Aboriginal and Torres Strait Islander gay men and Sistagirls to discuss HIV/AIDS and sexual health for the first time. The conference generated a series of recommendations, including the establishment of the National Aboriginal and Torres Strait Islander HIV/AIDS Project at the Australian Federation of AIDS Organisations (AFAO) and contributed to a growth in the number of Aboriginal-specific positions and projects in AIDS Councils around Australia. These events helped pave the way for the foundation of the ANA.*



In 1994, the Australian response to HIV/AIDS was well established and underway. The second national HIV/AIDS strategy had been released. However, very little was known about the impact of HIV on the Aboriginal and Torres Strait Islander community. Reporting methods and data collection was limited and a national overview was incomplete.

At the same time, stories were starting to emerge within these communities about friends and family who were contracting HIV. A group of Indigenous gay men, concerned about these recent trends, decided to pursue a national forum that would bring together the concerned people in the community.

The outcome was the inaugural Anwernekenhe conference, which commenced late October 1994, on the lands of the Arrernte peoples at Hamilton Downs in the Northern Territory. Participants at the conference included representatives from the Commonwealth, AFAO and the Aboriginal Community Controlled Health sector, alongside approximately 70 community members.

The conference made a range of recommendations for improving the national response to the epidemic,

acknowledging that Indigenous gay men and Sistagirls were amongst the priority groups most at risk of contracting HIV. Anwernekenhe conference participants selected AFAO as the potential host organisation, based on its expertise in developing and implementing HIV/AIDS responses in the gay community. However, it was agreed that for a national response to be effective for Indigenous communities, a national working and advisory committee would need to be created.

A working committee was established, made up of Anwernekenhe participants and was given the mandate to pursue the conference recommendations and oversee the establishment of a national project. By late 1996, the AFAO-based National Aboriginal and Torres Strait Islander Gay and Sistagirl HIV/AIDS – Sexual Health Project was created, and work had commenced on a national consultation.

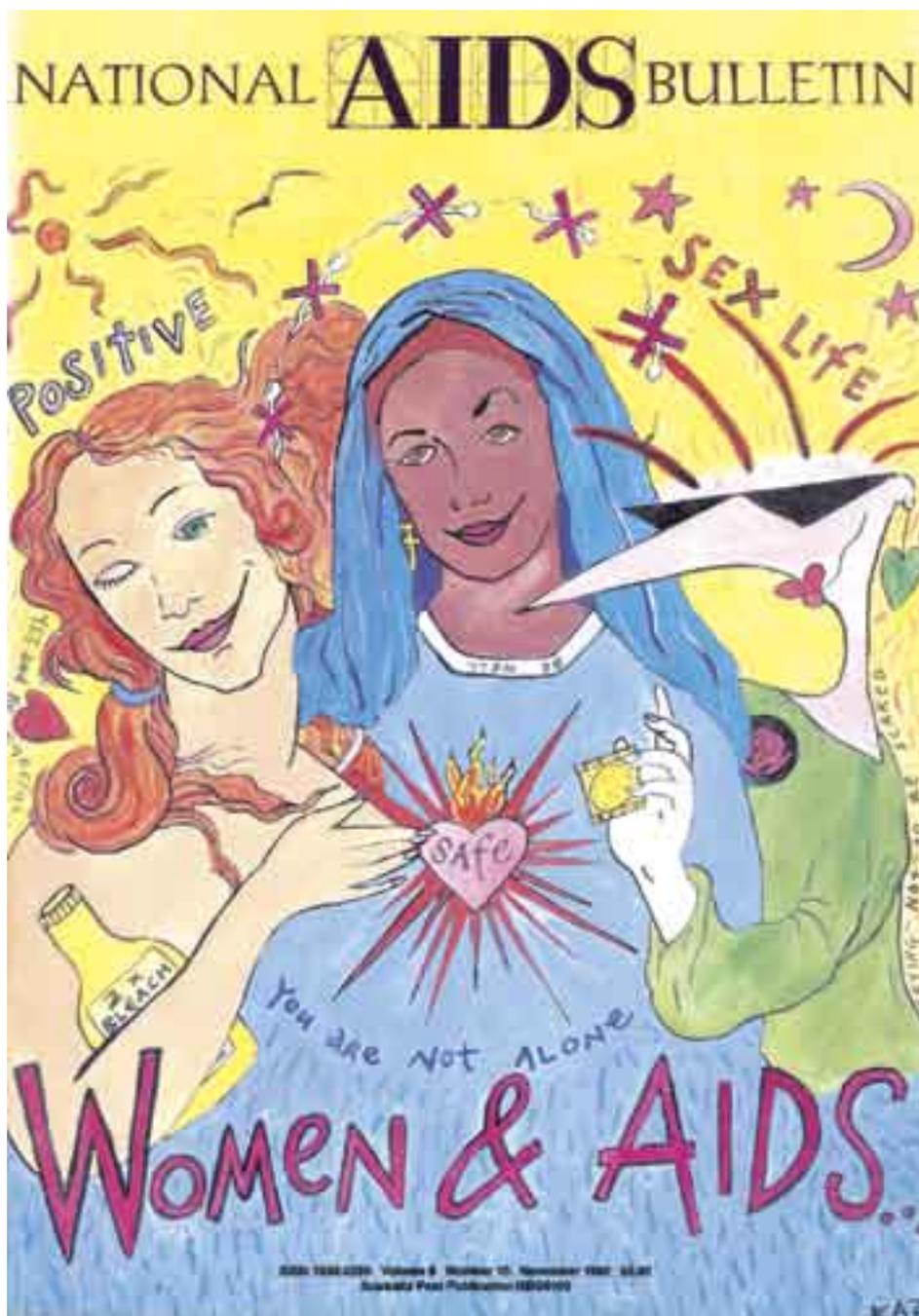
The project undertook a two year consultation needs assessment process with Indigenous gay men and Sistagirls, AIDS Councils and the Aboriginal health sector. What emerged from the consultations were issues ranging from poor and limited access to health services, treatment, care and support, and also many accounts of sexual abuse stories.

The consultation process and outcomes were published as part of the *AFAO Indigenous Gay and Transgender Project National Consultation Report and Sexual Health Strategy 1998 – 2000*. This was the first work to consider the experiences and sexual health needs of Indigenous gay men and Sistagirls.

The spirit and impetus of the Anwernekenhe conference continued into 1998, with the staging of Anwernekenhe 2 in Queensland, where delegates endorsed the report and strategy. When the idea of a project at AFAO first emerged from Anwernekenhe 1, there were no Aboriginal & Torres Strait Islander AIDS Council-based projects. By 2001 there were three projects operating out of AIDS Councils.

Recommendations contained in the consultation report and strategy informed the work of the AFAO National Indigenous Project. The focus of AFAO's Indigenous work commenced by concentrating on capacity-building to promote increased collaboration between AIDS Councils and the Aboriginal Community Controlled Health Sector around delivery of education and prevention strategies for Indigenous communities.

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## Hidden lives

By Jennifer Power

While the global face of HIV/AIDS is increasingly that of a young woman, this is not the case in Australia, where HIV-positive women have been described as a 'minority within a minority'. In 2006, the National Centre for HIV Epidemiology and Clinical Research estimated that there were approximately 1,500 Australian women living with HIV, less than 10 percent of the total number of over 16,000 people.

What these statistics do not describe, however, is the important role HIV positive women – as activists, advocates, educators, carers and supporters – have played, and continue to play, in the history of HIV in Australia.

In a piece written for the *Sunday Herald* in 2007, Marianne Peisl wrote of her HIV diagnosis: "So, at 26, began my own secret life, hiding my diagnosis from my family, concealing medical info in my car boot and pretending hospital appointments were work meetings." Peisl was diagnosed in 1988. She was only the fifth woman in Victoria to be diagnosed at a time when panic about HIV was at its height and knowledge about the virus was only just starting to emerge. Even among health professionals, very little was known about the extent to which women were susceptible to HIV, let alone the impact it would have on their bodies and their lives. Peisl's doctor at the time responded to her diagnosis by commenting that he had never before seen a woman with HIV.

Fortunately for Peisl, she managed to make contact with a small group of women who had been slowly pulling together the first organisation for women living with HIV/AIDS in Australia, Positive Women Victoria.

Positive Women Victoria was established in 1988, a response to two women's experiences of isolation following their positive HIV diagnosis. Bev Greet was told she had HIV in 1984. She didn't know any other women

Clockwise from left AFAO's Executive Director Leanne Joyce with Libby Woodhams, Mrs Dallas Hayden, and Bill Whittaker at the Quilt unfolding, Parliament House, reproduced from AFAO's Annual Report, 1990; 'From all walks of life', reproduced from the *National AIDS Bulletin*, February 1989; 'Safe', reproduced from the *National AIDS Bulletin*, March 1988.

# Reflections: 25 years of HIV



with HIV, so set about trying to make contact, leaving her details with doctors and HIV specialists with a request to pass them on to any other women. It wasn't until four years later, when Deborah Gillies got in touch with her, that she met another woman with HIV.

"I joined a group called Positive Friends in 1985, but it was all gay men," says Greet. It wasn't until 1988 that Deborah called me at home and said, "I am HIV positive." I said, "me too" and she didn't hang up ... We met several times and were always talking about our problems and concerns and issues. We were sure that there must be other women out there facing the same things, so we decided to set up a group for positive women."

It took a while for Positive Women to take off. Greet and Gillies advertised the meetings around Fairfield Hospital and the Victorian AIDS Council. Despite their best efforts, for the first six months it was just the two of them at fortnightly meetings.

"One other woman came to the first meeting. But then [information about her HIV status] was overheard by her employer and she was put off coming to any other meetings," recalls Greet. "So it was just the two of us. We put up flyers around Fairfield Hospital and other places and were starting to wonder if it was all pointless. But slowly, slowly women started to come."

In the beginning women had concerns about joining a group for HIV positive women. While most were keen to meet informally and have cups of tea at each others' houses, they were frightened to be associated with the group in any formal way.

"There was a lot of stigma then," explains Greet, "you were a bad girl. Positive women were seen as sex workers or drug users, not that those girls are bad at all, but there was stigma there. I don't think stigma and discrimination has disappeared today, but people are more open to the idea that anyone can get HIV."

In the early days, Positive Women ran fortnightly meetings in a small room at the Victorian AIDS Council offices in Collingwood. Over the years, however, the group became larger and the organisation more structured. In 1992, Positive Women received funding from the Victorian Department of Human Services to employ a paid worker and upgrade their premises.

"We didn't get much support at the beginning. We were told that we were such a disparate lot that we wouldn't gel as a group," says Greet. "We were banging on the door of the Health Department asking for funding, and we were told there wasn't enough of us ... it wasn't until 1992, when we had about 50 people, that we finally got funding."

From this point, the organisation has gone from strength to strength; organising and being involved in a range of arts, cultural and sporting events that demonstrate the strength

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and life-energy of women living with HIV/AIDS, while also getting the message out that HIV can affect anyone.

In 1999, Positive Women entered a triathlon team in the World Master's Games – believed to be the first HIV-positive team ever to be represented in an international sporting event. The success continued with the 2002 Triathlon team receiving sponsorship from Maurice Blackburn Cashman Lawyers.

Cultural achievement added to sporting glory in 2005, when Positive Women produced a critically acclaimed play, 'In the Family', based on interviews with HIV-positive women. The play, which few years later was included on the VCE Theatre Studies List, was also developed into a series of monologues that are still performed at public events. In 2007, a powerful photographic exhibit, 'A Body of Knowledge', was also produced, depicting the experiences of members of Positive Women Victoria in images and text.

These initiatives notwithstanding, Greet describes the greatest achievement of Positive Women as the support that group members have provided for women over the years, both through formal events, such as annual weekend retreats and informal day-to-day support.

"I do believe that peer support is a strong element in survival, breaking down that sense of isolation," says Greet. "Our *raison d'être* was to provide peer support, to make sure people did not feel alone and to help people feel (even though it was hard at the time) that we could live long and productive lives and even have children. We provided support by visiting women in hospitals, or if they had a crisis in their family or relationship we would go and visit, or we would go to funerals."

Advocacy has also been at the core of what Positive Women have achieved. The role of women who had the courage to publicly tell their stories of being HIV-positive was incredibly important in the mid-1980s and early 1990s, when the dominant image of a person with AIDS was one of someone who was 'deviant', criminal or in some way deserving of their fate. Women who were mothers and grandmothers, many of whom had acquired HIV through heterosexual sex, came out in the media to demonstrate that HIV can happen to anyone, even 'good' women. In 1987, the television documentary 'Suzi's Story' aired on Australian television to an immensely positive public reaction. The award-winning program, which chronicled the last months of Australian woman Suzi Lovegrove's life and death from AIDS, went a long way toward dispelling the myth that HIV/AIDS only affected gay men.

The political power of positive women also comes from the capacity to speak from experience. For example, the Women's network of the National Association of People with Living with HIV/AIDS (NAPWA) have been strong campaigners for appropriate policies regarding routine HIV testing in pregnancy. This issue again reared its head publically in Australia in 2005. Canvassing the opinion of women who have been in the situation of being diagnosed with HIV through antenatal screening, NAPWA women's network is in a strong position to present a powerful argument on the issues.

For better or worse, the need for organisations like Positive Women Victoria is not going away. In Victoria, the annual number of HIV diagnoses among women is increasing and the organisation has experienced an escalation in the number of women seeking support over the past few years. The needs of positive women

have changed over the years, however. With new treatments available and life expectancy increasing, women are now seeking support around issues such as pregnancy and ageing.

"It used to be more that women would call us in crisis, soon after being diagnosed. They thought they were going to die," says Greet. "But now it's no so immanent. People take three months or so to digest things, then they may decide they want some support or information, or to meet other women. Then they call us. We also have a bit of a baby boom going on now."

Positive Women Victoria reached its 20 year anniversary this year. Despite much activity among various organisations and positive women across the country, Positive Women Victoria continues to be the only independent group for women living with HIV/AIDS in Australia.

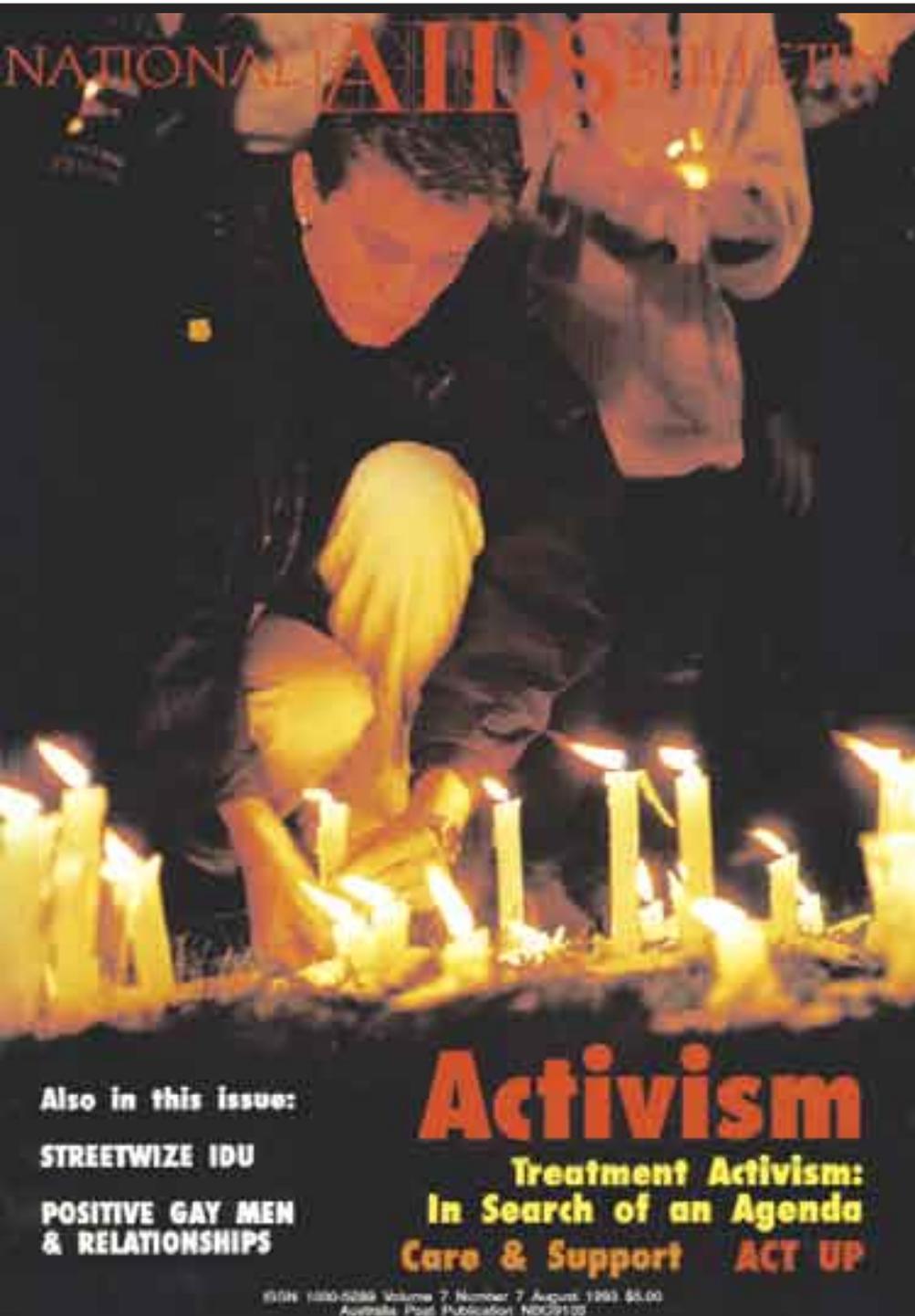
"We were quite determined to achieve that," says Greet. "We saw what the gay men had done; they had so much knowledge and so many skills and it was great. But we needed to do it for ourselves. It was part of our healing process to do it for ourselves. We have now passed our 20 year anniversary. That is a big achievement ... we are also a model for the rest of Australia. I'm so glad in those early days that we persevered."

**More information about Positive Women Victoria can be found on their website [www.positivewomen.org.au](http://www.positivewomen.org.au)**

**Jennifer Power is a Research Officer at the Australian Centre for Sex, Health and Society**

# Reflections: 25 years of HIV

The cover of the *National AIDS Bulletin*,  
August 1993



## World AIDS Day 20th Anniversary

A personal reflection by **Dr Garrett Prestage**

2008 marked the twentieth anniversary of World AIDS Day, though AIDS has been with us in Australia since the early 1980s. We've been living with this virus in our midst for so long that we've started to take it for granted. Even those of us who are old enough to remember a time when there was no AIDS, find it hard to imagine living and loving without taking this virus into consideration.

In the early 1980s our community was celebrating itself. Sex between men was still illegal, but we were clearly winning the battle. Gay men and lesbians were taking a stand and our community was becoming more and more visible; Mardi Gras was a bigger and bigger spectacle each year, and there seemed to be more and more hot gay men in Sydney every week. My friends and I were having a great time.

In 1981 to 1982 we first heard reports of AIDS cases in the US – mostly it was just a curiosity at first. Michael Glynn, the editor and owner of *The Star* wasn't sure how to report it, but he provided consistent coverage so people had good access to information. By 1983, panic really set in, because no-one understood how the virus was transmitted and we didn't know how to respond.

Gay social groups and networks of friends became concerned about who would care for the men that were getting sick. Leathermen were largely responsible for setting up groups like the Bobby Goldsmith Foundation, while social groups, mainly led by drag queens, started leading the charge to raise funds for these services.

The mood in Australia changed as the situation worsened in the US.

Everywhere we looked, the beautiful men we admired, we danced with, we fucked with, were disappearing.

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At that point we still had no test, so the only way to diagnose AIDS was when someone got sick.

People were getting strange cancers or pneumonias, wasting away to skeletons and, far too often, dying no more than a few months later. It seemed like we were all facing a potential and very imminent death sentence. It really was frightening because it was impossible to know if you, or someone you loved, would be next – until they were sick. After that, all you could do was comfort them and prepare your goodbyes.

In a crisis situation you can either panic, run away and hide and just give up; or you can make yourself busy with practical things that you know you can do. Gay activists, people like me who had been involved in the gay rights and gay liberation movements, had skills in organising and mobilising people to take action. ACON, Positive Life and safe sex education each had their origins in the actions of those gay movement activists.

The support provided by lesbians at this time was incredible. Gay men didn't have a lot of allies at that time, everywhere we turned we were being portrayed as disease-ridden, infectious, and immorally promiscuous drug-users. But dykes stuck by us in ways we really had never stuck by them. Lesbians cared for their gay friends when no-one else would. They could easily have distanced themselves from us, and said, "it's a gay men's issue". But instead they stood beside us all the way. I don't remember a single lesbian voice raised publicly against us, although there were a few crazy gay men that tried to condemn our community.

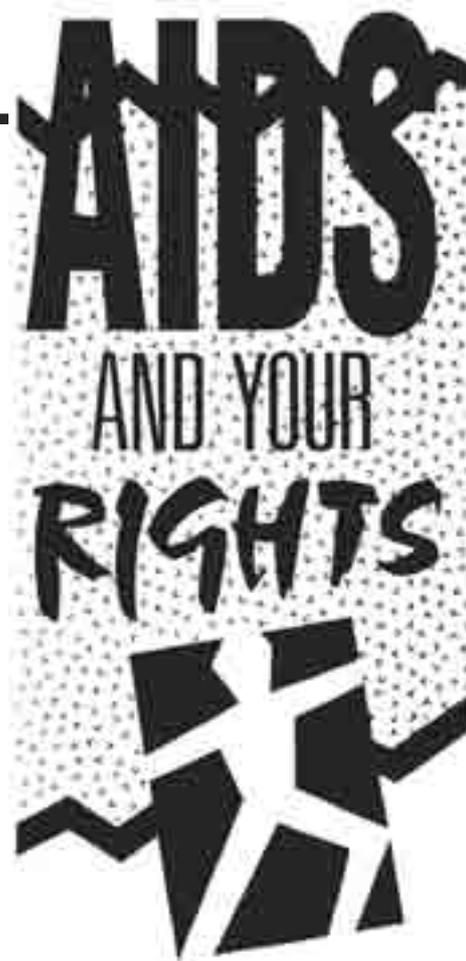
Personally, like most gay men, I was very scared. Some of my friends began to get sick and die. We all felt the same: if we didn't already have it ourselves, it was hovering over us so heavily that

we felt doomed. Everything that had brought us together – our very sexuality and the partying we'd done together – now seemed tainted. We couldn't even celebrate our achievements.

The mainstream media and conservative politicians were taking their leads from the US, with closure of the sex venues being a real possibility. Somehow, us old-time gay liberationists seemed to reach the same conclusion: we as a community needed to mobilise around AIDS, instead of being carried along by it. We needed to use gay liberation politics as our foundation and to be sex-positive, even in the face of the most profoundly moralistic hatred. We needed to celebrate sexuality in all its aspects and, above all, to not become victims. There was a real sense of urgency that we needed to do something immediately to tell gay men that it was still OK to be gay, that they could still have sex, without risking getting sick. This was a bit tricky because we still didn't really know how the virus was transmitted.

At the beginning of the 1985 Mardi Gras season, we launched the very first Safe Sex campaign in Sydney. We very consciously chose a sauna – the Roman Bath – as the venue to counter the campaign against the sex venues. Nick Lorschei was the owner of the Roman Bath and KKK. There were times when Nick's motives were questioned, but I think he was one of the real heroes of our community. He could easily have just sold off his properties and abandoned the whole thing as too hard. Instead he joined us in the hard work and took some real risks with his business, as well as his reputation.

From all of this, in New South Wales, ACON emerged as the voice of our community's response to AIDS. Its earliest activities included the defence of gay men's capacity to continue to live freely in the face of overwhelming opposition. This all happened before Governments began funding AIDS



Councils and before the Grim Reaper ad campaign in 1987. We're often told the epidemic was turned around through a partnership between the community, government and research, but this partnership really just consolidated and protected what gay communities, injecting drug users and sex workers had already done

There has been a lot of talk about how effective the government funded Grim Reaper campaign was, because it scared people into action. It certainly scared a lot of straight people into avoiding anything to do with gay people, sex workers or drug users, and it scared many gay men into thinking sex could kill them. The truth is, the epidemic was turned around under the leadership of sensible and committed gay men and lesbians, sex workers and drug users, well before governments had acted. To their credit, some of those in government at the time recognised

Clockwise from opposite 'AIDS and your rights', reproduced from the *National AIDS Bulletin*, September 1989; 'CounterAID' – Kate Cebrano and volunteers at Grace Bros, reproduced from the *National AIDS Bulletin*, November 1990; ACON's 'Let's face it together' campaign, reproduced from the *National AIDS Bulletin*, August 1993.

# Reflections: 25 years of HIV



this. Some of those who were the community heroes back then are still with us, but many of them died over the next few years. However, they did not die as victims, but with dignity – the community is a better and safer place because of their actions.

Our funerals were rarely sombre, maudlin affairs; the men who were dying demanded that we celebrate their lives and remember them as joyful beings – gay men who loved their friends, and families. Some of my dearest friends died: men I'd fought with and men I'd fucked with; men I loved and men I respected. But also, men I knew only as faces on the dance floor, or people that I'd admire on the streets or at the gym. All of their passing was a loss and it made our lives change. We owed it to those who died to protect our community, our friends, and our rights – and we still do.

In some ways the coming of treatments has changed AIDS so fundamentally

that we run the risk of forgetting both our past and the real challenge our community still faces. Internationally AIDS is a huge burden, but we should never forget what it means here at home as well. Like everyone of my age, I've experienced the miracle of men I'd loved seeming so close to death being brought back to health within a few months, and mostly staying healthy (despite side-effects). While that is wonderful, we still have good reason to protect our friends and our communities from HIV. We still lose people to AIDS. Maybe not so often now, but every life lost to this virus is one too many.

Just a few short years ago I lost a very dear friend. He refused to go on treatments because he'd had such bad experiences with the health system over the years, and had grown so distrustful of medicine that he couldn't bring himself to do it. I joked that he was a stubborn old man, but he was really just

living his life on his terms. I miss him enormously, but admire and respect that he had the dignity to decide how he wanted to live and die.

There isn't a day goes by I don't think about Michael Adams – but I'm a much better person for having been his friend. We all have our 'Michaels'; World AIDS Day gives us the chance to commemorate their lives and to re-commit ourselves to ensuring that their legacy lives on through the way we live our own lives; how we work and fight, together as a community.

**Dr Garrett Prestage now works at the National Centre in HIV Epidemiology and Clinical Research and the Australian Research Centre in Sex Health and Society. In 1985 he inspired 'Rubba Me', the first condom promotion education resource produced in Australia.**



## Think again

By Dean Murphy and Jeanne Ellard

We identified a shift in the focus of these HIV educational materials over time, from notions of collective responsibility towards one of individual accountability.

In 2006 we undertook a project examining the issue of responsibility and agency (or the power to act), as articulated in HIV education materials targeting gay men. We wanted to see if the way responsibility is constructed, and where it is located, has changed over time. We also looked for any correlation between the language used in the education materials and the way gay men talk about responsibility.

Our aim was to examine the language used, according to *who* was being spoken to and *what* they were being asked to do. We were interested in the *explicitness* and *visibility* of the education, the *relationship* between the

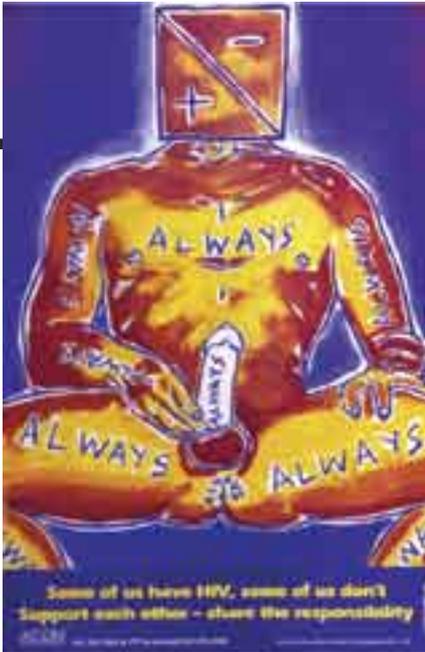
author and the reader, and assumptions about the readers' disposition.

We analysed the language used in over a hundred HIV education posters and advertisements targeting gay men, produced by the Australian Federation of AIDS Organisations (AFAO) and the AIDS Council of New South Wales (ACON) between 1988 and 2006. We coded the language used, with particular focus on the issue of 'responsibility' and HIV transmission, use of pronouns, the term 'safe sex', language style, whether or not the language was directive and explicit about actions the reader should take, as well as what kind of authority was being drawn on in the text.

We identified a shift in the focus of these HIV educational materials over time, from notions of collective responsibility towards one of individual accountability. We identified three relatively distinct phases within the materials, marked by two decisive events: the arrival of new HIV treatments around 1996, and then the increase in HIV infections in NSW around 2003. We believe these events had a major impact on the way HIV education was conceptualised and delivered.

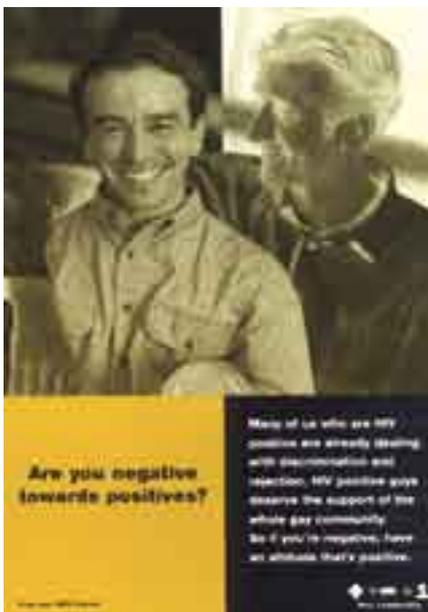
### First period

The first period we identified preceded the introduction of antiretroviral therapy and viral load testing technologies in 1996. During this time, HIV transmission was conceptualised as a shared, community responsibility. Materials developed during this period reflected a sense of joint responsibility, irrespective of a person's HIV status.



This poster, produced in the early 1990s, communicates the notion of shared responsibility through the use of the pronoun 'us'. There is also a reference to 'each other', which assumes a sense of community. This choice of words is important because it positions the producers of the campaign as 'insiders', speaking from within the community they are addressing.

During this period there were efforts to prevent discrimination based on HIV status. This was not just related to the selection of sex partners, but also extended to addressing wider issues and the effects of an HIV-positive diagnosis. There was an emphasis on caring for lovers and members of the community.



This emphasis can be seen in this advertisement from 1995, entitled *One Community*. It refers specifically to discrimination and rejection, again referring to 'us' (the whole gay community). This campaign actually had a complementary message for HIV-positive gay men, namely that HIV-negative men struggle with HIV in a different way – for example the struggle to always have safe sex.

The term 'safe sex', as used in this poster, is significant because this was the last time it was used in a public health campaign in Australia. After 1996, it virtually disappeared from use and has only rarely been seen since.

During this period there was also an effort to reduce division along serostatus lines by adopting a 'don't ask; don't tell' policy in relation to disclosure of HIV status. This was made possible by having a universal message and a universal solution: use a condom every time.

## Second period

After 1996, there was a clear shift in the language and framing of the educational messages, compared to earlier examples.

Materials from this second period addressed individuals, rather than a collective 'us'. The take-home message had changed from 'look after each other' to 'look after yourself'. With all the hopes, uncertainties and possibilities brought about by the new treatments and the potential for undetectable viral load, what it meant to look after yourself was a highly individualised project.

During this time there was also an acknowledgement that some gay men did not always use condoms with casual partners, so there was an emphasis on risk-reduction strategies. These strategies included the use of partner selection, and the adoption of the insertive or receptive roles based on HIV status (or 'strategic positioning'), as seen in the following example:



In general, these campaigns were more narrowly focused on anal sex and HIV risk, rather than the multiple effects of HIV that were covered in the first period. In previous campaigns, anal sex had been covered simply by references to condoms.

Another interesting shift in the educational messages was the assumption of a more authoritative voice in the materials, which drew on published research – from virology and epidemiology, to social and behavioural research. The above poster is an example of this, referring to HIV risk

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# Reflections: 25 years of HIV

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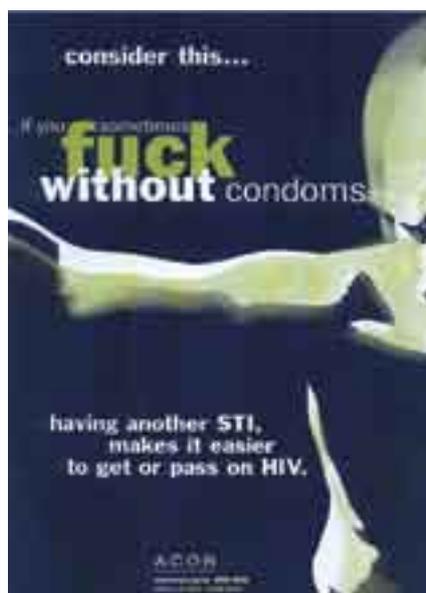
being greater for a negative man if he is the receptive partner, as well as the fact that many gay men get infected with HIV despite taking the insertive position.



This poster from the same campaign addressed the use of viral load test results as an HIV risk reduction strategy, arguably the most individualised strategy of all. These materials assumed the reader to be a rational risk taker who had the capacity to process complex, often new information and then act accordingly.

There was also a kind of tension in the materials from this period. On the one hand there was an acknowledgement that some gay men were choosing not to use condoms, and on the other hand a concern that perhaps men were doing this based on misinformation. The above example illustrates this, through its emphasis on dispelling the belief that being the insertive partner poses no risk if a person is HIV-negative.

This next example from the same period covers the impact of sexually transmitted infections on the risk of HIV transmission and acquisition.

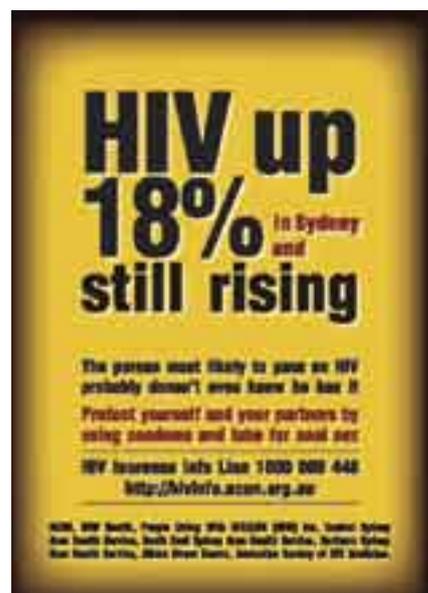


Language used during this period often positions the reader as somewhat distant from the author, through the use of pronouns such as 'you' and 'he'. It could be argued that this absence of community within the text is a reflection of a real gap that was emerging between community organisations and their increasingly professionalised workforce on the one hand, and the community of gay men they were speaking to, on the other.

Campaign materials from this time also tended to address HIV-positive and negative men individually – sometimes within the same ad and sometimes in separate ads. As already noted, the term 'safe sex' had completely disappeared, possibly because in this highly-individualised era there was no longer any shared understanding of what it meant.

### Third period

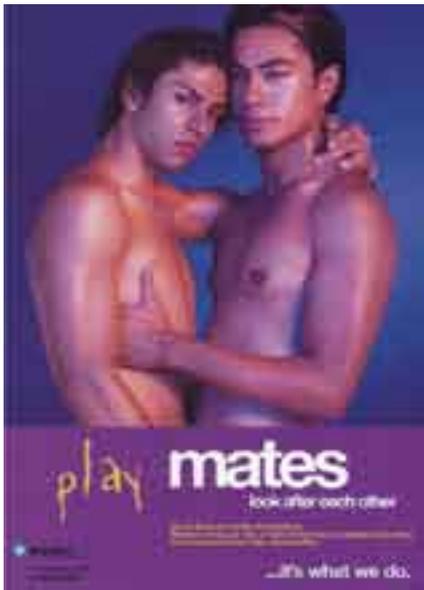
We identified a third, more recent period in HIV education which began around 2002/2003, when HIV infections in Australia started increasing after having been stable for some time. These newer campaigns aimed to alert the community to this change, as seen in the following example:



People were being told that HIV infections were increasing and a community response was being invited. After providing a rather alarming statistic at the top, the language that follows is very neutral and urges a non-panic response. Importantly, it is careful not to blame HIV-positive men, rather it focuses on the potential role of men who are seroconverting, or have recently seroconverted and don't know it.

Responsibility once again took on a collective flavour, although this was somewhat different to the way it had been in the past. Some campaigns returned to using collective pronouns 'we' and 'us' when referring to the gay community, urging people to look after or care for each other – in relationships, as sex partners and as fellow party-goers and community members.

Responsibility once  
again took on  
a collective flavour ...



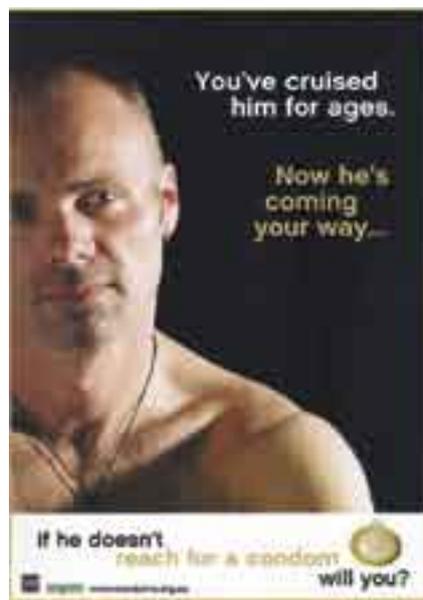
This period also saw an emphasis on disclosure of HIV status, although not necessarily the promotion of this as a strategy. Certainly the emphasis on not disclosing had long disappeared, but campaigns such as this one asked HIV-negative men to consider the difficulties of disclosing HIV status, especially to new or casual sex partners, as shown in this next example.



Typically, the approach in this period invites the reader imagine what it might be like to be the other person

in a hypothetical casual sex scenario, in order to move towards a shared understanding of the rights and responsibilities of sexual citizens.

This is evident again in this next poster, where the reader is asked to re-examine his assumptions and expectations in relation to introducing condoms.



In some ways these materials are an attempt to open up a discussion about sexual ethics – what can and cannot be assumed in a sexual situation – and to instill cultural norms, i.e. to care for each other and not allow HIV-positive men to bear the full responsibility for preventing HIV transmission. The fact that disclosure is risky and difficult for positive men, is also explored.

In a sense, these recent education materials are more focused on speaking to HIV-negative men, and this is obvious in the *Think Again* poster (left).

The materials from this period tended to focus less on specific sexual practices and more on context, marking a shift from the previous period. Campaigns tend to be less explicit than the first period and maybe also the second period, both in terms of what is being asked of the reader, as well as the types of images used.

## Conclusion

So, early education campaigns targeting gay men took for granted a shared and community responsibility. Although this sense of community can no longer be assumed, these recent examples from the third and current period of HIV education show that it is still possible to think about HIV, responsibility, risk and agency in public and collective ways through appeals to citizenship. We think that there has been a shift towards individualism and individual risk management over time, occurring alongside the development of new technologies (HIV antibody testing, viral load testing, and antiretroviral therapy). However, recent examples of HIV education materials show that this individualism is not the same as the immediate post-HAART free agent or 'strategist'. Individual agency and decision-making does not mean responsibility just for the self, or self-interest. Rather, recent HIV education messages address a reader who makes choices, while also taking account of the 'other'.

**Dean Murphy and Jeanne Ellard are Research Associates at the National Centre in HIV Social Research.**

... recent HIV education messages address a reader who makes choices, while also taking account of the 'other'.



## Unfinished business: reflections on Australia's efforts to embed human rights in our HIV responses

By John Godwin

Australia has prided itself in being a global leader on HIV and human rights, with a history of over 20 years of law reform and community mobilisation to support a rights-based approach. Recent developments indicate that gains made in these areas are fragile.

In the 1980s and 1990s, Australia's partnership approach to HIV resulted in law reform across a broad range of areas. Laws to support the operation of needle and syringe programs were introduced as early as 1987, before evidence of the effectiveness of harm reduction as an HIV prevention measure existed. By the mid 1990s, the States and Territories had moved to develop new regulatory frameworks that enabled decriminalisation of much of the sex industry. Gay sex was decriminalised for adults. Most jurisdictions had introduced protections from HIV related discrimination in the early 1990s, and some extended this to protection from vilification.<sup>1</sup>

The push for HIV law reform came from several directions. Lawyers, academics, clinicians, activists and politicians all played a role. As most Australians living with HIV are gay men, the gay law reform movement and HIV law reform were, to some extent, entwined. Homosexuality was not decriminalised in Western Australia, Queensland and Tasmania until the 1990s, and in these states the importance of decriminalisation to an enabling environment for HIV prevention formed a significant part of the argument for law reform. The Tasmanian Gay and Lesbian Rights Group ran a high profile campaign to overturn that state's sodomy laws and included public health considerations in the rationale for reform. The Group gained international attention with its successful case to the UN Human Rights Committee, leading to a High

Court challenge that paved the way for decriminalisation in 1997.<sup>2</sup>

Bureaucrats and parliamentarians were, of course, essential to the law reform process, and many were passionately committed to human rights. Significant Commonwealth resources were applied to an exhaustive mapping of a law reform agenda to inform the National HIV/AIDS Strategies. The 1992 Report of the Inter-Governmental Committee on AIDS (IGCA) Legal Working Party was a milestone, setting a rights-based law reform agenda for the following decade. The Legal Working Party urged the introduction in each state and territory of a range of far-reaching measures, including anti-discrimination laws, decriminalisation of sex work and homosexuality, and legal recognition of same-sex relationships.

In implementing the Legal Working Party's recommendations, state and federal politicians delivered in a number of important areas. Australia gained a global reputation for rights-based approaches to HIV and our law reform models influenced international thinking. Australian lawyers played a key role in drafting the International Guidelines on HIV and Human Rights. Justice Michael Kirby played a leadership role, chairing the UNAIDS Reference Group on HIV/AIDS and Human Rights and the UNAIDS Expert Reference Group that developed the *International Guidelines on HIV/AIDS and Human Rights*.<sup>3</sup>

Since the late 1990s, the consensus of progressive forces that built the rights-based approach appears to have weakened. As the sense of HIV as a crisis has declined, it seems that there is reduced engagement from the constituencies that fought for a rights-based approach in the 1980s and 1990s. With HIV redefined as a chronic

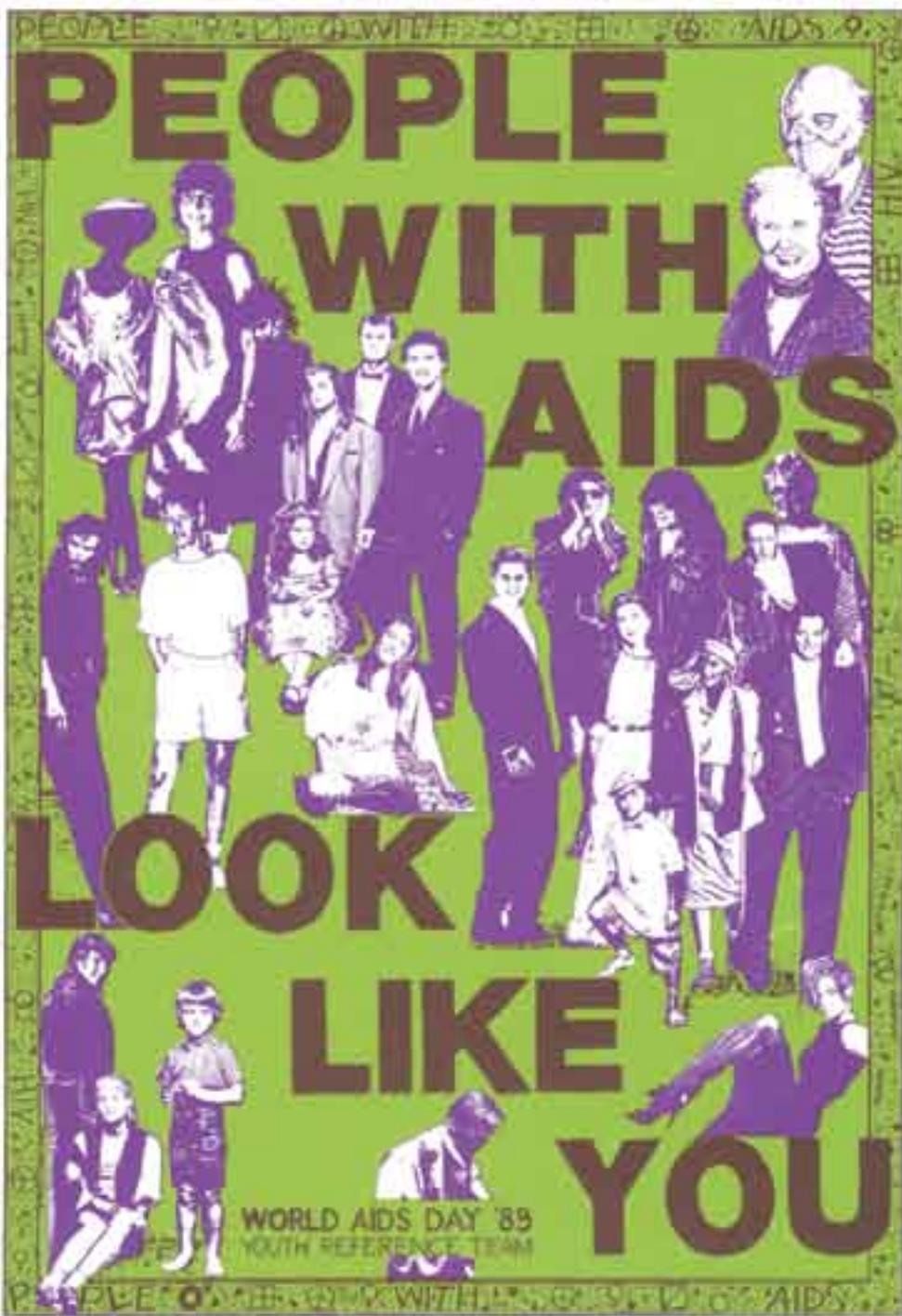
manageable condition, the focus is increasingly on medical management rather than on policies and laws.

Yet many issues are yet to be addressed. There is still no national comprehensive sexuality anti-discrimination legislation, and existing anti-discrimination laws have many loop holes and offer little, if any, protection to sex workers. Drug use remains primarily defined as an issue of criminality rather than health. Needle and syringe programs are not available to prisoners, despite international evidence that prison-based programs are effective.<sup>4</sup> Sex work regulation is in place, but is patchwork and inconsistent. Over-regulation results in many sex workers having little choice but to work in brothels to avoid sanctions, which can be to the detriment of the most marginalised workers. Street based workers suffer police harassment and are criminalised.

Events over the last two years should be sounding a wake-up call to Australians who value the public health benefits of an HIV response built on a foundation of respect for human rights.

Since 2006, the criminal law has been invoked as never before to prosecute Australians living with HIV, to punish non-disclosure of HIV status to sexual partners and transmission of HIV through sex. In some jurisdictions, police action suggests that authorities may be moving towards more punitive approaches to HIV management. Indeed, there is mounting evidence that Australian criminal laws are being applied in circumstances that are likely to deter people from testing and treatment. In September 2008, an HIV positive sex worker was imprisoned in the ACT for working while knowing his HIV status, a move condemned by Scarlet Alliance.<sup>5</sup> There

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The emergence of HIV has generated unprecedented scrutiny of the sexual practices of those sectors of the community considered to be 'at risk'. Over the years, hundreds of thousands of dollars have been made available for research, public dialogue and, thankfully, funding for services. Paradoxically, the tragedy of HIV/AIDS has helped facilitate, for the first time in Australia's history, public money to support groups previously lacking visibility in mainstream society.

Arguably, the HIV/AIDS epidemic was one of the major drivers for the development of the many gay and lesbian youth support services and groups that exist today. While community-based youth services, such as 2010, were set up independently of the HIV sector, the virus brought with it an imperative to pay attention to young gay men and lesbians. Youth sex education began to include discussion of homosexuality, and community-based AIDS organisations developed youth-oriented information and support campaigns. This did not occur without controversy.

According to classic developmental psychology and the 'commonsense' versions of this that float around in the public consciousness, adolescence is a time when people are developing their identities. Young people are seen to be in flux, moving toward their fully formed adult self. It is a common view that sexuality develops over the teenage years, and that young people are yet to reach full sexual understanding or maturity. As such, homosexuality is often not acknowledged among young people. It is frequently assumed that no one can be capable of defining themselves as gay or lesbian when they are still young, and if they do it must be a 'phase'. Moreover, social norms often maintain that young people need to be safeguarded from sex, or any sense of their sexuality. Assertion of their homosexuality by a young person

## The controversy of youth

By Jennifer Power

is associated with a loss of innocence. Unfortunately, HIV/AIDS threatens more than innocence. It poses a real risk to the health and lives of sexually active young people. In the early 1990s, community AIDS organisations responded to this by initiating campaigns and projects directly targeting young gay men.

When such programs first began they triggered widespread backlash. A major public eruption occurred in 1990, when the Victorian Government banned a poster and print campaign that had been produced by the Victorian AIDS Council's (VAC) Youth Project Team. The poster targeted young men who were considering having sex with another man. The poster's slogan, written prominently across the bottom of an image of two young men kissing, was 'When you Say Yes, Say Yes to Safe Sex'. The poster also stated that homosexuality was natural and it encouraged young men to seek out support groups and people to talk to.

Initially, *TV Week* refused to publish a print-media version of the poster on the basis that it would offend their readership (despite allegedly having the highest gay readership of any magazine in Australia at the time). The then Victorian Shadow Health Minister, Marie Tehan, followed suit, calling for a ban on the ad and demanding the withdrawal of funding to the VAC. In a media statement, Tehan stated that, "It is scandalous that state or commonwealth money should be spent on advertisements encouraging young people to engage in homosexual activity, with statements such as: 'it's natural and if you're safe you'll have a great time.'" The Advertising Standards Council went on to recommend that no media outlets allow publication of the poster.

In protest, a 'Kiss-in' was staged in Melbourne's Bourke Street Mall on World AIDS Day, 1 December 1990. Organised and advertised by several AIDS Groups, including the VAC



Front and back of a peer education publicity card aimed at gay youth, funded by the National AIDS Program, reproduced from the *National AIDS Bulletin*, June 1989.

and the AIDS Coalition to Unleash Power (ACT UP), the campaign message was 'Kissing Doesn't Kill: Greed and Indifference Do.' The VAC adopted the stance that social support and self esteem were key factors in ensuring young people make informed choices about their sexual activities and sexual health and successfully pressed ahead with the campaign, despite public criticism.

In 1997, AIDS councils again found themselves embroiled in public controversy around two programs

launched by the Western Australian AIDS Council (WAAC). The first was an anti-homophobia education package for high schools. The second was a public campaign titled, 'Trust Your Feelings'. Targeting young gay men and lesbians, the aim of the 'Trust Your Feelings' campaign was to prevent suicide. The campaign's marketing materials included a poster that had images of young lesbian and gay

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# Reflections: 25 years of HIV

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couples kissing on the cheek. Following media controversy, the *'Trust Your Feelings'* campaign was refused funding by the then Commonwealth Family Services Minister, Judi Moylan. The basis for Moylan's argument was that it was "more of a recruitment campaign for lifestyle preferences" than a message for suicide prevention.

Letters to editors and general media commentary revealed that underlying the public concern about the campaign was a belief that adult homosexuals were deliberately seeking to influence the sexuality of young people and 'recruit' them to a gay lifestyle. A letter published in *The West Australian* on 6 August, 1997, read: "It is of great concern to our community when these types of organisations actively promote their homosexual behaviour as an acceptable or alternative lifestyle to all impressionable teenagers in our schools."

Another letter in the same publication read, "I am concerned because [this campaign] is a joint project for the WA AIDS Council and the Gay and Lesbian Counselling Service. They are not in a position to give a balanced view of behaviour toward homosexuality, because both organisations endorse homosexual behaviour as an acceptable lifestyle for teenagers. They could make young, impressionable students quite vulnerable".

It is not uncommon to hear debates such as this. Even today, the view that homosexuals actively 'recruit' young people sneaks its way into public dialogue more than occasionally. However, despite the negative publicity cloaking a number of the youth campaigns run by AIDS organisations in the 1990s, the media attention on these issues opened important space for publically debating ideas about the nature of both adult homosexuality and youth sexuality. By insisting on the

need for programs to protect young people from HIV, the AIDS movement introduced a perception of gay and lesbian youth as mature, capable and, above all, likely to be sexually active.

Moreover, AIDS activists had an opportunity to openly discuss and publicly refute the notion that gay mens' concern for young people had sinister motives. For instance, WAAC issued open statements arguing that it is not possible to 'turn' heterosexuals into homosexuals. One of these statements, which was published *The West Australian* on 7 August 1997, read, "No parent or teacher should ever assume their child or student is heterosexual. Statistics show that at least five per cent of the population will develop a gay or lesbian identity. No amount of 'promoting, encouraging or teaching' can influence sexual orientation. There is, however, a separate need for responsible education, support and counselling for young homosexuals."

The extent to which such debate has prompted change is hard to judge. However, in 1998, just over a year after the WAAC controversy, the Western Australian Health Department released a report which aimed to reduce the suicide rate in gay and lesbian youth. The report stated that, "The existence of gay, lesbian and bisexual young people is often denied, ignored or treated with contempt by society, especially the media and the education system, so that there is little opportunity for them to recognise, take pride and act on their sexual identity."

While the timing of this report could be read as an attempt by the WA government to undermine WAAC or reclaim control over youth services, it is also testament to the influence of AIDS organisations. The government was forced to respond to the youth issues raised by WAAC. Without doubt, the path by which such a statement could be released by a government department without controversy was

laid by those early years of community-run AIDS campaigning.

In many ways, rising HIV rates muted much of the public criticism directed at youth-oriented HIV prevention campaigns. The need was obvious and community services and schools increasingly came to recognise and provide supports for gay youth.

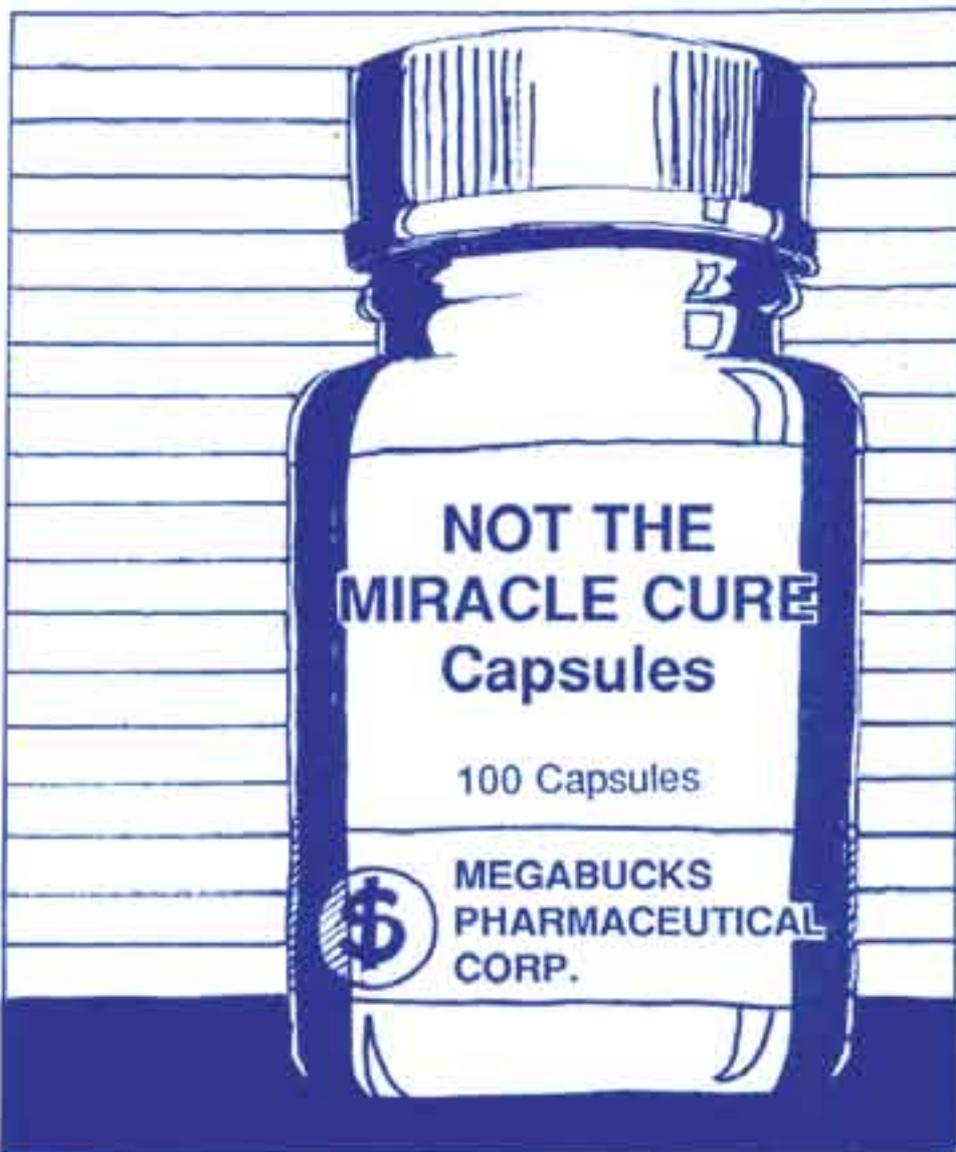
In WA, heated media debates around gay youth emerged again in the lead up to the 2001 passing of a gay law reform bill, which brought the age of consent for young gay men down to 16, in line with heterosexuals. The current Executive Director of WAAC, Trish Langdon, says, "Interestingly since the law reform was passed, there has been little fuss in the media and the Health Department continues to fund the Freedom Centre, an early intervention program for same sex attracted young people."

WAAC still encounters some resistance from schools, and the occasional right-wing politician, seeking to score conservative brownie points. This doesn't relate so much to gay youth, but more to attitudes surrounding youth and sex in general. As Langdon explains, "In 2005, Matt Birney, the then leader of the State opposition Liberal Party, was concerned that WAAC was handing out condoms to young people during the School Leavers Campaigns, which apparently encouraged rampant sex – so it doesn't always relate to *gay* young people."

**Jennifer Power is a Research Officer at the Australian Centre for Sex, Health and Society**

# Bringing Australia's drug approval and clinical trials systems into the 21st century

By Bill Whittaker



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

Of course, such unawareness is hardly the fault of that audience, or the wider community, for that matter. HIV community groups sometimes 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

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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 with HIV/AIDS (NAPWA) is about ensuring that 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 (PBS). If there are bottlenecks or problems, NAPWA tries 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, achieving substantial

reforms which continue to benefit all Australians to this day.

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 and inquiries had been set up over the years, but none succeeded in effecting real change. A small group of long-ensconced bureaucrats and others, preoccupied with never having another Thalidomide, played on public fears about drug safety and suspicion of pharmaceutical companies, successfully resisting all attempts at reform.

However, in the early 1990s, the HIV epidemic brought matters to a head. It became 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 of the system.

Weeks 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 groups supported the call for change.

At the end of the day, change is unlikely to come unless there is

political will to achieve 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 some quarters – 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 that so many Australians accepted. As a result of the review, the first national HIV treatment information project was set up at ACON, 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

ACT UP's 'Die-in' outside the Benetton store in central Brisbane, reproduced from the *National AIDS Bulletin*, June 1992.



review for two reasons: firstly, because we were re-assured by Brian Howe that it was a genuine process, and secondly because he was appointing former Liberal Senator and Health Minister Peter Baume to conduct the review. Peter Baume 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. This is not only because of our outstanding doctors and scientists, but also because our clinical trials system is now viewed as efficient and effective. We have achieved a good balance between safety, ethics and accountability issues, with rapid enrolment as our HIV community has a more sophisticated understanding of clinical trials processes and confidence in their conduct here. The contribution

of the HIV community sector in helping to build this world's best practice 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 responses to other diseases. However, the work is never finished. Difficulties will continue to emerge and glitches happen. It is 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 like HIV and of keeping ourselves and our communities healthy and dynamic. It is a good reason to remain involved in activism and to encourage others to join in.

*This article is dedicated to HIV activists past and present, to former Deputy Prime Minister and Health Minister Brian Howe, and to John McEwan and Des Threlfall, who served in the Commonwealth Health Department and who exemplify the best traditions of the public service.*

**Bill Whittaker is treatments spokesperson for NAPWA, a former CEO of ACON and a former President of AFAO.**



## Regional postcard: A snapshot of Indonesia's epidemic and Australia's assistance to the response

By John Godwin

### An escalating epidemic

Indonesia is experiencing one of the fastest growing HIV epidemics in Asia. Most of this growth has occurred over the last decade. There are now over 270,000 people living with HIV in Indonesia, and it is expected that<sup>1</sup> this will rise to one million by 2015<sup>2</sup>.

There is a serious epidemic unfolding in Papua and West Papua. These provinces have sexually driven epidemics affecting 2.4 percent of the adult population<sup>3</sup> and over 20 percent of sex workers at some sites<sup>4</sup>. To give some indication of the prevention challenge, in 2006, 48 percent of people surveyed in

these provinces had not heard of HIV or AIDS<sup>5</sup>.

Outside of Papua, Indonesia is experiencing concentrated epidemics among injecting drug users, sex workers, men who have sex with men, *waria*<sup>6</sup> and prisoners. Prevalence among injecting drug users is particularly high,

(52 percent in 2007), and the growth of the HIV epidemic has closely followed Indonesia's epidemic of drug use that has escalated since the social dislocation associated with the financial crisis of the late 1990s.

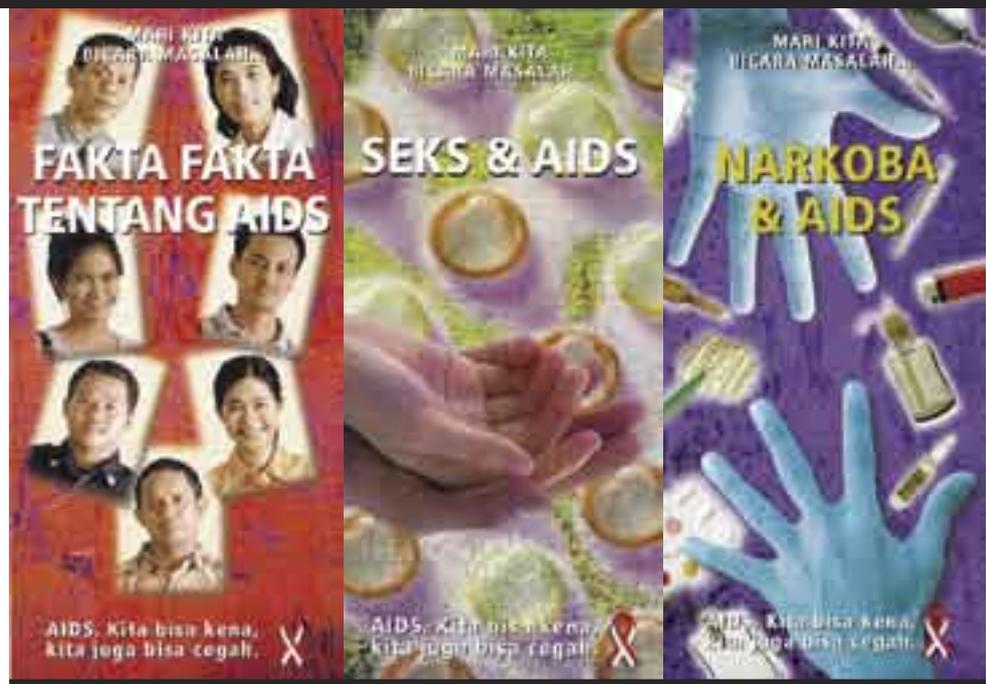
Prevalence is also high among male sex workers (20 percent), and is 7 percent among female sex workers, 5 percent among men who have sex with men, and up to 17 percent among *waria*. These epidemics are interrelated. Many injecting drug users also buy or sell sex. Some men who have sex with men and *waria* also inject, or sell sex. The densely populated province of West Java and the mega-city of Jakarta have the highest absolute numbers of people living with HIV in the country, most of whom are injecting drug users or their sexual partners.

## Community organisations and the national response

Indonesia's response is coordinated by the National AIDS Commission within the framework of the *National HIV and AIDS Strategy 2007–2010*. There is not a strong tradition of community-based organisations in Indonesia, particularly at a national level. The HIV groups that have emerged are pioneering new ways of organising and networking. Although there are over 100 local HIV support groups, most rely on volunteers and have little financial security. Spiritia was established in 1995 and has been a key NGO at national level, supporting local groups and working on a range of care, support and human rights issues. Some of the other key civil society groups are the Positive After-Care Foundation, Indonesian National Network of People Living with HIV/AIDS, National Network of Positive Women, Men's Sexual Health Network, National Drug User Network and Pelita Ilmu Foundation.

## Donor programs

The national HIV response relies heavily on international support. The



One of the Indonesian publications which is part of the HIV/AIDS prevention campaign. Image courtesy of AusAID.

main donors are the Global Fund, USAID and AusAID. Most HIV activities are delivered through Global Fund projects, the AKSI Stop AIDS project and the Australia Indonesia Partnership for HIV.

The UK Department for International Development (DFID) has also been a significant donor but is now reducing its assistance. DFID established the Indonesia Partnership Fund for HIV/AIDS, which funds activities of the National AIDS Commission. The Australian Government also contributes to the Indonesia Partnership Fund.

The Global Fund has helped cover treatment costs and provides prevention, care and support in the hardest hit provinces. A new five year project funded by Round Eight of the Global Fund is to commence in 2009. The Indonesia Planned Parenthood Association has been proposed as Principal Recipient of this grant in respect of civil society activities.

Aksi Stop AIDS is a project funded by USAID and the Indonesia Partnership

Fund for HIV/AIDS, and is managed by Family Health International. Aksi Stop AIDS works with local NGO partners to provide prevention, treatment and care services to injecting drug users, sex workers, men who have sex with men and prisoners.

UN agencies also implement a range of projects and provide technical assistance, particularly UNAIDS, UNDP, WHO, UNODC and UNICEF.

## AusAID support to Indonesia's HIV response

The AusAID-funded Australia Indonesia Partnership for HIV/AIDS commenced in 2008 and is to receive up to \$100 million over an eight year period, ending in 2015. The program is a partnership between Indonesian authorities and the Australian Government. Local partners include the National AIDS Commission, Ministry of Health, and the Ministry of Justice and Human Rights.

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The program operates in Java, Bali, Papua and West Papua Provinces, and the national prison system. Priorities include strengthening the Indonesian Government's response at national and provincial levels, harm reduction with injecting drug users, prevention in Papua and providing support to the Clinton Foundation in scaling up access to anti-retroviral therapy.

## **Australia-Indonesia NGO and research partnerships**

AusAID funds the HIV Capacity Building Program to link Australian organisations to Indonesian partners. This program funds a consortium of Australian organisations to implement the following activities:

- AFAO is working with the Indonesian Men's Sexual Health Network to address the needs of men who have sex with men. Activities include supporting the Network's strategic planning, linking the Network with Australian AIDS Councils and supporting representatives to attend ASHM conferences.
- The National Centre for HIV Social Research at UNSW and the Australian Research Centre in Sex, Health and Society at La Trobe University are partnering with Indonesian researchers to build social research capacity in Indonesia. Activities include working with the National AIDS Commission's Research Working Group, partnerships with Universities to build individual and institutional research capacity, and work with community-based organisations on community engagement in research. In addition to capacity-building activities, research relating to men who have sex with men, sex workers and injecting drug

users is being conducted. The Universities are also partnering with Scarlet Alliance and AIVL to engage with local sex work and drug using communities.

- UNSW's National Centre for HIV Epidemiology and Clinical Research is implementing a field research training program with partner institutions, establishing mentoring relationships and supporting development of a national HIV research network.
- ASHM is working with the Indonesian Medical Association (IMA) to strengthen its capacity to represent the HIV clinical workforce and contribute to the national HIV program. IMA staff have attended ASHM conferences, short courses and spent time at ASHM offices. ASHM is also supporting IMA to develop links with organisations representing allied health care workers working in HIV, such as nurses and dentists.
- Australia's National Serological Reference Laboratory (NRL) is working in partnership with the Clinton Foundation and Ministry of Health to strengthen laboratory systems and enable more accurate test results. This includes a training program and an External Quality Assurance System for laboratories. The work is helping a central organising laboratory to support a national network of laboratories.

## **Development NGOs**

Australian international development NGOs have a range of HIV projects in Indonesia. Oxfam Australia is educating secondary school students about HIV and is involved in an income generating project for people living with HIV. The Australian Red Cross has been working to raise awareness about HIV in Aceh, while Caritas has been conducting HIV education in Papua.

The Burnet Institute has offices in Indonesia and has been involved in a range of HIV projects with local partners including building a comprehensive response in Nusa Tenggara Barat, counselling services development, responses for vulnerable populations in Bali, treatment adherence, and training for NGOs to conduct prison-based harm reduction.

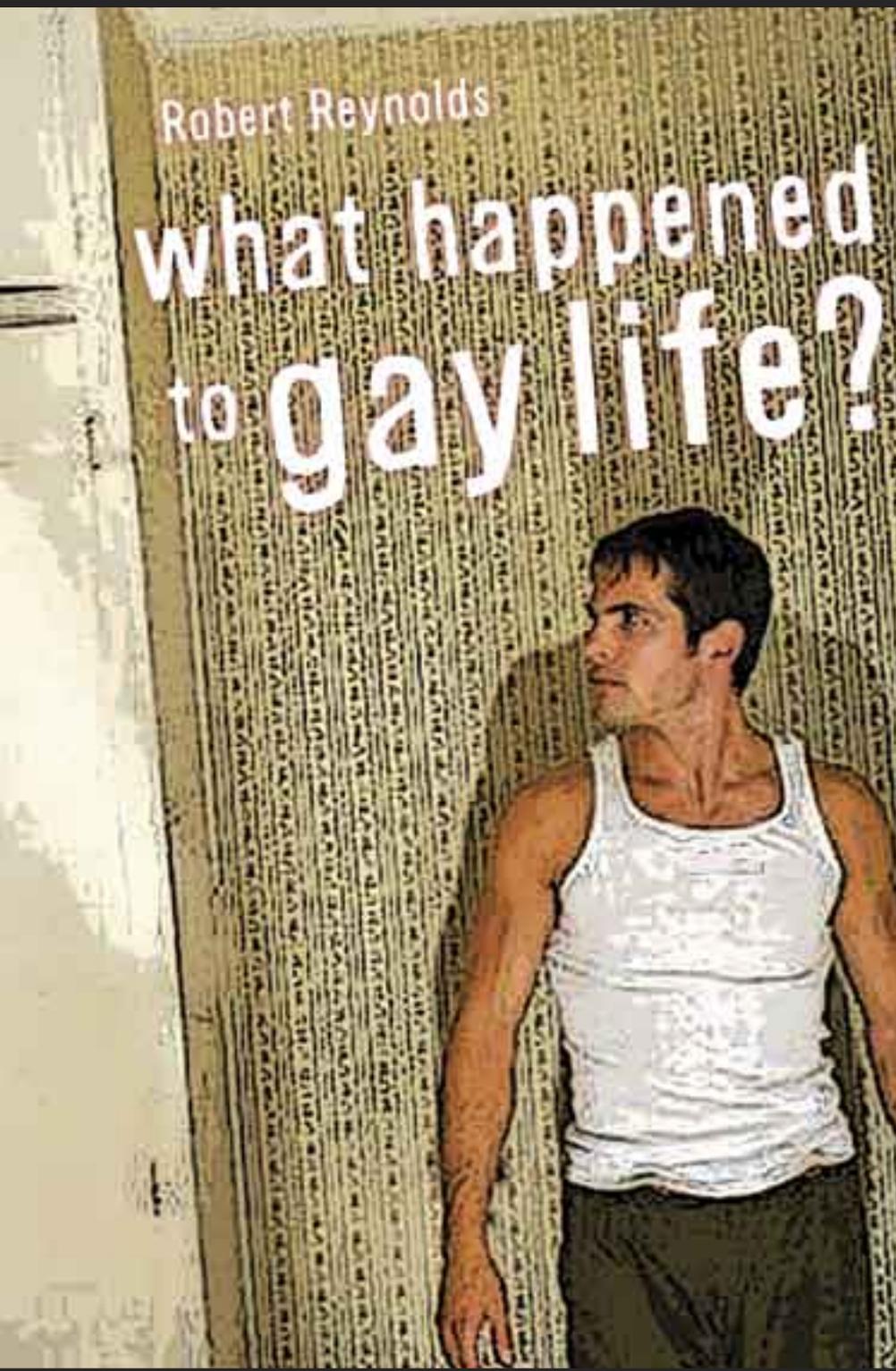
## **Bali ICAAP**

In August 2009, Indonesia plays host to ICAAP 9 (International Congress on AIDS in Asia Pacific). AusAID is providing support to the Conference in conjunction with UNAIDS and AIDS Society of Asia Pacific. The Conference is shaping up to be a major milestone in the history of the national response, and a great opportunity for showcasing and strengthening the diverse Indonesia-Australia partnerships that are evolving in response to the epidemic.

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- 2 *Country Report on the Follow up to the Declaration of Commitment on HIV/AIDS (UNGASS) Reporting Period 2006-2007*, National AIDS Commission 2008.
- 3 *Risk Behaviour and HIV Prevalence in Tanah Papua 2006 Results of the IBBS 2006 in Tanah Papua*, Ministry of Health Indonesia 2007
- 4 *Op. cit. (fn. 2)*
- 5 *Op. cit. (fn. 3)*
- 6 'Waria' describes a range of identities, including male to female transgender persons, those who identify as male but present as female, those who identify closely as female but are biologically male, and those that imitate women in dress and mannerism but identify as male, and those that neither identify as male or female.

**John Godwin is a consultant on HIV/AIDS issues and former Policy Analyst at AFAO.**



## *What happened to Gay Life?*

Andrew Burry reviews Robert Reynolds' book

I arrived in Sydney in the mid eighties as a heterosexual. In 1990, after a week as a bisexual, I turned to the gay life. I was always conscious of the debt I had to those who had undertaken the fight to allow sexuality to be expressed more freely. Also, I appreciated that a lack of these rights had more than a little to do with my own reluctance to accept my homosexuality. *What Happened to Gay Life?* provides insight into the motivation of some brave souls who have my gratitude. It provides illumination on the scene as it was and as it evolved; a process which mirrored what was happening in New York, San Francisco, London and other places.

This book is based on several key premises: that 'gay life' is disappearing; that gay culture emerged from the rights struggles of the 1970s; and that gay culture developed further through the community response to HIV/AIDS in the 1980s.

At the outset, it is important to know that Robert Reynolds' book deals primarily with gay life in Sydney and is developed through the life stories of a group of ten diverse men.

The book links gay life to activism and suggests that gay life was sustained by a sense of homosexual men being outsiders. As more gay men choose to live their lives in the mainstream, Reynolds concludes that if gay life has not disappeared, it has changed forever.

The early chapters describe the thoughts and experiences of three gay activists who reacted in different ways to their sexuality. The act of becoming activists is suggested as means of developing identity within a society from which they felt excluded. For these three, there is disillusionment with the idea that being gay is no longer an identity in itself, but rather has become more akin to a lifestyle.

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Mardi Gras crops up at the beginning and at regular intervals throughout the book, as if it were a barometer for gay life itself. These older activists seem most critical of what they perceive Mardi Gras to have become and the distance it has moved from its political roots, into what they now describe as a “social club”. Reynolds himself suggests that the troubles of 2002, when Mardi Gras’ survival seemed in doubt, were not so much indicative of managerial incompetence as they were of a movement having lost its way. Whilst its original purpose had become diluted, it hadn’t evolved a new one.

The final chapter of the book describes the views and experiences of three younger gay men – all under 25. These are labelled The Romantic, The Individualist and the Indie Kid. It’s hard to know how typical these may be in the broad spectrum of Sydney’s gay community. However, these are interesting snapshots of where gay life fits within a whole-of-life context and how opinions might be shaped by a more tranquil coming out experience. One of the men says that being gay is not a big deal, another doesn’t feel his homosexuality keenly, whilst the third doesn’t feel that the world cares much either way for his sexuality.

These are interesting contrasts, and Reynolds has been sensitive in presenting the thoughts and comments of his subjects and relating them to the bigger picture of events taking place within the Sydney community. He also explores the role, importance and relevance of Mardi Gras to each of them.

As I finished the book, I wondered if I had understood what this ‘gay life’ actually is. After all, if you are gay you have some kind of gay life as a matter of course. Is it in fact more about the



‘Use them safely’, reproduced from the *National AIDS Bulletin*, July 1989.

nature of gay community that this book is discussing? Disappearing gay life seems more about disappearing oppression and the politics that it generated. The fact that activism has succeeded in diluting the outsider status of gay men need not spell the end of this gay life; rather it can be a rejuvenation or redefinition.

If I was disappointed in this book, it was because I felt an overlaying sense of *ennui* – perhaps also of nostalgia. Perhaps that lies in the nature of the majority of the subjects and even the author himself. I think I was also distracted by the idea that gay life had a beginning point sometime in the 70s, reached a peak sometime in the 90s and is currently declining. By coincidence, at the time I read this book I had just finished reading *The Secret Life of Oscar Wilde*, a biography by Neil McKenna. Oscar himself remarks that the truth is rarely pure and never simple. McKenna says that Oscar’s place in a small but

courageous band of men, who strove to bring about the legal and social emancipation of men who loved men, has rarely been acknowledged. They described their social and political aspirations simply as ‘the Cause’.

I don’t see an end to activism and I don’t see an end to gay life. I see a change and I see an infusion of new people with new ideas about what it means to be gay. Gay life will evolve and meet the needs of younger generations and, of course, it’s possible that we older gay men may feel disenfranchised in the process. *C’est la vie!*

*What Happened to Gay Life?* is a great read; it is well constructed and written. That it leaves questions unanswered and provokes diverse reactions is to its credit.

**Andrew Burry is the General Manager for the AIDS Action Council of the ACT.**

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in alerting the Minister to the issue, but it was largely intense lobbying on the issue by AFAO and the National People Living with AIDS Coalition (NPLWAC) that led to the Baume Review, which recommended changes to the country's drug regulatory system and much easier access for patients to new therapies from overseas.

I was also a member of NPLWAC (the forerunner of NAPWA), which had a part-time staff member based in the AFAO offices. Without resources and opportunities for many face-to-face meetings, we struggled to make an impact as a national peak organisation for HIV-positive people, although we were involved with some major decision-making at the time. I remember an agonising NPLWAC teleconference over whether we should support the recommendations of the Baume Report, which didn't quite meet all the demands from ACT UP, but which moderates on the committee (including me) thought were worth agreeing to in the interests of change.

The environment for HIV-positive people in the early nineties was full of angst. We struggled to deal with the deaths of so many friends, a sense of despair over whether effective treatments would ever be found and a lot of political volatility which surrounded any significant gathering of the "HIV community". I remember some fractious AFAO meetings where interstate rivalry between agencies led to awful personal attacks and close votes on contentious issues. Sometimes the issues would come from HIV-positive people, who felt that their voice was often lost amongst the discussions and that AIDS Councils needed to empower positive people to take on greater leadership roles within their organisations.

As a member of AFAO Executive as well as a NPLWAC committee member, I didn't enjoy being pulled both ways with my allegiances when relations became frosty during these debates. The creation of NAPWA around 1993 was to start a turnaround in the creation of an organisation that could give a more effective voice to positive people's perspectives on the national scene.

Through all of this, of course, positive activists had to deal with our own health issues. Like many others, I was dealing with a series of AIDS-defining illnesses, chronically low T-cell counts and lagging energy levels. Many times I would be told by friends (and the occasional doctor) that I was doing too much on the political scene and that I should be spending my days more quietly, looking after my health.

The life of the HIV sector, for all its acrimony and competitiveness, was absorbing to me. I felt no doubt that we were contributing to important policy debates and bringing about changes in attitudes in many of the things we were involved with. Most importantly, positive advocates were giving a face to people with the virus, humanising and give a profile to something that had dared not speak its name for so many years: the experience of being HIV-positive and the need and hope for our survival.

That some people did manage to survive was remarkable, albeit imbued with the grief of so many we had lost. Those lost included some of the firebrands of HIV activism – people like Andrew Morgan, Bruce Brown, Keith Harbour and Bill Hathaway. I have lasting images in my mind of the front cover of the *National AIDS Bulletin* (predecessor to *HIV Australia*) with Bruce Brown and a partner in a sexual embrace, plus other photos of



David Menadue, 2009

Andrew Morgan and Jamie Dunbar in a similar pose on the cover of PLWHA NSW's *Talkabout* magazine with a drip attached to one arm, giving the message that positive people *did* have sex.

This spirit of defiance in reclaiming sexuality for positive people at a time when Government funding agencies and, in fact, many people in society, didn't want to contemplate such a thing, was an affirming thing for many positive people. It gave hope that some day, maybe things would return to normal and everybody could love and live without fear and stigma. All these years later, I am still sustained by the energies of some of those early HIV-positive activists who dared to challenge the status quo and ask for improvements in the lives of people with HIV/AIDS in this country.

**David Menadue has been involved with HIV activism for over twenty years. In that time he has held the roles of President of NAPWA and PLWHA Victoria, among others and sat on the boards of numerous HIV community organisations and Government committees. He is a regular contributor to *Positive Living* and published an autobiography *Positive*, in 2003.**

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Initial outcomes from this early work included the signing of a Memorandum of Understanding between NACCHO, NAPWA and AFAO, and the establishment of the Aboriginal and Torres Strait Islander Projects Officer Network (ATSIPON). The first national Indigenous Sistagirl forum, held on Magnetic Island, also resulted from this initial work.

Some key resources were developed during this time, including the 1999 'Indigenous Pride' calendar, the 'We're Family Too' poster, the 'Access For All' training package and a Cultural Awareness and Sensitivity Package. Later work included the development and implementation of the *HIV/AIDS and Us Mob* booklet, the 'Keep Yourself Covered' – Sistagirl self-esteem campaign and 'Something is Going to Get Us' – a consultation project on the educational needs of ATSI people who inject drugs.

By 2001, the AFAO National ATSI Project had been operating for five years and the strategy was well into its implementation. AFAO and the National Indigenous Gay, Sistagirl & Transgender Steering Committee (NIGS&TSC) decided it was time to reconsider ways to maximise Indigenous input and advice to the project. Discussions between AFAO management and the steering committee highlighted the need for alternatives to be developed whilst allowing the project to respond to new issues.

An independent review was conducted to assess the effectiveness of the Indigenous Gay & Transgender/Sistagirl project. The review found that the Project had made significant achievements in service delivery, developing networks and partnerships, as well as organisational development. The review went on to say that the

“project’s greatest strengths in relation to service delivery appear to have been its ability to genuinely seek input and ideas from Indigenous gay and transgender people via several forums, conferences and consultations at a national level.”

Importantly, the review also recommended expanding the target group to include other Indigenous people at risk. The “whole of community” approach was considered a sensible and culturally appropriate method of ensuring that all Indigenous people at risk were engaged in campaigns or programs developed through the project.

Women’s issues (both heterosexual and lesbian) were highlighted as extremely important. Both these groups of Indigenous women were considered at risk of missing out on services, due to their inability to access culturally appropriate and/or “lesbian friendly” services in both the Indigenous and mainstream health sectors. The review noted that the AFAO Project was in a strong position to advocate for culturally appropriate services for both groups of Indigenous women and to flag the need for more research to be done into how to best provide this support.

Other recommendations were that the project should increase its national policy work, while retaining a focus on education issues. The need for greater community participation and self-determination within the project was also highlighted, in order to provide genuine opportunities for decision making and to create a sense of ownership for Aboriginal and Torres Strait Islander people affected by HIV.

Overall, the review concluded that the HIV environment was in the Aboriginal and Torres Strait Islander community was changing, and the AFAO National ATSI Project and the NIGS&T Steering Committee were ideally placed to respond.

During the third Anwernekenhe conference in 2003, the Indigenous Strategic Alliance (the ISA) was formed. The ISA was comprised of a combination of gay and Sistagirl community representatives, as well as organisational representatives from ATSIPON, NACCHO, ASHM and Indigenous Positive Network (now known as PATSIN). This allowed women’s issues to be included in the work of the ISA and the AFAO National Project for the first time.

By 2005, following the mandate that had emerged from Anwernekenhe 3, the ISA unanimously decided that it would proceed with an expanded brief, broadening its focus from Aboriginal and Torres Strait Islander gay men and Sistagirls to all Aboriginal and Torres Strait Islander communities at risk from HIV/AIDS.

In April 2006, the expanded brief proposal was presented to delegates at the Anwernekenhe 4 Conference, who, for the first time in its history included Indigenous women alongside gay men and Sistagirls. The proposal was discussed at a plenary session on the final day and delegates unanimously supported and endorsed the ISA’s proposal to move forward with an expanded brief.

One of the key questions asked throughout the consultations was how to develop a governance structure for the ISA that would support an expanded brief. The ISA recognised that if it wanted to work with and represent other communities, then these communities would need to be included in the ISA’s decision-making structures.

There were obvious problems with membership – the ISA was not reflective of all Aboriginal & Torres Strait Islander communities affected by HIV/AIDS, so the question of who would be members of the broader group, and how would they would be



elected, was an important one. The ISA deliberately did not decide how this would be achieved, as it wanted this to be one of the key questions for the consultation, in order to give every opportunity for those not yet involved to contribute.

By June 2006, the ISA national consultation process had been completed, showing widespread and enthusiastic support for the expanded brief that would include all Aboriginal and Torres Strait Islander communities affected by HIV.

There was also strong support for the idea that the ISA should seek to become a member of AFAO, in order to enhance the visibility of Aboriginal and Torres Strait Islander HIV issues at a national level, while also strengthening AFAO's capacity and commitment to Indigenous health issues. It was also decided that the ISA should become incorporated, in order to become its own legal entity. Incorporation would also increase access to funding, help the Alliance to be taken more seriously as an organisation and facilitate greater accountability to members.

In June 2007, the ISA held a landmark meeting resulting in a formation of the organisation's objectives and proposed membership. The name of the new organisation is the Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (the ANA). The objectives of the ANA have been developed to ensure an inclusive and meaningful approach to the work that the Alliance plans to undertake, working to address the risk that HIV/AIDS poses to the Aboriginal and Torres Strait Islander community. The people involved in the ANA strongly believe that they have taken an idea and built it into a genuine vision for the future.

There is no denying that there are many challenges ahead that will require wholehearted support, from the community right through to the Federal Government. However, the new ANA committee have hit the ground running, establishing a two year work plan and becoming a member of AFAO. The ANA is structured to ensure that it is a fair and transparent entity. This will allow greater participation by all Indigenous people,

to work together in a partnership that will address the needs of all communities affected by HIV.

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**Michael Costello is the National Aboriginal and Torres Strait Islander Senior Policy and Programs Officer at AFAO. Colin Ross is the Gay Men's representative of the Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA).**

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has been an unprecedented rise in prosecutions across the country, with at least ten cases brought to court. The circumstances in which criminal laws are applied to people living with HIV appear to be broadening.

Health professionals, prosecutors, police and communities need to understand the potential negative public health outcomes from application of the criminal law to HIV transmission through sex, other than in exceptional cases of sexual assault and premeditated, intentional acts where HIV has actually been transmitted. The development of new *National Guidelines for the Management of People with HIV who Place Others at Risk*<sup>6</sup> is a step forward, based on the principle that a variety of interventionist strategies may be needed, with preference being given to public health strategies that are least restrictive.

The challenge over coming years is not only to ensure that we don't lose the policy ground that was so hard fought for, but also to lift our vision. How can lessons from two decades of law reform to support HIV responses be shared across related fields such as sexual health, hepatitis C and other public health priorities? How can we entrench a human rights approach as essential not only to HIV, but as a foundation of the 21st century approach to effective management of all of public health?

An important part of lifting our vision is to ask how lessons can be shared with other countries. In coming years it will be increasingly difficult for Australians to ignore the human rights dimensions of the HIV, TB, STI and hepatitis epidemics affecting our near neighbours.

Over two percent of adults in rural areas across the island of New Guinea are living with HIV.<sup>7</sup> This epidemic is closely linked to the low status of

women and gender based violence. In PNG, there have been a number of reports of women killed due to their HIV status. Researchers from the Melanesian Institute report that as HIV cases in the highlands increase, sorcery-related killings double.<sup>8</sup> Increasing cases of HIV have revived beliefs in sorcery and women are disproportionately singled out for witch-hunts, in some cases being put to death.

A better understanding of the human rights dimensions of PNG's HIV epidemic should shape our efforts as the lead donor to PNG's national HIV response. With AusAID support, PNG enacted the HIV/AIDS Management and Prevention Act 2003<sup>9</sup> to provide human rights protections. However the reality is that rule of law is fragile and the incidence of gender based violence is horrendous. The protections of the Act "are not readily accessible to a population which is low-literate and based mainly in villages outside cities and regional centres".<sup>10</sup> If the law was changed to allow people to bring complaints through Village Courts under the Act, the law could reach every village in PNG.<sup>11</sup>

The human rights situation for people living with HIV in Indonesian Papua is at least as challenging, but with no similar legislative protections in place. The 2009 Bali ICAAP conference provides an opportunity to highlight these issues.

Twenty five years on, we have learnt much from our efforts to legislate the HIV epidemic. It is well understood that laws alone are ineffective in changing risk behaviours. Nonetheless, protective legislation is an essential element of the enabling environment that underpins a successful response. The challenge is to maintain engagement of opinion leaders on the importance of a rights-based approach, including the health and legal professionals, politicians

and bureaucrats, the activists and international development workers, in a period in which HIV has a lower political or public profile than in years gone by.

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**John Godwin is a consultant on HIV/AIDS issues and former Policy Analyst at AFAO.**

## Interleukin-2 shows no benefit in two large clinical trials

Gus Cairns & Edwin J. Bernard

The Sixteenth Conference on Retroviruses and Opportunistic Infections heard in February that two large, seven-year-long, international trials of the immune-stimulating drug interleukin-2 (IL-2, *Proleukin*) in people with HIV had produced a negative result. Both trials found that there was no clinical benefit in using the injectable therapy and that it produced significant serious side-effects. Exactly why these trials, which involved 5800 participants and cost \$85 million, made no difference in terms of deaths or AIDS diagnoses, despite producing CD4 cell increases in participants, is still unknown and

may lead to other discoveries about the immune system.

### Background to both studies

IL-2 is a cytokine, a natural substance produced by T-cells, which can also be made artificially. It stimulates the production and maturation of CD4 T-cells. Investigators have been interested for 15 years in whether it is beneficial to treat people with HIV with IL-2 to boost immune functioning and delay disease progression.

ESPRIT (Evaluation of Subcutaneous Proleukin in a Randomised International Trial) and SILCAAT (Subcutaneous IL-2 in patients with Low CD4 Counts under Active Antiretroviral Therapy) were international, open-label phase III studies examining the effects of IL-2 injections on the progression of HIV disease and death.

The main difference between the two studies was the CD4 count of study participants at entry: ESPRIT participants had to have a CD4 cell count of at least 300 when they

entered the study, whereas SILCAAT participants had a CD4 cell count between 50 and 300.

In both studies, half the participants received injections of IL-2 under the skin alongside their antiretroviral therapy (ART), while the rest received ART alone. In ESPRIT, participants received three five-day courses ('cycles') of IL-2 injections at eight-week intervals, followed by additional cycles, as required, to keep CD4 counts either at least twice the baseline level or over 1000. In SILCAAT, participants received six five-day cycles of a lower dose of IL-2 at eight-week intervals, followed by additional cycles as required to maintain CD4 cell counts an average of 150 above baseline.

The primary endpoint – the main outcome measured – for both studies was death from any cause or AIDS-related illness; serious non-AIDS events and serious clinical reactions to treatment were also measured.

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ESPRIT included 4111 participants from 252 clinical sites in 25 countries, and SILCAAT 1695 patients from 114 sites in eleven countries. The studies needed a minimum number of primary endpoints in order to be able to demonstrate a significant effect. In ESPRIT, 320 primary endpoints were required in order to demonstrate whether or not it worked: in fact, 323, affecting 7.8 percent of participants, were seen. In SILCAAT, 300 were required but only 227 had been seen by November last year, affecting 13.4 percent of participants. At that point the trial's Data and Safety Monitoring Board decided SILCAAT was unlikely to reach the number of events needed, and it was decided to close the trial on 18 November.

## Results

The participants in both trials were similar in some respects. Their average age was around 40 and they had been on ART for about four years, with 80 percent having an undetectable viral load at trial entry. Twenty-six percent of ESPRIT patients and 32 percent of SILCAAT patients had had an AIDS diagnosis. By the time the studies had closed the average time spent in the study was 6.9 years in ESPRIT and 7.6 years in SILCAAT. The ESPRIT participants' average CD4 count at trial entry was 457 and their mean lowest-ever CD4 count (the CD4 nadir) was 197. In SILCAAT, participants' average CD4 count at entry was 202 and their CD4 nadir was 60.

After seven years, the bottom-line finding was that in both trials and

for all endpoints (with one crucial exception) there was no difference in the clinical outcomes for participants on IL-2 and those on placebo, despite higher CD4 gains in the IL-2 patients.

## Verdict on the trials

The verdict of the trial investigators was definitive. ESPRIT investigator Marcelo Losso told the conference that, "Any potential benefit of IL-2, however moderate, can be ruled out." SILCAAT investigator Yves Lévy was if anything even more emphatic. When asked at a press conference if this was "the death knell for IL-2", he replied: "I think so. I don't see any possible benefit in continuing with IL-2 studies." Both investigators were keen, however, to emphasise that they did not regard the trials as failures. There had been strong laboratory data gathered in the early 1990s that suggested the CD4 gains produced by IL-2 might have an effect on clinical progression, but large phase III trials were the only way to find out.

The fact that the CD4 gains did not translate into clinical benefit was itself a puzzling finding, which needed to be investigated further. It was calculated that the kind of cell increases seen *should* have resulted in 27 percent fewer deaths and AIDS diagnoses, but this was not seen. Losso and Lévy suggested two explanations. Firstly, any clinical benefit of IL-2 might simply be cancelled out by its adverse effects. Alternatively, the kind of CD4 T-cells produced by IL-2 were not as effective in fighting disease as the ones arising from the suppression of HIV. A third explanation might be that the body has

a finite reservoir of embryo T-cells and all that IL-2 therapy was doing was depleting it faster.

DVTs and another common side-effect, high blood pressure, might be caused by IL-2 inflaming the lining of blood vessels. Since the studies started it has been discovered that both HIV infection and some drugs (such as abacavir) do this, and it might be possible to analyse stored samples to find out if there are higher levels of inflammatory marker chemicals such as D-dimer in IL-2 recipients.

The investigators also emphasised that it was not the end of the cytokine story, even if it was the end of IL-2. Yves Lévy is investigating another one called IL-7 which appears to have fewer side effects. Marcelo Losso commented: "The lesson is that when you perturb the immune system in some way you may be surprised by the clinical outcomes you get. This may apply to IL-7 too."

Source: [www.aidsmap.com](http://www.aidsmap.com).  
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19–22

#### **IAS 5th International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention**

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9–13

#### **ICAAP: 9th International Conference on HIV/ AIDS in the Asia-Pacific**

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### September

7–9

#### **ASHM: Australasian Sexual Health Conference**

in conjunction with

9–12

#### **21st Annual Australasian Society for HIV Medicine Conference**

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22–25

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