

Making a difference: **A History of Positive Life NSW**



Unless otherwise indicated, images of people appearing in this publication do not indicate HIV status either positive or negative.

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1. Wotherspoon Gary
2. Sex and gender studies
3. History

**Acknowledging the strength and resilience of
people with HIV, our friends, families and allies.**

**Remembering with love - friends, partners,
lovers and colleagues who have passed on.**

Acknowledgements

Many people have been involved in the 'creation' of this work. One of the best sources for material has been **Talkabout**, which has provided an ongoing history of the organisation and the issues it has confronted, for which I give thanks to its numerous editors. As well, interviews, some done a decade ago, have given different perspectives on events past and present. Most organisations have a storeroom in which 'boxes of treasures' have been discovered, and Positive Life is no exception: several boxes of photos and photocopies have also added their flavour to this story. And the work of Kirisha Thanapalasuntheram should be acknowledged: she prepared an internal document for Positive Life last year, and this has been helpful in identifying leads to follow up. I would also like to thank Phillip McGrath for his work in preparing the images, and Paul Kidd for his beneficial editing.

A note on terminology. In the beginning, when the new disease was still unknown, it was given different names, with GRID (Gay Related Immune Deficiency), 'the Gay Plague', the "Black Plague of the Eighties" being the best known. And before the discovery of the fact that it was the HIV virus that could lead onto AIDS, all cases were often referred to as AIDS. I have tried to use the terminology of the time, (often in inverted commas, to acknowledge that that is what it was known as then, although not now).

Abbreviations: to avoid repeating long titles continuously, I have taken the liberty of giving the title of various groups their initials in the first instance and then, usually, using only those initials thereafter – thus PLWH/A NSW Inc is given as PLWH/A.

Images: Thanks to many anonymous photographers, and thanks in particular to Jamie Dunbar and Mazz Images who have documented so much.

Any written history reflects selections and omissions, and this work is no exception. Not everyone who deserved mention will have their names recorded here, but this is not a reflection on their contribution, and I hope their spirit pervades the pages.

Finally, in writing this history of Positive Life, I have also been mindful of Paul Young's call of so many years ago, to **talk with us, not about us**, and have endeavoured, wherever possible, to allow the actors in this history to speak for themselves: hopefully, their voices will have come through.

***talk
with
us,
not
about
us***

Paul Young

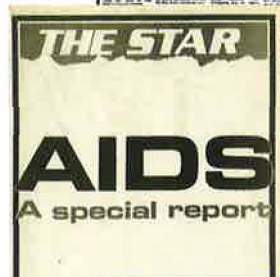
Introduction

It is just over a quarter of a century since Australia reported its first case of AIDS – in Sydney in November 1982 – and just over twenty years since Positive Life NSW (then PLWA, later PLWH/A) was formed, also in Sydney; it was formally incorporated in July 1989. So it is an appropriate time to put together a history of how this organisation emerged and developed – an organisation that came into being as a community response to what was once called 'the gay plague'.

Sydneysiders had survived many epidemics and pandemics in the past, from the year after the arrival of the First Fleet until recent times. But from the early 20th century, a range of medical developments, with treatments and vaccinations on top of existing quarantine regulations, led to a belief that medical science had at last got 'disease' under control. Since World War II, new generations grew up in Australia secure in the belief that such epidemics were a thing of the past: they themselves would not have to face something that had been almost commonplace as recently as their grandparents' generation. But then along came HIV.

While we now know that HIV is an infection contractible by anyone, irrespective of age, gender, ethnicity or sexuality, the first reported cases were among gay men, both in the USA and here in Australia. And at first no one knew what it was, how it was transmitted, or how to deal with it.

Known initially as GRID (Gay Related Immune Deficiency), it was first thought to have something to do with the 'homosexual lifestyle'. And in NSW in those days, when gay men's sexual and emotional lives were still illegal and gays were still a little-known and less accepted minority in our multicultural society, this new 'gay disease' gave additional ammunition to the bigoted and prejudiced with which to attack gays. Moral pronouncements abounded, and



there were calls for gays to be locked away; for Mardi Gras to be banned; for gays not be allowed to travel in or out of the country; and for all gay venues to be closed. Hysterical media coverage didn't help.

In those early days, such perceptions affected how those who contracted HIV were treated. Fear and prejudice were predominant. Homophobia became more overt, and there was an increase in violence against gay men; staff at institutions with a duty of care, like hospitals, sometimes fell down in the execution of their duties; friends and neighbours might have viewed us differently; and death notices became a weekly aspect in the gay papers.

It also affected how people with the infection saw their own prospects. In the face of such a presumed future, many people with HIV did what those with death looming often do: they sold up everything, and prepared to enjoy what might be left of their life.

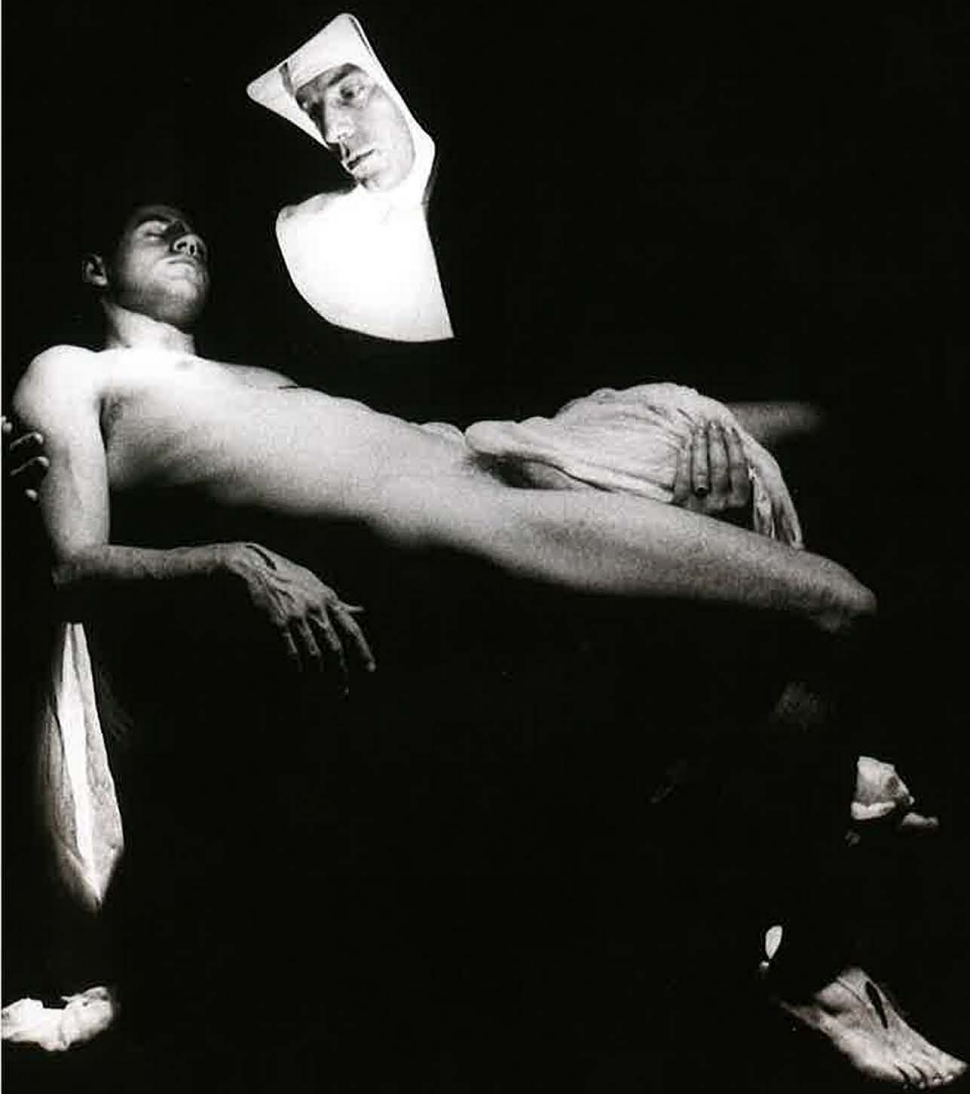
By the early 1980s, Sydney was a very multicultural city, and part of its diversity was a flourishing gay community. This gay world was far more open, cohesive and active than it had been a mere decade before, and the arrival of HIV triggered an overwhelming response from within this community, well before authorities started treating HIV as a public health issue. As well as the AIDS Action Committee, formed in mid-1983 (it became ACON), a wide range of support services were established to deal with various aspects of the disease. Groups providing legal, emotional, financial and physical support all were set up from within the gay community.



'In the face of death, we were left with a choice of how to live.'

In the beginning

It is hard today to imagine the atmosphere that prevailed in those early days. With the first deaths of people with HIV, public anxiety about the new disease grew, manifested in a variety of ways: in August 1983, a Sydney dentist banned homosexual patients from his surgery; in November 1984, New South Wales police called for an end to random breath testing, then insisted on being issued with plastic gloves because they believed HIV could be transmitted via the saliva of motorists;¹ in mid-1985 two Australian airlines announced that, to protect their crews, people who were HIV-positive would be banned from travelling on their planes; while in July 1985, a newly-diagnosed three-year-old girl from Gosford was banned from attending her pre-school after fearful parents threatened to withdraw their own children if she was not removed. And the death notices in the gay papers continued to appear in growing numbers.



The limited public understanding about its transmission, and the virtual 'death sentence' associated with contracting HIV generated profound public anxiety about HIV and contributed to the stigma associated with infection. In those early days, people with HIV were treated with fear and trepidation. Even in hospitals, they might find their food left outside the door to their rooms by fearful staff.

By the late 1980s, with the rising death rate, people in the gay community were forced to face up to the deaths of friends or lovers, or possibly even themselves, well before they might normally expect to.

So action was required – and fast. While initially there was limited knowledge about how to respond to AIDS, by late 1983 'epidemiological evidence had made clear that the causative agent of AIDS was sexually transmissible', and within two years researchers at the Pasteur Institute in Paris had managed to isolate the 'AIDS virus,' which eventually came to be known as the Human Immunodeficiency Virus or HIV.²

In 1986 the US Food and Drug Administration (FDA) approved the first antiviral drug, zidovudine (AZT), for treatment of people with HIV.³ Other drugs followed in the early 1990s, but the speed with which new treatments were made available soon became a political issue. The death rate was rising and the development of new treatments proved agonisingly slow. So there was a resurgence of political activism to fight to protect the interests of both gay men and people with HIV.

At the Third National Conference on AIDS, in Hobart in August 1988, a group of Sydney activists met to set up an organisation to fight for greater representation and advocate on behalf of people with HIV. The new organisation would build upon the Sydney gay community's existing activist strengths, with several of the group already involved in activism for gay law reform and broader social causes. Those involved understood the considerable challenges ahead of them, especially in providing a better quality of life for those who were HIV-positive, and combating widespread prejudice and stigma.

"The very first HIV conference that I went to was in Hobart when Wilson Tuckey got up and said that people who got the virus deserved it. Homosexuality was illegal in Tasmania those days, and people 'who had been involved in an illegal act' were invited to identify themselves. Half the audience stood up. It was quite dramatic".

Garry Trotter

"for the first time, positive people got up on a stage, and self-identified...it was just amazingly emotional...and very soon after that, we set up PLWH/AIDS".

Bill Whittaker

People Living With AIDS NSW (PLWA NSW, now Positive Life NSW) was formed at the Trade Union Club, in Foveaux Street Surry Hills, in September 1988, an important and decisive occasion with approximately 150 people present.

The gathering brought together a range of activists and advocates who were concerned with different issues and represented different interests: apart from those living with the virus, there was an ex-gaol inmate who saw the importance of prison issues; a 19-year-old drug user who was concerned with matters such as needle exchange; Julie Bates, whose primary concern was HIV in its relation to sex workers; as well as others who were passionate about fighting the emerging epidemic. They included doctors, nurses, social workers, families, friends and gay and lesbian activists.



Paul Young and Julie Bates

PLWA's "Mission Statement"

LIVING WELL II CONFERENCE

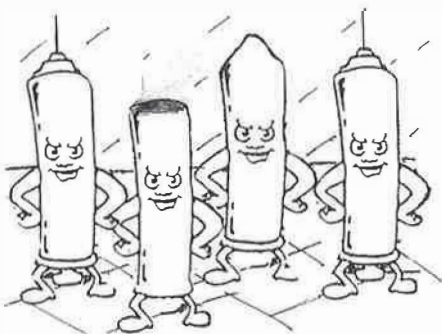
PEOPLE LIVING WITH AIDS (NSW)*

The following statement of purpose and rules were adopted by PLWA (NSW) at the Living Well II Conference held February 11-12 1988.

STATEMENT OF PURPOSE

The aims and objectives of the People Living With AIDS (PLWA) (NSW) shall be -

- (1) To empower people affected by AIDS in New South Wales with information and advice on all relevant AIDS issues; in particular information concerning treatment of HIV infection and information on care and support for those affected by AIDS.
- (2) To lobby relevant community groups, governments and other organisations about issues of concern to PLWA, with the aim of ensuring the best possible levels of care, support and treatment for those affected by AIDS.
- (3) To promote a positive image of people affected by AIDS, with the aim of eliminating prejudice, isolation, stigmatization and discrimination arising from AIDS.
- (4) To work closely with the AIDS Council of NSW, the Community Support Network, the Bobby Goldsmith Foundation, Ankali and other relevant organizations in the pursuit of these aims and objectives.



Making things safer - condoms and needles came into focus.

The name PLWA was important. It was not just People with AIDS, it was people *living* with AIDS. The group also welcomed the involvement of friends and supporters: 'it was decided that it should not be an organisation only for people who actually had the virus ... it was acknowledged as early as that, that the virus affected people who didn't necessarily have the virus themselves.'⁴



'Public demonstrations were aimed at getting the message out'.

TALKABOUT

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

PLEASE TO THE EDITOR: The aim of this newsletter is to provide a voice for the people living with AIDS. It is not a place for a mouth of getting things done. It is a place for people to express their views, concerns and feelings. It is a place for people to share their experiences and knowledge. Please send us your articles, photos, letters, etc. to the editor. We will be happy to publish them.

This newsletter has been put together by a small committee for the purpose of providing information and support to people living with AIDS. It is not a place for a mouth of getting things done. It is a place for people to express their views, concerns and feelings. It is a place for people to share their experiences and knowledge. Please send us your articles, photos, letters, etc. to the editor. We will be happy to publish them.

We hope you enjoy TALKABOUT

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Editorial Board: David Urquhart, Paul Young, etc.

ALL VIEWS EXPRESSED IN TALKABOUT ARE THE OPINIONS OF THE RESPECTIVE AUTHOR AND NOT NECESSARILY THOSE OF PLWA (NSW)

two early issues were the best organisational structure for the group, and identifying its immediate priorities. But at least the establishment of PLWA NSW gave people a platform to work from on the issues surrounding HIV in the late 1980s. And there were many issues to be confronted: 'It was a time of incredible urgency to do things on a number of fronts, to care for the people who were sick, to overcome stigma and discrimination in the provision of services.'⁵

One key issue was to get access to AZT. It had not yet been licenced for use in Australia, and Special Access Schemes for unapproved HIV drugs had not yet been developed.

But there were also other issues: stopping people being quarantined or detained, developing prevention programs to stop the spread of HIV, and educating people about how to avoid infection.⁶ On a community level, PLWA NSW expressed concern at the lack of dedicated hospital beds for people with HIV: many such patients were left in the corridors of wards, as there was no specialist AIDS ward to take them: even in our hospitals, people were being discriminated against.⁷ So members of PLWA NSW soon became active in hospital visits, and canvassed the necessity for an AIDS-specific ward at St Vincent's Hospital in Darlinghurst⁸. Over the years, the nursing and social work staff at these wards, particularly St Vincents, RPA and Sacred Heart Hospice worked tirelessly to provide a safe, friendly, caring environment for the many patients there for lengthy periods or as they died.

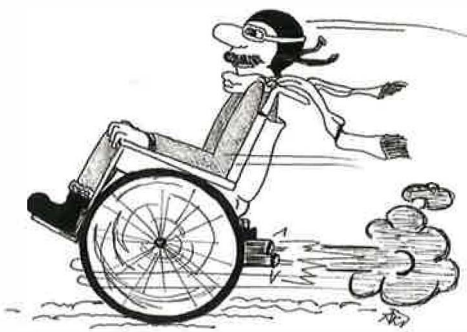
In December 1988 PLWA NSW put out the first issue of its newsletter, *Talkabout*. It was an obvious development, even if it wasn't flagged at the very beginning. There are two different versions of how the title was arrived at. One is that the title was thought of by Paul Young, who was tired of people talking about – but never with – people living with HIV. He called for HIV-negative people within the community to 'talk with us, not about us.' David Urquhart, a volunteer from the earliest times, has a different

We NEED
AIDS BEDS
not Club Meds
People LIVING with
AIDS (NSW)



recollection: 'the title just came to me ... I remembered that years and years ago there was a magazine which was some kind of a travel magazine ... called *Walkabout* and I thought, *Walkabout*, oh *Talkabout* ... it fitted all the criteria.'⁹

With limited resources, there was some debate within the new organisation about which objectives should be pursued first, and how to go about this. There were a number of areas – political, social, economic, and personal – that required action, and over the next 12 months these to a large extent shaped responses to AIDS in Australia. People with HIV called for representation on the various state and national advisory committees, given their expert understanding both of living with the virus and of the medical and social services that they needed to access. They asserted their rights to live satisfying emotional, sexual and physical lives, and insisted upon swift access to new drug treatments that might prolong their lives. They sought to recast the dominant media portrayal of them as 'doomed, dangerous and deviant', and drew attention to the fact that white gay men were not the only people who contracted HIV. They also called for an end to discriminatory behaviour, especially on the part of employers, landlords, and providers of medical care, many of whose actions denied them the possibility of living relatively normal lives.



'Enjoying the possibilities of living a relatively normal life'.

"why the word 'living' was included... was [because] it was decided that it should not be an organization only for people who actually had the virus... it was acknowledged as early as that, that the virus affected people who didn't necessarily have the virus themselves".

David Urquhart

'Some doctors wanted ALL patients tested for HIV – but the worry



'Parties were a bright spot, even in the darkest of times'.

The battling years

Such examples of commitment and progress were discussed in PLWA NSW's first annual general meeting, held in March 1989. This was followed closely on 21 July 1989 by the group's official incorporation.¹⁰ Paul Young and Terry Bell initially took the lead, and although this partnership didn't last long due to several differences of opinion,¹¹ they were soon joined by others. Advocacy, support, advice and information were the first main areas of activities. There were difficult decisions to make: there were those who didn't want PLWA NSW to be solely focused on personal issues; 'It needed to be more political ... or more educational; and there was that, at the same time, another dichotomy between infected people and uninfected people, so between prevention education and between support of, or education for, people with HIV.'¹²

But as the magnitude of the epidemic became apparent, it also became clear that the gay community did not, on its own, have the resources to deal with HIV. As with other newly affected groups, PLWA NSW turned increasingly to governments to gain access to financial support. At the same time, as governments became aware that they were facing a major public health problem, they turned increasingly to the gay community, both for more information about aspects of gay lifestyles that might influence transmission, and also to utilise and build on the support networks already established there.

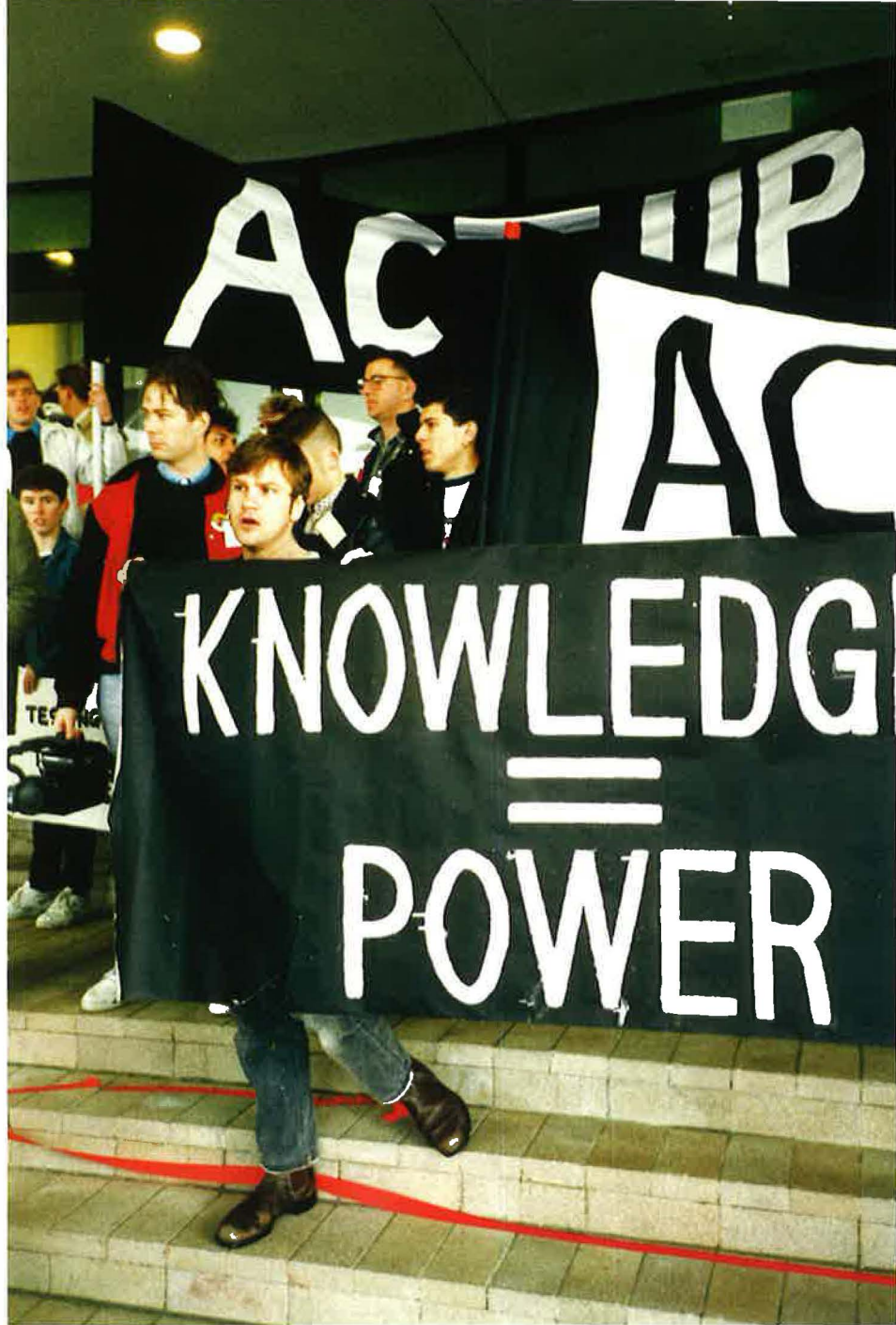
The government's attention became more focused as HIV spread into the wider community, with the potential for disastrous social ramifications as panic spread. Lacking



'So many issues to be addressed'.

“The idea of negotiating safe sex assumes a fairly rational decision-making process...It means having a feeling of self worth, not being a risk taker, being assertive, having good communication skills, [and] being able to bring up and talk about sex...”

Kerri Allwood



a vaccine or cure, a national education program on how to respond to HIV was a key priority, as part of an integrated national HIV strategy. One of the more important roles that PLWA NSW played was by providing input into the national education campaign. This federally funded program was based on 'rationality and reason', respecting the importance of evidence both from medical research and from the perspective of the experiences of those living with HIV.

Probably most notorious of the early education efforts was the 'Grim Reaper' campaign, in which a black-clad figure of death, scythe in one hand and bowling ball in the other, knocks down a group of 'average' Australian adults and children. The ad polarised public opinion, drawing responses ranging from the critical (some argued that the campaign demonised gay men) to the supportive (some applauded what they saw as a long-overdue effort to make non-gay people aware of the risk of HIV): but after that campaign, public awareness of HIV increased dramatically. The Grim Reaper campaign was undoubtedly controversial, and it fed into developing tensions in the gay and HIV communities over the question of whether the growing collaboration between community and government compromised the integrity of the community response – were we 'getting into bed with government'?

In the late 1980s NSW Health acknowledged the need for research to look at the social and psychosocial issues related to HIV – to determine the ways in which people deal with HIV, ill-health and the prospect of dying, to ensure that the needs of this group were considered.¹³

Increased knowledge could come from unexpected sources. One of the early committee members, Kathy Triffitt, began a 'self-documentation, self-imaging' project for people with HIV. The aim of the

"Our aim is to collect this information on a large scale. Then, if something looks good, we will have a powerful case for going to research institutions and saying, 'people with HIV have been trying this and it seems to be working, so we want you to do a full scientific investigation to find out if it is really working'".

Terry Bell

'Imaging AIDS – Visual, Written, Oral AIDS Project'¹⁴ was to capture personal stories and record a more truthful view of the lives of people with AIDS, in contrast to the bleak mainstream media representations at the time.

By now medical researchers were beginning to make significant advances in understanding how HIV infection progresses to AIDS. In particular, the early belief that individuals went into a latency period of ten years or more after their initial infection with HIV, was replaced with the understanding that viral replication continues throughout the entire period of infection, even if there are no symptoms of illness. Thus, HIV disease progression is now known to be the result not of a sudden resurgence of a latent virus, but rather of a slow 'war of attrition' between HIV and the host immune system, with the latter slowly being whittled away by the former.¹⁵

With the benefit of hindsight, it can be seen that monotherapy – treatment with a single drug – was of limited usefulness against HIV, because the virus could

'People learned to live with their pill regime'

¹Side effects of medications were common.

photograph: paul young, 2003

body image
intimacy
pleasure
relationships
disclosure
myths
pos-neg relationships
communication
desire
sexual health
self-esteem
treatments

HIV Positive Sex

PLWHA (HIV)
a series of workshops
HIV positive sex
to find out what
for us and why?
(Leslie Proudman)
aim to improve an
understanding of
of risk, mental
health issues as
HIV positive sex
interested in
a workshop for
interested play
on 02 9361 60
healthpromotion

People Living With HIV/AIDS (HSW) Inc. www.

'Sex – or 'safer sex' – received appropriate

Making a difference:

Talkabout

No. 32 May 1993

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆

SEX



centrefold

The work of the organisation continued to expand and evolve, as our understanding of and response to HIV was changing. A key difference understood by PLWA NSW was that those living with HIV faced the same discrimination, hurdles over treatment, and general difficulties as people who were living with AIDS. This acknowledgement led to a name change: in April 1992 the organisation's name was changed to People Living With HIV/AIDS New South Wales (PLWH/A NSW).

World AIDS day, 1 December 1994, saw the establishment of the Positive Speakers' Bureau, which provided a vital new platform for people living with HIV to speak directly to the wider Australian community. In schools and community halls, 'ordinary Australians', young and old, met with people living with the virus with whom they could discuss HIV issues. The speakers would share their personal stories, putting a human face onto a condition that most people understood only through media stereotypes, and hopefully helping reduce prejudice against people with HIV.

In another effort to support people with HIV in living their lives to the full, PLWH/A established its first 'time-out' room at the Gay and Lesbian Mardi Gras in Sydney in 1999.

When HIV-positive people today talk of the struggle of living with the virus, they usually begin with remembering two incidents: the day they received their diagnosis, and how hard it was to reveal for the first time to others

Talkabout
the 30 December/January 1992-3
• Where We Speak For Generation •



Chilling out at the 'time-out' room at Mardi Gras.

Talking to school students about living with HIV.





'The Quilt was a poignant reminder of all those who were no longer with us'.



Disclosure – could be a party stopper!

that they were HIV positive. From 1988 onwards, these were issues that PLWH/A paid close attention to. Even today, receiving a positive HIV diagnosis remains highly stressful, but in the early years of HIV this was especially so: it was, at the time, a virtual death sentence. PLWH/A was involved in efforts to get counselling services provided. Disclosure was (and remains) another great hurdle. Since it included the possibility of abandonment by one's lover, friends or family and, in the longer term, discrimination and intolerance by workmates and employers, co-tenants and landlords, there were good reasons not to disclose. But for people whose health began to fail, and who needed time off work or had serious medical problems, then at some point disclosure would become necessary.

Both diagnosis and disclosure were – and have remained – among the more pressing personal issues that Positive Life NSW has developed strategies to deal with. They were certainly among the issues that were regularly addressed in *Talkabout*. Other issues canvassed in *Talkabout* included services available to affected people, reports from the PLWA annual general meetings, the shift to new offices in Riley Street, progress on the Quilt project, injecting drug use, living in rural areas, and family issues. There was also a letters section, and the ever-popular 'Olga's Personals' provided a useful service for those seeking others like themselves, for friendship or something more intimate. Over the years, *Talkabout* has sought to be a voice for anything – and sometimes everything – that might be relevant to the lives of those affected by HIV.

The end of the beginning

It was from the medical research front that the next 'good news' came. After 1991, several other drugs were added to the anti-HIV arsenal: these included new classes of anti-HIV drugs, the non-nucleosides and protease inhibitors, distinctly different from the reverse transcriptase inhibitors, which became progressively available from the mid-1990s.¹⁸

Talkabout reported in its mid-1996 issue that research was underway in Australia and the US to determine whether combinations of three or more antivirals, including a protease inhibitor, could completely eliminate HIV from a person's body.¹⁹ While that early hope for complete viral elimination has remained unfulfilled, the arrival of combination treatment represented an unparalleled advance in HIV treatment.

The impact of the introduction of combination therapy became apparent almost immediately, even though no one then knew what their long-term effects might be, and despite the ongoing challenge of side effects. But as the benefits of the new treatments became apparent, PLWH/A and ACT-UP continued to fight to ensure that those living with HIV had meaningful input into policies and campaigns, particularly over quicker access to the new drugs.

From the earliest days, PLWH/A had worked to educate affected communities, with input into various publications, via lengthy and informative articles on current topics. The intention was to ensure that people living with the infection had the most up-to-date information available, an approach that has continued to this day.

positive president of PLWH/A as it was called then; and I think it was a steep learning curve for the guys. I was quite shocked that even though some of them were speakers and educators, they knew nothing about HIV and pregnancy. So it was probably good for them to learn about that. Not being able to breastfeed, for example. The issue that came up for me, I was happy to share all that".

Amelia McLoughlin

Education has always been a major role for Positive Life.



"Contacts" launch 2003
John Robinson and Carmel Tebbutt

In line with its advocacy role, PLWH/A expanded on its commitment to treatment activism, with awareness raising about, and promotion of, combination therapy – in various campaigns in 1996; in the publication of the educational booklet *Getting the most out of your HIV treatments* in 1997; and with the launch of the AIDS Treatment Project in 1998. This project stood at the forefront of treatment activism, as it incorporated a range of concerns – from the promotion of treatments and health monitoring to the importance of providing education to those who were living with HIV, to pursuing access for all to the best possible antiviral treatments.

With the advent of these new drugs and combination therapy becoming increasingly available to all HIV infected persons, the burden of illness was reduced, and with it the need (at least on a community-wide level) for some of PLWH/A's services. The organisation began to shift its focus to other issues that it thought were still pressing. One was people living longer with HIV, rather than dying of AIDS.

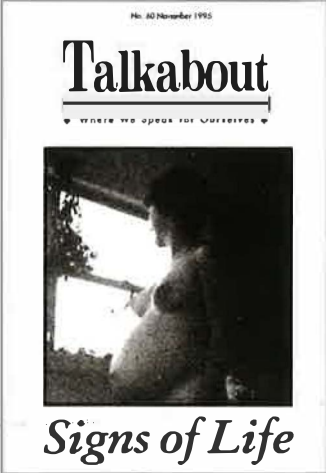
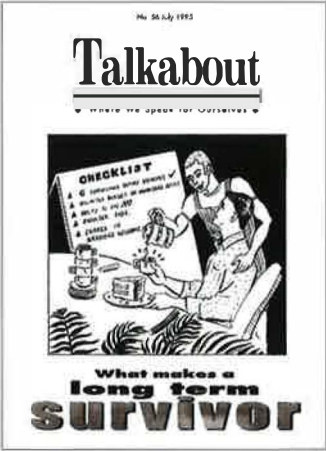
As *Talkabout* reported in its July 1996 issue, 'Now people aren't dying when they're 'supposed' to ... They're living longer or simply not dying.'²⁰ There was a need to assist people to rebuild their lives. PLWH/A identified the problems faced by many positive people returning to work after extended periods of time: they faced financial difficulty and, at times, social exclusion. Such difficulties led the organisation to launch Positive Decisions, a work experience program which assists HIV-positive people in re-joining the workforce, through goal planning and implementation, as well as by disclosing their illness. The program demonstrated 'a power and pride in people living with HIV/AIDS', as it was run by this group for themselves and their peers.

While PLWH/A was often perceived as a gay community organisation, from the start it had a variety of stakeholders, reflecting the diversity of the population of people living with HIV. But balancing the different priorities of all the



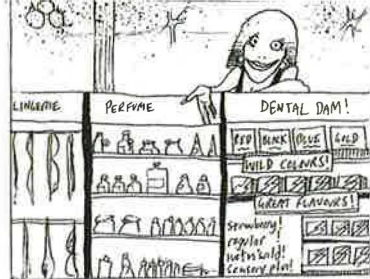
'While combination therapy brought a brighter health future, there were other issues'.

'Living longer brought new challenges – and new opportunities'.

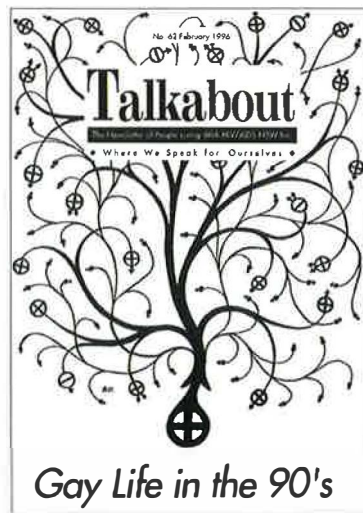


affected groups required both tact and vision. As well as gay men, there were heterosexual women with HIV, one of whose very pregnant belly appeared on the cover of *Talkabout*; families affected by HIV; lesbians with HIV, heterosexual men and the partners of HIV-positive men or women, there were inmates of the state's gaols, for whom unprotected sex or access to clean needles were major priorities; and injecting drug users (IDU), for whom there was not necessarily a sense of an "affected community" with its supportive institutions. And there were also the young, for whom seroconversion and its consequences might be particularly frightening. In 2000-2001, PLWH/A's President was Amelia McLoughlin, a heterosexual woman. *Talkabout* tried to speak to all, with articles in *Talkabout* on everything from 'Gay Life in the 90s' to disclosure concerns, new treatments and their possibilities.

And in *Talkabout* in those early days there were always the death notices, tributes to those who had been there from the earliest days: Robert Ariss, Dodge Traffic (Don Carter), Jacques Monroe, Terry Bell, Andrew Carter, Jen Websdale, Andrew Morgan, Anthony Carden, Megan and Richard Mkwanzani, Terry Giblett, Matt Bradshaw, Richard Johnson, Luke Coomey, Peter Steinheuer, Warwick Witt, Amelia Tyler, Matthew Cook, David McDiarmid, Gary Pye and Neil Sanderson among others. It was like a roll call of those who had fought the good fight.



'Everything a girl needs, at the local pharmacy'.



Gone but not forgotten – Robert Ariss, Tony Carden, Terry Giblett, Gerald Lawrence, Jacques Monroe, Don Carter



A new optimism

From being a largely amateur group set up in the late 1980s, by the late 1990s PLWH/A had moved itself to become a more structured organisation. This was partly necessitated by new demands, and partly enabled by better funding. As new or different needs were identified, more staff were employed to cope with the growing work load, with the introduction of a variety of campaigns and new educational resources.

Health promotion became a major focus and the social marketing and education work saw various resources – booklets, postcards and fact sheets – produced; these emerged from a constant interrogation of the HIV positive community. One initiative was the series of Fact Sheets dealing with the physical and sexual well-being of all HIV-positive people. They initially came out as inserts in *Talkabout*, the first appearing in February 2003. But such a pace of production was unsustainable, and they were eventually released in a more measured manner. The first one dealt with the effects of the drug efavirenz, while later titles included *Boosting your Energy* (a fact sheet about HIV-related fatigue). Some titles were self-explanatory: *I Want to Return to Work*, *Positive Pregnancy*, *Clinical Trials*, while *Get the facts: Syphilis*, *Getting Back my Butt*, and *A Night with Tina* (Methamphetamine & HIV) followed in later years.

In 2003, the organisation unveiled its first stigma and discrimination social marketing campaign targeting the general public. The message 'HIV doesn't discriminate, do you?' was posted on a billboard in the Sydney CBD, at Town Hall railway station. Postcards with the same message were distributed.



Fact sheets dealt with a wide range of relevant issues.

“...the US Immigration Department requires that the individual's passport be stamped 'HIV POSITIVE', and that the authorities at the point of entry retain the right of veto and refuse entry if they consider the person a 'danger to society'!”

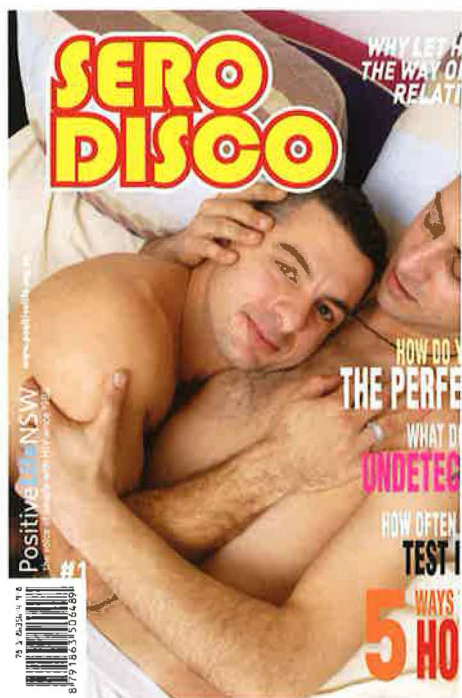
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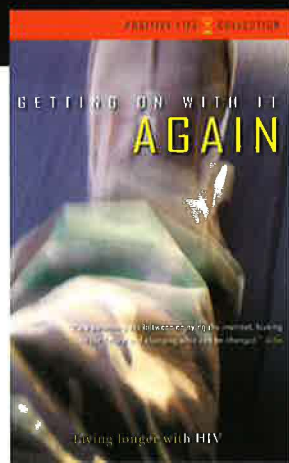
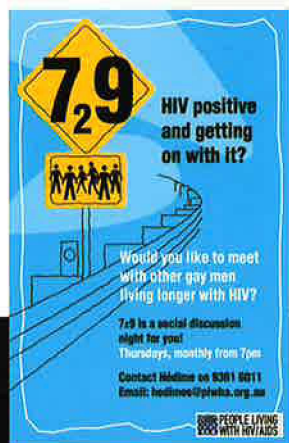
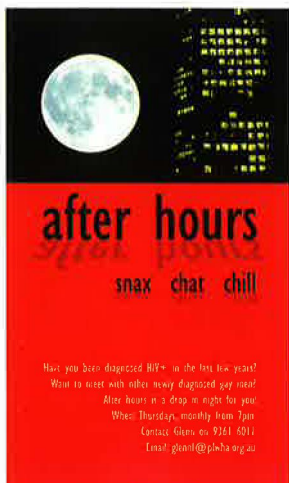


In your face – the poster at Town Hall station gave commuters some face

Another major ongoing campaign has been *Words to say it*, the title acknowledging that disclosure can be an obstacle in negotiating a range of activities, especially sex, since sometimes, for positive people, it is 'difficult to find the words to say it'.

Another area where PLWHA saw it worthwhile to venture was in supporting relationships. There were positive people in the early days, as there are today, who said 'I'm never going to have a relationship again', and likewise there are those who say 'I'll only have a relationship with someone who is positive, because it would be too frightening to have a relationship with someone who's negative in case I infect them', and those who say 'I don't want to have a relationship with someone who's positive, because I'm not sure if I could cope with that person dying'.²¹ The magazine *Sero Disco: Why Let HIV Get in the Way of a Good Relationship?*, published in December 2008, was a response to this.





The year 2003 also saw the introduction of After Hours, a venue for gay men who have recently been diagnosed with HIV to meet to share info, ideas, build support and social networks. Genesis was another innovative project: it was designed to help newly-diagnosed people make sense of the range of issues immediately confronting them, and to provide an opportunity to meet others in the same situation. ACON and Positive Life have continued to host peer support events ever since then. In 2007, there was a new regular discussion night – 729 – launched for people living longer with HIV. Similar to *After Hours*, 729 provides a regular discussion evening for gay men who were living longer with HIV; to coincide with this, PLWH/A had previously developed *Getting on with It Again*, a campaign developed using personal accounts of people who were living longer with HIV.

By voicing HIV-positive people's varied experiences, PLWH/A sought to encourage and provide helpful strategies for those coming face to face with the challenges of having lived with the virus, and its associated impacts, for a long time.

Living a positive life today

Positive Life NSW has achieved a phenomenal record of HIV advocacy over its two decades, often in the face of formidable opposition. This is demonstrated as one reflects on its beginnings as a group of volunteers focused on advocacy, advice and support within the community, to its becoming an accredited organisation, working in cooperation with the government, people with HIV, health care and HIV service providers to develop health promotion, education and prevention strategies, as well as continuing its advocacy work to improve the lives of people with HIV in NSW.

Talkabout continues to play a central role, as one of the great success stories of Positive Life. *Talkabout* has drawn great praise, for a variety of reasons and from a variety of sources: 'There's not a lot of publications that have gone for this long, and they have continued to be appreciated and have been widely accepted... the consistency of it, it is the most important, impressive thing.'²²

Health promotion has become the guiding force for the work of Positive Life, and indeed, its contribution to both the organisation and the community cannot be overstated. The diversity of the topics covered in the various publications help ensure that HIV-positive people have quick access to accurate and relevant information – information that plays a vital role in their ongoing health and well-being. And the psychological well-being of HIV-positive people is also catered for in the various peer and social support groups and events that Positive Life and ACON organises, from *After Hours* and *7z9* to *Planet Positive*, a bi-monthly social evening for HIV-positive people and their friends.

Making all this possible has been one of the greatest resources of Positive Life: its people, both paid staff and volunteers. And while work at Positive Life NSW can be hectic and stressful, its staff remain committed to supporting, and providing a voice for, people living with HIV: people whose voices may not otherwise have ever been heard over the last two decades:

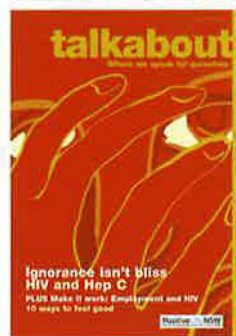
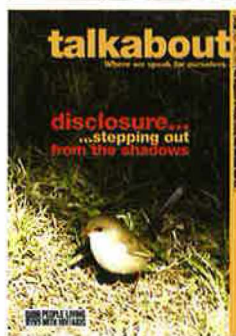
[There are] a lot of different angles which is an important thing for me, and that's why I've stayed here. The work is very interesting and very exciting, and forever changing. Sometimes you might feel really

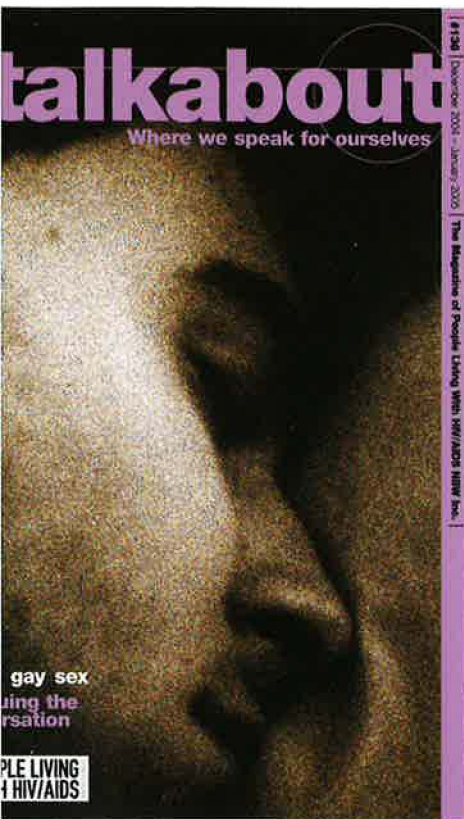
There's not a lot of publications that have gone for this long, and they have continued to be appreciated and have been widely accepted... the consistency of it, it is the most important, impressive thing".

Bill Whittaker

"The high point about Talkabout is it is constant, is its consistency, its being there".

Levinia Crooks





"My partner and I travelled as much as we could. HIV impacted on where we could go and how we could travel. In those days there were some drugs you had to keep in a refrigerator. I remember contacting an airline and asking if I could put some things in the freezer. They said no. I once posted the drugs to a hotel and they didn't arrive. Chasing courier companies to forward the package onto the next hotel. It was pretty scary stuff. You're running around the USA with or without HIV drugs, and you shouldn't be even entering the country. So we were able to create the first-ever travel brochure."

John Robinson



tired, because the work is full-on but the feedback makes you continue [working]. I've had emails with people saying 'Well, yeah, you do listen, and my opinion does matter,' and I think that comment stays with me.²³

There are still issues that matter greatly for people with HIV. The ongoing availability of effective HIV medications continues to be an issue, especially as new drugs are continually coming on the international market and must be licensed for use in Australia and payment via the PBS.²⁴ And while infection rates are low and 'stable' in NSW,²⁵ this very ability to manage HIV illness over long periods has been accompanied by a change in community concern about HIV, both among those likely to contract it, and even among those with it.

But while the epidemic has now lost much of its anxiety-creating aspects, it is no time for complacency. For complacency has its costs; not only in fluctuating infection rates – leading to the need for new targeted education programs (and the Grim Reaper has come back, this time as the 'Glam Reaper', a creature of the first decade of the 21st century) – but also in support, from people willing to be active in helping out. The end of the 'death sentence' for people with HIV was only achieved by concerted action from communities, governments and educators alike. But most important was the role of those activists, in keeping our concerns on the public agenda.

Today, with HIV for many a chronic illness, is HIV still THE rallying point? Has the need for an HIV identity started to wane? The immediate and ongoing impact of HIV is significantly different for a 55 yr old person HIV-positive since 1990 and for a 30yr old who has only recently seroconverted. Positive Life needs to



There are always new campaigns.

“Positive Life offers people the chance to find out more about HIV for themselves and be more actively involved in the positive community if they wish. From the hospital here, it’s a resource that I can draw on - that I know I can rely on. Now people live longer, and with our increased focus on ambulatory (outpatient) care, I see more people who I can refer to the organization - because they are looking for information or advice. Positive Life can take up where the hospital leaves off.”

Garry Trotter

ensure its advocacy and health promotion work support the needs of all people with HIV. These are questions that Positive Life is actively engaged with. A good barometer of the degree to which people with HIV have achieved acceptance is whether disclosure is no longer an issue. And disclosure clearly is still an issue, because the stigma still associated with HIV has not been eliminated.²⁶ In light of all this, advocacy remains a high priority. 'The advocacy role needs to be one that's never diminished...And I think that advocacy is going to be increasingly important as we look at HIV as a chronic manageable illness.'²⁷

Positive Life must never forget who it is advocating for: we are the stakeholders. But we have also learned the importance of working together, whether this is within our own community or with other communities, or with governments

that have the resources to deal with such an issue.

And we have learned that it was the courage of some people – their willingness to be frank and open about their condition, at a time when it was considered either foolish or dangerous to do so – that helped so dramatically in those early years. The standard of bravery and honesty established by those early advocates is part of our shared history and an ongoing inspiration to us all.

Perhaps a final lesson is that, for people with HIV, having an HIV-positive focused community organisation, able to speak and act for us, and set our own agenda, still remains important, even essential. Indeed, who better than us to articulate our concerns to the wider world?

And if we continue to believe in that, we need never give up hope.





Mardi Gras Parade, 1999

- 1 Paul Sendziuk, 'Denying the Grim Reaper', *Eurekastreet.com*
- 2 Michael Shernoff and Raymond A Smith, 'HIV Treatments: A History of Scientific Advance', *The Body*: at <http://www.thebody.com/content/art30909.html>
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- 4 David Urquhart, interview with Douglas Barry, 28 September 1998
- 5 Bill Whittaker, interview with Douglas Barry, 30 September 1998
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- 7 Ibid
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- 9 David Urquhart, interview with Douglas Barry, 28 September 1998
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- 11 Kirsha Thanapalasuntheram, 'A Reflection: 20 Years of Positive Life NSW', (internal document, Positive Life NSW), p3
- 12 Levinia Crooks, interview with Douglas Barry, 29 September 1998
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- 14 *Talkabout*, Vol 1, Issue 2, p16
- 15 Michael Shernoff and Raymond A Smith, 'HIV Treatments: A History of Scientific Advance', *The Body*: at <http://www.thebody.com/content/art30909.html>
- 16 Ibid
- 17 Irwin Diefenthaler, interview with Douglas Barry, 30 September 1998
- 18 Michael Shernoff and Raymond A Smith, 'HIV Treatments: A History of Scientific Advance', *The Body*: at <http://www.thebody.com/content/art30909.html>
- 19 'The good news', *Talkabout*, July 1996, p4
- 20 'Twopenny Opera', *Talkabout*, July 1996, pp10-11
- 21 Levinia Crooks, interview with Douglas Barry, 29 September 1998
- 22 Bill Whittaker, interview with Douglas Barry, 30 September 1998
- 23 Kathy Triffitt, interview with Kirsha Thanapalasuntheram, July 2008
- 24 'HIV drug reforms needed', *Sydney Star Observer*, 20 May 2009, p1
- 25 'HIV rate stable', *Sydney Star Observer*, 3 June 2009
- 26 See "'AIDS' has had its day", *Sydney Star Observer*, 27 May 2009, p13
- 27 Levinia Crooks, interview with Douglas Barry, 29 September 1998



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Day, 2009

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the voice of people with HIV since 1988