

UNITED WE STAND

A STORY OF SURVIVAL

For more than a quarter of a century the world has been battling AIDS and, as Nick Cook discovers, Australia has done better at it than most thanks to the cooperation between several very unlikely groups. The slogan for 1983's Mardi Gras was "On Our Way To Freedom"; by 1985 it was "Fighting For Our Lives". That's how quickly the world changed for gay men.

By the early '80s it looked like the worst of the equal rights struggle was behind them, with law reform on the agenda in most states, but that optimism faded in the face of a terrifying new killer that began striking people down by the hundreds.

1985 was also the year the AIDS Council Of New South Wales (ACON) was created. As it celebrates 25 years of achievement in the face of sometimes overwhelming adversity, it's worth looking back and reflecting on the epidemic that wracked Australia for more than a decade, defined gay culture as we know it and is still lurking in the shadows waiting for a moment of carelessness to pounce.

Even now, the speed and breadth of the toll as HIV took hold seems incredible. The first Australian case was diagnosed in 1982 and 500 people had died by 1988. By 1990 that had climbed to 888, by 1991 it was 1406 and by 1994 – the year the number of deaths peaked – it was 3017.

Yet, for all of that, the story of Australia's reaction to the HIV epidemic is a positive one, as this was one of the first places in the world where AIDS met its match. That happened largely because the three groups who were most vulnerable – gays, sex workers history, having to put a condom on. There's no way in the world you can make that fun."

Ultimately, though, there was no choice. ACON set a precedent by running an information and condom distribution stall at the 1985 Sleaze Ball, something they have continued at every Sleaze Ball and Mardi Gras to the present.

Those of us in our twenties and younger have trouble imagining the fear that gripped society. My only memory of it - my earliest memory, in fact - is of having nightmares about the Grim Reaper advertisements, but my mother, a nurse, remembers it only too well. Working in a regional area, she only saw a few cases of AIDS, but they've stuck with her in a powerful way. "I remember nursing one young man and everybody had to wear gowns, masks and gloves around him at all times," she says. "It must have been very frightening for him, because all he would have seen were eyeballs coming at him, but we didn't know enough about how it was transmitted and we were honestly terrified of taking this strange new disease home to our children. We were just ignorant."

When the kitchen staff found out he had AIDS they refused to serve him on regular crockery or bring meals to him, leaving them in the corridor instead, and when he died the undertaker would not touch his body. "They left a coffin for him to be placed in, his funeral

"Every day somebody you knew would die."

and injecting drug-users – joined together to cooperate with their traditional enemies: government and law enforcement.

At first there was doubt about the best approach to take. Bob Hawke's Labor came to power federally in 1983, just as the first Australian cases were being reported, and Health Minister Dr Neal Blewett found himself in the hot seat. By all accounts he acquitted himself admirably and is one of the heroes of Australia's AIDS response. He recalls conversations, as it became apparent the disease was spread by sex as well as blood contact, in which they tried to decide if they could sell abstinence and mutual masturbation to the gay community. They agreed it wouldn't be effective and condoms became the main line of defence.

Even that met some resistance. "It was unfathomable," says Oxford Street DJ Stephen Allkins. "The idea of having to wear a condom for sex for any reason while two gay men were having sex wasn't even outlandish, but just unnecessary. We couldn't get pregnant and that was part of the way we had fun because we could just splash anywhere. Condoms go against the natural dynamics of male sex and really, no matter what anybody says or how safe it is, it's the most boring practice in sexual was held in the hospital chapel and he was taken to be buried on the back of a ute. It's the only time I've ever known that to happen," Mum says, regret heavy in her voice. "All us nurses, when we're out together, still talk about that because it's haunted us for years how terribly he was treated."

It was by no means an isolated case. Kathy Triffitt and Julie Bates, two founding members of the People Living With AIDS Committee, recall some of the awful treatment received by hospitalised AIDS sufferers. "I remember being invited as a committee member to visit people in hospital," Kathy says. "They were dying. Staff put them in darkened rooms and bagged all their personal belongings. I remember one situation where they had even taken away someone's walking stick because they said he didn't need it. They had taken away his dignity."

"Every day somebody you knew would die," Julie says. "People were being left outside hospital wards. Bodies being double-bagged. Families not being able to see and pay their respects to their lost loved ones. There were many, many issues."

Discrimination was in no way limited to the medical profession. Kathy and Julie recount the story of a positive friend who worked for the Department Of Social Security and went out for lunch one day only to return and find they were disinfecting his office. Meanwhile, gay men were evicted from their homes, at least one dentist banned homosexual patients from his surgery and telephone engineers refused to carry out repairs at the Pitt Street mail exchange because it was staffed by a large number of gays who they said "probably had AIDS". Ansett and TAA airlines even banned HIV-positive people from travelling on their planes.

It was, in many ways, a perfect storm. Not only was the community facing a terrifying new fatal illness, in the public's mind it was coming from groups that had always been seen as outside normal society and vaguely threatening – gay men, injecting drug users and sex workers. In the early days it was actually called GRIDS, which stood for Gay-Related Immune Deficiency Syndrome. When three babies in Queensland died as a result of receiving infected blood transfusions a gang of men took to Oxford Street looking for somebody to punish.

"You couldn't make up a list of victims that was more charged politically," says HIV support group Positive Living's Rob Lake. "It was all the things that play on people's minds most: sex, death and blood."

Rob moved to Sydney from New Zealand in 1987, walking into the eye of the storm. "It was all pretty frightening and very much in your face. You would see people who were really sick on the street, in wheelchairs going up and down Oxford Street. Usually when you stop seeing an acquaintance you might think they've moved away or something, but back then it was, 'I wonder what's happened to them' and you feared the worst. There were a few acquaintances of mine I hadn't seen for a while, then I saw their obituaries in the paper."

Rob compares that first decade of the epidemic to a war. "I remember at various points it felt like being in the middle of some horrible battle. In the early '90s, when it really started to get more and more intense, there was that sense of everybody struggling to keep up. There were people queing in emergency wards, waiting for days because they couldn't get a bed on the wards."

I ask Rob about the more hateful reactions from the mainstream community, fishing for stories of homophobia and gay-bashings, but he's careful not to generalise, saying there were both good and bad responses. "There was real fear, and a lot of the tabloid media didn't help that at all, but there was also the other side as well. It was a really intense time, so people reacted really intensely and sometimes they went one way, sometimes they went the other. The number of straight people who jumped right in to help us, particularly around the care and politics, was huge. It wasn't only gay men and lesbians – we had a lot of allies."

One of the most heartening things was the government response, at many levels. As the epidemic worsened there was considerable pressure to follow the American model - which focused on sanction, isolation, quarantine and identification - but they chose instead to follow a course of prevention, forming alliances with community-level groups, such as ACON, to spread the message of safe sex and responsible drug use. The campaigns produced were targeted very specifically at the high-risk groups, could be very confronting and were often pornographic. "To get to the gay community you had to use language and material that it was very difficult to put the Government's stamp on, so it was very useful to have groups we could fund that would have responsibility for actually preparing the

parliament this year – caused outrage when he suggested that transmitting HIV is akin to drink-driving. Meanwhile, arch-conservative Fred Nile was swept into the NSW parliament by more than a quarter of a million votes that he attracted with anti-gay rhetoric. "When doctors called it the gay plague then people said to me, do you think God has actually sent this disease? Is it actually punishment? The Bible is fairly explicit about homosexuality," he says, in defense of his propensity in the '80s to quote Leviticus' pronouncement that lying with mankind as with womankind is an abomination. "Abomination is a very strong word. It means something God hates."

Ask many gay men what *they* hate and the name Fred Nile will appear very close to the top of the list. The deliberate and systematic

"We were angry that our friends were dying. We were angry that we were sick."

material," Dr Blewett told ABC's excellent documentary on the epidemic, *Rampant*.

It must have been very tempting for the opposition to turn it into a political issue and they no doubt would have been rewarded with a swathe of votes from conservatives who were unhappy about all the resources that were being directed to the "poofters, whores and junkies". In America the religious right used AIDS to consolidate their political power, but fortunately in Australia all major parties stood together on the issue. From the early days the approach was overwhelmingly bipartisan, an agreement that was formalised in 1988 with the National HIV/AIDS Strategy, which ensured committed funding over a four-year period.

Not that support was universal. Liberal MP Wilson Tuckey – who was finally booted from way he marginalised and demonised gay men and other HIV-affected groups infuriates people like David Buchanan, who was an ACON board member for almost 20 years. "Nile was exploiting a public health issue for personal gain," David says. "I remember him using his radio to spread lies, trying to scare people about gay men and lower their opinion of gay men."

There were calls to reopen quarantine camps, to stop gay men leaving or entering the country and in 1988 Fred Nile tried to introduce legislation that would ban the "blasphemous" Mardi Gras. The chair of the National AIDS Task Force, David Penington, supported that last idea. "I was concerned homosexual men, but also particularly bisexual men, would be likely to be visiting Sydney to participate in the sort of extreme promiscuous sex."

For gay men, it was the line in the sand, and they weren't going to back away. "All those debates were about, 'We're scum, we should go and hide," Stephen Allkins says. "No we shouldn't. We should be fighting harder or at least to show we are human."

Victorian AIDS Action Committee's Adam Carr had predicted the coming situation as far back as December 1984: "The community's tolerance for our existence, and its respect for our rights, have always been fragile at best and are now rapidly eroding... Unscrupulous politicians, extreme right-wing fringe groups, powerful religious bigots and a sensationhungry media will combine to exploit public fear and channel ignorance into bigotry and the search for a scapegoat... There is no doubt that we will have a real fight on our hands to defend our rights, our freedoms and even our personal safety."

Bill Whittaker, who was the first ACON executive director, describes the mood in the gay community: "You shouldn't underestimate the anger that was around in the '80s and '90s that was driving the response. We were angry that our friends were dying, we were angry that we were sick."

Bill quotes Dickens' *A Tale Of Two Cities* when he describes the period: "It was the best of times, it was the worst of times; it was the age of wisdom, it was the age of foolishness; it was the season of light, it was the season of darkness; it was the spring of hope, it was the winter of despair."

The challenges, he says, sometimes seemed overwhelming. "The gay community was understandably scared and despairing, as our friends and loved ones got sick and died in growing numbers. On top of the discrimination and stigma that gay men >>



Fashion company Benetton's controversial 1992 advertisement tapped into public anxiety about AIDS.



A poster issuing a rallying cry to fight AIDS.

>> had endured for so long, when AIDS struck it seemed like the cruelest of fates. Like many others, I feared our community would be wiped out. Other marginalised communities, particularly sex workers and injecting drug users, were being vilified as well. So in many respects it was the worst of times."

Bill says it was obvious to all that a collective approach was needed, though the exact form that would take was very much up in the air. He paints a vivid picture of the public meeting in 1985 that eventually led to the creation of ACON. "There was endless quibbling about the minutiae of the constitution, quite a bit of shouting... The meeting chair, Lex Watson,

with the media to counter the nonsensical views of some politicians and an impressive range of crackpots and pseudo experts."

The fight was tough, but ultimately the gay community won, emerging from the crisis stronger and more unified than ever. Mardi Gras was never banned and continues today as Australia's premier gay event.

Gay men represented 90 percent of the casualties from HIV, but sex workers and injecting drug users were also at extreme risk and both responded in a similarly admirable way. Prior to HIV it was common practice for sex workers to service their clients without condoms, something the men frequently

"Like many others, I feared our community would be wiped out."

pulled his hair out and smoked hundreds of cigarettes as the meeting went on and on."

Ultimately, though, an organisation emerged that was strong enough to last the next quarter of a century and provide invaluable help to HIV sufferers - and the gay community in general - along the way. "What counts is that the gay and other affected communities grew stronger, not weaker, during the first decade of ACON's work. ACON built bridges to all major political parties - we helped build the bipartisan political approach to AIDS. We built a strong relationship insisted on, but it quickly became clear that practice had to stop. To make it happen the women joined together, organising themselves into a Prostitutes Collective to convince those working on the street that it was in everybody's best interests to make the change to condoms. Eventually it got to the point that if a prostitute was found servicing clients without protection she would be run off. The brothels held out for a little longer, partly because they were not sanctioned by the law and were fearful that having condoms on the

premises could be used as evidence of illegal activity. However, as the AIDS epidemic worsened and there was a resultant drop in business they finally came on board, beginning with the Nevada, Australia's largest brothel, which made the conversion with much fanfare and publicity. The long-feared epidemic among sex workers, which would have infected the heterosexual population in a large-scale way, never eventuated.

Tackling the problem in the drug-injecting community presented its own problems. It very quickly became obvious that supplying clean needles was the only effective way to stop users from sharing and putting each other at risk, but that simply wasn't possible because the penalty for supplying needles for the use of illicit drugs was two years in jail. Doctors at Sydney's St Vincents Hospital tried numerous times to gain approval for a legal needle exchange, but were repeatedly stymied by bureaucratic red tape. Finally, with lives in jeopardy, they decided to act anyway and began illegally handing out the needles. When one of the doctors was taken in by the vice squad for questioning over the matter he explained the situation and was released, with a wink and a nod, to continue the work. Today more than 32 million needles are given out each year Australia-wide and there are clear distinctions between the rates of infection in those cities that were slower to introduce

> Recently retired Bingay Hostess Mitzi Macintosh. The wee event has helped ra st \$1 million fo CON since 1999



their own needle exchanges.

In the early years the fight against HIV was carried out mostly in a low-key way, with the general public only hearing about it when it surfaced in the media around panic-fueled reporting such as that which occurred when it was discovered that large parts of the donated blood supply were infected. That all changed in 1987 when HIV hysteria went mainstream, largely because of the notorious Grim Reaper advertisements. Everybody who was alive at the time, even those of us who were too young to properly understand it, remembers the chilling gothic imagery of a hooded Death picking up one bowling ball after another in his bony claw and sending them down the alley at trembling people.

"There was shock, horror, complaints, praise, concern – counseling services were jammed," says Ita Buttrose, who chaired the National Advisory Committee On AIDS. "It worked beautifully."

Dr Blewett chuckles when he recalls the feedback from that campaign, which has gone down in advertising history as one of the most effective. "It offended just about everyone, even ten pin bowling people who felt it was bad for business."

The point of the campaign was to make the wider community aware of the risk of AIDS, scaring them into practicing safe sex and proper drug hygiene. It certainly worked, but it also had the unintended consequence of stigmatising gay men by making it seem like they were the Grim Reaper striking down innocents. Despite that, Dr Blewett stands by the campaign. "I'd much rather have that attack than be slow to react and have lots of heterosexual cases in 10 years time. Also, by making the disease mainstream it made it harder for my colleagues to resist putting money into it."

"Personally, I didn't like it," says David Buchanan. "I understood the need to stop people in their tracks. Whether that was the best way to do it... I'm not convinced sensationalism is the best way to address a

"It was all the things that play most on people's minds: sex, death and blood."

public health issue. What's always been more effective is the print media that generated the safe sex culture."

Professor Ron Penny, who diagnosed the first AIDS case in Australia and whose name is synonymous with the response to the epidemic, was on the Government body that approved the release of the campaign and has apologised for its negative side effects. "I think that was unfortunate and we had never intended that to happen," he says. "I think there's never been anything on television or any media that has ever matched it in terms of impact, but no advertising can be without some downside and that was never intended. But it at least made people aware and probably it did change sexual practices of heterosexuals."

Whatever your opinion of the advertisement, one thing cannot be disputed: the "second wave" of infection that swept through America and Europe infecting drug users and their sexual partners, as well as heterosexual men, women and their babies, did not eventuate in Australia.

Of course, Australia's response to HIV was not perfect. There were significant gaps, including the fact that Tasmania refused to

decriminalise gay sexual activity and Western Australian set the age of consent for gay men much higher than that of straight people, making it difficult in both cases to target the community with safe sex campaigns without seeming to condone illegal activity. Meanwhile, the Queensland Government refused to communicate with its AIDS Council or distribute educational materials, meaning the Commonwealth had to channel funds through the Catholic Sisters Of Mercy – who Dr Blewett called the "most cheerful and >>



>> altruistic of money launderers".

Overall, though, Australia's response is held up as an example of world's best practice, particularly when compared to the United States, where abstinence was preached over condom-use and clean needles were never handed out in the widespread way they were in Australia, and Britain, where Margaret Thatcher's notorious Clause 28 prevented anybody from "promoting homosexuality", which severely limited the ability of AIDS groups to educate the community.

Paul Sendziuk, a postdoctoral fellow in history at Monash University, studied the epidemic for his book, Learning To Trust: Australian Responses To AIDS, and says that Australia's reaction to the virus is the role model that other nation should aspire to. "Countries such as Russia and the Ukraine, without explicit safe sex education or needle exchange programs and now experiencing the fastest growth in new HIV infections in the world, have much to learn from Australia's pragmatic approach. Australia's success should also prove illuminating to those public policy-makers and community leaders who scorn 'harm reduction' approaches to social and health problems such as drug use, and who are still reluctant to trust and empower marginalised communities to care for themselves."

Australia's doctors and health care professionals – and especially the gay, drug-injecting and sex-worker communities – recognised the problem early and acted together in a way that mimimised harm but, for the most part, allowed all those involved to keep their self-respect and civil liberties. In all, 6,500 have died from AIDS, which is well short of the 50,000 deaths that were predicted at one stage. All those who were involved in the battle against AIDS deserve to be congratulated.

But none of that lessens the tragedy for those who were close to the 6,500. Some lost the majority of their friends. Of all the founding members on the People Living With AIDS Committee, only Julie Bates and Kathy Triffitt are still alive.

"My feelings about that time?" Julie says. "Mixed. More sadness than happiness. But you took the sadness with the happiness. Every day was a new challenge. You didn't take time out to grieve too much. I think if we had we would have been overwhelmed by it."

"There was laughter and sadness," Kathy says. "I think we were tighter as a group back then. They were very difficult times. Times when you thought you were losing it, but something would just come along and sweep you up and you'd find the energy to go on. I think there's a feeling of pride."

"And honour," Julie adds.

"Yes, pride and honour." *



Community Support Network volunteers in 1985, the year ACON was established.



A series of HIV awareness images by artist David McDiarmid, commissioned by ACON in 1992.