

THREE DECADES OF (ACON)IC MOMENTS

SINCE ITS TRAUMATIC ORIGINS IN AUGUST 1985, DURING THE EARLY YEARS OF THE HIV AND AIDS CRISIS, ACON HAS EVOLVED INTO A DYNAMIC AND MULTIFACETED HEALTH PROMOTION ORGANISATION. WITH THE END OF HIV TRANSMISSIONS NOW IN SIGHT, IT IS STILL AN ESSENTIAL AND ENDURING PART OF NSW'S HEALTH SECTOR.

DON Baxter can still remember when he received nasty fax messages while he was chief executive of ACON.

It was during the organisation's early years, when it worked closely with political activists — including ACT UP.

"As a radical activist organisation ACT-UP was publicly critical of ACON, in some cases, quite properly," Baxter recalled.

"At one point... in the early 1990s I received faxes labelling me a 'serial killer'. It wasn't fair — but in those years thousands of our friends were dying so it was understandable that emotions ran high."

As it celebrates its 30th anniversary this August, ACON has not only come a long way but it also continues to operate as a key player in NSW's and Australia's ongoing response to HIV.

"This is certainly an achievement worth celebrating, especially when you consider how we got here," current ACON president Mark Orr said.

"In many ways, ACON's story is the story of our community over the last 30 years — an incredible journey full of sadness and suffering but also marked by compassion, joy and, most importantly, love, in all its glorious forms."

Baxter could still recall when ACON was founded, with the purpose of responding to the onset of the HIV and AIDS epidemic.

"By mid-1984 a number of other AIDS organisations and groups had been established to provide care and support for the sick and HIV-infected, educate the gay community, advocate to government and raise funds," said Baxter, who was an early member of the AIDS Action Committee that formed in 1983.

"The newly-elected (Hawke) Government indicated it would fund a community response but wanted the existing groups to coalesce so there was one funding contract.

"Within four months, the existing separate organisations agreed to form what was to be called the AIDS Council of NSW. This proposal was unanimously endorsed by a large community meeting at the NSW Teacher's Federation in February 1985 — under the large

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banner 'Fighting For Our Lives.'

When ACON's first Governing Committee was subsequently formed, Baxter was elected. He then became its president in 1987 before taking on the role of chief executive from 1990 to 1996. Baxter's rise in ACON came on the back of his work in gay law reform in South Australia before he relocated to Sydney in 1978.

"From 1981 became concerned about reports of the mysterious deaths of gay men in California," he said.

"By 1983 a number of us were becoming gravely concerned about the future of the emerging gay community we had helped establish and decided to organise and address this worrying challenge."

Indeed, the brutal reality of what ACON was confronted with during its early years overwhelmingly shaped its service delivery.

"When ACON was founded it was operating under crisis conditions and everyone was scared," Baxter recalled.

"Even back then with all the disfiguring disease and death around us and the sense of incomprehension, helplessness — [there was] also anger and determination to protect the gay community."

Initially, ACON had a small staff and many volunteers, but from 1987 to 1992 the organisation expanded rapidly. Nonetheless, in its first decade it was HIV-focused. A lot of people living with HIV were doing it

tough and ACON helped look after them by providing the care and support they needed.

"Our objectives were to influence government policy, achieve appropriate government funding, increase our volunteer base, ensure the sick were cared for, to educate high risk communities, to stimulate research, and promote our prevention work," Baxter said.

"We also advocated for changes in the law. For example, HIV tests were not confidential back when the epidemic first began, which put a lot of people off from being tested. If you tested positive your name would be lodged with the Department of Health."

ACON also advocated for the reform of drug evaluation processes. Perhaps the most significant success story from this area was when it helped make AZT available to the public.

"The 'Make AZT Available' rally in 1987 saw several thousand activists and supporters rallying outside the State Parliament because the NSW Government was not going to pay for AZT, which back then was the only drug that was offering any hope to people with HIV," Baxter remembers.

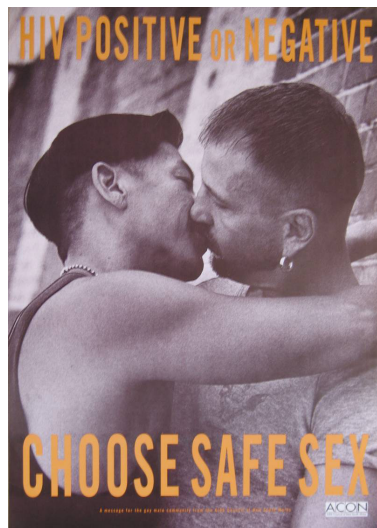
"The rally was very successful because the government caved in immediately and set the precedent of HIV drugs being automatically available to all people with HIV."

The success of the AZT rally certainly set the foundation for future milestones. In 1994 ACON became one of the first to get large numbers of people on Anti-Retroviral Treatment (ART) into trials. Baxter believes that was a "major game changer," as ART was eventually listed under the Pharmaceutical Benefits Scheme in 1996.

"[It] saved many lives," he said.

"There were some people who had literally said goodbye to their families and were preparing to die, yet when they were given this new treatment they literally were able to leave the hospital a week later feeling better and on a course to a long term recovery."

Another one of ACON's major contributions was its work with state and federal governments to develop a National AIDS Strategy in 1987. It became the first



of the five-year strategies that are now routine and set out a uniform and positive response to HIV involving the communities at risk – men who have sex with men, injecting drug users and sex workers – at all decision-making levels.

Mark Orr said ACON has played a key role in mobilising and embedding affected communities into the HIV response.

“Our models of peer-based education are a great example of this approach, as were the care and support that ACON staff and volunteers provided to the sick and the dying during the devastating early years of the epidemic,” he said.

As treatments have improved overtime, the services ACON provides for people with HIV have also evolved to respond to the changing impact of the epidemic. Because of this, since 2000 ACON has branched into new areas of health covering drug and alcohol, mental health, healthy ageing, and family and domestic violence.

“We’ll see a lot of organisational growth and development over the next 10 years in this area, as governments at all levels increasingly recognise the distinct health needs of LGBTI people and communities,” Orr said.

“[This] has also helped foster a wider interest among employers about making their services and workplaces inclusive and supportive of LGBTI people. To meet the demand, we’ve created a new training and consulting division within ACON, which includes our Pride in Diversity program, and we anticipate strong growth in this area over the next decade.”

However, peer education and support remain ACON’s core services – especially for newly-diagnosed HIV-positive people who may be left wondering what it would mean for their work, family relationships and sexual relationships. In addition, there remains a population of HIV-positive people who need specialised support.

“ACON’s education campaigns throughout the years have also

helped change the way people in our community engage with health issues, especially those related to their sexual health.” Orr said.

“The success of our approach has been through reflecting the lived experience of LGBTI people and people with HIV, and delivering information in a positive, evidenced-based and non-judgemental way.”

Orr added that today’s confluence of political will, scientific know-how and community support can significantly reduce the impact of HIV. In addition, more gay men are testing for HIV than ever before, while over 90 per cent of HIV positive guys now on treatment and the majority of gay men use condoms.

“Advances in HIV treatments mean the health outcomes of HIV positive people will continue to improve over the next 10 years, so we’ll continue to adapt our services to provide the most useful support and assistance that we can,” Orr said.

“We have our sights set on ending HIV transmission in NSW by 2020 by getting gay men to test more, treat early and stay safe.

“To help meet our goal, we’ll continue to promote innovative education campaigns as well as work to get gay men access to the latest HIV testing, treatment and prevention technologies, such as PrEP and home-based testing.

“We’re well on the way to achieving this.” ✱

Photos in order:

ACON’S Positive Women Mardi Gras parade float, 1996. ACON has supported women since 1985 by providing a range of services and support groups.

Former Bingay Hostess Mitzi Macintosh with Bingay’s original barrel boy 1999. Bingay supporters have helped raise over \$1 million since 1999.

ACON’s first Mardi Gras Float, 1986. Since this first entry, ACON’s Mardi Gras float has grown to one of the largest in the parade.

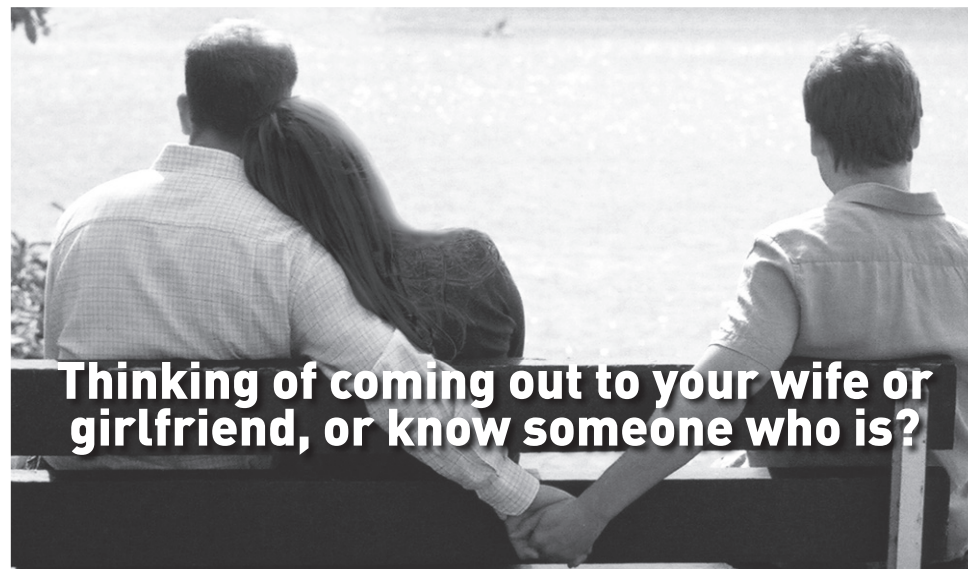
Community Service Volunteers 1985. Since 1985 more than 1500 volunteers have provided home-based care and support.

Out West support group, 1994. ACON has provided location-based and outreach services to western Sydney since 1989.

Lismore Mayor and ACON Northern Rivers Staff launch an anti-homophobia campaign 2000. Since 1987, ACON has worked throughout regional NSW through its offices in the Hunter, Illawarra, Northern Rivers, mid North Coast and southern NSW.

ACON float from Mardi Gras 2015.

Choose safe sex advert from 1994.



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