

20 years on

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In his speech at NAPWA's 20th anniversary reception, Kenn Basham recalls NAPWA'S vital role in the community response to HIV.

Twenty one years ago, at a conference on AIDS in Hobart, a group of HIV positive people from around Australia met face-to-face for the first time. There had been national conferences on AIDS before this, but they were attended by epidemiologists, doctors and clinicians from various fields of interest. In 1988, the Federal government made available funds for HIV positive representatives from all of the States and Territories to attend. Already, groups had coalesced in many of the capital cities. Set up by the generally political savvy gay communities, they were answering a need for both service provision and the lobbying and advocacy needed on behalf of those with HIV.

Those of us who were there as positive people were presented with a total lack of content that was directly of benefit or interest to us. There was little or no discussion on the direct needs of those with the [virus](#) [1]A small infective organism which is incapable of reproducing outside a host cell.. We felt as though we were there as the subject of the research, with no ability to feed into the system ourselves. Remember that this was a time when our friends and loved ones were dying at an alarming rate. People were visibly ill, and there was no time to waste. Action was needed now. By the end of the conference, we were wearing large badges that proclaimed 'Talk to us, not about us', and had stood on the stage as a group HIV positive people and addressed the audience as to what we saw our needs and priorities as being. The national voice of HIV was heard for the first time.

Following on from this was a Melbourne meeting. Most of these same people plus many more positive people from around the country attended. At a time when a 'long term survivor' was someone alive two years after diagnosis, things had to happen quickly. Luckily, we were in a rare time and place politically. There was a Federal Health Minister who was willing and able to listen. Through his staff and advisors, the gay communities had a voice direct to someone who could make a difference. As early as these times, the necessity, and power, of a combined national voice was recognised at a high official level. Combined lobbying was proving much more powerful.

The problems of access to therapies, Medicare coverage, advocacy in the hospital system and legal fields and lobbying of governments needed a united national approach. It was early on in the days of being open about your status. Some amazing people came forward to fill these public roles. To be a spokesperson or representative on behalf of HIV positive persons was still a brave thing to do. From each State and Territory came representatives of the peer based HIV organisations. Other parts of what was to become the HIV sector were also forming. The Australian Federation of AIDS Organisations ([AFAO](#) [2]Australian Federation of AIDS Organisations. AFAO is the peak non-government organisation representing Australia's community-based response to HIV/AIDS. AFAO's work includes education, policy, advocacy and international projects.), representing the AIDS Councils, came into being at around this same time, and largely with the involvement of the same pool of people. The Australian chapter of ACT UP (Aids Coalition To Unleash Power) began its protests soon after. Those who felt the need for more direct action took part in the zaps and protests offered here.

In many ways, this ability to pick and choose the level of action or protest at which you wanted to be involved was essential for the success of the new AIDS movement. Yes, there was that 'hard core activist' who had a presence in all or most of them. Others chose to use their talents in a targeted political lobby. Some were working within the system itself, gently 'suggesting' and 'guiding' the discussions. A broad spectrum public faces of 'the HIV/AIDS problem' was there for the choosing, and allowing some, such as NAPWA and AFAO to be seen as the 'respectable and sensible' face of HIV. 'The easy ones to work with' was a reputation it took a long time to acquire. Anger and frustration could be channeled through the more direct route of ACT UP and the like. They could be the loud and obnoxious attention seeking face of those working for the rights of positive people. Of course, the perception that there was only one group of people sometimes worked against us. The different bodies had to be kept separate in the mind, if not the staffing.

I'm convinced that this is a large part of the reason for NAPWA's success. We have always had the reputation of a professional and effective organisation that genuinely represented the national HIV positive voice. This comes from the process that allows those willing and able to do some work for their HIV positive community to choose their

level of involvement in their area of interest that they feel able to commit to.

The other reason, in my belief, that we have always had such a professional reputation within the sector, is the remarkable calibre of person working for us. Whether as a State/Territory representative, member of a Working Group or Portfolio, Board Member or Secretariat member, theirs is a shared ethic that has kept NAPWA as the recognised peak body of representation for HIV positive Australians. I have observed the driving personal belief and commitment that is necessary from those in every level of our organisation.

David and I were asked to say a few words today, because we are two of the people who have had a relationship with NAPWA throughout its life. By no means are we the only two. There are many who have given an amazing amount of time and energy to NAPWA and are still involved within the sector, somewhere within the hierarchy that has grown over the years. There are those who are now taking some well earned R&R and will return. There are those who have made their contributions and moved onto other areas of their lives. But they have all been extraordinary people, driven by personal belief and commitment to work for others within their community. To improve the lives of HIV positive Australians has been the common goal, but each has brought their own special areas of interest and expertise to bear. We each have our own style of operating (and agenda that we operate to).

When Jo first spoke to me about today's celebration, one of the things she asked of me was to provide a few 'personal memories' and 'maybe a story or two'. In thinking over the last twenty years, it has brought back many memories involving many, many people. However, I find it hard to single out particular events and impossible to mention all of those who deserve to be. I also find myself in a much more reflective space than I anticipated, hence the lack of funny anecdotes I'm afraid.

We have been represented by many impressive Presidents and Vice Presidents over the years. Confident and assured people of both sexes have represented us in their areas of speciality. Executive Officers, some HIV positive, others not, have worked exceptionally hard to maintain our reputation and keep us in the loop. We are still involved with the forward planning of National Strategies, still present on inter-governmental panels and still considered the 'Umbrella Group' of Positive organisations throughout Australia.

Keith Harbour, our first public voice and face, was someone to whom we owe a lot and someone who is hard to forget. There have been people like Ian, having done return tours of duty in both NAPWA and AFAO. He and others have done multiple stints in various positions. There was our first female President, Gabe, who broke many of the stereotypes and presented a whole new face of HIV to the public and to the government. Charles, Bill and many others, all bringing their own areas of specialisation and expertise, each guiding us through the varying phases of this epidemic. To all of these people, and to far too many more to mention, we owe a great debt.

As an organisation that sits firmly within the community sector, it is rare for the combined beliefs, talents and abilities of a series of essentially volunteers, to maintain the standards we have held for twenty years. Our mission, to improve the conditions of HIV positive people's lives here in Australia, and our near neighbours in [PNG](#) [3] Papua New Guinea, remains as strong as ever. Whilst we have gained much, and many of the things we asked for twenty years ago are now reality, there still exists the need to represent the needs of the HIV community to the broader world. Advocacy is still required. Representation is still needed. NAPWA is still needed for the best outcomes to occur.

There are two slogans that stay with me from that far off time. 'Silence = Death, Action = Life' and 'Talk to us, not about us'. Both are still relevant and both still ring true. For me at least. And both still represent good reasons to be involved with this entity called NAPWA, an organisation that I still see as being relevant and useful. One that I still enjoy my relationship with, twenty years on.

- [20th anniversary](#)
- [NAPWA news](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/125>

[2] <http://www.napwa.org.au/glossary/term/385>

[3] <http://www.napwa.org.au/glossary/term/144>

