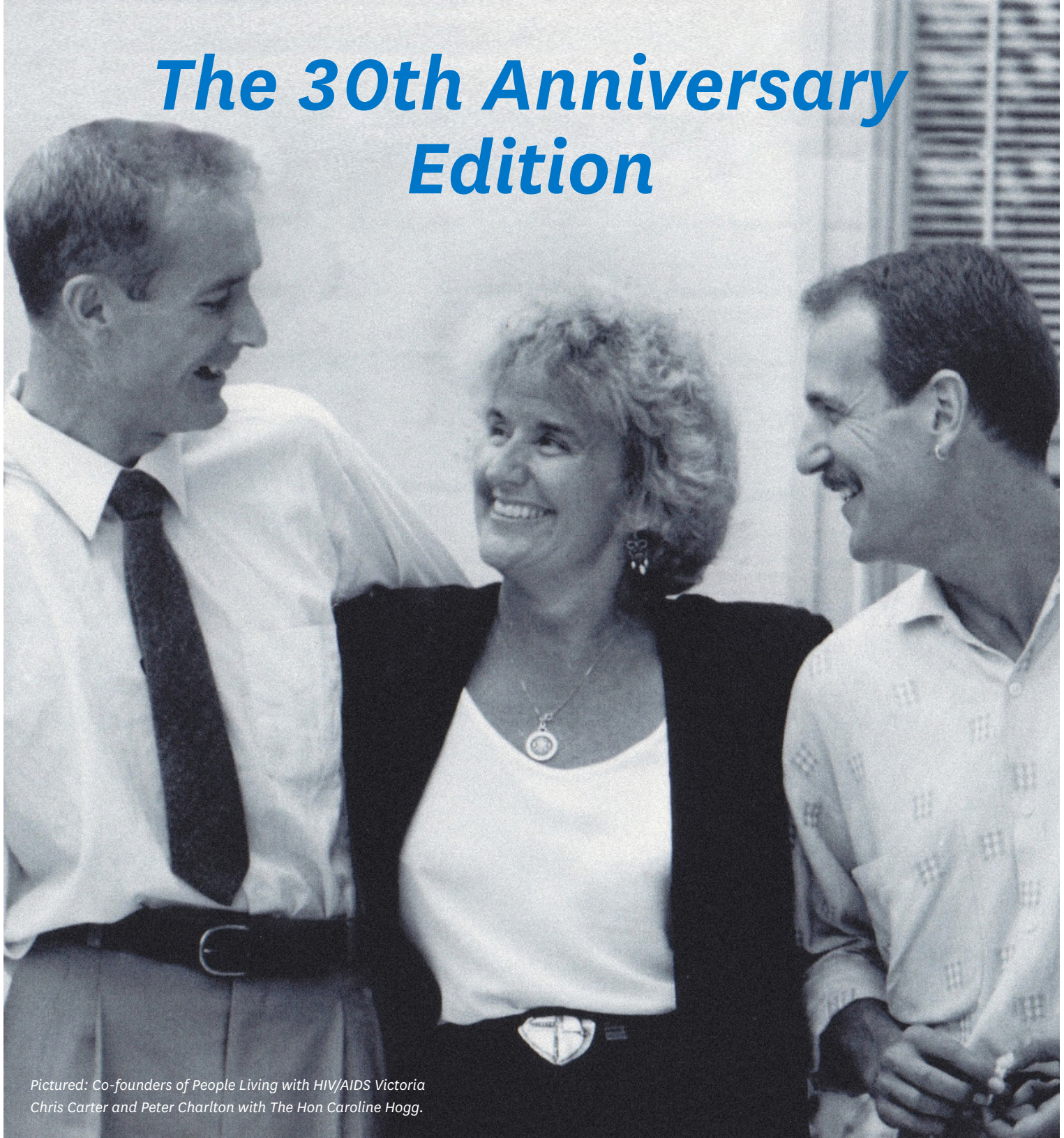


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*Pictured: Co-founders of People Living with HIV/AIDS Victoria
Chris Carter and Peter Charlton with The Hon Caroline Hogg.*

THE EARLY YEARS

By David Menadue

It's probably quite difficult for people to imagine how different life was for people living with HIV in 1988. For starters we didn't describe ourselves as people living with HIV. Maybe HIV-positive but often wrongly as people with AIDS (or PWAs) when many of us had not even had our first AIDS-defining illness.

We had no sense of our own identity as a particular group and certainly not as any political entity. The early cases of AIDS, when there were no antiretroviral treatments, often led to very quick and difficult deaths. The Victorian AIDS Council (VAC) had begun in 1983 with a strong prevention and education focus but providing volunteers to support people with AIDS was also a central part of its mission. People with AIDS saw themselves as largely passive recipients of care and without a significant peer-based organisation many were often unwilling to speak to the media or disclose their status to anyone else.

This was to change when Keith Harbour became the first openly HIV-positive President of VAC and when other prominent positive people like Chris Carter and Les Taylor became involved with the idea of setting up a peer organisation for people with HIV in Victoria. They had seen the developments in other countries like the USA where a political movement of HIV-positive people was beginning in cities like San Francisco and New York.

In July 1988 a meeting was held at St Martin's Theatre in South Yarra which decided to set up a People with AIDS group under the auspice of the Victorian AIDS Council. A few months later, People with AIDS Victoria was given money to appoint Peter Charlton as our first employee under a new program of the Council. Chris Carter was elected as our first Convenor and insisted that we be called People Living with AIDS Victoria (later changed to HIV/AIDS when we realised a number of people weren't developing AIDS illnesses). The accent was to be on living with (not dying with!) the virus. Unfortunately Chris Carter passed away not long afterwards and in October 1989 I became Convenor of the program.

Our first task was to find a Positive Living Centre. Money was given to us by the state government to find a suitable place where the nearby residents wouldn't object to people living with AIDS coming for lunch or meetings on a regular basis. We appointed a positive woman, Deborah Gillies, to find a building and we experienced a lot of knockbacks from estate agents and councils.



Eventually, after makeshift places were found in South Melbourne and then Prahran, we found an ideal place in Caulfield but it was clear the local residents were going to object once again.

Along with the mother of a gay man who had died from AIDS, Joan Golding, I was tasked with the job of speaking to the media to try to get support from the local community for the centre. Not only did the local press turn up (which we wanted) but all the major TV cameras and newspapers attended our press conference and before I knew it, we were on that night's news bulletins and in the next day's papers. I hastily rang my mother in the country to prepare her for this blaze of publicity. My family had been very supportive when I was ill in February that year with my first AIDS-defining illness (PCP/PJP) I hoped they could cope with this sudden revelation to their local neighbourhood that I had AIDS. To their eternal credit they coped amazingly well and my mother was to say that if anybody ever mentioned it to her, it was as a supportive comment to her or about me, in the hope that I would survive.

St Kilda Council (as it was then) came to our rescue when Caulfield Council refused to budge and they provided us with a lease on an old backpacker hostel in Acland Street St Kilda. In April 1993 we finally had a Positive Living Centre of our own. The program then started to build, with the employment of Centre workers, a Peer Support Officer and Treatment Officers. There were many things on our advocacy agenda too: fighting to keep Fairfield Hospital open, dealing with the state's "reckless endangerment" laws, access to AZT and the few other antivirals available and basically trying to establish the

role of a "positive voice" in the AIDS Council's deliberations.

Given the turmoil that HIV was creating in so many of our lives in the nineties, when the death rates were soaring, it is no surprise that there were tensions within the AIDS Council. One clear division developed over whether PLWHA Victoria should become a separate organisation as people were becoming more confident about disclosing their status and wanted to focus more on advocacy issues rather than the service provision work that running the Positive Living Centre mainly involved. After a Review of the AIDS Council's structure in 1997 it was decided to create a separate PLWHA Victoria organisation. John Daye became its first President and I was his deputy. This was the beginning of Living Positive Victoria as its own organisation (although the name change came later).

Over the years Living Positive Victoria has made a great contribution to the quality of life of HIV-positive people in this state, advocating for better services, working in partnership with hospitals, service providers and government. It has been the strong voice in our corner when stigmatising messages in the community or the media have reared their ugly heads and the wonderfully committed staff (many of whom have been with us for many years) have ensured that education and health promotion—including looking after those of us who are ageing—have been a vital part of its mission. Others can talk about our more recent history but from those of us who were there 30 years ago, we are so proud you are still here, probably more powerful than ever! Towards a cure but we'll need you for some time yet.



CHRISTMAS HAMPERS, DRAG QUEENS AND SEARCHING FOR A CURE

By Sarah Garner

I was in my early 20s and at medical school when my dad told me that he was HIV-positive. By that time, I'd already witnessed first-hand how the disease destroyed young lives. On the wards I tended to young men with eye infections, fungal pneumonia and brain lesions. Their conditions were debilitating and often terminal and their mental condition was even worse. I started delivering Christmas hampers with my dad and other volunteers in the hope that it would provide at least some measure of much-needed feelings of support—a tradition I continue to this day.

At the time my dad told me of his condition there was new hope in medical circles. It came in the form of newly-available combination anti-retroviral therapy, which promised incredible improvements in both quality and length of life for people. And it was during these early years that I first saw the wonderful work of Infectious Diseases physicians such as Ian Woolley that ultimately inspired me to follow the same career path.

I remember going to my first Living Positive Victoria (then People Living with HIV and AIDS Victoria) events with my dad back in the early 2000s. There were casual get-togethers in St Kilda, walking in the pride march on hot January days and health-focussed events with dietitians like Jenny McDonald and drag sensation Vanessa Wagner. I was an awkward young woman that was very shy, but I always felt welcomed by this extended family. My best friend from university often came to events with us as well and it was a real eye-opener for him as a young gay man.

I was often overcome with emotion listening to the stories of the men around me. Stories of desperation and abandonment. Of giving away all of their possessions thinking they were about to die. Brave activism and being openly gay and HIV positive when there was so much to lose and so much stigma —there still is today of course but it was so cruel and awful in those early days. Men like David Menadue became my heroes. I struggled with the dry parts of medicine and with the relentless long hours of study, impatient to quickly further my career so that I could truly make a difference.

It's been a long time since I first volunteered to deliver Christmas hampers with dad as a junior doctor. Last year was the first year we had missed in a long time due to his own hospitalisation, but not this year! Christmas just didn't feel the same. It's always been a great way to start Christmas morning. While others go to church or start their celebrations, we come to the wards of the public hospitals, to Berry Street and sometimes to private homes to deliver a bit of Christmas cheer. If I'm on for work we sometimes start a bit earlier and then I do my ward round after we finish.

It's often an emotional time—there are still some that we visit that tell us that we will be their only visitors for the day. There are tears, laughter and lots of hugs. As major causes of death in Australia such as heart disease and cancer capture public attention, HIV is being shoved into the background and our extended family members are being forgotten. But we can reach out with empathy and let them know that they are not alone—kind words can ripple out and touch those even in the darkest depths of despair. I continue to work and volunteer in the HIV sector as the story is not over yet. Many people are still without adequate treatment and support and continue to be debilitated by HIV. If we can find a cure and vaccine I know this could lead to more equality.

And it's with this conviction that I decided to pursue a PhD after completing combined physician and pathology training. I love seeing individual patients and enjoy taking a holistic approach to their care, but I wanted to have a go at tackling the disease with a basic science platform, as I saw this as a way to make a difference to many more people at the community level. I wanted to research HIV and the immune system and found a lab that was using exciting cutting-edge models to use our own cell mechanisms to try and kill latent cells. I wrote a passionate scholarship application that touched on my personal links to the disease and was fortunate enough to start at the Walter and Eliza Hall Institute in 2017.

PhD life can be hard. I'm 18 months in and there seems a long way to go with no end in sight. The laboratory work can be monotonous and feel a bit thankless. But I've had a much-needed boost after going to Living Positive Victoria's 30th Birthday celebrations with my dad and many of you amazing people. It was wonderful to catch up with many people I haven't seen for years and see a community that is really thriving! There is vibrancy in the organisation that reminded me of why I do the long hours in the lab and continue to challenge myself with study. Thank you to each and every one of you who are my inspiration!

CONTINUITY AND CHANGE: 30 YEARS OF PEER PROGRAMS IN VICTORIA

By Sara Graham, Manager of Peer Support

The face of HIV is changing as Living Positive Victoria enters its 30th year.

Recent reports that there has been a reduction in HIV notifications in Victoria provide welcome news. However, these figures hide an increasing rate of diagnoses among heterosexuals and Asian born men who have sex with men. The population of people living with HIV is also ageing, with 46% of people living with HIV aged 50 years or over¹ in 2017. The merger of Living Positive Victoria with Straight Arrows last year and the expansion and introduction of some key programs such as the Peer Navigation Program have been instrumental in building the capacity of Living Positive Victoria to respond to these developments.

Before effective treatment, Living Positive Victoria and Straight Arrows focussed on advocacy, fighting stigma and the care and support of people facing illness and death. With the introduction of highly effective HIV treatment in 1996, services shifted towards providing information and support to live well with HIV, including issues such as treatments and their side effects, having families, sex, relationships and disclosure, and planning for a future many people didn't expect to see.

In 2018, most of the newly diagnosed clients we work with have already started treatment. While many still have questions about their medication, they are typically on a one or two pill a day regimen with relatively few side effects. Today, people living with HIV are far more likely to need

support with growing older with HIV and we have introduced programs to address these complexities. We are also working with increasing numbers of people from migrant and mobile populations. Most recently, we have created several resources in Asian languages and have launched peer-led initiatives such as a support group for people from a Latin American or Hispanic background.

Sex, relationships and disclosure are still important concerns for our clients and members but the conversations are shifting. Campaigns about Treatment as Prevention or U=U, and knowledge about PrEP are beginning to break down the sero divide. These biomedical prevention methods give people living with HIV and their HIV negative partners confidence in their sexual lives and simplify conceiving a baby. However, there is still a lot of work to be done in getting the U=U and PrEP messages out there, particularly amongst people from migrant backgrounds, women and heterosexual men living with HIV. These groups can find sex, dating and relationships particularly difficult, as they negotiate the fear, stigma and lack of knowledge about HIV in the general population when they disclose their status to potential partners. This is a common theme discussed with our Peer Navigators and is addressed in our peer led programs.

We have responded to the increase in HIV notifications among women and heterosexual men with the introduction or expansion of some key programs. These address the perennial themes of social isolation, disclosure, treatment, sex, dating and relationships, and biomedical



prevention. Our annual retreat for women and heterosexual men is an effective way to provide information and support. The highly successful Phoenix workshop for women recently diagnosed with HIV was introduced in 2016 in partnership with Positive Women Victoria. Other initiatives are our bi-annual Women's Days and the monthly Cook 'n' Chat peer support group for heterosexual men. We have continued with our Christmas Party and Camp Seaside, and social events for men, women and families. Over time, we have increasing numbers of people who are attending these events and staying engaged with our services. Importantly, people are making friends and providing each other with social and emotional support outside of our services

The introduction of our Peer Navigation Program this year has been important in engaging with people soon after their diagnosis.

For example, in the past many heterosexual men would typically wait for years before approaching our service when they were in crisis.

Under the Peer Navigation model they are being referred to a Peer Navigator soon after diagnosis. This helps them link into services and adjust to their diagnosis sooner and with greater levels of emotional and practical support. Our Peer Navigators are also seeing large numbers of Asian born men who have sex with men, many of whom are socially isolated and have difficulties navigating the Australian health, immigration and community service systems. The Peer Navigators are providing important, trusted support in managing their diagnosis, social engagement and adjustment to living with HIV.

The strength of the Australian response has been its engagement with affected communities. This is echoed in peer based organisations such as Living Positive Victoria who work directly with our community and have the flexibility to adapt to changes as they arise. As the organisation turns 30 we recognise that it is important that our programs and services remain relevant to our community and adapt to the changing face of HIV in Victoria.

¹ https://kirby.unsw.edu.au/sites/default/files/kirby/report/KI_Annual-Surveillance-Report-2018.pdf