

# poslink

The Newsletter of Living Positive Victoria

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## *The Power of Positive Voices*



# FINDING MY POSITIVE VOICE

*By Richard Keane*

On July 2 of this year I started in the role of CEO of Living Positive Victoria.

It is an amazing honour as we celebrate our 30 year history of advocacy, partnership and an ever growing diversity of peer led programs and engagement opportunities for people living with HIV in the state of Victoria. Living Positive Victoria is also an organisation whose people and culture have helped not only myself but countless others to build resilience through a support and empowerment model.

I was diagnosed at the age of 20 – in the middle of that horrific first decade, prior to effective treatments – and given a prognosis of around five years to live. I knew I was in for the fight of my life and set about making an audacious bid to make it to my own thirtieth birthday.

A huge part of this plan was to be brave, regardless of the stigma or personal cost; to stand up, to come out and put a real face, my face, to living with HIV.

Initially, I found my own unique and powerful “positive voice” through AIDS activism as a member of ACT-UP Melbourne and working with marginalised high risk populations employed as AIDS and Injecting Drug Use Educator, then Boys and Transgender Project Worker at the Prostitutes Collective of Victoria.

There was an energy and urgency of that time that is hard to put into words, even with the precious privilege of hindsight that we have today.

I lost my partner to an AIDS-related illness in February of 1993 just after I turned 24. I experienced the utter disorientation of being surrounded by and consumed within the

heavy oppressive atmosphere of numbness and unspoken grief and loss that was both community wide and now intensely personal.

The emergence of effective anti-retroviral treatments in 1996/97 meant that there was new hope, but the side effects left me with some conditions that I still deal with today, and delays in approval of some new drugs meant that deaths of mates and mentors continued to be commonplace.

I had no concept of what is now known as AIDS Survivor Syndrome, post-traumatic stress, or how to identify, let alone address, my grief or mental health. There was no answer to why it was. It just was. Like why I lived when some of my friends did not.

Self-medication with drugs and alcohol became entrenched and problematic and led to extreme depression and social isolation. I felt defeated like my best days were behind me. I decided that I would rather people remember me fondly than see me as faulty and stopped taking my HIV meds hoping to reach what I’d convinced myself was the inevitable conclusion of my life: to die.

For me, self-stigma created an unconscious barrier to tapping into my own potential.

At the depth of my darkest days I reached out for support. I reconnected via the Positive Living Centre and then decided to take a step sideways and join the Board of Living Positive Victoria. This provided me with a new challenge and opportunity to use my voice as a voice for others. Having been on both sides of the HIV response equation of service provider and service user gave me a unique and powerful insight to what I felt was working and what wasn’t.

In 2013 I attended the pilot workshop for the Positive Leadership Development Institute of Australia and New Zealand. It had a transformative effect on my life. I found clarity and conviction around what I still had to offer. It reinforced how to set goals towards living my life to its full potential.

Conceding for the first time that yes, HIV had an indisputable and sometimes negative impact on my life, but it really was me who had let those barriers remain entrenched and immovable. I realised I had the power to change my circumstances through participation and connection within my positive community.

I returned to study and continued my engagement and leadership and became President of Living Positive Victoria working hard to represent our diverse membership and bringing communities together.

My life was not over, it was only just beginning.

Overcoming such significant personal challenges left me with empathy and insight into some of the complex issues that can attach themselves to living with HIV, but also lived experience and evidence of how to overcome them and rebuild a sense of integrity and resilience.

As CEO I’m determined to translate all those learnings into action and create a more inclusive response for **all** people living with and communities affected by HIV.

I can balance the ledger from the support I received and pay it forward to other PLHIV through representation within the strength of the local HIV partnership response and continue the creation of opportunities for meaningful involvement of people living with HIV that this organisation provides like no other.





# LISTENING, LEARNING AND DISCLOSING IN AMSTERDAM

By Sarah Feagan

I set out to the International AIDS Conference in Amsterdam as a gal with a plan. A plan that would ensure that I would get the most out of the conference. I would see the key sessions that affect my community – not burn myself out – and still have time to network and reconnect with my global community. I had learnt from my experiences at the last two conferences in Durban and Melbourne; this time I was going to do it all. But as soon as I arrived all of that went out of the window...

Most of my time at this conference was spent at the Global Village helping to bring the Disclosure Sofa to AIDS 2018. The Disclosure Sofa is a community engagement activity that invites conference delegates to record and share experiences of HIV disclosure. It provides a space for everyone at the conference to speak out against stigma and discrimination and build community resilience. I had first seen the Sofa at the last Global Village, but I never even had a chance to record my own story. But now, I was so excited to be part of the team bringing it to life at AIDS 2018!

***My excitement was unwavering. Every day I would head down to the booth and be blown away by people's willingness and openness to participate. There were all sorts of stories from people living with HIV and those who work in or are affiliated with the HIV sector.***

One story that stood out for me was a man from Canada, whose story of criminalisation was harrowing. He told me that despite disclosing his HIV status to his partner he was charged and convicted of causing grievous bodily harm and imprisoned for four years. He said that for the first few months of his term he was not given treatment and that he was continually harassed by guards and inmates. It sounded like four years of torture. After he was released he explained that being on the sex offender registry meant that he could not see his own grandchild and made getting work or a home impossible. However, this experience lit a fire in him and spurred him to become an activist. This man's story left such a mark on me and truly opened my mind and heart to the global issue of criminalisation. I cannot un-hear his story or many of the other stories I heard at the conference about HIV criminalisation, an issue we all need to understand and stand up to, even here in Australia.

Another story challenged my own stigma and perceptions. Most of the peer education and support work I do is with women who are living with HIV, many of whom contract HIV from their husbands and partners. Often it is their stories that I hear – including experiences of rejection, violence and homelessness following diagnosis and disclosure. Although I often feel anger towards the husbands and partners of these women, one story I heard opened my eyes to how they too must feel. It was about men in India going through the extreme trauma of acquiring HIV through sex with men and transmitting the virus to their families. I had never thought about how these men must have felt having unknowingly transmitted HIV to their wives, and in many cases their babies. How could they have known that what they were doing carried such a high risk if they did not have the education, tools and freedoms to protect themselves and their families from HIV?

Hearing stories from my peers and allies of the lived experience of HIV is so powerful and humbling. We have so much to learn from each other. The power of storytelling is an ancient custom that has been done in many cultures for many millennia. Visiting the Disclosure Project I hope will give you those feelings and insights on how to disclose or what a loved one might be going through after disclosing to you. I want to give a huge thank-you to everyone who participated in the project, the team of incredible volunteers and the opportunity to participate in such open space.

AIDS 2018 inspired and shocked me. I feel that what I planned to do and what I was able to achieve are one and the same. I came to connect, to learn and listen. I may not have made it to many scientific presentations but I had many invaluable, informal sessions around the Global Village with my community. I attended Women Now, the most incredible pre-conference for women from Africa and the dysphoria. I made new friends and solidified old relationships. I remembered those who are no longer with us and celebrated the next generation. So maybe next conference I won't worry about a plan.

To view or submit a disclosure story visit [disclosureproject.org.au](http://disclosureproject.org.au)  
The Disclosure Project gives many thanks to the contributions of people living with HIV who make this resource possible and is proudly supported by Living Positive Victoria, ACON (formerly the AIDS Council of NSW), Thorne Harbour Health and The Institute of Many.

# JOINING THE SEARCH FOR A CURE

*Have you ever wondered what it's like to be part of a clinical trial for a cure for HIV?*

Although antiretroviral therapy means that people living with HIV (PLHIV) in many countries have similar health outcomes and life expectancy to the general population, HIV research continues to search for a cure.<sup>1</sup>

The focus of most cure research is towards understanding where and how HIV persists on antiretroviral therapy. The virus hides most efficiently in the gut because of local inflammation that impairs the immune response. However a new study in Melbourne, VIVA, is looking at the effect of high dose vitamin D on HIV latency, anticipating a possible reduction in inflammation and leaky gut, improvement in the immune response to HIV and a reduction in the amount of HIV hiding in the body.<sup>2</sup>

People living with HIV that participate in clinical trials like VIVA have been at the centre of furthering our knowledge of HIV and helping to find new and better treatments. While participants may no longer risk as much through their participation, the ongoing value of these contributions cannot be understated.

So what is a stake in current research? And what's it like to be one of the people with HIV participating in a clinical trial? *Poslink* spoke to two participants of the VIVA trial, Gareth Graham and Ian Muchamore to find out.

## CAN YOU TELL US WHAT MADE YOU WANT TO TAKE PART IN THE TRIAL?

**Gareth:** I have always wanted to get involved in trials and do my bit for the community where I can. When I heard about a trial involving vitamin D, I knew that it was something that came with not too many risks.

**Ian:** I think it is important that health consumers engage in research and especially clinical research because we do not get health improvements without participation. When we look historically at clinical research, the risks that PLHIV took in clinical trials, and the ways that advocacy changed how health and clinical trials are undertaken worldwide, my contribution is pretty negligible.

## WHAT WILL YOU BE REQUIRED TO DO AS A PARTICIPANT?

**Gareth:** My understanding is I will get either a placebo or vitamin D for six months. I won't know whether I have the placebo or not and I'll have my blood taken every three months.

**Ian:** The most important part of what I am required to do is understand the consent process and what the potential risks might be. Although there are probably few risks, one is that my calcium levels may become too high. I came back with a very slightly elevated level of calcium last week so I now have the joy of collecting a day's sample of urine in the office in a plastic bottle to take back to the survey team.

## HOW HAVE YOU FOUND THE EXPERIENCE SO FAR? IS THERE ANYTHING YOU DIDN'T EXPECT?

**Gareth:** I don't really have any expectations other than that I'm excited to be a part of it. I have wanted to get involved with something like this for a while and I hope I get the vitamin D and not the placebo. It will be hard to not be tempted to go and get a blood test to find out but of course I won't!

**Ian:** I am about halfway through taking one, horse pill-sized of either vitamin D or placebo a day. It's a big brown-reddish pill. It has been just a matter of remembering to take an extra pill each morning for me and to remember to have a bit of extra calcium, which is important for absorption. I've been back for a couple of extra visits and the clinical team has always been really charming – it's actually enjoyable to find out what's going on in the sector. My expectations of the study? I am not expecting this to be a mind-blowing breakthrough in cure research but you never know. I have been surprised in the past when certain aspects of HIV science that I have not understood have proven to be important in the long term. So I am prepared to be surprised.

## DO YOU HAVE ANY THOUGHTS ABOUT THE INVOLVEMENT OF PEOPLE LIVING WITH HIV IN CLINICAL TRIALS?

**Gareth:** I do not like to put people in the same basket because we all have different points of view and some people want to be more involved than others are. I think if you are healthy and able and you want to get involved, you should. Considering what PLHIV used to have to put up with, showing up once every three months to get a blood test to try and help find a cure or see what vitamin D can do for us is a fairly small contribution. I am happy to do it!

**Ian:** I think the contributions historically have been huge and cannot be overstated. That said, I think we can do more to ensure that there is meaningful engagement of PLHIV in framing research questions and protocols. Even 30 years on, we need to reflect how we can better engage PLHIV – not just treating us as research subjects.

I also think it is important to explain to the wider community what a clinical trial means in everyday terms and to move away from the tremendously harmful hype that we see around HIV breakthroughs and poor reporting. I think that it is seriously damaging to over-report and misrepresent HIV studies to the extent that they suggest that an HIV cure is around the corner.

*The VIVA trial has now completed enrolment. Researchers at the Doherty Institute, Royal Melbourne Hospital, the Alfred and Melbourne Sexual Health Centre would like to express their sincere gratitude to all those who have expressed interest in the trial.*

- 1 Hogg R, Lima V, Sterne JA et al. (2008) Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. *Lancet* 372(9635):293–9.
- 2 Pitman, M (2017). 'VIVA trial: Vitamin D in HIV latency,' HIVcure.com.au.



*Ian on his last clinical appointment for the VIVA study*