

Biography

Max Niggl

Max Niggl has been employed with People Living with HIV/AIDS Victoria Inc. since September 1999. Part of his Executive Assistant position was the responsibility for the re-establishment of the PLWHA Victoria Speakers Bureau.

In September 2004 he was appointed to the newly funded Speakers Bureau Coordinator's position that entails speaker recruitment, facilitating public speaking training and professional skills development for HIV Positive speakers, coordinating speaking engagements and marketing of the Bureau's services. Since 1999, speakers have been empowered to effectively speak to the wider community on the actuality of living with HIV/AIDS, thus helping to reduce stigma and discrimination.

Max has presented abstract papers, workshops and been a panel member at various Conferences including Australasian Society of HIV Medicine 2001, 2002, The International Conference on AIDS in Asia and Pacific 2001, The HIV/AIDS, Hepatitis and Related Diseases Social Research Conferences 2002, 2004, and the HIV Educators Conferences 2002, 2004 and 2006, highlighting the importance of an HIV Positive Speakers Bureau as primary educators.

Max had an abstract paper accepted for the 2002 Barcelona International AIDS Conference. Max co presented a workshop at the 2006 Community Services and Health Industry Training Conference on "Education – the Pathway to Empowerment for People Living with HIV/AIDS"

In 2005, the Speakers Bureau, in collaboration with ParaQuad Victoria was co-winner of the Victorian Community Services and Health Industry Training Awards for 'Innovation in Training and Assessment - Innovative Service Delivery – Private Provider.'

In 2004, Max received PLWHA Victoria's "Special Acknowledgement Award' for his work with community workers and PLWHA in Papua New Guinea as part of the National Association of People Living with AIDS Collaboration for Health in PNG.

Max has held several voluntary committee member positions including AIDS, Hepatitis and Sexual Health Line (2002 – 2004), ParaQuad Victoria Steering Committee for the Innovation in Training Delivery (2003 – 2004) and the VAC/GHMC David Williams Fund (2002 – 2005). Max was the ex officio PLWHA Victoria Board minutes recorder 1999 - 2004

Max has a Diploma in Community Services (Community Work) and is a qualified Assessment and Workplace Trainer.

Max was born in Melbourne. He lived and was educated in country Victoria. His first job was in Melbourne where he has continued to live and work. He has traveled to many countries and lists politics, art, books and food as some of his interests.

Max was diagnosed with HIV in November 1987 (but didn't want to know the test result), an AIDS defining illness in August 1988 and given six months to live (based on scientific

evidence and average survival at the time). He remembers deciding at the time that the virus was not going to get him and that somehow he would beat the odds.

He was dismissed from full time employment in 1992 because of another AIDS defining illness and disclosure of his HIV status by the employer to other employees. (Discrimination at its worst but something that occurred on a regular basis back then).

Max has been able to continue in paid and self employment since.

Max has been fortunate in having total support from his parents and family after they got over the shock of the “triple whammy” as he calls it (finding out he was gay, HIV positive and with an AIDS defining illness).

Max is described medically as “a long term HIV/AIDS survivor” and one of maybe 20 Victorians who have survived the ravages of the late 1980’s and the early 1990’s when there were not the effective treatments that are available now.

In 1994/95 Max nursed his long term partner who died of AIDS related conditions and blindness in September 1995.

Everything changed again in late 1995 with a cancer diagnoses and surgery.

In 1996 the advent of new treatments arrived and suddenly Max’s very low T cells started to slowly rise and he was able to sense a longer future.

Max was re-diagnosed with cancer in 1996 and received radiotherapy to be declared “cured” until mid 2004 when he was told that the cancer has recurred. Further complicated surgery was eventually successful and after a long recuperation and more surgery he has been able to continue his life with all its ups and downs and feels privileged to have endured and to be able to tell his story.

Max met a new partner in 1999 and the relationship continues to this day.

August 2006

Biography **Dr Eric M Glare PhD**

Brought up on a wheat-barley-sheep farm on Eyre Peninsular, SA, Eric Glare was greatly influenced by rural life, his schoolteacher mother and by religion –four generations of Eric’s family had belonged to a fundamentalist Christian religion with no name. University and a medical research career was an escape from family expectations. Specialising in molecular biology, Eric has conducted research in microbiology, cholesterol metabolism, asthma, cardiovascular disease and HIV.

Despite this “head-knowledge” of HIV/AIDS, Eric became HIV positive in 1994, whilst in a long-term relationship. When the couple met in 1990, they talked about HIV testing but Eric’s partner was a uniformed member of the Defence Force. To ask defence doctors for a HIV test would have meant dishonourable discharge and termination of a prospering career. Whilst the ban on gays and lesbians in the military was lifted in late 1992, Eric’s partner still preferred to be tested for HIV outside of the defence medical environment but did not have a Medicare card. After 5 years of relationship, neither Eric nor his partner could believe they

could be carrying HIV as they seemed too fit and healthy, and too socially responsible to be HIV positive.

Eric's life after becoming HIV positive has had 2 distinct phases. For the first 8 years, he was quite well, maintaining a gym physique whilst working long hours on his PhD studies in asthma genetics at The Alfred Hospital. However, in 2002, he contracted viral meningitis experiencing migraine-like headaches for 6 months. A long period of poor mental health followed and early in 2005, Eric was diagnosed with Bipolar II Disorder.

Through the PLWHA Victoria Speaker's Bureau, Eric has found that speaking out about having both HIV and a mood disorder has given him a much needed sense of meaning and purpose.

Relationships:

Eric came out as gay in 1987 and has had 3 long-term relationships, being single for only 5 months since then. He has been with his current partner who is HIV negative for 2 years.

November 2005

Biography

David Menadue

My name is David Menadue and I have been HIV-positive since 1984 and had my first AIDS-defining illness in 1989. I am now one of the longest surviving people with AIDS in Australia, after surviving the disease for more than sixteen years.

I first became involved in the PLWHA Victoria Speakers Bureau when it was first established in 1989 – a time when few people were prepared to be open about their HIV status due to the prevailing discrimination and hostile attitudes sometimes expressed in the media and in broader society. In those days we struggled to get enough people to do out talks, to reveal to the public – to schools, University students, nurses, doctors or community groups—that they were positive and were prepared to talk about the experience.

Apart from the discrimination experienced in those times, there were feelings of grief and loss which many of us went through at the death of many friends. I lived through these trying times when there were no viable treatment options and many of us were regularly visiting hospital day care facilities for treatment for many opportunistic infections.

The advances in treatments in the mid-nineties brought about a major turnaround in the health and prognosis of many positive people. I was lucky enough to stay alive long enough to get the benefit of these new drugs and to see my T-cell count go up from a zero count to 400 today. These treatments have their side-effects and I have experienced lipodystrophy (a condition caused by the HIV drugs which causes a loss of fat from the arms, legs and face and unusual fat deposit in the abdominal area), diabetes and severe diarrhea as a result of taking many pills each day.

I published an autobiography of my life including my experience with AIDS. The book, called *Positive*, was published by Allen & Unwin in August 2003. I can talk about a range of topics from the experience of living with HIV/AIDS since the eighties, the treatments and their side-effects, the changes in education and support needs over the years and about my involvement in HIV community organisations. I am a former secondary teacher and feel I am

able to tailor my Speakers Bureau talks to different ages and levels of understanding about HIV/AIDS.

August 2006

Biography Glenn Filbin

My name is Glenn Filbin and I was diagnosed HIV Positive in 1997. I am about to turn 48 and I am one of the lucky ones. I was admitted to the Alfred Hospital Emergency Department very unwell. I had Toxic Shock Syndrome. Three days later I was told I was HIV Positive. I had 3 T cells and a rampaging viral load. In a short space of time it was discovered that I had Toxoplasmosis in my brain, a bacterial infection contracted from cats. I experienced what can only be described as the equivalent of two strokes. My speech, vision and memory were impaired and left me with a legacy of epileptic seizures.

I have also had 3 full hip replacement surgery operations and my knee will be done in the not too distant future. Apart from that I am fine. For the last 4 years I have had a non detectable viral load and encouragingly high T cell counts. I am healthy enough but there are constant reminders of my HIV status.

I no longer enjoy full time employment and live in an HIV rental assistance flat on a disability pension. My independence and freedom of choice have been compromised more than I ever thought possible. However I have never experienced discrimination or vilification for my HIV status in any shape or form. My partner of 5 years, friends, family and medical profession have loved me, nurtured me and cared for me respectively throughout this HIV life journey.

By speaking about my personal experiences with the disease under the auspices of the Speakers Bureau, it is my intention to keep people informed and educated about the relevant issues regarding HIV/AIDS. It is still here, not as evident, but as insidious and destructive as ever.

Living with HIV is not a death sentence but it is a life sentence. There is no room for complacency. It could happen to you.
Live long and prosper.

November 2005

Biography Susan Paxton, PhD

I am an AIDS activist, facilitator, trainer and community-based researcher and I have been living with HIV for seventeen years. I first started speaking out about HIV/AIDS six months after my diagnosis in 1991. I have since spoken to thousands of people, including health care workers and students in Australia and overseas, in order to challenge the myths surrounding

AIDS, decrease stigma and discrimination and help people to realise that anybody can be vulnerable to HIV infection.

Over the past ten years I have been very involved in APN+, the Asia Pacific Network of People Living with HIV/AIDS, first as the Australian representative on the APN+ Board and since as an Advisor. For APN+ I wrote, "Lifting the Burden of Secrecy", a two-volume training package for HIV-positive people who want to speak out in public, now translated into six languages and AIDS-related discrimination in Asia, a study indicating that the majority of people diagnosed as HIV-positive face subsequent discrimination, particularly within the health sector, and women face disproportionately much more discrimination than men do in the community.

In the run up to the Sydney 2000 Olympic Games, I carried the Torch on behalf of HIV-positive people.

I was an inaugural recipient of the Australian Government's Jonathan Mann Memorial Scholarship. My post-doctoral research, based at the Australian Research Centre for Sex, Health and Society, La Trobe University, investigated the challenges to involving HIV-positive people in the regional response to AIDS.

I spend a great deal of my time in Asia, training HIV-positive people to gain skills and confidence to run their own organisations, advocate for themselves and ultimately take their place as equal partners in the response to HIV.

August 2006

Biography

Jeffrey Robertson

I am an AIDS activist, facilitator, trainer and community-based volunteer coordinator of an HIV and Hepatitis C support and education group based in Warrnambool. I have been living with HIV for ten years. I first started speaking out about HIV/AIDS after my status was disclosed in 2001 and at which time I underwent gross discrimination and defamation and also had my house spray painted with the words "HIV positive and faggot" and letters sent to my church saying I was a child molester and HIV positive. So the fight began and the support group "breaking the chains" was conceived.

That was when I first became involved with People Living with HIV/AIDS Victoria and was supported and encouraged during this difficult time. PLWHA Victoria also provided advocacy on my behalf and this helped to put an end to the ongoing problems. I then became involved with the PLWHA Victoria Speakers Bureau and through their training began speaking in our local schools, many forums and community awareness education projects in our community around prevention, discrimination and stigma.

Over the past two years I have completed a Certificate IV Assessment and Workplace Trainer course which now gives me the opportunity to present education modules and has given me the skills to present training and create modules around the complexities of chronic illness and the common denominators with other chronic illnesses and HIV i.e. symptoms, medication and lifestyles etc.

I have also completed courses in Hepatitis C, HIV pre and post test counselling and am now completing a Certificate 4 in disability care work and also a telephone counselling course with AIDS Hepatitis & Sexual Health Line.

I have spent the last 2 years fighting paralysis in my right side due to my HIV related symptoms and complications

I am blessed to say that I am now able to give something back to the community

With all of this I believe I can only value add to the community and only help to educate in the adult education fields despite my disability.

Biography Peter Davis

Peter caught HIV in 1985 at the age of 18 in Melbourne after just two sexual risk exposures: unprotected sex once with a man and also once with a woman. *Is his 20th anniversary since that infection something that he will celebrate?*

Peter works as a documentary freelancer for ABC Radio National. He is also a creative writer having been published in The Age as well as various literary journals.

Peter is a father. His marriage of ten years ended in friendship in 2004.

In 2004, Peter commenced for the first time pharmaceutical treatments for HIV. He often wonders just why he survived the earlier period of HIV/AIDS (late 80's and 90's) when so many others that he knew died then. He embraces the new found optimism of the new and improved treatments.

Peter is one of the founding members of a support group for heterosexuals living with HIV in Victoria called Straight Arrows. He is a regular speaker about HIV and other blood borne viruses in Victorian secondary schools.

Biography Wayne

My name is Wayne, I'm 47, I'm heterosexual, and I'm HIV positive.

I come from Hobart, Tasmania. I was diagnosed with HIV in 1996.

I was living in Thailand when I was diagnosed. Just a quick test in a Thai hospital that came back positive in an hour. The doctor suggested I have another test to make sure, but I knew I was positive. It explained how I was feeling and the infections I had at the time.

You never forget the time when you are first told you're HIV positive. You just go numb with the shock.

You can't move, everything is so surreal. It's almost like you're out of your body, or maybe you just wish you were.

You start thinking of how short a time you have left, and those things you wished you had time to do.

Then the denial sets in. And usually you stay in denial until you're woken up with something serious like PCP. At this point I didn't go on Antiviral treatments.

In 2000 I did get PCP and went into hospital, my CD4 was 2.

When I recovered I started on Antiviral treatment. They cost me \$1,000 a month in Thailand. After I left my job, I couldn't afford to stay on the medication. I stopped treatment at the end of 2001.

In 2003 I got PCP again. I couldn't eat because of the severe thrush I had. I was so weak I began to faint when I went outside. I couldn't even go across the street to the market safely without maybe collapsing. Once I fainted and cut my forehead open, I'd just been to the market across the street.

It was time to come home.

My CD4 count was 3, and I weighed 52kg (I used to weigh 86kg).

I've been on 8 different combinations since I started on Antiviral treatments. 2 in Thailand, and 6 since I've been back in Australia.

I've had a few setbacks with my treatments because of side effects.

HIV isn't what defines me, I don't let it control my life. I try to keep things as normal as possible.

I take my medications on time every day and get on with living. I'm stuck with it and it's stuck with me. Sometimes it's frustrating though, you don't know what you're going to feel like from day to day. Some days I feel like shit.

Since coming back to Australia I've made a lot of good friends that are HIV positive. All positive people share a common bond, it doesn't matter what gender you are. We all have to live with this virus.

In Asia, I've seen people dying of AIDS - it's not a pretty site.

I'm lucky. I could come back to Australia and start on treatments that saved my life.

Wayne.