

# talkabout

Where we speak for ourselves

**IN MY**  
OWN WORDS

**INCLUSION.**  
RESPECT.  
EQUITY.

**NOTHING**  
ABOUT US  
WITHOUT US

**OUR**  
SHARED  
HUMANITY



# TALKABOUT

WHERE WE SPEAK FOR OURSELVES

## EDITION #207

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## *This December edition of Talkabout offers community reflections as we remembered friends and loved ones.*

In this edition, Adrian Eisler offers a thoughtful piece (**page 8**) reflecting on volunteering for the International AIDS (IAS) conferences over the years, especially in the light of the sad impact of the events of IAS 2014.

Board Director and PSB speaker, Greg Horn shares his 2023 World AIDS Day speech as a guest speaker (**page 10**) reflecting on HIV advocacy and mobilisation since 1984 across the HIV sector. He shared the stage with Board Director and PSB speaker Melissa Carolus, who offers her contemporary perspective (**page 19**) as a woman of colour living with HIV.

Priscilla Njeri who manages the Positive Life Ageing Support program reminds us even though we might be living with HIV, we're always more than our medical status or diagnosis (**page 17**).

I interviewed Austin (not his real name) as part of the ongoing series 'In my own words' (**page 14**). Austin highlights how disclosure can be tempered by a desire for privacy rather than a fear of revealing your HIV status. Our CEO Jane Costello offers a powerful reflection on the impact of The Denver Principles (**page 22**) on today's healthcare frameworks, medical privacy, use of person-first language, and standards for respect, inclusion and equity for many other marginalised groups.

A big thanks to Charlie Tredway who filled in between November 2022 to June 2023, taking care of Positive Life NSW communications and Talkabout. His stewardship of the role was greatly appreciated in my absence.

The **Talkabout Advisory Committee** has been refreshed with three Positive Life members, all from rural and regional areas. I look forward to the guidance and input from Tim Alderman, Maria and Kim throughout 2024.

If you want to share your thoughts or story, or would like to explore how you might be part of Talkabout, please get in touch. **I'm on the lookout for the voices of young people living with HIV who can contribute regularly to a column dedicated to younger voices. If you'd like to develop your writing skills as well as contribute to a regular magazine, please get in touch!**

Sharing your story in Talkabout is easy and simple. I can interview you by phone, Zoom or face-to-face as part of 'In My Own Words' to make it easier than ever to get your story in Talkabout.

Call me on (02) 8357-8386 or 1800 245 677 or by email on [contact@positivelife.org.au](mailto:contact@positivelife.org.au). I look forward to hearing from you in the near future.

**CRAIG ANDREWS**  
**EDITOR**

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# LOOP IN THE EYE



*As we come to the close of another year, I am reminded of the tenacity and dignity of all people living with HIV, here in NSW and across Australia.*

It has been another full year where the Positive Life team has delivered on our firm commitment supporting our community to reach an optimal quality of life while championing inclusivity and equality for all people living with HIV across NSW.

Our Peer Navigation Programs have connected over 170 women living with HIV, over 220 heterosexual people living with HIV, and at least three times as many gay and bisexual men living with HIV with peers who provide support from someone else with a lived experience of HIV, advice and understanding. The team hosted 93 social inclusion events, workshops, and health promotion campaigns, and our programmatic work reached 2,122 community members across NSW.

Our team is mindful of the challenges ahead. The evolving landscape of healthcare, economic uncertainties, and social dynamics present hurdles that demand innovation, adaptability, and resilience. Within these challenges lie opportunities for growth, collaboration, and new approaches to better serve our community of people living with HIV.

I extend my heartfelt gratitude to our dedicated team, volunteers, sector partners, funders and particularly our membership.

Your unwavering support and commitment have been instrumental in the successes we have achieved. Together, we will continue to make a difference in the lives of all people living with HIV in NSW.

**JANE COSTELLO**  
CEO



*Firstly, I acknowledge the traditional owners of all the lands in NSW. We are truly fortunate to exist in a country with such a special culture, knowledge and heart that has stretched out before us for many, many, many generations.*

Secondly, I thank you, my community, for supporting me in this appointment as President of Positive Life NSW. I am both humbled and excited to be taking up this post. I am fortunate to have Robert Agati's support in the role of Vice-President as part of the Positive Life Board's succession planning process.

I was very encouraged by membership engagement this year. We had a higher than usual number of Board nominations, and a higher than usual number of members who voted.

Our communities are broad and diverse, and our Board goes a long way towards representing these communities. Our strong collective skill set places us well to deliver on our strategic work going forward.

The full 2024 Board members are Stephen Lunny, President; Robert Agati, Vice President; Greg Horn, Secretary; New Chaimongkol, Treasurer; Melissa Carolus, and Directors, Gareth Graham, Natasha Io, Frances Parker, and Sebastian Zagarella. Our staff team are an exceptional group of people, led by our thoughtful, experienced, and hard-working CEO, Jane Costello.

We are the voice of all people living with HIV in NSW and we are keen to hear yours. Positive Life NSW will continue to work with currency, conviction and kindness in representing you. You can always get in touch, share feedback or contact the Board on [president@positivelife.org.au](mailto:president@positivelife.org.au)

I encourage you all to reach out to both our teams. Get involved. Find out more about Positive Life NSW and what it has to offer you.

**STEPHEN LUNNY**  
PRESIDENT

*Positive Life NSW represents and advocates on behalf of our members and the NSW Body Positive in a range of NSW HIV/AIDS sector areas. Below are brief details of topics, events and issues we've carried out that impact the interests of people living with HIV in NSW.*

## HETEROSEXUAL RETREAT

In June 2023, Positive Life held a weekend retreat for all people living with HIV who identify as heterosexual. The 'Life Beyond' 2023 Heterosexual Retreat welcomed 23 people to discuss and share life experiences and strategies around living with HIV. The program provided opportunities for participants to reflect on their HIV journey to date and examine their thinking styles in relation to their health diagnosis through art and psychotherapeutic tools.

The 2023 Life Beyond Retreat Report has been published on our website and can be downloaded at [www.positivelife.org.au/blog/health/life-beyond-heterosexual-retreat-report/](http://www.positivelife.org.au/blog/health/life-beyond-heterosexual-retreat-report/)

## ABORIGINAL & TORRES STRAIT ISLANDER HEALTH PROGRAM

In 2023, the Board made a difficult decision to terminate our Aboriginal and Torres Strait Islander Health Program until longer-term funding can be secured to continue this important work. We farewelled Michelle Tobin, our Aboriginal Program Health Officer and thank her for her dedication supporting Aboriginal people living with, or at risk of acquiring HIV. Michelle continues in her role with Positive Life NSW as a valued member of the Positive Speakers Bureau (PSB).

## IAS BRISBANE

Positive Life represented people living with HIV in NSW at the 12th International AIDS Society (IAS) conference on HIV Science in Brisbane in late July 2023. Positive Life CEO Jane Costello participated in a pre-meeting *Living with HIV and HPV* and Panel Discussion *Session 5 – Call to action*. During the conference, Positive Life was represented at the *Global U=U Policy, Practice and Research Workshop*, the *ACT NOW Pre-Forum on Global HIV Migration, Mobility and Health Equity*, and the IAS stakeholder consultation event on the concept of person-centred care in the HIV response. Positive Life Peer Navigator Billy Suyapmo's Digital Mentors abstract was accepted in poster form and selected for oral presentation. Positive Life CEO Jane Costello and Positive Life Ageing Program Officer Priscilla Njeri participated in a Satellite Session - *Fostering cognitive and mental health in aging people with HIV while prioritising the community and lived experience perspectives* as part of a panel discussion.

## 2023 WORLD AIDS DAY

Positive Life hosted a World AIDS Day event on Friday 1 December 2023 at the Sydney Conservatorium of Music, in partnership with the Bobby Goldsmith Foundation. MC Robert Agati welcomed guests and Yvonne Weldon to conduct a Welcome to Country. CEOs Jane Costello (pages 24-26) and Nick Lawson made introductory speeches on the Australian World AIDS Day theme, *Inclusion. Respect. Equity* and the International World AIDS Day theme, *Let Communities Lead*. The Siam Classic Dance Studio group provided a performance showcasing ancient Cambodia and North-Eastern Thailand dance styles. Keynote speakers, Greg Horn (pages 12-13) and Melissa (pages 20-21) shared their thoughts on the World AIDS Day themes as well as reflections on living with HIV. 8 performers from the Cantabile Choir concluded the event. Photographs from the event are throughout this edition and on page 22-23.

## INFLAMMATION, CO-MORBIDITIES AND AGEING

At the 1 June In the Know: Treatments and Research evening, Professor Mark Polizzotto and Associate Professor Mark Bloch presented on the interrelationship between inflammation, co-morbidities, ageing and HIV. Both presentations shared information about the recent promising new branch of aging-related research, inflammaging and how low-grade, chronic, systemic inflammation impacts people living with HIV, especially for those of us who are aging.

## COUNSELLING SERVICE

In 2023, Positive Life successfully secured funding from Gilead for a pilot program, *Positive Minds*. This dedicated mental health and counselling service delivers counselling services within a safe, supportive, person-centred approach by two accredited, qualified and trained counsellors, both of whom are either living with HIV or directly affected by HIV.

To discuss your needs and participate in a confidential initial intake process, people living with HIV in NSW can call Positive Life NSW on (02) 8357 8386, 1800 245 677 (freecall outside metro areas) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



## Melbourne, July 2014: I was about to head out the door of my hotel when I stopped to look at the TV screen in the lobby.

I was stunned to see what appeared to be wreckage of a large aircraft strewn all over fields of sunflowers. The reporter was saying that a commercial airliner had been shot down somewhere over Ukraine! It was flight MH17 from Amsterdam.

I was on my way to a pre-conference meeting as part of the International AIDS Conference (AIDS 2014). I was to volunteer at the conference for the first time. Little did I know the significance of this disaster for that conference. Amongst those who were killed that day were some of the most respected researchers, scientists, and clinicians in the world of HIV/AIDS medicine. I have never forgotten that morning.

I was reflecting on that memory in Brisbane recently as I was about to volunteer at the International AIDS Conference 2023 (the 12th IAS Conference on HIV Science). The International AIDS Society (IAS) is based in Geneva and organises global meetings each year. These meetings alternate between this **HIV Science** conference and the larger, broader **International AIDS** conferences (which attracts a substantial number of community-based organisations and attendees and includes a Global Village 'expo' which is open to the public as well as conference delegates).

Since Melbourne, I have volunteered at four other IAS conferences (Vancouver, Paris, Amsterdam and now Brisbane). This unpaid 'work' has provided some of the most rewarding and stimulating times of my life. As volunteers must make their own way to the conference location and pay for all living/ travel costs, there is a depth of commitment and dedication which is impressive. Luckily, I have managed to turn these assignments into holidays to travel to places I might not ever go. (In Brisbane, I also got to see the Matildas play one of their World Cup matches!)

It was entirely appropriate that in the Opening Ceremony for IAS 2023, there was an emotional memorial to those killed in 2014. A stunning piece of music was played on stage as we all thought back to that time and the huge loss we felt for all the lives cut short and the potential future contribution to HIV/AIDS medicine and research that was also lost that day.

The Brisbane conference lasted four days and I was able to attend sessions when not on a work shift. I never fail to be amazed by the skill, commitment and determination of those who work in the field and come along to present their research/ clinical findings. Some of the detail is mind-numbing in its complexity and reminds me why, in the 42 years since the start of the HIV/AIDS pandemic, we still have not yet found a cure/ preventative vaccine or viral eradication strategy.

However, we have made enormous strides in treatment and reducing the death rate for people living with HIV (although access to life saving medication/treatment is woefully inequitable across the world). The reason I could attend the Brisbane conference was because I did have access to life-saving treatment in Australia.

I have often felt a 'time traveller' at these IAS Conferences, never expecting to be still alive to attend them! I was a classic 'late presenter' in June 1995, with near life-ending pneumonia and barely a handful of CD4 cells. I skipped the testing HIV positive step and went straight onto a 'full-blown' AIDS diagnosis (as it was often termed in those days). However, my life was saved in hospital, I commenced AZT monotherapy and a host of other medicines to ward off several nasties (like going blind). Prognosis: I could expect to live another 2 or 3 years if I was fortunate.

Having lost so many of my contemporaries over the intervening years, I now find myself a long-term survivor or a 'HIV/AIDS Elder', if you like. Perhaps you can now understand my sense of being a time traveller at HIV/AIDS conferences? Much of the latest HIV research continues to add to our knowledge of how to combat this most tricky of viruses, even if we can't yet completely defeat the bastard!

For example, a major announcement was made at Brisbane demonstrating the potential benefit of adding a statin to the medication regime of people living with HIV (PLHIV). Whilst all medication decisions are the right of individual PLHIV





to make, hopefully in close consultation/ dialogue with their treating medical staff, this existing class of medication could usefully reduce the incidence of cardiovascular disease. It was suggested that this could also benefit those who would usually be considered at low risk of developing cardiovascular disease.

Other conference presentations dealt with long-acting injectable medication options and updates on work to develop vaccines and potential eradication approaches. However, much more work still needs to be done.

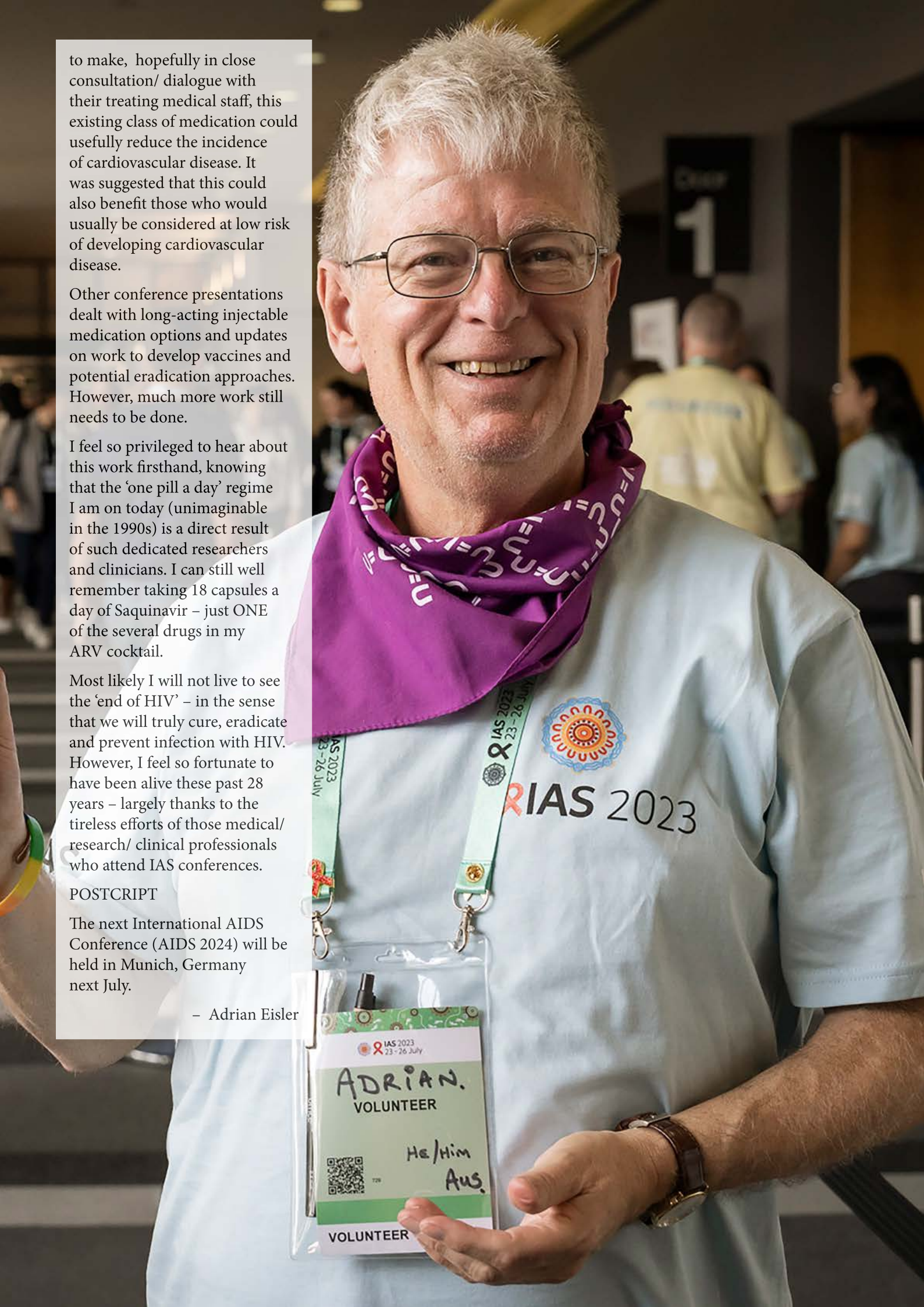
I feel so privileged to hear about this work firsthand, knowing that the 'one pill a day' regime I am on today (unimaginable in the 1990s) is a direct result of such dedicated researchers and clinicians. I can still well remember taking 18 capsules a day of Saquinavir – just ONE of the several drugs in my ARV cocktail.

Most likely I will not live to see the 'end of HIV' – in the sense that we will truly cure, eradicate and prevent infection with HIV. However, I feel so fortunate to have been alive these past 28 years – largely thanks to the tireless efforts of those medical/ research/ clinical professionals who attend IAS conferences.

#### POSTSCRIPT

The next International AIDS Conference (AIDS 2024) will be held in Munich, Germany next July.

– Adrian Eisler





Today is World AIDS Day 2023, and I want to share some of my story with you. I have been living with HIV for 40 years, since I was diagnosed in 1983 (only some 3% of people diagnosed that year are still alive). That makes me one of the first cases of HIV in Australia.

I have seen many of my friends and loved ones die from this disease. But I have also seen many advances in treatment and prevention, and I have learned to cope with the challenges of HIV and deal with the stigma that comes with being HIV positive over these 40 years.

To day is not about me; it is about us as a diverse Community, a family if you will; the Body Positive: a body of people who have lived with HIV for a long time, and others who have lived with HIV for much shorter time.

So 40 years. What have we learned as the Body Positive?

At the earliest meetings in response to HIV we met in friends' homes. At one of those meetings someone said, at the centre of everything we do should be the concept of "helping our friends out". It was as simple as that, no career paths, no excel spread sheets, no timelines, no minutes, no agenda sheets, no cost centres and/or no income line, just doing what we could for "our friends".

Things have grown a bit since those days: all those things are important, but simple friendship should be the touchstone for all we do for each other.

These days our 'friends' are gender diverse and culturally diverse, sexually diverse and linguistically diverse, young and old, HIV+ and HIV-. This diversity is a very good thing and days like today are a good time to remember our 'friends'. Our 'friends' form the 'Body Positive'.

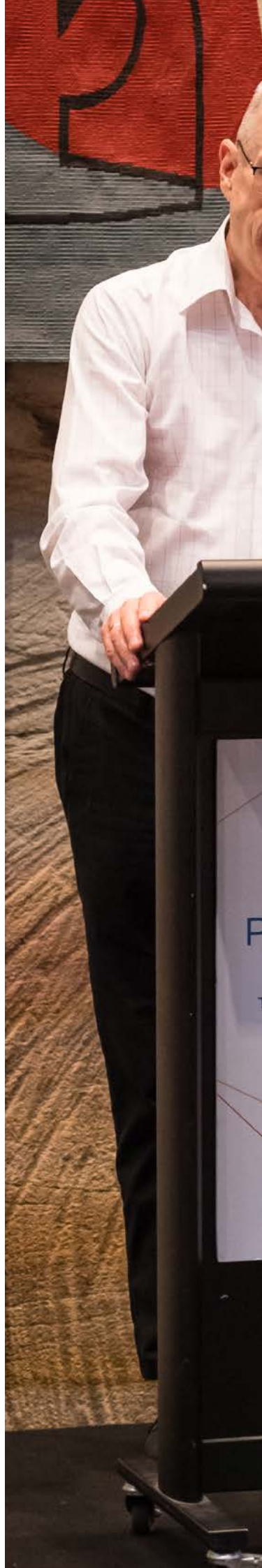
From the earliest days we refused to be labelled as 'victims' and 'patients'; we are not passive, neither are we helpless. Together we make a difference to the wellbeing of other HIV positive people, and our friends and allies: we cared for each other and we let others care for us when we are in need.

For well over 40 years we have stood with people – all people; we protest when people do not give us quality care (especially our First Nations peoples and people newly arrived in Australia), when people seek to fire us from our employment, try to evict us from our homes (a home is a very good determinate of health) or when people separate us from the wider communities in which we live and love. Unjust discrimination and stigma is of no value to anyone at any time.

This year, we use the Australian World AIDS Day theme of 'inclusion, respect and equity'. We believe for the United Nations theme that our communities should be leading us. To be very clear: HIV positive people should be leading the way as we move into the future and continue to respond to the challenges that HIV places in our lives. Yes, we will get the help of professional bodies, and we must also be there in the room when decisions are being made that effect and affect any of us.

Recently I became aware that the circumstances for people living with HIV in the west and south-west of Sydney have changed, and yes throughout NSW. There seems to be a disturbing trend of new HIV acquisitions. In some cases, HIV that has been poorly and/or diagnosed too late has been among women. A number of deaths have occurred this year: these deaths were avoidable. We need to ensure that all women and men are tested for HIV where possible: in emergency departments, prenatal clinics and sexual health clinics etc. Our experience has told us that the earlier a diagnosis is made, the better the long-term outlook. Yes, this will cost money. In the long term, I believe we all will be better off. This springs from a notion as old as health care itself: prevent harm i.e., to do good.

So looking a little into the future, we need to continue to form and reform groups with us as representatives where decisions are made that are about us: as the slogan goes –







Positive Life NSW

The voice of all people living with HIV

nothing about us without us. Any media or statement that concerns us must have our voice in it.

I encourage anyone with skills that are useful to us, to be on boards and committees that serve our interests, both in the cities and in the regions of our state.

Whenever HIV issues are being discussed, at whatever level, we need to be there; be it simple committees, conferences, or symposia etc, to the highest levels of government and health care. Our knowledge and experience will ensure that good decisions are made, and harm avoided.

We, the Body Positive are the most credible people to speak of matters about HIV. We may need technical assistance at times; some of that science and statistics can be complicated. We, the Body Positive, have done this in the past and must continue to be active – all of us, women and men of diverse gender, culture and sexuality. To be blunt we know our own lives best, we live those lives daily.

For our part, we will take our medications regularly but only as informed people and with advice from our own people.

Positive Life NSW is our legitimate voice. Advised by Positive Life, we can live full and satisfying lives, as sexual people, emotional people, with dignity and respect.

I am not ashamed of my HIV status, nor do I let it define me. I have a fulfilling life, have a supportive family and a 'family of friends'. I take my medication every day, and I go for regular check-ups. I also volunteer with Positive Life and other organisations. It is not that hard, but living is best done in the company of friends!

Once we were people *living with* HIV and dying with AIDS: that has changed. We are now a Body Positive L\ living with HIV. I may not be here in another 10 years (men in my family die at about 80 years old) but I trust our movement will be here long after I am gone.

We owe it to the many, many, people who have gone before us, people we have loved and cared for, whose company we have enjoyed and celebrated, mourned and grieved, and fought for, to live our lives in community with pride, dignity, equity and respect: and we owe it to each other too as we continue to live our lives with pride in self and each other, with dignity in self and each other, ensuring equity amongst each other, and most of all respect for each other.

Thank you.

*Delivered as a speech by Greg Horn at a 2023 World AIDS Day event in Sydney, NSW.*



# halc

## The HIV AIDS Legal Centre

The HIV/AIDS Legal Centre is a not-for-profit, specialist community legal centre, and the only one of its kind in Australia.

We provide free and comprehensive legal assistance (within operational guidelines) to people in NSW with HIV or hepatitis related legal matters. This includes areas of law as: privacy, discrimination, immigration, end of life planning, insurance, superannuation, social security, criminal, family, housing and more.

For confidential legal assistance please contact us: Phone 02 9492 6540 or email [halc@halc.org.au](mailto:halc@halc.org.au)



### Positive Conversations - a monthly online event for all people living with HIV

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Positive Life NSW

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# 2024 is my year to..

January is a time most of us make New Year's resolutions, and set personal goals for the year ahead.

When counsellors or coaches talk about goal-setting they often mean setting 'SMART' goals. This stands for specific, measurable, achievable, realistic, and time bound. SMART goals have their use and can be useful checkpoints to reach your target.

For example, a weight loss SMART goal is "I will eat five servings of vegetables each day" or for exercising "I will walk 20 minutes each morning before 9am".

The problem starts when you grabbed a comfort bucket of KFC for dinner or that 20 minutes' daily walk slipped to include weekend sleep-ins and walking only the first three days of the week. Now the goals are sliding, and a certain amount of self-blame makes things worse.

Rather than make the same old resolutions and goals only to be disappointed by April, there might be another option to see you through the whole year. Instead of focusing on the usual goals along the lines of weight-loss, healthier diet, and greater fitness, in 2024 how about trying something completely different?

Instead of weight-loss, how about a goal of 'enjoying life more'? Setting a personal goal to do something enjoyable each day.

These would be the free, simple, and pleasurable things like walking past the florist and smelling the roses or jonquils (which costs nothing), wearing a favourite pair of shoes to work or school, or a hot shower and drying

off with that sun-dried towel. It could be the smell of the coffee in the morning, or looking forward to a favourite nighttime TV show or podcast.

Instead of a 'better diet', how about 'doing one self-care activity a day'?

Anything that gives you a feeling of renewal or that 'recharges your batteries' is a self-care activity.

Listening to music that lifts your mood, getting out from behind the desk and taking a lunchtime stroll, noting what makes you say 'yay!', taking 10 minutes to watch a favourite comedian on TikTok, unfollow social media accounts or people who bring you down.

Self-care also includes noticing how you're talking to yourself and not beating yourself up.

Instead of 'greater physical fitness', how about 'learn one new thing a day'? This includes asking 'why' as a way of learning. Why is the sky blue? Why is water wet? Why do we smell rain? These days it's easy to find the answers to these questions or thoughts, and learn something new in the process.

It can also mean starting a new hobby, or doing a daily crossword. Today there's a number of free online learning platforms offering courses. A 20-minute TED talk usually offers at least one new thing to learn.

This 2024, look at what refreshes and renews you, so you enjoy the next 365 days in a deeper, happier and more balanced way.

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Visit [karumah.org.au](http://karumah.org.au)

**KARUMAH**

Enriching the lives of People Living with  
HIV in the Hunter-New England region



**Austin shares his story growing up in Western Sydney during the early days of the epidemic. His experience highlights the tension between privacy, stigma and disclosure.**

I was born and raised in a very multicultural Western Sydney as part of a conservative family of five boys. I'm in the middle, with two older brothers and two younger brothers. Our cultural background is from a northern middle-east area of Eurasia.

We were all taught to read and write in the language of our culture and also brought up with the whole gamut of our religion, which was adhered to from Friday, Saturday, and Sunday. My father was a very strong Catholic, and decided that he was actually going to create the first church in Western Sydney. So that's what he ended up doing. He established two churches in Western Sydney, and then a school and a church at Kellyville. He was also the treasurer of our local church. So, you can imagine!

All my brothers are married with children, so yes, basically I'm the black swan, if you want to call it that. You've heard of the middle kid syndrome? The one that's mostly neglected? Yeah, I think I preferred it that way. I grew up in an era where HIV was stigma, and in the back of my mind, it's still there. That goes with even sexual activity and things of that nature.

I've always brushed the HIV under the carpet and never really addressed it in terms of sharing it with immediate family. I wonder what will that achieve? Will it actually mean any particular support? Is it going to be a point of ridicule? Is it going to be something that's shamed? It's all of that kind of thought process that goes through my mind.

Recently, I had a triple bypass in April. As part of that recovery process, my mother insisted that I come and stay in my single bedroom that I had for many, many years. Even though I like my independence, I couldn't get out there fast enough!

My niece, Rachel, decided she was going to take ownership of my ten medicines including diabetes, cholesterol and so on, to make sure it was all sorted for me.

Rachel is my brother's daughter. I pulled her under my wing when she was younger, because her mother and father were constantly working, and basically educated her. Otherwise, she would have grown up completely conservative. For example, she knew I was gay from a very young age.

So, as she was going through my medications, she asked, 'what was this medicine for? With that, my HIV status was disclosed. And she just ran with it.

She said, 'oh, okay' and wasn't fazed. She's very savvy. All she said was 'well, that's your gig, you can deal with that. Clearly, you don't want anyone to be informed.' So she hasn't shared it or informed anyone else, I think, out of sheer respect for me, because she grew up around me. I'm completely comfortable for Rachel to know about my HIV status and leave it at that. She's got a lot of respect for me, so she wouldn't necessarily disclose that.

After my mother passed three months later in July, I've thought if I'd told her, it wouldn't have achieved anything positive for her. Bringing it up with family is not going to achieve a great deal. So that's why I've kept it to myself, and besides, it's something that's very personal. Even coming out as gay, for example, that was a really difficult thing for me to do as well. So when it comes to the status of my HIV, I put the stop sign there, because I knew how difficult that was being gay, let alone having HIV as well.

I was twenty-six when I was diagnosed with HIV. Oh, it was a huge shock! I think my world stood still. I didn't necessarily have a huge support network at the time. And of course, there was contemplation of self-mutilation and suicide and all of that. I was going through a fairly dark time, and felt everything was going against









me in terms of my health and so by that stage I reminded myself I had to stay positive. Mentally I mean, yeah. I went through that era, where a lot of my friends...well, I went to a lot of funerals, put it that way. Quite a few.

I think it was the Albion Street Clinic which had an offshoot clinic that actually provided support in those early days, which we really didn't have. So I kind of leaned on them. Growing up in Western Sydney, there wasn't a huge support network at all. Particularly, we're talking pre-internet. I had some horrific circumstances with support in the general community. Based on my experiences, I wasn't really leaning towards counselling services.

Western Sydney needed a lot more services and resources which were based here in the city. So I had to travel down from Cabramatta into the city, anytime I wanted to go for entertainment, anytime I wanted any support, anything on a social level, so it was kind of restrictive in that regard.

In those early times, '92, '93, '94, a lot of men just did not have sex during that time, because we were unsure how HIV/AIDS was contracted. Combination therapy didn't come in until '96. I remember taking my first medication with AZT in particular, and it really does throw you around. Thankfully, my body was able to actually cope. I also tried self-injections with another piece of medication that was on trial. I injected myself constantly for a good year, and thankfully, they eventually put it in tablet form. I mean, even to this very day I can still feel a lump in that site that's still bad and is never going to go away.

In that time, we didn't have the internet either. The sort of information we were desperate for was not readily available. It was only if you had a GP that was familiar with the processes and medications and therapies, then you were lucky.

I was one of the luckier ones with my GP, and we didn't try medication for at least two years actually. I basically sat on my status for two years, and then he said, 'well, your T-cell count is really low, let's try something'. So yeah, he was very good. He's recently retired.

I've never had any hospitalisation whatsoever with my HIV status. I've been very fortunate in terms of how my body can actually cope with it. So I've been very grateful in that regard. But yeah, the only thing that got me into hospital was a triple bypass. That's only because I had type two diabetes and high cholesterol and all of that sort of stuff. So, HIV didn't get me. Go figure, right?

For me, HIV is one of those things that are very personal, so I've never disclosed it. In fact, I only disclose it with my partners. Aside from that, no one really knows.

I don't disclose that information at work. I don't disclose any information on a social level. I just think it's no one's business. I think that's the main reason why disclosure was never high on my priority list. I'm the one that's living with it, I'm the one that's coping with it, I'm the one who has to manage it. Realistically, telling my mother, or my siblings, whatever the case may be, it's just not one of my

priorities. It just wasn't an issue. And it's not because of the stigma.

It's basically because I'm a very private person. Right? I mean, if people ask, then I'll be honest and tell them of course. I've had work situations where people have actually asked me, 'are you gay?' I'm like, 'yes, of course. Why?' They say, 'just curious. That's all. Just curious.' Okay. So that sort of conversation still occurs with people who are much older, and never occurs with the younger generation. I feel as if the generations coming through are more open minded as well.

Today, I'm in touch with all my brothers. We still have a good relationship. Great. Even though both my parents have passed. Yeah, I think when you've got a negative situation, you've got to turn it into a positive. I think I've used that kind of philosophy throughout my life, you know, when you get something thrown at you, that's going to impact you in a negative way, I think you've got to turn it around and make sure you either change it or accept that. For me, most times I have to accept it. I guess being a Taurean, as well, I'm very practical. So I take things on a practical level and look at them. Logically, I look at them, you know, ethically, politically, you know, I take all of that into account.

So I think it's important to actually establish personal standards as I think I've gone through life just doing that.

— Austin



**In My Own Words**

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Phone Craig (02) 8357 8386 or 1800 245 677  
Email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



Priscilla is a Peer Support Officer at Positive Life NSW responsible for our Ageing Support program as well as programs and events supporting people living with HIV who identify as heterosexual.

With over 10 years counselling and clinical community experience working in the Kenyan HIV sector with the Kenya Network of Women with HIV/AIDS (KENWAS), Priscilla offers person-centred support to all community members living with HIV. She has a passion to build the health and wellbeing of all people living with HIV from culturally and linguistically diverse (CALD) backgrounds and is a strong voice for the well-being and human rights of all people living with HIV in NSW, especially women.

Good morning. My name is Priscilla, and I am here before you not just as an individual, but as a woman living with HIV from Kenya.

Life often takes unexpected turns, and my journey with the HIV virus began in a foreign country which has become my second home, a place where I least expected to confront my HIV status just three months after arriving.

The memory of that moment is fixed in my mind—the mix of emotions, the uncertainty, and the shock that accompanied the news. It was a crucial moment in my life, one that led me to a place of both vulnerability and strength.

My journey has taught me the importance of resilience, the strength that resides within each one of us, and the power of community and support. HIV does not discriminate based on nationality, gender, or age. HIV can find its way into anyone's life, anywhere in the world.

Now, I want to share with you a particular chapter of my journey that unfolded in the Albion Centre. This place became more than just a testing ground; it became a sanctuary of warmth and understanding. Even in the face of an HIV-positive diagnosis, the Albion Centre embraced me with compassion, providing a haven where the essence of my humanity was acknowledged.

Today, I proudly share that I have not only received support from the Albion Centre but have also become a part of the movement to empower and uplift others facing similar challenges.

I am now working at Positive Life NSW. This is an organisation that shares my passion for advocacy, awareness, and support for those of us living with HIV.

This year, as we gather under the theme of inclusion, respect, and equity, I am reminded of

the profound spirit that defines the community of people living with HIV.

We are more than statistics; we are resilient individuals who navigate a world that sometimes misunderstands us. Our determination, strength, and agility that characterise our community spirit are the driving forces behind the progress we have made and continue to make.

It is crucial to recognise that being a person living with HIV is not synonymous with being a perpetual patient.

I am not defined by my medical status alone; I am defined by the richness of my experiences, the depth of my character, and the aspirations that fuel my journey forward.

Each of us living with HIV is a person first, deserving of the same respect, dignity, and opportunities as anyone else.

As we focus on the theme of inclusion, respect, and equity, let us remember that our shared humanity binds us together.

Let us challenge stereotypes, break down barriers, and foster an environment where every person, regardless of their HIV status, is seen for who they truly are.

I stand before you not just as someone with a diagnosis, but as a testament to the resilience that exists within each person living with HIV.

Together, let us embody the spirit of inclusivity, respect, and equity, forging a path toward a world that embraces us all without judgment.

*Delivered as a speech by Priscilla at a 2023 World AIDS Day event in Sydney, NSW.*



Positive Life NSW

The voice of all people living with HIV



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Positive Life NSW

**Good evening. My name is Melissa. I am a heterosexual woman of colour. I'm a mum, a daughter, a sibling, a friend, a manager and I've lived with HIV for nine years. I am also a speaker with Positive Life's Positive Speakers Bureau, on the Board at Positive Life NSW, and a faithful member for the last four years.**

**T**onight, I want to share some of my thoughts about World AIDS Day, and what this day means to me with all you beautiful people here tonight.

The 2023 Australian World AIDS Day theme is Inclusion. Respect. Equity. and I would like to share with you what each of these words mean to me.

Inclusion, respect, and equity are fundamental principles in addressing HIV/AIDS. They are words that also are used loosely and there may not always be emotions or thoughts behind these words by people when they talk to us as people living with HIV.

By incorporating these themes into World AIDS Day, the focus can be placed on ensuring that all people, regardless of our background or circumstances, are seen as equal and treated with respect, are included and accorded equity.

I will start with **INCLUSION**.

When I think about this word, I automatically think about including someone, making people feel welcomed, not leaving anyone behind and that's all actions I must say, I feel are words that are used loosely for people living with HIV.

It's a word people try to portray but don't practice when they interact with someone living with HIV. I am specifically speaking about health professionals that have made me feel like I was not included. I've also experienced this when dating.

Discrimination is a way to not include people and I have experienced this far too many times.

I am so glad that at Positive Life NSW, they have built a culture of inclusiveness. They have created a safe space for me to be myself, and they are what I call "my people".

The bonus about interacting with people who attend Positive Life events and staff at Positive Life, is that they live and breathe this word: **INCLUSION**.

Having HIV is not a one size fits all.

At Positive Life NSW, I have been treated with respect, treated equally and I have felt a sense of inclusion.

I believe the inclusion of diverse people promotes respect and pride and in return, this empowers communities and raises awareness of HIV/AIDS.

A way to promote inclusiveness in NSW especially for a heterosexual women living with HIV is making us feel empowered, educate us about places like Positive life NSW because not all of us know about

this organisation and the other services that are out there. I only found support five years after I was diagnosed. This could have been different if I had been told about the support out there.

Things could have been different if I saw billboards or posters out there of people who look like me. Black, a woman, a young woman, a heterosexual couple. This would have made me feel more comfortable to get out there and connect sooner and find my 'tribe' within the HIV community.

Support community-led initiatives and organisations that work towards inclusion, respect, and equity in HIV/AIDS prevention and care. This is what we need to see more of. Promote comprehensive education and awareness programs that focus on the importance of inclusion, respect, and equity in the setting of HIV/AIDS.

## **EQUITY**

I feel that there is a need for equitable access to HIV prevention, testing, treatment, and care services for all individuals. Having equity is addressing the discrepancies related to gender, race, ethnicity, status, geographic location and other factors that creates barriers to accessing necessary services.

This inclusive message highlights the message that health rights are human rights. The WHO (the World Health Organisation) says everyone has the right to "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

This encompasses a good quality of life and an absence of stigma and discrimination, ensuring that all individuals, regardless of their background or circumstances, have equitable access to prevention, treatment, care, and support services.

If we equip people with accurate information this will in turn reduce stigma, and foster supportive relationships. We need to develop awareness campaigns that are inclusive and sensitive to diverse populations, addressing the unique challenges we face in relation to HIV/AIDS.

This could involve collaborating with community organisations, cultural leaders, and must include people living with HIV/AIDS to create materials that resonate with different communities and reduce stigma.

## **RESPECT**

This word I love. It's earned but also a right of ours that sometimes gets taken for granted.



Respect can come in small ways. It's about respecting my privacy or views on my health.

I should not feel like I need to respect you just because you are a doctor or nurse and in a position of 'power'.

Once I sit in your seat at your practice and hear the questions "how I got HIV"? "who gave it to me"? and so on - this is something you don't need to know, to take care of me as your patient.

I should feel like I have a voice and a choice and be shown a level of respect around these questions as a heterosexual woman.

As a heterosexual woman, I have been asked many questions so many times about living with HIV and other inappropriate questions just because a medical practitioner needed to satisfy their curiosity. My gay male friends living with HIV tell me, they never get asked these questions.

Why?

My HIV is a very small part of who Melissa is. It's my right to feel respected.

Asking me how I got HIV is disrespecting me.

I think medical professionals should encourage open and honest dialogue about sexual health and safer sexual practices. The elimination of discrimination and prejudice is something that we need to see more of.

You know, when I tell people that I am living with HIV, they almost always assume I acquired HIV in my home country (South Africa). As everyone knows, South Africa has a very high population of people living with HIV especially among heterosexual women.

But no, I got HIV here in Sydney, NSW.

Assuming who I am, or things about me or my health, is not fair.

Let me feel like I want to share, or allow me time to tell my story and respect my boundaries.

World AIDS Day is a day that we can all come together and remember people who lost their lives to HIV/AIDS. This day we celebrate who they are and how far we as a nation has come, and look to what we can now do in the future to cultivate an inclusive, equal, respectful platform for all.

In closing, like the late Aretha Franklin said, R.E.S.P.E.C.T, find out what it means to me.

Get to know me before my status, and you may even find a beautiful, intelligent and funny woman in there.

Thank you and enjoy your evening.

*Delivered as a speech by Melissa at a 2023 World AIDS Day event in Sydney, NSW.*









**In 1983, the Denver Principles were written by activists living with HIV. This year is the fortieth anniversary of the Denver Principles.**

Concepts we take for granted such as doctors consulting patients about changes in ongoing care, the right to access healthcare services without discrimination, and the privacy of medical records all were introduced in the Denver Principles.

In part they state: “We condemn attempts to label us as ‘victims’, a term that implies defeat, and we are only occasionally ‘patients’, a term that implies passivity, helplessness, and dependence upon the care of others. We are ‘People with AIDS’” – this at a time when people were not living with HIV, but instead dying of AIDS-related illnesses.

This demand for a place at the table, for the right to be part of community, the right to make decisions and speak for themselves, and the fundamental right to dignity and respect was in hindsight, ahead of its time. It also radically changed the way people living with HIV/AIDS were viewed, and helped revolutionise healthcare advocacy.

It is difficult to convey to those who were not present, the devastating impact of HIV on an entire generation in the early 1980s and 90s. It is equally difficult to convey the resilience, strength and humour of those who died and/or lived through the early days of the epidemic.

For the past four decades, those of us living with and affected by HIV have continually advocated to be meaningfully involved in the medical decisions concerning us as well as the research that informs the understanding of, and responses to, our health, wellbeing and quality of life. The HIV response in Australia has benefited from a bipartisan approach to the epidemic and a wide range of organisations that are led by and for communities affected by HIV.

Forty years ago, the notion of a community of people being empowered and The Denver Principles’ use of person-first language has since become standard practice not just in HIV care, but across a broad spectrum of healthcare fields and disciplines. The Denver Principles have been a foundational document in the history of the AIDS epidemic, and declaration of empowerment for people living with HIV which has acted as a model for other historically marginalised groups who have fought for rights and dignity.

A decade later at the 1994 Paris AIDS Summit, heads and representatives of 42 governments agreed to “support a greater involvement of people living with HIV at all [...] levels [...] and to [...] stimulate the creation of supportive political, legal and social environments.” This set of principles is commonly referred to as the “Greater Involvement of People living with HIV/AIDS” or GIPA and was endorsed by 189 UN member states in 2001. This evolved over time to the ‘Meaningful Involvement of People Living with HIV’ or MIPA, which ensures the communities most affected by HIV are involved in decision-making, at every level of the response..

Both sets of principles have highlighted two important things:

1. To recognise the important contribution people living with HIV can make in the response to the epidemic, AND
2. To create space within society for our involvement and active participation in all aspects of that response.







The participation of all people living with HIV benefits everyone, even when the burden of competing agendas seems overwhelming.

This year's International World AIDS Day theme is *Let Communities Lead*. Communities begin to transform when organisations seek out the expertise of those impacted, and people living with HIV begin to view ourselves as subject matter experts. It is by the persistent guidance of people living with HIV that we continue to innovate and improve our methods of managing the HIV epidemic; and influence the public health messaging here in Australia.

Today, considerable inequities remain in the HIV care continuum particularly in more marginalised populations of overseas-born men who have sex with men, people from culturally and linguistically diverse backgrounds, heterosexual men and women and Aboriginal and Torres Strait Islander people. Health equity-focused approaches are necessary in this next decade to close these gaps in our HIV epidemic.

History informs our present. Without it we risk repeating harms. Without it, we lose valuable lessons and the richness of lives intertwined in the HIV epidemic. Without accountability mechanisms around diversity, inclusion, and equity, meaningful community engagement remains an aspirational mantra rather than embedded reality.

Which brings me to the Australian 2023 World AIDS Day theme – *Inclusion, Respect and Equity*.

Inclusion means more than mere acknowledgment; it means actively dismantling the barriers that perpetuate stigma and discrimination. It requires us to champion policies and programs that not only prioritise the physical well-being of all people living with HIV but also recognise the importance of mental and emotional health. Inclusion means being seen for the whole person we are, not just as patients or carriers of a virus. It means a seat at the table where decisions are made about our health and well-being.

Respect becomes a fundamental pillar. Respecting the dignity and autonomy of every person living with HIV is not just a slogan; it is a call to action. It compels us to challenge the lingering stereotypes and prejudices that have hindered progress for far too long. Respect is about empowering people living with HIV to be agents of change, acknowledging our expertise in our own lived experience. Respect means our voices will be heard AND valued — that our stories will be listened to with empathy and without judgment.

Equity is both an aspiration and our demand. Equity means recognising that the burden of HIV is not distributed evenly across communities and populations. It demands a commitment to addressing the social determinants of health that perpetuate health disparities. It urges us to ensure that access to prevention, treatment, and support services is not a privilege, but a right for every person, irrespective of their background or circumstances.

Equity, for each one of us living with HIV provides accessibility to opportunities and resources. Equity dismantles the systemic

barriers that impede our progress and perpetuate the disparities that persist within our communities.

While public health messaging about the HIV epidemic has evolved substantially over the past 40 years, future HIV messaging must be driven by co-designed health equity principles that include an increased representation of other populations in nuanced and targeted ways.

Future HIV messaging must not leave diverse populations behind in our quest for the virtual elimination of HIV transmission.

In closing, HIV-related disparities and health inequities are both a public health and moral imperative.

As we commemorate World AIDS Day, let's continue to be guided by the Denver Principles. Let's create a world where our HIV status does not define us, where societal attitudes reflect compassion rather than judgment, and where healthcare systems are designed to meet our needs without discrimination.

Thank you.

*Delivered as a speech by Jane Costello at a 2023 World AIDS Day event in Sydney, NSW.*

## Letters to the Editor

**Your messages, comments, thoughts and opinions are welcome here.**

Emails should be short  
(less than 200 words)  
and may be edited.

All letters to be considered for publication must have a name, street address and phone number for verification.

Please specify if you want your details withheld from publication.

Email Talkabout  
[editor@positivelife.org.au](mailto:editor@positivelife.org.au) or

Write to Talkabout  
PO Box 831  
Darlinghurst NSW 1300

## JAN'Y

- 30 **Digital Mentors Sydney 12.15pm**  
*For all people living with HIV*
- 30 **Positive Conversations Online 6pm**  
*For all people living with HIV*

## FEBRUARY

- 2 **Social Club Sydney 6pm**  
*For all people living with HIV who identify as heterosexual*
- 14 **Peer2Peer Sydney 6pm**  
*For all gay and bisexual men living with HIV*
- 15 **Tai Chi Sydney 8am**  
*For all people living with HIV*
- 18 **Fair Day Sydney 10am-3pm**
- 20 **The Women's Room Online 6.30pm**  
*For all women living with HIV under 45 years of age*
- 20 **The Men's Room Online 6.30pm**  
*For all men living with HIV who identify as heterosexual*
- 27 **Digital Mentors Sydney 12.15pm**  
*For all people living with HIV*
- 27 **Positive Conversations Online 6pm**  
*For all people living with HIV*

## MARCH

- 1 **Social Club Sydney 6pm**  
*For all people living with HIV who identify as heterosexual*
- 2 **Mardi Gras Parade**
- 9 **National Day of Women Living with HIV**
- 14 **Tai Chi Sydney 8am**  
*For all people living with HIV*
- 19 **For Women Online 6.30pm**  
*For all women living with HIV over 45 years of age*
- 21 **[+Connect] Casula**  
*For all people living with HIV, our partners, friends and family*
- 23 **TORQUE Sydney**  
*For all people living with HIV who identify as heterosexual*
- 26 **Digital Mentors Sydney 12.15pm**  
*For all people living with HIV*
- 26 **Positive Conversations Online 6pm**  
*For all people living with HIV*

### FOR MORE DETAILS

**Call (02) 8357 8386 or 1800 245 677 or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)**

Event details are correct at time of printing.





**As people living with HIV, we're often focused on our physical health, taking medication, getting enough sleep, watching our diet, weight and exercising.**

It can be really easy to let one of the main aspects of good health slip completely, and that is our mental and emotional wellness. Hang on, you might say. I'm not mentally unwell. I certainly don't have a mental illness! Mental wellbeing is much more than the absence of mental illness.

For people living with HIV, mental wellbeing means we take extra care to build a supportive network of friends and allies, dismantle our internalised stigma and cultivate our own self-acceptance. People living with HIV in NSW face a range of unique stressors, especially if we live outside major cities.

Today, one of the main challenges of HIV extends beyond the medical side of HIV. In a time of living with HIV with access to free, effective medication that controls the virus and prevents transmission, our challenges are about living well with HIV. Today many of us face the challenges of social biases, fears, and misconceptions about HIV that impact our mental health and wellbeing. The fear of HIV stigma or discrimination adds to these extra burdens.

The pervasive stigma surrounding our HIV status can cause reluctance or shame to seek emotional support. Even if we want support, finding accessible and affordable support, that we can trust, can be difficult. For people outside the metropolitan areas where wellbeing resources are limited, mainly due to the lack of mental health professionals, these stressors can be amplified.

Seeking mental health support is a sign of strength, not weakness. When HIV is along for the ride, it's important to reach out for mental health support from professionals or from your peers (others also living with HIV) when you need it. You might call a free helpline, call a trusted friend for a chat, or get in touch with Positive Life NSW for peer support or some counselling.

Talking about how you're feeling is a great start to get your wellbeing back on track. Making time for regular physical activity, mindfulness practices, and creative activities you enjoy also helps.

Nurturing good mental health and wellbeing is more than just a priority for those of us living with HIV, it's a lifeline. It is critical to manage our overall health. Along with our healthcare providers, other elements of our support system include understanding friends and supportive family, and the safe haven of a peer support group. A support system can become a reliable strategy to manage feelings of anxiety or depression.

Talking with someone else in similar shoes offers one of the fastest ways to feel better and find solutions to live well with HIV. Positive Life NSW offers a range of peer social support groups, online and face-to-face as well as counselling by accredited counsellors living with or affected by HIV. If you're living with HIV and feeling low or need an understanding, non-judgemental listener, give Positive Life NSW a call on (02) 8357 8386 or 1800 245 677 or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

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- Connect with other heterosexual people living with HIV

### WEBSITE

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### EMAIL

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Pozhet is a government-funded NSW-wide service for heterosexual people at risk of or living with HIV, their partners and family.



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HIV Health Promotion

Advocacy + Policy

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Talkabout Magazine

Counselling

a[STARTx]

Ageing Support

Treatments Information + Support

Social Support

Aboriginal Health Program

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Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and practices that discriminate against all people living with HIV, our partners, friends, family and carers in NSW.

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