talkabout

Where we speak for ourselves

#214 | September 2025 | ISSN 1034 0866 | Positive Life NSW – the voice of all people living with HIV since 1988

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TALKABOUT
WHERE WE SPEAK FOR OURSELVES

EDITION #214

CONTRIBUTORS Kim, Tim Alderman, Stephen Lunny, Melissa Carolus, Michelle Tobin

COVER AND INSIDE PHOTOS NAIDOC Week Art Exhibition at Positive Life NSW

CENTERFOLD PHOTOS Australasian HIV&AIDS Conference 2025

2025 TALKABOUT ADVISORY GROUP Kim, Maria, Tim Alderman

EDITOR Positive Life NSW

FEEDBACK & SUBSCRIPTIONS editor@positivelife.org.au

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Positive Life NSW acknoweldges the traditional custodians of the land on which we live, work and play. We pay our respects to Elders past and present. Always was, always will be, Aboriginal land.

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SUBMISSIONS AND ARTWORK: **FRIDAY 6 MARCH 2026**
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THIS EDITION

This edition of Talkabout highlights the 2025 Australasian HIV&AIDS Conference, featuring photographs from the event. In the centerfold on pages 14-15, you'll find images of Positive Life NSW CEO Jane Costello, along with Peer Navigators Billy and Priscilla, as they deliver their presentations.

We're excited to announce the return of our much-missed segment, Nutrition Bites! Kicking things off with a deliciously healthy recipe for chocolate tofu mousse. Head over to page 10 to find out how you can make it yourself!

Long time writer and Talkabout Advisory Group member, Tim Alderman reflects on the challenges faced by people with disabilities and emphasises the importance of respecting disabled individuals' autonomy and decision-making. Read *'Disabling the Disabled'* on page 20.

The voice of one of our four-footed friends Obin, runs in *'Molly's Musings'* on page 9. If you are a proud pet owner (fluffy, four-legged, feathered or otherwise), please consider responding to the callout for your stories.

Melissa Carolus, Member of the Positive Life NSW Positive Speakers Bureau team, reflects on her enriching experience attending the Heterosexual Positive Impact Residential Workshop, organised by Positive Life NSW (page 12).

Talkabout Advisory Group member, Kim highlights key themes from the 2025 IAS Conference on HIV Science in Kigali, Rwanda including advancements in HIV prevention and Africa's forward leadership in HIV research (page 18).

Michelle Tobin, one of our Positive Speakers and members, shares her speech from the NAIDOC Week event held at Positive Life NSW (page 16).

The edition wraps up with the sixth part of Tim Alderman's historical commentary, *A 40 year journey into (and out of) fear* (page 24).

Sharing your story in Talkabout is easy and simple. We 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.

If you have thoughts or a story to share, or would like to explore how you might be part of Talkabout, please get in touch. Call Positive Life on (02) 8357-8386 or 1800 245 677 or by email on contact@positivelife.org.au. We look forward to hearing from you in the near future.

Talkabout Editor

Former Editor of Talkabout and Communications Officer for 10 years, Craig has recently moved on from Positive Life NSW.

The Talkabout Advisory Group want to warmly acknowledge the incredible contribution Craig has made to the magazine over so many years.

As Advisory Group members, we have been fortuante to benefit from Craig's expertise, guidance and support. Craig brought to the group clarity, insight and a spirit of collaboration. Our Zoom meetings were something to look forward to - great discussions and idea-sharing, laughter and camaraderie. Thank you Craig, you will be missed and we wish you the very best.

Maria, Kim and the ever indomitable Tim (Talkabout Advisory Group)

IN THE LOOP

STEPHEN LUNNY, POSITIVE LIFE NSW PRESIDENT

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.

As we swing into the Spring season, I would like to recap on a few Positive Life NSW Events from the previous couple of months.

[+Connect]

On Wednesday 9th July community members gathered at The Aerial Function Centre Rooftop and Bar for another [+Connect] evening. If you haven't attended this event before, I highly recommend that you give it a go. Great company, positive conversations, tasty treats to eat and fantastic views of the backend of the CBD. One not to be missed. The next instalment of this event and the final for the year, will be held on Wednesday 19th November. Reach out to the team if you are interested in attending.

Yaralla House BBQ

Every quarter, Positive Life NSW visits Yaralla House where we host a BBQ Lunch for the residents at this wonderful property. Yaralla House is located on the grounds of the Yaralla Estate, part of the Dame Eadith Walker Estate and is a dedicated residence for palliative care for people living with HIV-related dementia (HAND or HND). Our recent BBQ was held on Wednesday 9th July. Together with residents and the great multidisciplinary care team at the House, we share lunch, laughter, and talk about things that are going on for the residents in the open courtyard. We also provide community with the opportunity to access health information or other support should they require.

Peer2Peer

On Wednesday 13th August, a facilitator-led discussion around relationships was held at our monthly Peer2Peer evening. It was so fulfilling to be part of one of the more engaging sessions that I have been fortunate enough to attend. Separate to the conversation, connecting with other gay and bisexual men living with HIV means a lot to me. Feeling connected to others with similar experiences to ourselves cannot be underestimated.

Positive Life NSW is a peer-based organisation. With this in a mind we have worked hard to broaden representation and diversity in our team with the hope that our community will see themselves reflected in the both the operational staff and the Board. This leads to more meaningful connections between the Peer Navigators and our community members where empathy and understanding are central. Evidence shows that there are increased positive impacts when peer-based health promotion is incorporated into events such as these. These outcomes include improved quality of life, self-care skills and increased confidence. This principle lies at the heart of Positive Life NSW and the work we do.

Enjoy the change of season, hopefully a little less rain (!) and for those of you who experience hay fever at this time of year, I hope that the pollen count reduces very soon.

Go Well.

TALK SHOP

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.

THE NEW AGED CARE ACT: WHAT IT MEANS FOR OLDER AUSTRALIANS & HOW IT WILL IMPROVE CARE

On November 1, 2025, the new Aged Care Act will take effect, bringing significant changes aimed at improving the lives of older Australians. The goal is to empower them, protect their rights, and ensure they receive the best possible care. Here's what's changing and why it matters for anyone navigating aged care:

1. PUTTING RIGHTS FIRST

One of the biggest changes is the Rights-Based Framework. This new Act ensures that older Australians have control over their care, including the right to make decisions about what's best for them. It's all about making sure people can make choices about their own care, including what risks they're willing to take. A new Statement of Rights will clearly outline what older people can expect when accessing aged care, with the Aged Care Quality and Safety Commission making sure these rights are respected.

2. STRONGER CARE STANDARDS

Under the new Act, aged care quality standards are being strengthened. This means that good care isn't just a goal; it's something that's expected. Older people will be more involved in planning and managing their own care, so it's tailored to meet individual needs. The aim is simple: to make sure care is safe, high-quality, and focused on the person receiving it – not just the process.

3. BETTER PROTECTION FOR SPEAKING UP

It's never easy to speak up when something's not right, especially in a care setting. The new Act offers stronger protection for whistleblowers, those who raise concerns about issues within the system. This is about making sure people – whether they're residents, families, or aged care workers, can voice concerns without worrying about retaliation. Everyone should feel safe to speak up and know that issues will be taken seriously.

4. SUPPORTED DECISION MAKING

Another key part of the Act is supported decision-making. This means older Australians will have the right to make decisions about their care, with support available if needed. For those who may require extra help, a registered supporter can assist with the decision-making process. This ensures that older people stay in control of their lives and care, with the assistance they need to make informed choices.

5. AGED CARE WORKERS

The changes also impact aged care workers. The Act will help workers deliver better, more personalised care, with a focus on empowering older Australians. It's not just about doing a job, it's about working together with older people to make sure their needs are met in the best way possible.

6. HOW AGED CARE IS FUNDED

The new Act also brings changes to how aged care services are funded. One of the biggest updates is the introduction of the Non-Clinical Care Contribution (NCCC). This applies to services like mobility assistance, bathing, and lifestyle activities, things that aren't medical care but still vital for daily life. Those who can afford it will contribute, but safeguards, including a lifetime cap, will protect lower-income individuals. A Hotelling Supplement will cover services like catering and cleaning for those who can afford it, while ensuring financial protection for those with fewer resources.

7. SIMPLIFIED ACCESS

Let's face it, navigating aged care can be confusing. The new Act aims to simplify the whole process. Instead of jumping through hoops, there will be a single assessment process to determine eligibility for different aged care services. This will make it easier for older Australians to access the care they need, when they need it.

8. SUPPORT AT HOME PROGRAM

The new Support at Home Program will replace Home Care Packages and the Short-Term Restorative Care Program starting 1 November 2025. Its goal is to make home care services more accessible, flexible, and easier to navigate, helping older Australians live independently and stay at home longer.

For support navigating the aged care system and making informed decisions, contact Positive Life NSW's Peer and Ageing Support Officer at **(02) 8357 8386, 1800 245 67 (freecall)** or email **contact@positivelife.org.au**

For more information on the New Aged Care Act, please visit the Older Persons Advocacy Network (OPAN) website or the Australian Government Department of Health, Disability and Ageing website.

For a comparison of the key differences between the Support at Home program and the Home Care Packages program, please refer to the table in this article.

Positive Life NSW

Ageing Support

Supporting people living with HIV aged over 45, through the maze of aged care, disability, and healthcare services in NSW

Contact Positive Life NSW on
(02) 8357 8386 or 1800 245 677 (freecall)

MOLLY’S MUSINGS

OBIN

Hi, I’m Obin, a seven-month-old dachshund with a long body, short legs, and a very big story.

When I first moved in four months ago, the world felt enormous and noisy. Bins rumbled. Leaves chased me. Even friendly humans looked like giants with jangly keys. Walks were the scariest thing. I perfected the ‘Pancake’ - belly flat, legs spread, refusing to move an inch. Outside toilets? No, thank you. I preferred the reliable comforts of home and privacy. My human was kind and patient, offering treats, cheering my tiny steps, and never rushing my sniffing investigations.

Something changed. One day I smelled a breeze that said, ‘adventure.’ Another day a kookaburra laughed at me, and I laughed back (quietly). Then I learned a secret - footpaths are like scent newspapers, and every lamp post prints breaking news. Now I wake up, stretch my long sausage body and sprint to the door for my headline walk. I trot down the street like the king of the neighbourhood, ears bouncing, my tail drawing happy exclamation marks.

And yes, I’ve mastered outdoor bathroom etiquette. I pick my patch, circle like a professional landscaper, and do my business with pride. My human celebrates like I’ve won a gold medal. We both love a good victory snack.

At home I’m cheeky, but in a charming way. I relocate socks to important new locations, reorganise the couch with strategic digging, and practise my speed when the treat jar opens.

I’m working on “stay” (boring) and “leave it” (rude), but I’m nailing “cuddle” and “nap.” At the park I’m making friends, trading sniffs and zoomies. After a big walk, a long snooze in a warm sunny spot is always on the cards.

If you have a nervous pup, here’s my dachshund wisdom: tiny steps count. Sniffs are science. Bravery grows when someone believes in you and packs the good treats. One day you look up and realise the big wide world is actually your playground.

I used to be frightened of every new street, now going outside is the highlight of my day. The horizon keeps getting bigger and although my legs may be short, my courage and my heart, are incredibly vast.

The pets of the Talkabout Advisory Group members are calling for all pets (and their owners) to contribute to ‘Molly’s Musings’ column by sharing a short written piece (approx 500 words) from your pet’s perspective introducing themself and including a picture of them for the Talkabout magazine.
Send to contact@positivelife.org.au

NUTRITION BITES | CHOCOLATE TOFU MOUSSE

THIS IS A MUCH HEALTHIER VERSION OF CHOCOLATE MOUSSE WHICH IS EASIER TO MAKE AND DELICIOUS. GIVE IT A TRY!

INGREDIENTS

- 300 g silken tofu
- 150 g dark chocolate melted
- 2-3 tbsp maple syrup or honey to taste
- An optional pinch of salt

INSTRUCTIONS

1. Break up the chocolate into a heat-proof bowl and melt in the microwave (20 second bursts), stirring every few seconds to make sure the chocolate doesn't burn.

2. Place tofu in a bowl and warm in the microwave. This will ensure that the melted chocolate doesn't set when you add it to the tofu

3. To a food processor, add the tofu, melted chocolate, maple syrup and and optional pinch of salt. Blend until smooth.

4. Transfer into serving glasses or ramekins

5. Top with grated dark chocolate and fresh raspberries or strawberries (optional)

6. Serve!

CALENDAR

For more info call Positive Life NSW
(02) 8357 8386 or 1800 245 677 or visit
www.positivelife.org.au/events-calendar/

Oct

3 Social Club Sydney 6pm - *heterosexual people living with HIV*

11 Parramatta Pride Picnic - *free community event*

14 In the Know 6pm - *all people living with HIV*

18-19 a[START]X - *workshop for gay & bisexual men*

21 Women's Room Online 6pm - *women living with HIV under 45 years of age*

22 Peer2Peer Sydney 6pm - *gay/bisexual men living with HIV*

24 Digital Mentors Sydney 12.30pm - *all people living with HIV*

28 Positive Conversations Online 6pm - *all people living with HIV*

Nov

7 Social Club Sydney 6pm - *heterosexual people living with HIV*

11 Men's Room Online 6pm - *heterosexual men living with HIV*

18 For Women Online 6pm - *women living with HIV over 45 years of age*

19 [+Connect] Ultimo 12noon - *inclusive of all people*

25 Digital Mentors 12.30pm - *all people living with HIV*

25 Positive Conversations Online 6pm - *all people living with HIV*

Dec

1 World Aids Day - *held each year to help raise awareness about HIV and AIDS*

3 AGM/Christmas Party

12 Peer2Peer & Social Club Sydney 6pm

Details correct at the time of printing.

REFLECTIONS FROM A WEEKEND OF SELF-CARE & COMMUNITY

MELISSA CAROLUS
POSITIVE LIFE NSW BOARD MEMBER AND POSITIVE SPEAKERS BUREAU SPEAKER

I was selected to attend the Heterosexual Positive Impact Residential Workshop over the weekend, and it was an incredible experience. This was my third time attending a workshop with Positive Life, and as always, I knew we were in for a treat.

I arrived at the Positive Life office on Friday afternoon and was greeted by the usual warm smiles from both the staff and fellow attendees. We had a chance to chat and mingle before the bus arrived, and as it got closer to departure, my excitement grew. From past experiences, I knew Positive Life always organises a fantastic weekend, and I couldn't wait to dive in.

The bus ride was just under two hours, taking us from Sydney CBD to Wiseman's Ferry. The weather was perfect, and the scenic views were breathtaking. I spent some time chatting with fellow passengers and also enjoyed some quiet moments, listening to music and preparing for the weekend ahead.

Upon arrival, we dropped off our luggage and headed across the road to a cozy place for lunch. This was a great opportunity to meet more people and make new connections. Afterward, we returned to the venue to unwind before our first session - an introduction and mingling event followed by a group session. Later, we had dinner and roasted marshmallows, then took part in a sound healing session. It was a relaxing experience, with soothing sounds guiding us into a peaceful state. My favourite part was the gong and humming, which left me

feeling deeply connected and calm.

Saturday began with yoga, which I passed on, but my friends who attended said it was wonderful. After breakfast, we spent the day in workshops centred around self-care, with sessions titled 'More Than Your Diagnosis' and 'Becoming Who You Want to Be.' The group discussions were insightful, with everyone sharing personal stories about overcoming challenges and living with HIV. The openness in the room created a strong sense of community, and it was inspiring to hear diverse perspectives.

That night, after a delicious three-course dinner, we had a fun games night. Many of us played Uno, and we danced the night away, building connections and enjoying each other's company.

Sunday morning offered a special session, 'Mandala Moments in Rhythm with Nature.' We went on a nature walk, connecting with the environment and creating a mandala using natural materials. This meditative practice was a beautiful way to merge our inner and outer worlds, inviting mindfulness and reflection.

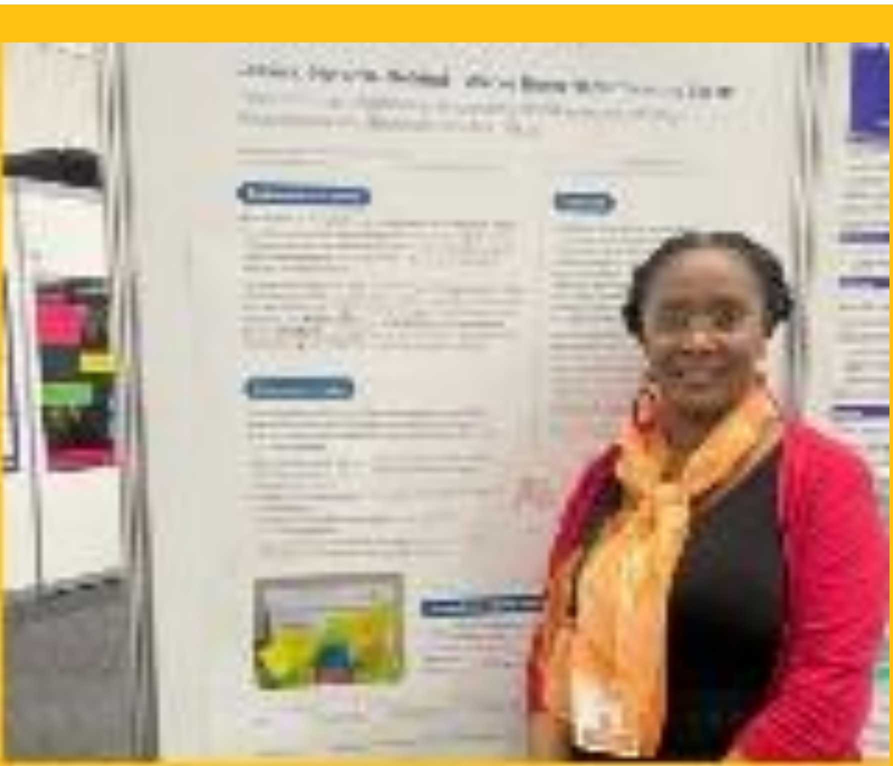
After breakfast, we gathered for a session on 'Building Life-Changing Habits,' where we discussed goals and habits - both good and bad. I reflected on my own habits, particularly my love of chocolate and the habit of not feeling 'enough.' The group shared tender moments of support and encouragement, reminding each other that we matter. I learned to use more empowering language, such as adding 'yet' to statements - 'I haven't done it yet' rather than 'I can't.'

As the weekend came to a close, I felt a mix of gratitude and sadness. I knew the bus ride back to reality was just a few hours away, but I cherished the final moments spent connecting with others, whether at the pool, chatting in the sun, or sharing a meal. The weekend helped me discover more about myself, and when I returned home, I wrote down both short and long-term goals, along with strategies to overcome my bad habits and cultivate positive ones.

Thank you, Positive Life, for an unforgettable weekend. Your workshops are not only relaxing and fun but also deeply informative and well-organised. I'm already looking forward to the next one.

Positive

The voice of all pe



Life NSW

ople living with HIV

NAIDOC WEEK ART EXHIBITION AT POSITIVE LIFE

MICHELLE TOBIN

Transcript of speech given at Positive Life NSW's celebration of NAIDOC Week

We are here to honour and remember proud Ku Ku Imidijii man, an acclaimed Aboriginal artist, painter, sculptor and printmaker Arone Meeks, as we mark this year's theme – The Next Generation: Strength, Vision & Legacy.

Arone was a proud Aboriginal Man from Leura who passed away on the 5th May 2021

Arone was an accomplished artist and leading advocate for Aboriginal and Torres Islanders living with HIV.

Arone provided a unique contribution to the HIV sector including, Anwernekenhe National HIV Alliance (ANA), Positive Aboriginal and Torres Strait Islander Network (PATSIN), National Association of People with HIV Australia (NAPWHA) and the Australian Federation of AIDS Organisations (AFAO) and pioneered a new way of storytelling. Through art, he shared his story and that of his community by interconnecting Aboriginal culture, HIV and health promotion.

His art was ground-breaking, giving a voice to those previously voiceless. Arone Meeks' legacy is a collection of artwork which will continue to have a profound impact on the way we understand the history of the HIV response in Australia. Arone's artistic works are on display in galleries around the world, including the National Gallery of Australia here at home.

Arone's artworks have supported PATSIN and the ANA in a most culturally appropriate way that educates our Aboriginal and Torres Strait Islander LGBTIQ+ Brother Boys and Sister Girls, and the HIV positive community and HIV Sector more broadly across the country.

Most recent works was that his art has graced the cover of the newly updated Us Mob & HIV Booklet & the virtual website.

Arone was my friend, my brother, my supporter. We first met in 1997 in Chiang Mai at an International AIDS Conference; we were both activists, him with his art and me, well learning how important my voice was to be. Whilst there, we entered a pageant about safe sex messaging, and managed 2nd and 3rd place. This was to be the first of many conferences that we were to attend together from NAPWHA, AFAO, Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), pre-Indigenous Conference in 2014 Sydney prior to the World AIDS Conference in Melbourne. No matter where we were, his amazing art was being shown. It was an honour walking through Parliament House back in 2018 for the Aboriginal & Torres Strait Islander HIV Awareness Week (ATSIHAW) Parliamentary Breakfast alongside Federal Ministers and with Prof James Ward and seeing his art lining the corridor walls. Arone's artwork has been used to promote educational resources for peer responses in Indigenous communities and resource poor-settings, from the 2Spirits Program up in Cairns, to being involved with the Sistergirl and Brotherboys group, to the ANA, Our Vision, Us Mob Stronger Together working to stop HIV for our People and our Community.

The PATSIN logo, Arone describes the imagery as, the male image to the right of the Rainbow Serpent (our creator) and to the left a female image …. The central serpent shape also carries designs of 'creation' and the virus that some of our mob carry …. The overall colours of the logo are that of the Aboriginal and Torres Strait Islander flags.

In 2019 we came together to facilitate a health and wellbeing retreat with Queensland Positive People (QPP), for newly diagnosed mob in Far North Queensland, where he facilitated an arts session with the positive mob.

It was in December 2020 during lockdown that Arone facilitated two inspirational art workshops with Positive Life NSW for our communities of people living with HIV to explore Aboriginal art history and painting techniques. We were privileged to learn from Arone as he proudly shared his heritage and culture with us through the medium of art and storytelling. His stature as an acclaimed and respected artist and elder will not be forgotten. Arone carried the mantle of tradition, activism and dignity with leadership and honour. He also helped create this banner of our positive mob from around the country who left their mark after attending the A5 conference in Cairns.

We remained close friends through the years fighting for the rights of our brothers and sisters living with HIV, this was done through words spoken and through your art. The impact and the legacy that you have left us will be felt for many years to come. We have lost some strong proud leaders over the past few years. We are forever guided by your spirits, your strength and passion.

IAS ANNUAL CONFERENCE

Highlights from the IAS Annual Conference 2025, Kigali, Rwanda

BY KIM

The International AIDS Society (IAS) hosts the world's leading scientific gathering on HIV, bringing together researchers, clinicians, policymakers, activists, and people living with HIV. The purpose is to share the latest advances in prevention, treatment, and cure research; to translate science into policy and practice; to promote equity and human rights; and to track global progress in the HIV response.

The 13th IAS Conference on HIV Science took place from 13 to 17 July 2025 in Kigali, Rwanda, with nearly 4,000 participants attending both in person and online. The scientific programme covered a broad spectrum of topics, including clinical trials, implementation science, behavioural studies, and community-driven approaches. This reflects the diversity and depth of current HIV research.

The Global Funding Crisis: One of the most pressing themes was the sharp decline in HIV funding, particularly from major international contributors. Concerns focused on the uncertainty surrounding continued support for technical assistance, HIV prevention and testing, and the provision of antiretroviral treatment in low- and middle-income countries. Speakers cautioned that without urgent reinvestment, decades of progress could be reversed, leading to millions of preventable infections and deaths by 2030.

Advances in Prevention Strategies & (Pre-exposure prophylaxis PrEP) Innovation: A central focus of the conference was progress in HIV prevention strategies. The twice-yearly injectable PrEP, lenacapavir, attracted significant attention after trial data demonstrated strong efficacy. In July 2025, the World Health Organization (WHO) issued guidelines recommending lenacapavir as an additional prevention option, and efforts are underway to expand access in low and middle income countries.

Africa's Growing Scientific Leadership: Another major theme was the growing role of African scientists and institutions in leading HIV research. The launch of the Africa Cure Consortium highlighted efforts to advance cure strategies from within the region most affected by the HIV response. Rwanda also shared its experience in responding quickly to public health threats, emphasising the importance of African-driven innovation, infrastructure, and policy in shaping the global HIV response.

Sustaining Treatment, Care & Health Services: A further concern was how to maintain HIV treatment and health services in low- and middle-income countries amid shrinking donor support. Discussions focused on differentiated service delivery, integrating HIV care with reproductive health, and promoting person-centred approaches. Attention was also given to building resilience through community-led monitoring and managing HIV alongside other chronic conditions, particularly in settings affected by conflict or humanitarian crises.

The conference highlighted the contrast between major scientific progress and the political and financial challenges that could limit its impact. Calls were made for renewed commitment to sustain funding, expand equitable access to prevention and treatment, and strengthen low- and middle-income countries' leadership in research and policy. Outcomes included updated WHO guidelines, agreements to expand access to lenacapavir, and greater momentum toward integrated, person-centred health systems. The overall message was that ending HIV remains achievable, but only if scientific advances are matched by solidarity, investment, and a firm commitment to equity and human rights.

Photo credit: www.iasociety.org

Bobby Goldsmith
Foundation

Living with HIV?

Want to improve your quality of life?

You may be eligible to take part in a study aimed at improving your social, mental, physical and financial health.

What's involved:

- Complete two of our free Health & Wellbeing Programs
- Undertake three easy assessments
- Participate in a short survey

Eligibility:

- Aged 18 years or older
- Live in Western Sydney
- Able to speak and read English

You will receive:

- Gift vouchers for completing each of the programs, doing the assessments and for participating in the survey (if selected)

All data gathered in this study is completely confidential and anonymous. Your participation is voluntary - you can opt out of the study at any time

Interested in learning more? Scan the QR code, visit www.bgf.org.au/study or email study@bgf.org.au to express your interest.

2023/ETH02059

DISABLING THE DISABLED

TIM ALDERMAN

Can I be blunt here?

One of the biggest problems of living with disabilities is that people think you are disabled!

Forgive me for delving into my nightly vice of 'Home and Away' but they were covering the touchy subject of Alzheimer's recently. Irene Roberts had been diagnosed with this, and not only were they handling the subject quite sympathetically, there is a touch of scary realism that many of us with disabilities are faced with. Irene had decided to travel overseas for whatever remains of her lucid periods.

However, John Palmer is convinced that this is a bad decision on her part, and was being quite vocal about it, telling her that travel overseas is dangerous, and that selling her home to finance it would leave her with no assets. Irene was sticking with her decision, and had put plans in place to cover any contingency. But can you see what John was doing here? He's decided that seeing as Irene has to deal with the disabling effects of Alzheimers, that she's become incapable of making decisions for herself. Everyone is doing what they consider to be helping her…but no one asks her if that is what she wants! She doesn't necessarily want things to be easier! She wants to be seen as an independent person, capable of making her own decisions.

Yes, this is only happening on a daily soap, but it raises an important issue…the attempts by outside forces to influence the decisions of someone with a disability, attempts to downplay their ability to make decisions, to try to control their lives, and disempowers them.

I'm legally blind (an important label when accessing services), and have mobility and balance issues due to medication-induced peripheral neuropathy. I'm on an aged care home support package, and access services through a service provider. Overall, I'm pleased with the services I get, which includes cleaning and assisted shopping. One of the workers who takes me shopping mothers me! I hate it… my friends will tell you I'm very independent…and despite attempts on my part to assert that I do not like it, and can make my own decisions, they persist, so I just grin and bear it. I know they mean well, but they have been taught that disabled people are DIS-abled, so they need to take control when out with us.

Many well-intentioned people make the mistake of trying to take control from us, with unwanted assistance. When I used to use a white cane (something I no longer use, as they can be dangerous on badly maintained paths and concourses), when crossing roads at crossings or lights, they would just grab my arm to guide me across. It would seem logical to me that if I'm out and about on my own, that I'm capable of doing things like crossing roads without help. The problem is…they don't ask if I need help, it is just assumed I do. It is not only rude, it's an attempt to take away my power to decide things for myself!

Every morning I walk my dog, I walk down the street to meet friends for lunch, or to do shopping. I go to an exercise physiology gym to do balance and stretch classes (they go out of their way so ensure I can navigate a very equipment-crowded gym, and that my requests for easily seen equipment…and placement of…during classes is seen too). Obviously I write articles, using a large font. I read books, also using a large font, or access audiobooks. I look after myself on a day-to-day basis, doing laundry, bathing, preparing meals, I memorise the number of steps I need to negotiate, in the absence of disability ramps, the safest routes to take to access shops and services. So I actually lead a pretty normal, mundane life despite the absence of vision. If I need to access things in unfamiliar territory, I either use my service providers drivers, or ask friends to go with me. In other words, I'm regulating my own life. If you want to assist me…please just ask me if I need help!

Despite the Invictus Games, the disabled Olympics, and other peer led examples of blind and physically disabled activities, there is still a perception that when we are in public places, we need to be helped, as we are incapable of making decisions for ourselves. Please…don't just move in to help without asking permission! We are more than capable of developing our own coping mechanisms. This is how we empower ourselves. Of course, this doesn't apply to everyone who wants to help, but experience has taught me that many act without thinking first.

Remember…if we need help, we'll ask! At that point, we appreciate it.

Please note that my use of language here is deliberate, and of-the-time! I make no apologies for it!

WOMEN'S SPACE

MELISSA CAROLUS

Just one year after Melissa sat down with her two children, Johannes (15) and Amari (17), to disclose and talk openly about her HIV status, she's back for another honest conversation. This time, they reflect on how things have changed since that pivotal moment, sharing their thoughts, feelings, and experiences with a renewed sense of openness. Here's what they had to say in response to her questions.

How has life been since we spoke about my diagnosis a few years ago? Has anything changed for you?

Amari: Not much, I guess. We're all older now, but we're still the same. Our relationship is still the same.

Johannes: Yeah, not a lot has changed, except that I'm taller than both of you. But you're still Mum to me.

What are your thoughts about me living with HIV?

Amari: I don't have any new thoughts. I'm just grateful that you told us, thank you. But I also think it's nice that you're trying to inspire other people with your story.

Johannes: I don't really have any thoughts either. It's normal for me now. Like I said, you're still my mum.

Do you ever tell your mates about it? Why or why not?

Amari: I don't tell people. The most important people, like our family, know, so I don't talk about it outside of that. I don't tell my mates because they might be funny about it, they're not as educated as we are. I just don't feel the need to bring it up.

Johannes: I agree. There's no need to talk about it. It's private. If I ever have questions, I'll ask you, Mum.

What do you think about me being a speaker with Positive Life?

Amari: I think it's cool. It's nice that you can inspire people.

I just don't think it would be good if you spoke at schools because what if someone knows me? What if they're like, "Oh, that's Amari's mum?"

When I'm older, I'd be more okay with it. But I think it's really nice that you get to go to universities and be on panels. That's awesome. But for my privacy, schools are a no-go.

Johannes: Yeah, like Amari said, I think it's great that you're sharing your HIV story with others. But if you ever do a magazine, I wouldn't want my face in it. And if you're going to talk at schools, I don't think I'm ready for that either.

I'm not sure if I've asked you this before, but what were your thoughts when I told you how I acquired HIV?

Amari: It was a bit of a shock, but only because at school they teach you that people can die from it. But I know that won't happen to you, Mum. I think the shock is gone now because I know you're doing okay, you have support and you're not unwell.

Johannes: Since you're my mum, you told me that I have to be kind. So I don't want to dwell on it or wonder who the person was. I think I've learned from this: in the future, I'll be honest with people, and I'll make sure to practice safer sex.

Do you ever worry about my future, living with HIV or being able to be your mum?

Amari: No, not really. I think you're doing well. You've got good medication, support, and a good doctor. I just hope one day you meet someone who's understanding and doesn't discriminate, like a partner. I know it doesn't affect you being my mum and I don't think it ever will.

Johannes: No, I don't worry either.

Do you know that I can't pass it on to you and why?

Amari: Yes, I'm confident you can't pass it on to me or anyone. You've explained it, and I've read about it too. You said something about being undetectable, right? Because your levels are so low, you can't pass it on. Is that right?

Mum: Yes, that's right. As long as I continue to take my medication and remain undetectable, I can't pass it on.

Johannes: Like Amari said, I'm confident that you can't pass it on. You told us about being undetectable, so I never worry that you'll give it to anyone.

What is something you noticed changed about me after I told you?

Amari: Nothing really.

Johannes: I think you've become more open about having HIV with people, which I think is great. But yeah, nothing else has really changed about you. You're just more open, that's it.

Do you have any questions for me as your mum living with HIV?

Amari: Yes, I do. How did you know you had it? What were the symptoms?

Mum: Well, I knew something felt off in my body, and I knew I hadn't protected myself during intimacy with someone. So, I went and did a test, and that's when I found out I was HIV positive. There are different symptoms that people might have, like mouth ulcers or fatigue, but everyone is different. The important thing is that I went to the doctor and got tested. If you ever feel like you want to take a test, it's not a bad thing at all.

Johannes: I have a question, if you have another baby, will that baby get HIV?

Mum: Nope, because I'm on medication, and since I'm undetectable, it's virtually impossible for me to pass it on to the baby or anyone else. Nothing is 100%, but I know I can't pass it on. If I have another baby, it won't be an issue. Do you want me to have another baby, J?

Johannes: Well, back then I wanted you to have another baby, but now I think the two of us is just fine.

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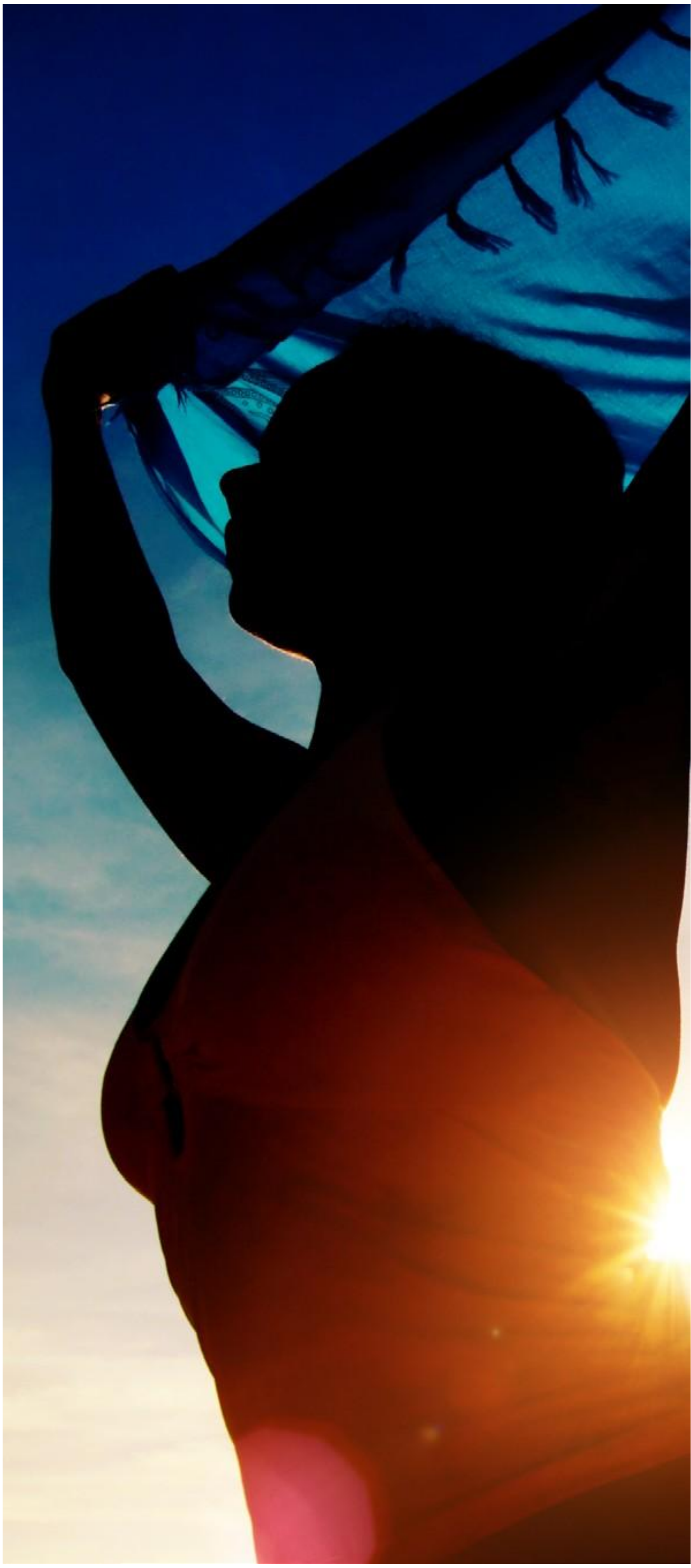
Amari and Johannes have been with Melissa to many Positive Life events. They've enjoyed them, and Melissa thinks bringing them along made disclosing her HIV status to them easier. They can see she belongs to a supportive community, and they have learned that HIV doesn't have a face.



A 40 YEAR JOURNEY INTO (AND OUT OF) FEAR – PART 6

TIM ALDERMAN

We had been forewarned!

Told that the new antiretrovirals were game changers. That people who were on the brink of death could be reprieved, could, like Lazarus, be brought back to life. The community organisations were given time to prepare for a change in how HIV/AIDS was handled! Did they listen? From my perspective…no!

I was discharged from Prince Henry Hospital on the 19th June 1996, after ten days in hospital. That was how quickly things were turned around. It was winter. I weighed just under 50kg, and I really felt the cold. I got a taxi from the hospital to Bondi Junction. My first port of call was Target for a new doona, and warm clothing, then home.

And so began a period of self-imposed boredom. For those of us who survived the final ravages of AIDS, we were, for a time, in a no-mans land. Caught between recovering from something we thought would be our end (and under earlier circumstances would have been), and having to mentally and physically readjust ourselves to an ongoing life, with minimal support services, not knowing what to do with ourselves, and realising that nobody else knew what to do with us either. It was a new world for all of us!

For anyone who thinks that surviving something as devastating as AIDS would send me back to my old life…think again! For the next 18 months, life became an often tiring and frustrating round of clinics, doctors appointments, specialists, support services, support groups, and pharmacy trips. When not doing that, I was stuck in front of the television watching "Days of Our Lives" and other trash daytime television. I ruminated on, and disected my previous life, as it was now a pre-AIDS, and post-AIDS existence…as that is what it was! It wasn't a life!

Change was going to be essential!

So reality started setting in…where exactly was I going from here? Taking vast amounts of antiretrovirals came with its own problems. In these early days of HAART, compliance was drummed into you. The drugs came with both dietary and time constraints. You often couldn't eat fatty foods prior to dosing, or they had to be taken on an empty stomach. This both restricted eating out with friends, or involved rising at ridiculous times to conform. Likewise, doses had to be eight hours apart, so you were often getting out of bed in the early hours just to take pills. So I was often tired, and cranky! Added onto an already heavy pill burden were prophylaxis drugs like bactrim, dapsone, ketaconizole, clarithromycin, and the list goes on, which were often taken a couple of times daily. Then we have side effects…mainly diarrhoea and nausea. I was getting scripts for Imodium as I was buying 15 by five boxes (yes, 75) at a time. If I was lucky, they'd last one month. They often didn't! A bucket of Napisan was permanently in the bathroom for soiled underwear. It was a nightmare, and I often wondered if I had survived AIDS, to die of organ failure from all the drugs I was taking! It, or more sounds like exaggeration when I tell people that initially I was taking around 340 pills a week…but just look at Imodium, where I was taking a staggering 140 pills a week, or more!

Help came from the wonderful, empathetic Pene Manolas, and her "Calao" Project. Caleo was a treatment management program, whose sole purpose was to encourage and empower those attending to remain compliant despite the burdensome load of pills we were taking. Over the six (or eight) weeks of the program you were given tools to help you achieve that aim. It was incredibly successful, and lasted for two years, then ceased due to funding. It was not my last encounter with Pene.

At the outpatient eye clinic at Prince of Wales (POW) hospital in Randwick, I was still attending on a monthly basis, and continued, at least for a time, to get the ganciclovir injections directly into the left eye. In 1998, Professor Patrick Versace asked me if I was willing to participate in the Vitrasert Implant trial. The tiny implant was inserted into both eyes, and leached ganciclovir into the eyes over a nine month period. The chances of developing a cataract were estimated at 4%. I was a more than willing participant in this trial, knowing how stressful it was having the intraocular injections. So, two operations to insert the implants, which were held in place with a stitch. The 4% chance of developing cataracts became 100%, so then another two operations to remove the cataracts, and insert new lenses. The whole sad part of this was, that with HAART proving so successful at keeping opportunistic illnesses away, they were never needed, despite their success. It is still present in my right eye.

Then the panic attacks started. I would wake up during the night and feel like my bedclothes were suffocating me, and had to throw them off. I'd get claustrophobic in underground trains, and stopped getting them. I had a panic attack one Sunday night, home on my own watching television. A gay lifeline had been established by one of the community groups… can't remember who. I rang the line, needing someone to talk to, only to find their phones weren't manned on Sundays…just an answering machine. They rang me the next day to apologise, but it would have been a bit late if I was suicidal!

I had a transition period getting used to bad vision, and only one eye. I had a couple of serious accidents. I was on my way to the POW eye clinic one week day, and got caught in this crush of people rushing to get a bus on Crown Street. There was a wooden bus seat just out of my line of vision, and my knees hit it, and I went for a sixer. Took the skin off my knees and shins. Only one guy stopped to help me! One! He checked me over, and despite how serious the wounds were, I told him I was on my way to the hospital anyway. He saw me onto the bus, and the nurse in the eye clinic patched me up. The second time, on the opposite side of Crown Street, I tripped over some tree roots which had pushed the asphalt up. This time the skin was off both knees. I then realised that I had no perspective in my one working eye…the footpath looked flat to me. I started slowing down my walking from that time on. My peripheral neuropathy was setting in at this stage as well, moving from my feet to my ankles and lower shin. This caused me to stagger when I walked, and was responsible for getting me banned from three gay hotels over time. I wrote a letter to the Star Observer about it when the bouncers denied me entry to the Colombian Hotel on the night of my 50th birthday, and refused to get a manager or supervisor for me to speak to. The Colombian apologised in a return letter, saying the bouncers had been out of line.

The most serious falls happened in Bondi. I went to visit a favourite gift store down there, and while wandering around the store, my legs just gave out on me and I collapsed on the floor. The shop assistant, who had been talking to the owner, helped me up. Five minutes later, it happened again. Thankfully I didn't break anything. But this time, with a frustrated look on their faces, without asking me what was wrong (in retrospect, I should have requested an ambulance) and assuming I was either drunk or drugged, just grabbed my arms, ushered me out of the shop, and sat me on the footpath up against their window. I was in a pretty serious state of shock, not knowing what was going on. I sat there for over an hour, not game to try standing again in case the same thing happened.

When I eventually tested them, they seemed to be fine. I started walking home…we had moved from Penkivil Street to Ocean Street at this time…up Bondi Road. Deciding to visit a cafe on the other side, I crossed at an intersection that had both lights, and a small pedestrian crossing. I crossed through the lights fine, but on using the crossing my legs just gave out again, and I collapsed on the road, hitting my head on the gutter. Thankfully there was no turning traffic, and a guy sitting in the window of a nearby pub rushed out, grabbed me and helped me to the footpath. I eventually got up, had a coffee in the cafe, and walked home. The gash on my head was serious enough to go to hospital.

It never happened again, though I suspect it was a precursor for what was to come!

Feeling a bit lonely and outcast at this time, I decided to try a personal classified in the Star Observer. I was quite open about my HIV status, and that I was damaged goods (yes, I really did say that!) from AIDS. I received about 10 letters in reply…I still have them…all from HIV+ guys. I met a number of them, though none really compatible except for about three.

One was a serial replier to classifieds whom I had been warned about. He was a bit of a problem, so dropped very quickly. Had a one-nighter with another (I'd had no secxual encounters for about two years at this time), and I liked him, but he didn't want anything further. Then I met Michael, who lived at Rose Bay. We started a bit of a 'thing', though I think it was more a matter of us both being lonely, more so than being compatible, and we both had someone to go places with. Having had a number of bad experiences through the classifieds, the first thing he said to me when I knocked on his door was "Wow…you're actually good looking!".

Between 1996, and 1997 antiretrovirals started being pumped out at a staggering rate. Over this period, I must have been, in HAART combinations of three or four drugs, on every drug that was released (thank heavens for the PBS, who approved them very quickly). These included AZT, 3TC, Indinavir (a high dosage caused nausea), Nelfinavir (caused chronic diarrhoea), Saquinavir, Neverapine, Retonavir (more on this shortly), Combavir (AZT+ 3TC) l Efavirenz, and Abacavir. The quick approval of drugs, due to their efficacy, had its drawbacks. Long term side effects often popped up as time went on, for example it was found that Indinavir could cause kidney stones. For me, with both AZT and 3TC still being included in my combinations, my peripheral neuropathy got worse (even now in 2025 I have totally numb feet, which now affects my balance).

In early 1998, through a mutual friend I was out with one Sunday night, I met David in the bottom bar of the Midnight Shift. I was in a casual relationship with Michael, and he was in a relationship as well. We finally surfaced a couple of days later, both deciding to end our current relationships. David and I then went on to be in a relationship for 16 years.

Nelfinavir was the worse drug of all as far as diarrhoea went. David and I were both on it, and it was a nightmare. We were both scared to go out for any length of time, as we would inevitability be caught short. Nelfinavir gave you no warning (and it over rode any amount of Imodium) so you were often caught out grocery shopping, at a movie, or on a walk. We discovered that public toilets were disgusting! There were often underwear changes several times a day. I got so fed up with it restricting my life, that I just charged into Cassy's consulting room, and demanded she change it! She did! Shortly after, David was also taken off it.

However, despite all this, my viral load continued to initially drop, then maintained itself at undetectable. My CD4 cells continued to do a slow, but constant, rise. Probably the only reason we put up with what we did.

Please note that my use of language here is deliberate, and of-the-time! I make no apologies for it!

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