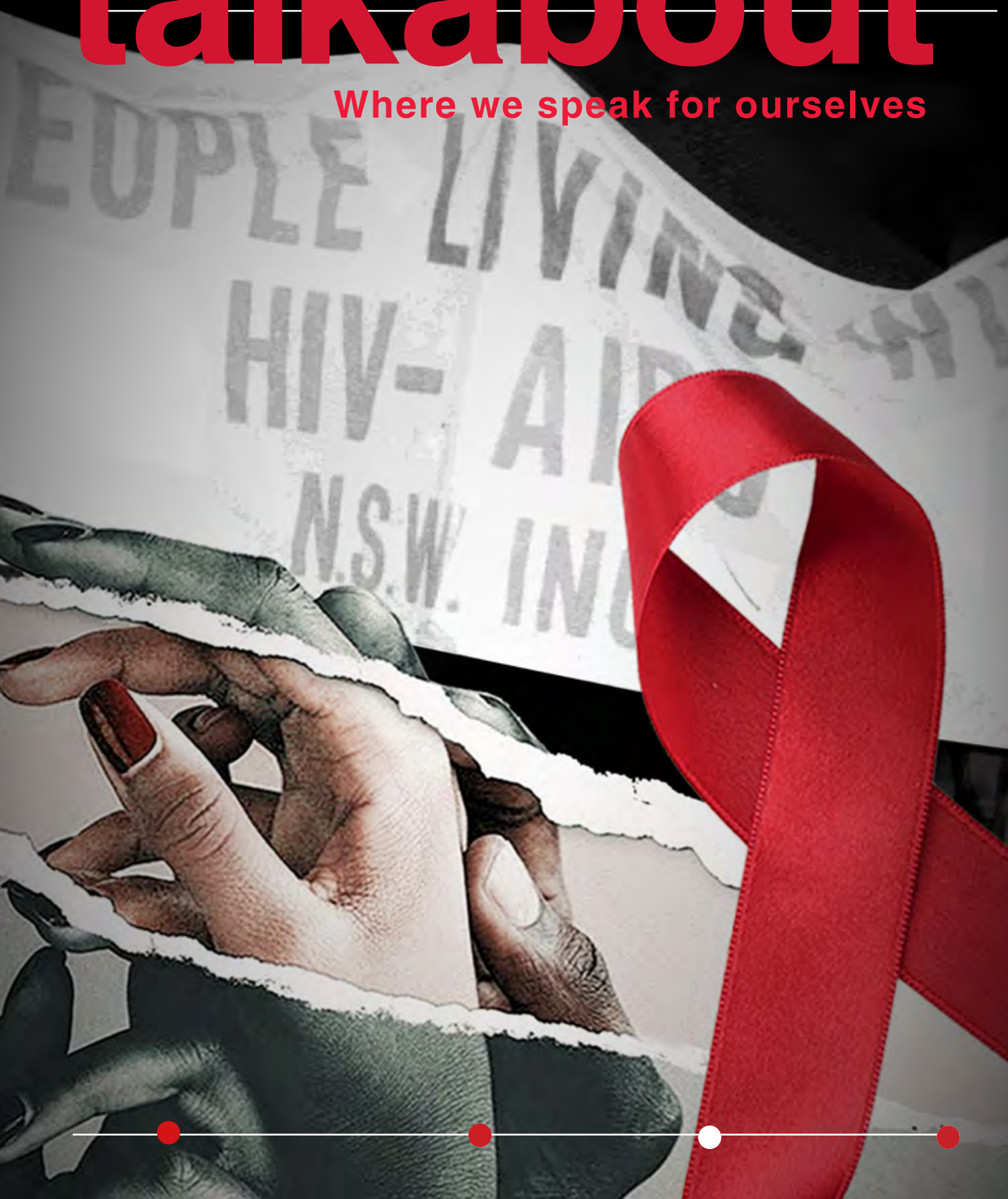


# talkabout

Where we speak for ourselves

#205 | January 2023 | ISSN 1034 0866 | Positive Life NSW – the voice of all people living with HIV since 1988



 **POSITIVE CONVERSATIONS**      **WORLD AIDS DAY**      **NUTRITION BITES**      **PAUL MAUDLIN IN MY OWN WORDS**

# TALKABOUT

WHERE WE SPEAK FOR OURSELVES

## EDITION #205

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Acknowledgement and thanks  
to our eagle-eyed proof readers  
for this edition

Cover photo: Design by Charlie Tredway for World AIDS Day  
Inside artwork: Positive Life - Mardi Gras Parade 2022

*This January edition of Talkabout reflects on how we view ourselves as PLHIV, World AIDS Day, Ageing & Acceptance and the journey to quality of life.*

Featured on the cover is the design for the program for the 2022 World AIDS Day event held at The Sydney Conservatorium of Music. In this issue we have also featured images from the event taken by Rhinannon Hopely.

This edition highlights personal experiences and community voice across a gamut of topics; from how we view ourselves (page 8), Connecting with Culture through creativity (page 9), and World AIDS Day 2022, its theme of 'Equalise', and what that means for the future of the HIV response as we strive to leave no one behind (page 10).

In his own words, Paul Maudlin shares a fifth instalment about his journey living with HIV, from 2011 to 2016 (page 17).

We report on some of the collaborative work we contributed to for the St Vincent's Clinical Excellence Awards in Talkshop (page 6) and introduce you to another Positive Life staff member (page 15), who joined us last year as the Peer and Vocational Support Officer.

The Albion Centre Nutrition Team speaks to the vital part nutrition plays on our health as people living with HIV (page 26), even including a couple of healthy recipes perfect for entertaining in 2023.

Once again we call on the membership to let us know if you have any contacts who might be interested in advertising in

Talkabout. A couple of small half page or quarter page advertisements would make all the difference to sustain Talkabout. So, if you have any suggestions or questions, please get in touch!

If you have a story in mind, or want to explore how you might be part of Talkabout, please contact us. **We're 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. We can interview by phone, Zoom or face to face as part of 'In My Own Words' to make it quicker than ever to share your story in Talkabout.

Call us 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.

**CHARLIE TREDWAY**  
EDITOR

**EDITION 5 OCTOBER - #205**

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*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 undertaken that impact the interests of people living with HIV in NSW.*

## **IN THE KNOW**

In October last year we held our In The Know event where Professor Graham Brown spoke to us about the concept of Quality of Life, and how to measure it, and the things that impede on it, in research.

It was a dynamic event with a great turn out of community members learning and, more importantly, connecting with each other.

## **ST VINCENT'S CLINICAL EXCELLENCE AWARDS**

Last year Positive Life NSW was asked to collaborate with Professor Richard Hillman on a video to support his nomination for the St Vincent's Clinical Excellence Awards for his team's revolutionary work on early HPV related anal cancer testing and treatment.

The video entitled "Making Anal Cancer History" featured community perspectives from the PLNSW research into awareness of the impact of HPV related anal cancer on PLHIV, as well as interviews with Professor Hillman and one of the community members who has benefitted from this groundbreaking work.

We congratulate Professor Hillman and his team for taking out the award at the gala event, in recognition of their achievements and look forward to working with him on more community awareness building work.

## **POSITIVE LIFE & GILEAD WORLD AIDS DAY DINNER**

At the annual event to mark World AIDS Day we heard from a range of voices turning their eye to the theme of 'Equalise' and what that looks like in the context of the HIV response.

CEO Jane Costello in her opening remarks delivered a bold call to action as we move forward.

"People need to see people like themselves represented in this messaging, they want to see diversity, equity and inclusion in the HIV response, and peer navigation is critical to achieving these outcomes. We must build strong, resilient, health literate communities who are empowered to make evidence-based, informed decisions for themselves through sustainable capacity building supported by a robust peer framework. We need to ensure access and availability for all regardless of background, to culturally appropriate, co-designed and suitable

services that meet people where they are at, providing person-centred, trauma-informed care and support."

This theme of 'Equalise' was further brought to life in a community voice panel moderated by Charlie Tredway, featuring PLNSW Peer Support Officer Priscilla Njeri, Positive Speaker Natasha Io, and NAPWA & PANA's Jimmy Chen, and their vital lived experience and perspectives.



## **COMMUNITY CHAMPIONS AWARDS**

Positive Life was proud to see our nominees Professor Graham Brown & Katherine Leanne honoured for their deeply impactful work in service of people living with HIV in Australia.

We had this to say about our wonderful nominees:

"Katherine is an inspiration to her PLHIV peers, and her generosity in sharing her expertise, knowledge, information, and skills is unparalleled.

Today, as an openly positive woman Katherine continues to strongly advocate for the rights of the diverse community of PLHIV ensuring that our issues remain high on both the national and jurisdictional agendas"

"Professor Graham Brown is an innovative researcher of the highest order in the HIV field, focusing without fail on the needs of PLHIV in being able to lead fully realised and supported lives free of stigma, and with a sense of, and right to, self-determination and autonomy.

Graham's programs and research projects have directly benefitted the communities of people living with HIV in Australia, and conclusively demonstrate the agency and resourcefulness of our communities, and our world-leading clinical and policy response to HIV in Australia."

Bravo Katherine & Professor Graham Brown.





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# CAN WE BE PROUD OF OUR HIV STATUS?

By Charlie Tredway

At first glance, the question whether or not we can feel proud of our HIV status may seem provocative. HIV is often framed in language of being a deficit, a source of shame or something that requires us to be resilient in the face of something we didn't choose.

For many of us, we may refuse to let HIV define us. We say, it's only a small part of our life, one that we don't want to give weight to, or dwell on. For others, HIV can still play a significant part in how we view ourselves and how we navigate in a society that has for the last 40 years been quite stigmatising and discriminatory.

Learning how to process your diagnosis, navigate things that impact our quality of life, and choosing to thrive is an ongoing journey.

At our latest Positive Conversations event, facilitated by Peer Navigation Manager Andrew Heslop and our Peer Supports Project Officer based in the Northern Rivers NSW, Tobin Saunders, we posed this question to our community attendees to get a fuller picture of self-esteem, what we have learned or how we have grown as people living with HIV. We also asked what skills or 'superpowers' may have manifested through connection to knowledge, support, and our peers.

Many in the session expressed a sense of pride and self-determination in how they learned to navigate and steer relationships with their HIV specialists and other healthcare practitioners. The ability to become more knowledgeable and be an equal partner in control of your health can be a really validating feeling, knowing that you are the expert in what it means to live with HIV, and how it feels for you, as a deeply personal and individual condition.

For others, a sense of pride and empowerment came through what they viewed as their heightened capacity for empathy and connection to a diverse community of peers. We can draw strength from our HIV positive community, and sometimes seeing other people also living with HIV, who have unpicked their sense of shame and are open and doing amazing things can inspire us or 'give us permission' to view ourselves and HIV differently.

Finding a way through stigma, to a personal sense of acceptance, and maybe even the possibility of pride, is a challenging and sometimes long process. The most important ongoing relationship we have, is the one we have with ourselves. We need support, guidance, connection, and validation to grow and flourish and re-evaluate the impact of HIV on our lives.

What all of us can be proud of, are the lessons we learn along the way, our choices to live and hold space regardless of stigma we may have faced or continue to face, and our ability to seek out community and care for each other.





# CONNECTING WITH CULTURE

by Michelle Tobin

On Friday 15 July, Positive Life NSW ran our annual NAIDOC Week event, this year with Koori Kinnections, who introduced participants to traditional elements of Basket Weaving.

This face-to-face event was not just for our Indigenous brothers and sisters but welcomed everyone who wanted to participate including community members, Positive Life staff and volunteers. We met in Darlinghurst at the East Sydney Community and Arts Centre (Heffron Hall), and I started the workshop with an Acknowledgement of Country. All attendees introduced themselves and shared what they hoped to get out of the day.

We began the morning inside the Centre, however once the sun started to shine, we moved the tables and the weaving materials outside. I think many of us had forgotten how good it felt to be in good company, having a yarn in the sun with each other in person.

Our workshop facilitator, Jess was a great teacher going around to each of us and assisting when we needed some expert support. This allowed participants to just sit back and have a yarn, laugh, de-stress from everyday life and learn a new skill. Many of us have continued with our weaving, using it as a calming and relaxation tool in our daily lives.

Our group of 15 participants were diverse group, with the only commonality for most of us being our HIV status even though that wasn't a focus of our time together. This was not just a time to learn how to basket weave but was also a chance to hear personal stories from Jess, Aunty Kerrie and myself. We shared stories and experiences from the past, impacts of colonisation, the effects of trauma and how we work through and support our family. We also spoke about what this year's NAIDOC messaging, 'Get Up! Stand Up! Show Up!', meant to us.

Since the workshop, attendees have shared what a relaxing event it was, with good food and great company. Our caterer even made a delicious lemon myrtle cheesecake.

Positive Life is planning to offer future Aboriginal cultural events to highlight and share more of our knowledge and practices with you. It was a wonderful time for all of us to share our stories of culture and dispel myths through truth telling.

Positive Life is here to support and empower all members of our Aboriginal and Torres Strait Islander community living with HIV in NSW. We can help you to access services and information that improve our health outcomes. As the Aboriginal Peer Support worker, I am available to assist you in navigating the healthcare system, connect you into the programs and events that Positive Life offer, provide health promotion information and onward referrals.

You can call us on (02) 8357 8386 or 1800 245 677 (freecall) and speak with Michelle Tobin, - Aboriginal Health Program Officer at Positive Life NSW, or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



# WORLD AIDS DAY

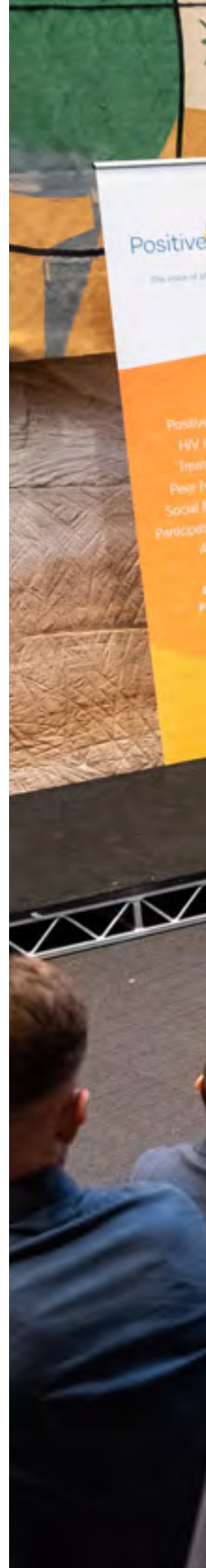
“Good evening, everyone. On behalf of Positive Life NSW and the Bobby Goldsmith Foundation I would like to welcome you to this NSW 2022 World AIDS Day event at the beautiful Sydney Conservatorium of Music.

Thank you, Nana Miss Koori, for your wonderful welcome to country, and I too would like to acknowledge the traditional owners of the lands on which this event is being held, the Gadigal people of the Eora nation, and pay my respects to their elders past and present. I would like to extend that respect to Aboriginal and Torres Strait Islander peoples who are here tonight, and acknowledge that sovereignty was never ceded, and this always was, and always will be Aboriginal land.

The international theme for this year’s World AIDS Day is Equalise, which is a call to action to address the inequalities which are hindering our target of virtually ending HIV transmissions by 2025, and barriers that prevent people living with HIV from achieving optimal health outcomes and quality of life. I have spoken recently to the fact that equality and equity are two quite different things, and this is highlighted in the latest data from the UNAIDS 2022 report which indicates that progress in prevention and treatment is faltering around the world. Just the title of this report ‘In Danger’ should give pause for thought. Here in the Asia/Pacific – the world’s most populous region, data now shows that new HIV notifications are rising where they had been falling over the past 10 years. While Australia and NSW have seen great success in reducing the number of new HIV notifications in Australian-born men who have sex with men, we have not seen these declines reflected in other populations including people who were born overseas and those who identify as heterosexual. Globally, HIV acquisition rates are higher in indigenous communities than in non-indigenous communities, and here in Australia Aboriginal and Torres Strait Islander people are 1.6 times more likely to acquire HIV than non-indigenous people, and have poorer health and social outcomes overall.

So, what does success look like? I would suggest a proven package for success needs to include; community and peer-led, people-centred services; the upholding of everyone’s human rights; the removal of punitive and discriminatory laws; the implementation of programs and services to reduce and tackle stigma including not making assumptions about people’s beliefs, cultures, behaviours, sexuality, gender or understanding of sexual health; support for the needs of populations being ‘left behind and their self-determination; the building of strong, resilient, health literate communities who are empowered to make evidence-based, informed decisions for themselves; equity in access to HIV treatment including new preventative technologies; and health services, education, and social justice for all. A tall order, but HIV activists of the past have already achieved so much, and I am sure today’s activists are capable of meeting these challenges ahead.

While we have the momentum to effect this change, we must be aware of what the acclaimed Nigerian author Chimamanda Ngozi Adichie calls the danger of the single story. While stories matter, and as people living with HIV the power of our individual stories are extremely dynamic, these stories are often portrayed as a single narrative about what it is to live with HIV. This risks leaving marginalised populations of people living with HIV behind. In the context of the HIV epidemic, HIV has moved further into the margins and has affected many communities, including people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander people, heterosexual people, people born overseas, people from diverse genders and sexualities, and women of all ages. These stories are often not told or heard because of misconceptions, misunderstanding and longstanding stigmatising attitudes. All too often we operate from the perspective of hearing and knowing a single story — about a person and/or a situation. The risk of the single story, the one perspective, is that it can lead us to default assumptions, conclusions and decisions that may be incomplete, and may







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lead to misunderstanding. Operating from the context of a single story can prevent us from having a more complex, nuanced view of a situation. We therefore need targeted messaging that doesn't make assumptions about people's beliefs, cultures, behaviours, sexuality, gender or understanding of sexual health, so that no-one is left behind.

This also speaks to a power dynamic or imbalance where who tells the story, how and when, can impact situations significantly. Power enables some to define individuals and situations from a particular lens or viewpoint. As Adichie says, single stories can have significant negative impact. They can rob people of their dignity, and emphasise how we are different rather than how we are similar. By giving space to hear a multitude of stories we can help to empower and humanise the HIV epidemic, and make real inroads on tackling stigma and discrimination, and achieve better health and social outcomes.

On this World AIDS Day we need to listen to the untold stories of the diverse communities of people living with HIV, to generate that context to for bold and courageous action.

John Robinson has very kindly donated his NSW World AIDS Day Award to Positive Life NSW that he was the recipient of in the 'Outstanding' category, which was bestowed upon him in 2003. In receiving this award John was acknowledged for his over ten years of volunteer service at the time and his long history of activism and governance with the HIV sector. The awardees noted it was a fitting time to award and acknowledge his work and dedication to numerous organisation the sector, and people living with HIV in NSW.

Positive Life is truly honoured, and we have had John's medal framed and wanted to present it to him tonight as this will hang in pride of place in our office.

I would like to thank and acknowledge all of the performers and presenters tonight. To Ilana Cooper, for hosting the evening with such style and grace; to Jono and Steph who were playing violin duets upon your entry; to Nana Miss Koori for such a wonderful welcome to country; to African Beat; to the Reverend Dr Jo Inkin and John Robinson for their heartfelt keynote speeches; and the ever-sonorous Sydney Gay & Lesbian Choir. I would like to acknowledge ViiV Healthcare for their generous support, and our partners BGF, Nick Lawson my co-host, and their Ambassadors, Board and staff. Finally, I would like to acknowledge the commitment of Positive Life NSW's remarkable staff, Board and our volunteers without whom this event would not be possible."

**Jane Costello- CEO Positive Life NSW**







We have seen a remarkable increase in our community development and support work since March 2022, no doubt highlighting the shock and the overall dearth that the COVID pandemic has wrought on our community and our place within broader society. With this increase in peer navigation and support work we have also been given the remarkable opportunity to refresh our existing service frameworks and introduce innovative models of care that enrich our delivery of expert peer support and community development that meets our people where they are at.

Positive Life NSW's work has always been built around inclusivity and diversity. In 2022, achieving equity in our work is more important than ever and aligns our agency with the divergent trends of HIV transmission that we are witnessing. People who come from migrant backgrounds, Aboriginal and Torres Strait Islander people, women, heterosexuals, and gay and bisexual men are now extensively represented in our services. We have witnessed changes in how HIV transmission has affected these populations recently and historically, as well as the ways in which community driven health promotion supports capacity building and health literacy in individuals and these communities.

We have focused on a long existing Positive Life NSW paradigm, which is the continuing development and understanding of how the work we undertake is reflected through the daily life experiences of our community members living with HIV in NSW. Positive Life NSW's Community Consultation and Engagement Framework is a robust mechanism through which we identify and respond to emerging community needs. You may have participated in one of our two surveys or forums this year, and we thank you for that contribution. Representing the voices of our community is critically important to our work, with an average of 63 clients being supported month on month through our Peer Navigation and Support Programs. We have a unique and privileged opportunity to identify community trends that are strongly underpinned by the social determinants of health, through the foundational elements of the work of our support programs in housing, ageing, and employment.

Our workforce capacity building protocol responds effectively within the systems in which we work, and has a nuanced understanding of the social inequities and disparities which are the key drivers of poorer health outcomes. Reinforcing our agency's structural competency has led to the centering of trauma-informed practice and person-centred care models that assist our peer navigators to provide wrap around service delivery in conjunction with and supported by our stakeholders, service networks and partnerships. Trust, empathy and support are the keystones of peer practice and when we include safety, choice, collaboration and empowerment within this framework our approach is around the whole person and working with them to achieve their long term, holistic health, wellbeing and societal aspirations.

**-Andrew Heslop - Senior Health Promotion & Peer Navigation Manager**

# BRINGING COMMUNITY ALONG



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**Positive Conversations - a monthly online event for all people living with HIV**  
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or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



**If you are an Aboriginal or Torres Strait Islander person and live with HIV,** you're invited to have a yarn with Michelle Tobin, the Positive Life Aboriginal Health Program Officer on telephone (02) 8357 8386, 1800 245 677 (freecall) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)



**B**illy Suyapmo joined the Positive Life team in September 2022, as the Employment and Vocational Support Officer for all people living with HIV in metropolitan and regional NSW to access, achieve and maintain study, training, paid (casual, part-time or full-time) or voluntary work options.

As a peer worker Billy brings a strong commitment to social justice, and believes in the inherent right to self-determination of all people. He speaks Indonesian fluently, as well as the Hokkien (Minnanyu) Chinese dialect, and he is currently learning Thai.

*We sat down with Billy to ask a few questions so our readers can learn more about him, and what drives his work at PLNSW.*

**So Billy tell us a bit more about yourself:**

I studied a Diploma in Community Services, but previously I received a Bachelor in engineering from my time in Indonesia. Most of my work experience was in agriculture and the labour hire industry. In that role I managed the team for clients across Australia, often moving between Far North Queensland and further south. After three years in that role I decided to switch career paths and start studying.

**What drew you to working with community?:**

The journey of navigating HIV can sometimes be a lonely one, where you might deal with complex feelings like uncertainty, fear, or anger. It was important for me to help get people the support and connection they need.

**What are some of the pressing needs you are seeing with community? And how important is peer support in that work?:**

Stigma is still very much one of the biggest issues faced by PLHIV. There are still a lot of moral judgements, and outdated information and views that get in the way of self-worth and security, and hope. Peer advocates, and peer support play an important role in showing how we can manage HIV, feel empowered and have a fulfilling life like anyone else.

**Can you tell me a little about your role?:**

My focus as a peer is supporting community to get the employment they want and helping them on their path. Anything from coaching for interviews, reviewing and helping with their CV, and anything else they need to feel more confident, and in the right headspace to succeed.

**What would you like to tell a community member who may be struggling with employment or other support needs:**

Looking for a job is definitely not an easy task. It can be daunting, full of mystery and scary for most people. Everything may seem out of your control, and there may be setbacks, but try to be kind to yourself. Reaching out for help is not always an easy thing to do, but we are here to support you at all stages of your journey.



**To enrol or find out more about the Peer and Vocational Support program, and how to connect with Billy please call Positive Life on (02) 8357 8386, 1800 245 677 (freecall) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)**



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- Get the latest information on topics such as pregnancy, treatment and living well
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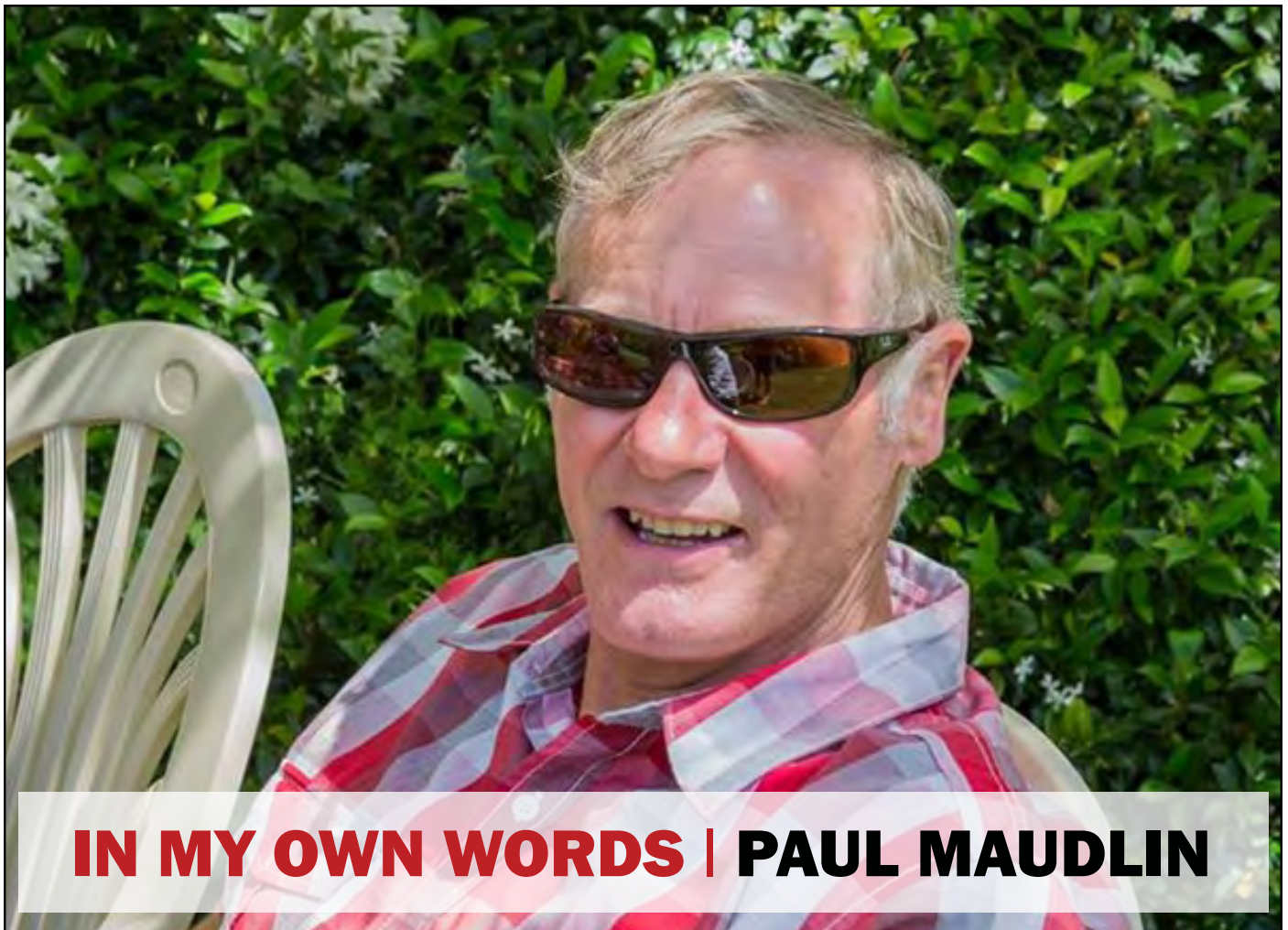
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Pozhet is a government-funded NSW-wide service for heterosexual people at risk of or living with HIV, their partners and family.





## IN MY OWN WORDS | PAUL MAUDLIN

### 2011: 'Maureen the Switch Bitch' aka 'The Pox Doctor's Clerk'

When I left Holden Street Sexual Health Clinic (HSC) in May 2010 I thought that my days in Sexual Health Administration were behind me. I was wrong!

I was enjoying my new challenge as the Manager for the Positive Support Network (PSN), and the organisation was once again more fully engaging local people living with HIV. At the time, some exciting initiatives were occurring with several others being planned, now that ongoing funding had been successfully secured from NSW Health and other sources.

Neil Sumners took over from me at HSC the previous year. I was very surprised when Neil rang out of the blue one day to tell me that he would no longer be working the weekly Thursday night Guy's Clinic. He wanted to advise me that a new part-time position was being created to specifically provide administration support for the Guy's Clinic. The person recruited would also be expected to provide annual leave relief for his position with other back-up duties being up for negotiation as they arose. He went on to ask me if I would consider applying?

When the position was advertised, I did not have to think twice about applying. So, a year after leaving, on the 26 May 2011 I began another ten-year tenure with HSC. This fitted well with my twenty-five hours a week with the PSN.

As my new 'boss', Neil and I had a great working relationship.

Our hours would cross-over late Thursday afternoons and together we shared many laughs as well as highlights of our individual working week. We remain friends today. Sadly, Neil left the clinic after eleven years in April 2021.

### 2011: HIV Trivia Quiz for Schools

One of my newly trained positive speakers, Kerry Taylor and I developed a HIV Trivia Quiz which PSN's speakers could take to their talks as a fun educational activity to supplement their talks or to be used as a standalone activity. Dr Kym Collins from HSC assisted with the technical aspects of appropriate HIV/AIDS questions and possible appropriate responses by the speaker.

The quiz was a multi-choice power point presentation which required students to organise themselves into small groups, so that they could brainstorm questions projected onto the screen one at a time. Students would then decide what they thought the correct response was. This quiz was extremely popular with teachers and students, who were always amazed that their answers were not always correct. For the groups that successfully achieved 100%, we were able to offer donated prizes from local businesses.

### 2011: A Generational Changing of the Guard

My father, Raymond James Maudlin passed away suddenly in Liverpool Hospital at 81 years of age, on 19 October 2011. On the morning of his death, before I could drive to Sadlier (near Liverpool) to be with my mother, I needed to first attend a job

## IN MY OWN WORDS / PAUL MAUDLIN

interview in Newcastle with another HIV non-government organisation, Karumah Inc. Despite enjoying my position managing the PSN in Gosford for fifteen months, I thought I could do something more challenging and mistakenly thought Karumah was the answer.

I had taken clients of PSN to events at Karumah in Hamilton on several occasions since commencing at PSN, and I had found that service to be better funded and its client base and organisation very different to that of PSN. My application for the Manager position was successful and in early October gave notice to PSN's Board and started my initial employment with Karumah on my days off from PSN.

I lasted one day at Karumah! What a disaster! Karumah's previous manager had already departed the organisation and my hand-over was left to another staff member. This experience was intensely unpleasant. Unfortunately, I had a clash of personality with that person and felt extremely uncomfortable. By the end of the first day, I made the decision not to return.

I rang the PSN Board Chairperson (Robert Byrd) to tell him my decision and to ask if I could revoke my notice and continue with PSN. Rob could not have been happier. I continued with PSN until its closure in December 2015. Karumah eventually got its new Manager and I worked collaboratively with that person sharing many ideas and initiatives while also having a great relationship.

### 2012: Happy 21st Birthday Positive Speakers Network

2012 was the PSN's 'Crown Year' and to celebrate this amazing milestone, I proposed to the Board that we had a party where

we could acknowledge and congratulate past and present Board, staff, clients, and volunteers for their contributions to the organisation. Planning for what became known as the 'Red Event' commenced in June 2012, a full six months before it occurred on 24 November, at the commencement of AIDS Awareness Week.

In July 2012, Hunter TAFE (Ourimbah Campus) Community Services Section were planning their student community development projects with local community-based organisations being invited to apply to participate. I proposed the Red Event as a suitable project where students could be involved with all aspects of planning and assisting to deliver this important milestone event.

Three students (Lesley, Victoria, and Gabriel) had part-time placements with me at PSN for four months, and together we staged what was a very successful and memorable event at Caroline Bay East Gosford Regional Gallery. The Gallery and adjoining gardens were lit up in red with attendees also wearing something red. One hundred and ten people danced the night away with music provided by DJ's Neil and Cindy, and awards were presented to people that had contributed to the care, support and wellbeing of people living with HIV on the Central Coast for 21 years.

### 2013: 'If its ain't broke, don't fix it'

After being under the care of Dr Sara Pett for seven years, Sara returned home to England in mid-2013 to be closer to her ageing mother and continue practising and researching HIV

*Paul Maudlin onboard P&O Pacific Pearl - 2014 / Photographer Ken Lasslett*





medicine. A month after Sara's departure, I returned a CD4 count of 528 and I know she would have been very excited for me. The nearest I had come to that count, was 660 in March 1998 (eight years before seeing Sarah). She would have been extremely pleased to know my CD4 counts did eventually reach the mid-700s for a brief period five-years later in 2018.

After Sara's departure, my care at St. Vincent's Immunology B and Ambulatory Care (IBAC) Unit was transferred to Professor Anthony Kelleher. From that point on, my HIV monitoring bloods were taken at HSC in Gosford before having face-face appointments with Prof Kelleher. I was responsible for providing Prof Kelleher with my results, as it was found to be the most effective method due to having pathology systems at two local health districts involved. Dr Kym Collins at HSC also became more involved with my HIV care, and together Tony and Kym would manage any HIV issues I had. This might sound like a complicated arrangement, however this worked quite well and effectively I had two HIV specialists. Any medication changes (only one minor change) were left to the discretion of Prof Kelleher.

I have had several discussions with Tony regarding reducing my pill burden over the past few years however, according to him despite my regimen being complex, the risks of any changes are not worth contemplating or in his cautionary words "If it ain't broke, don't fix it."

### **2013: HIV-associated Neurocognitive Disorder (HAND) Maraviroc Study**

In early August I consented to participate in this year-long study with the St. Vincent's Department of Neurology where I was randomised to the control arm of the study, administered by Professor Bruce Brew. This involved frequent neurological testing to determine my suitability to be treated with the HIV antiretroviral drug Maraviroc.

According to Prof Brew's final report dated 26 August 2013, I did not do very well on this study and as a result it was determined that my HAND status at baseline was Motor Neurone Disease (MND). At six months it was normal and at twelve months borderline MND. I recall having a long discussion with Prof Brew about my fluctuating results during the study.

In the early stages of the study, I reported that my father had died late in 2011, and I was finding it difficult dealing with my mother's ability to remain living independently while taking on an increased role in her care. I believe that this was exacerbating my cognitive difficulties in the study.

Prof Kelleher followed-up with his own letter to Dr Collins after a clinic visit with him on 28 October, also outlining that neuropsychological testing during the Maraviroc study suggested that I had some mild neuro-cognitive disorder. He further suggested that my varied viral load results during the year-long study could possibly be attributed to my HIV antiretroviral compliance.

Interestingly, follow-up testing was suggested for 6-12 months' time to ascertain whether I had any deterioration and if so, once again formally assess my Cerebrospinal Fluid (CSF) for viral replication, and a review of my HIV antiretroviral regime. I experienced two abnormal viral load results over the next seven months post study, and these returned to undetectable levels thereafter. There was no further neurological follow-up

testing done (or suggested) and my regime remained unaltered. I found the results of my neurological testing experience quite bizarre because my whole life I have been acknowledged and praised for always having good memory skills. This is something that I take great pride in. The Garvan Institute research printout on Motor Neurone Disease (MND) that I was given to read in 2013 left me feeling quite shocked.

Nonetheless that was nine years ago, and I guess that if nothing else I am now more aware of this condition and the possible signs to watch out for. My mother passed away in December 2019 at the age of eighty-seven, two weeks after an unforeseen accident in her wheelchair. Despite being a little senile, my mother was as sharp as a tack and was a long way off having any decline in her cognitive functioning. I like to think that I will follow her example in this regard. I guess time will tell as I age, hopefully reaching my late eighties as Mum did.

### **2014: International AIDS Conference Melbourne**

This took place over seven days (19-25 July) at the Melbourne Exhibition and Convention Centre. I attended the conference as a volunteer and fronted daily to be assigned roles to assist delegates and HIV/AIDS organisations as required by the Organising Committee. I travelled to Victoria two days before by train and while enroute, the second Malaysian Airlines disaster for 2014 occurred.

While checking in the day before the conference commenced, I learned about the MH17 flight being shot down over Eastern Ukraine. I was not aware of this tragedy until I arrived at the conference venue, and overheard concerned delegates talking about it. There were rumours circulating that the conference was going to be cancelled as a mark of respect for several prominent people living with or working in HIV/AIDS who were travelling on that aircraft. The conference did proceed as planned, however there was an invisible veil over-shadowing the entire proceedings.

### **2014: P&O cruise to nowhere**

Every year the PSN would hold its annual retreat for clients. During my tenure as Manager (2010-2015) I strived to hold the retreats at different venues and tried to steer away from the usual workshop model of events for clients during their time at a retreat. So, on 29 August to 1 September I organised something which was outside the box for nineteen people living with HIV.

The venue was the P&O cruise ship Pacific Pearl, which did a four-day cruise to nowhere, or more specifically Moreton Bay, Queensland. PSN paid (from fundraised monies) half of all attendees' fares with the balance then paid by attendees' either in full upfront or in instalments over six months before departure. The retreat was highly anticipated and gave people something to look forward to, and also was a tremendous success and something that was talked about for a long time afterwards. So much so, that a year later Karumah Inc. in Newcastle held a similar 'ship-related annual retreat' for their clients. Yes, we did hold a couple of get-togethers onboard the 'Pearl' including a formal dinner and short informal workshop activity which ironically had to be concluded early due to very rough weather.



**2015: Winding up PSN; the end of an era.**

After a year of agonising over the future of PSN, which was approaching its 24th anniversary, the Board consulted with members and clients to cease operating by the 31 December 2015. Assorted options for PSN's future were considered including transferring the organisation's activities to ACON Hunter. At the time ACON were interested in taking over PSN subject to NSW Health approval. However, the PSB Board felt that this was not a viable option for people living with HIV on the Central Coast and that potential services considered by ACON may not be forthcoming.

On 1 December 2015, World AIDS Day, the PSN had a dedication service at the Gosford Anglican Church for a time capsule that was buried later that morning in the grounds of the church. The event was attended by people living with HIV, Central Coast Local Health District representatives, other local organisations and others that had held a long association with PSN. The time capsule contained PSN memorabilia, photos and letters from myself and several other people and buried with a large oval bronze plaque above it to mark its location. Instructions were inscribed onto the plaque for the time capsule not to be unearthed for 50 years, (1 December 2065). As planned, the organisation formally ceased its operations on 31 December 2015.

**2010: Teaching Community Services atTAFE**

Patricia (Trish) Griffin was my Head Teacher at TAFE, after I was successfully head-hunted by her in April 2015 to join the Community Services Section at Ourimbah and Wyong Campuses as a part time casual teacher. Initially I worked on course development, validation, and planning activities for Certificate 3 and 4 curricula, before I commenced face-face teaching in Semester 1 (February 2016). This gave me a better understanding of what was expected for my future classes and the units of study I was required to research and teach.

The students I taught were mainly from disadvantaged backgrounds and this certainly had its own challenges. I enjoyed interacting with all students and seeing what they could achieve during the time I had with them. Over many years I had numerous positions in my working life where I trained people, and my time as a positive speaker certainly put me in good stead for working with and teaching adult learners.



Unfortunately, my first teaching assignment at Wyong TAFE was prematurely cut short six weeks after commencing, and I did not get to fully teach the units of study that I was required to present. My time with TAFE was temporarily put on hold for four months until Semester 2 (July 2016) due to me experiencing a heart attack on the 28th of March 2016.

## **2016: Easter Myocardial Infarction**

My son Phillip, his wife Emma and their young daughter Charlotte, were living in Manly and came to visit Adam and I for a couple of days over Easter. On the Monday morning before the family's departure, Emma and I had a protracted discussion about the use of mobile phones and accessing Facebook in the workplace. In the end, we agreed to disagree. After the family had departed, I was feeling somewhat stressed and decided to relax by heading to the beach for a couple of hours. That couple of hours ended up being almost three days.

I drove to the beach as usual and after a couple of hours suddenly felt very unwell. Initially I could not stand up and was sweating profusely while experiencing chest pain. My chest felt like I had an elephant sitting on it, with none of the other common symptoms. It took me ages before I could move to get myself back to the car park, get in the car and drive home. I had forgotten to take my phone with me. Being a public holiday, I thought I might be stuck there for some time until an ambulance came. I was not aware of anybody else helping or offering me the use of their phone.

I figured that I had to pass my home to get to Wyong Hospital, so I managed to successfully drive home. I got inside the house, found Adam, and yelled out to him saying "I've either had or I am having a heart attack." I insisted on having a shower to get the sand out of my hair (not very successfully), before Adam drove me to Emergency which was ten minutes away. I will never forget that short trip. Adam was as usual religiously sticking to the speed limit and due to traffic could not go any faster. I said to him "please speed up a bit, I know it is a public holiday and I will pay the speeding fine. Do not worry about the double demerits."

The staff at Wyong Hospital Emergency were excellent and I was in good hands. The emergency doctor in-charge was simply brilliant. However, he was totally justified when he berated me for driving myself home from the beach, explaining that I could have blacked out. While being stabilised, he asked me several times what my level of pain was on a scale of one to ten. At one point, he jokingly told me not to give a high number 'just to get a helicopter ride' to Royal North Shore Hospital (RNSH). My pain had dropped dramatically and so I responded by telling him that when I was in the Navy, I had flown numerous times in helicopters and loved doing so. Therefore, I didn't need another helicopter ride. We both laughed!

I have always maintained that even on my death bed I would be asking for a cup of tea. Well, that's almost what happened. After recovering in Trauma Room One after almost experiencing a

near death experience, I was asked by staff if I'd like a cup of tea. My much-needed cup of tea and sticky date pudding materialised almost immediately. At the time I wasn't aware of why I had the heart attack until the following day when I saw the cardiologist. So, I was initially thinking it was something to do with high cholesterol and here I was eating sticky date pudding!

A couple of hours later I was transferred to the cardiac ward for an overnight stay before being transferred the following day to Gosford Private Hospital where I underwent a coronary angiogram. During the procedure, Dr Andrew Hill implanted one stent in my Left Anterior Descending (LAD) Coronary Artery. Andrew later explained that a breakaway piece of plaque caused the blockage and subsequent heart attack. The artery blockage was <50% and that he wouldn't normally insert a stent in those circumstances.

I had a very quick recovery and did all the things required, post hospital discharge including taking things easy while also attending six-week Cardiac Rehabilitation Programme at Wyong Hospital which covered education (heart disease/risk modification), group sessions (psychological recovery) and supervised exercise sessions twice a week. After completing the programme, I was motivated to join my local gym and have been a regular attendee ever since.

After eight weeks of sick leave, I returned to normal duties at HSC and TAFE. Friends and family jokingly said that it was debatable who gave me the heart attack. My students or my daughter-in-law. As I said above, happily it was neither!

Before 2016 concluded I needed to have day surgery for a Left Inguinal hernia repair, which was possibly caused by helping to lift our outdoor spa which needed to be moved for repairs. By year's end my CD4/VL counts were very pleasing and were 559/Undetectable.

In the next edition I will write about the period 2017–2022, more teaching, nine operations/procedures in 39 months (including three potentially life-threatening conditions), remaining undetectable, retirement, a major change to HIV antiretroviral regimen after almost 6,000 days and finally Thank you. Goodbye and in the famous words of the Looney Tunes Cartoon character, Porky Pig. "That's all Folks!"

**– Paul R Maudlin OAM, JP**

# ACCEPTANCE & AGEING

Sitting in a chair at the local clinic, I received a diagnosis of HIV in 2007. Having accepted and come terms with the fact I am HIV-positive, a new reality of living with this chronic condition after 15 years, is now in the forefront; and posing a new challenge for both doctors and patients, aging with HIV.

This virus is becoming a double edge sword of sorts; in regards to long term treatment, medication side effects, and a continual immune system response to HIV, which leads to chronic body inflammation. As a result of the combination of these things, those of us living with HIV face the potential of new health issues and complications, to both our physical and mental well-being; due to non- AIDS related illnesses. These chronic conditions are seen in older adults and seniors, and are now being diagnosed in HIV patients under the age of 50.

Why? New research shows that HIV causes age acceleration of the body; and most critically, of the organs. Whether one is newly diagnosed with HIV or has had this virus over a long period of time, aging has given rise to additional fears, anxieties, and uncertainties, aside from HIV itself; a “second acceptance” of this chronic condition, and a second opportunity to realize and witness to others, how courageous, strong, persevering, and amazing individuals we are; living our lives to the fullest.

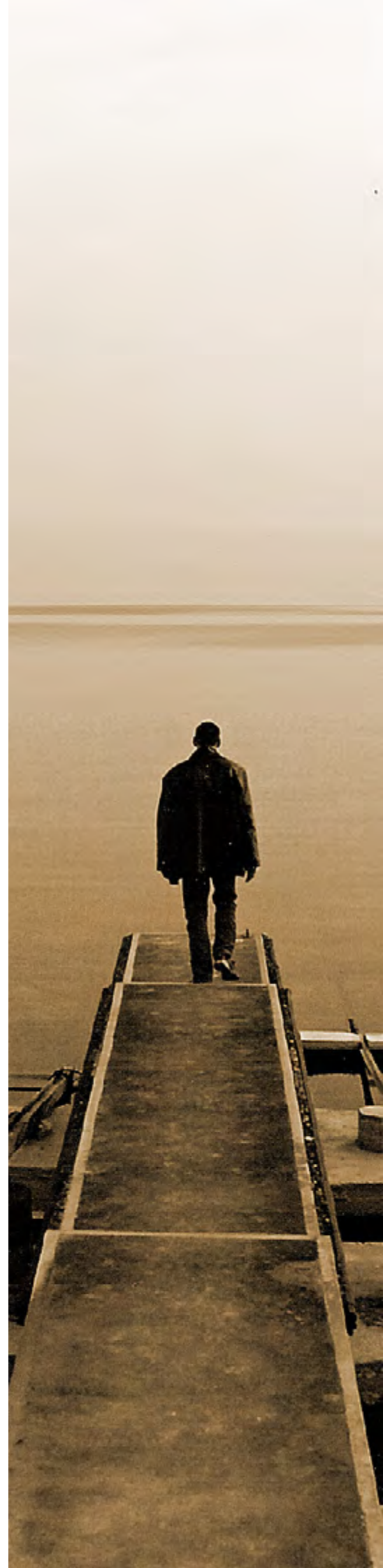
The challenges of comorbidity or multimorbidity; in combination with common and general issues experienced by those of us who are HIV-positive, (fatigue, sleep troubles, weight gain, etc.) can prove to be a long and rocky path to be walked. This being said, the progress and success achieved over the last 26 years in the advancement of treatment, has been absolutely amazing; and it is a blessing in disguise to have HIV if one is infected, at this time in history.

Every person's body makeup and chemistry varies among individuals; as genes, hereditary factors, medications taken, and the body's response to HIV itself, are each a factor; and play their role in the overall health, quality of life, and life expectancy of those in our community. Upon my diagnosis of arteriosclerosis and then osteoporosis, it was a time for me to regroup mentally and emotionally, while continuing forward in my physical care; the best I could and still do. My aging with HIV hasn't gone as I obviously expected, but HIV is a cunning, tricky, persistent, and unpredictable virus to have.

I do sometimes think about my physical health as a whole in light of my turning just 44 years old, in the coming month; in regards to my quality of life and life expectancy. How will things be in five or ten years, taking into account the changes and adjustments I have already made due to my multimorbidity?

In the end, my life continues to be a blessing. I will always have the present moment as long as I am still here. That is enough for me.

– James Cotromanes





# LIVING WITH HIV?

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## THE CHANGE

Menopause is a relevant topic for women because it is something we will all experience at some point. It is a natural part of the aging process. Knowing what symptoms to expect and knowing what symptoms are specific to women living with HIV may help deal with the experience. In saying this, like HIV, every woman's experience of menopause will be different.

Menopause, also known as the change or change of life refers to the point in time when a woman's menstrual periods have stopped and although this may mark the end of a woman's fertility, it is not the end of a woman's femininity or sexuality.

Women experience menopause in the same way whether they are living with HIV or not however there are some considerations for women living with HIV. Some studies have shown that women living with HIV may experience more severe symptoms. There is also some evidence to suggest that women living with HIV may experience menopause earlier than women who are not, however there is no definite proof of this. Menopause may have an effect on women's mental health or worsen existing mental health conditions. Some women living with HIV have experienced similar symptoms during menopause that they have experienced with HIV, as the symptoms can be quite similar.

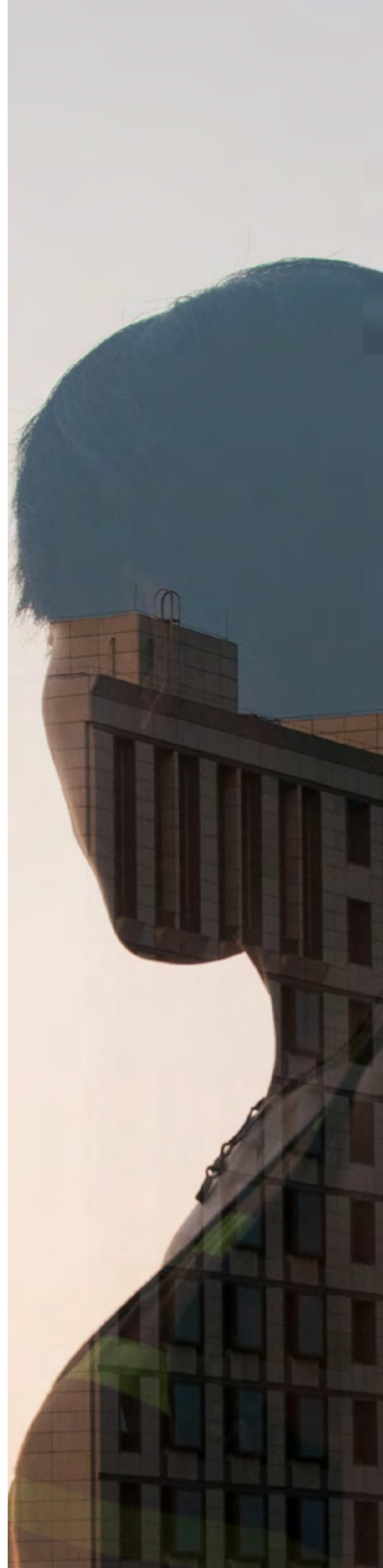
Women may experience symptoms such as increasingly irregular periods, hot flashes, night sweats, mood swings, depression. Irritability, vaginal dryness, forgetfulness, trouble sleeping, fatigue, lack of sexual desire and skin changes. Also, after menopause there are medical conditions that may develop, such as osteoporosis, cardiovascular disease and urinary incontinence.

Fortunately, there are many things that can be done to help manage menopause symptoms. Women may like to talk through their options with a medical professional. They may be able to offer solutions to reduce the symptoms associated with menopause such as HRT. HRT or hormone replacement therapy. There are different types of HRT and one of the safest is known as body identical HRT. Generally, the body identical types of HRT do not interfere with any HIV treatments. HRT may relieve many menopause symptoms and lower the risk of osteoporosis and cardiovascular disease.

There are things that women can do to stay healthy and look after their wellbeing after menopause such as eating a healthy diet, having calcium levels checked and taking calcium supplements if needed. Also staying physically active may help prevent cardiovascular disease and doing muscle strengthening activity may prevent bone loss.

Menopause is not always talked about openly and some women may not realize the changes they are experiencing are due to menopause. There are many symptoms associated with menopause, which can be effectively managed and living with HIV should not make it more difficult to manage menopause symptoms.

– **Kim and Priscilla**





## Get in Touch!

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

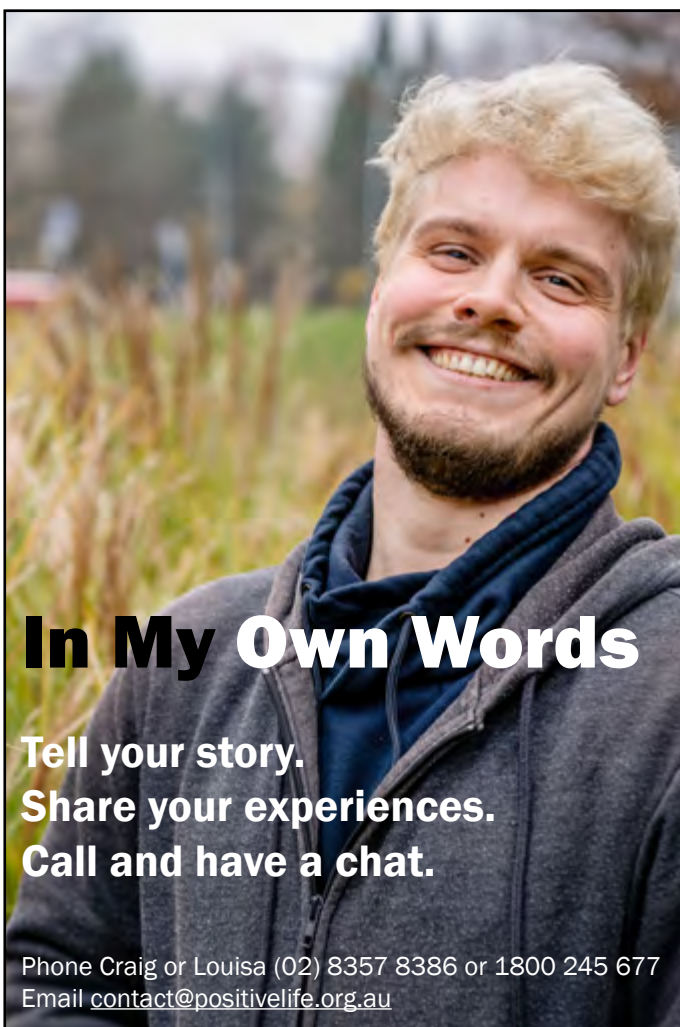
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Please specify if you want your details withheld from publication.

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## In My Own Words

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

## DECEMBER

1 World AIDS Day

9 Positive Life NSW AGM  
*Annual General Meeting & Christmas Party*

14 Peer2Peer  
*For all gay/bisexual men living with HIV*

16 Social Club  
*For all people living with HIV who identify as heterosexual*

## JANUARY

7 Social Club Sydney 6pm  
*For all people living with HIV who identify as heterosexual*

11 The Women's Room 6.30pm Online  
*For all women living with HIV under 45 years of age*

13 In The Know 7pm  
*For all people living with HIV*

18 Positive Conversations 6pm Online  
*For all people living with HIV*

19 Peer2Peer Sydney 6pm  
*For all gay/bisexual men living with HIV*

26 Digital Mentors Sydney 12.15pm  
*For all people living with HIV*

## FEBRUARY

7 Social Club Sydney 6pm  
*For all people living with HIV who identify as heterosexual*

8 For Women 6.30pm Online  
*For all women living with HIV over 45 years of age*

15 Positive Conversations 6pm Online  
*For all people living with HIV*

17 [+Connect] Ultimo 12noon  
*For all people living with HIV, our partners, friends and family*

24 Peers Connect HNE 12.30pm  
*For all people living with HIV*

30 Digital Mentors Sydney 12.15pm  
*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.

TALKABOUT August 2022 25

## Living a long and healthy life – does what you eat make a difference?

The short answer, YES! Whether you have HIV or you don't, it's the same recipe - a healthy eating pattern – and importantly over the long term. It's definitely NOT a part time diet or fad or trend. Neither is it a strict regimented set of rules.

PLUS even better, there's evidence to show you may be able to add some extra years by following such a healthy eating pattern. Imagine enjoying a few more Christmas holidays in your life than you might have thought!

How do we know this?

Research shows there are certain areas in the world where people live longer and have good quality of life too. These are called the Blue Zones, e.g. the Mediterranean, Okinawa in Japan and more.

Research has also shown that what you eat can affect your chances of experiencing the main chronic diseases affecting us in Australia, such as diabetes, heart disease, excessive weight, high blood pressure and kidney disease.

### **Common to the diets of the people living in the Blue Zones and the diets of people who stay well are:**

- A plant-based diet – eating mostly vegetables including legumes and lentils, fruit, nuts and seeds, and wholegrains. Herbs and spices are plants too. Animal foods like meat and chicken are like condiments, eaten in smaller proportions.
- Choosing a rainbow of colours when eating fruits and vegetables. The reason is that different coloured fruits and vegetables have different plant nutrients or phytonutrients. Phytonutrients are protective for our health. There are over 5,000 that are known and probably more that have not been discovered yet. Choosing a variety means you get the best mix. These can be fresh, frozen, dried or canned.

### **Colour Examples**

**Red** watermelon, strawberries, tomatoes

**Orange** pumpkin, carrots, sweet potatoes, apricots, oranges and turmeric

**Yellow** bananas, lemons and pineapples

**Green** green leafy vegetables, spinach, bok choy and other Asian green leafy vegetables, broccoli, rocket, avocado, asparagus, green beans

**Blue and purple** blackberries, blueberries, prunes, eggplant, red cabbage

**White and brown** onions, garlic, leek, cauliflower, potatoes, parsnips, mushrooms

- Eating few if any ultra-processed foods. Ultra-processed foods are foods which have been produced from a series of industrial processes. These foods include soft drinks, pastries, cakes and cake mixes, biscuits, lollies, savoury packaged snacks such as crisps, and reconstituted meat products like chicken nuggets or fish fingers.
- Keeping processed meats such as bacon, salami and ham to occasionally.
- Throwing out the saltshaker and eating fewer salty foods. Using herbs and spices and flavourings like curry powder, tomato paste, chilli and garlic for delicious tasting food instead.

*If you have any questions or would like to chat to a dietitian, call reception at The Albion Centre on (02) 9332 9600 to make an appointment.*

**The Albion Centre nutrition team**





## Pumpkin and Beetroot Salad

### Ingredients

- 750g butternut pumpkin
- 4 beetroots (fresh), peeled
- 1 red onion
- 120g spinach leaves
- 150g feta cheese
- 3 tbsp pine nuts
- 2 tbsp sunflower seeds
- 2 tbsp pepita seeds
- **Optional:** 1 can chickpeas, drained and the seeds of 1 pomegranate
- **DRESSING**
- 2 tbsp olive oil
- 2 tbsp balsamic vinegar
- 1 tbsp honey

### Instructions

- 1 Remove skin and chop pumpkin and beetroot into cubes. Slice onion into wedges. Place these on a baking tray and drizzle with olive oil. Roast at 200°C for about 30-40 minutes or until soft and golden.
- 2 Whilst the roast vegetables are cooling, toast nuts and seeds in a fry pan until golden.
- 3 To a salad bowl add spinach leaves, nuts, seeds, cubes of feta, roasted beetroot, pumpkin and onion. If using chickpeas and pomegranate add these now too.
- 4 Combine ingredients for dressing. Just before serving pour over dressing and toss salad.

## Fruit Stars

### Ingredients

- ¼ watermelon, peeled
- ½ honeydew melon, peeled
- ½ rockmelon, peeled
- **You'll need**
- 8 small skewers
- 3 graded star cookie cutters (5cm, 5.5cm and 6.5 cm)

### Instructions

- 1 Cut melons into 1.5–2cm-thick slices. Discard skin and seeds.
- 2 Cut star shapes from fruit with cutters. Thread three graded stars from the different fruits onto each skewer, going from the largest to the smallest star.
- 3 Stand the stars on a serving plate.





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