

talkabout

Where we speak for ourselves

#197 | June 2021 | ISSN 1034 0866 | Positive Life NSW – the voice of people with HIV since 1988

INSIDE

Money Talks

My Journey of Risk

Outing the Myths

The Rollcall: Candlelight Memorial

Spotlight: Newtown Neighbourhood Centre

Positive Life NSW

The voice of all people living with HIV



HIV IS EVERYONE'S BUSINESS



HIV affects us all

IT'S EVERYONE'S BUSINESS

The HIV pandemic is not over. There's still no HIV cure or HIV vaccine. HIV affects anyone who is sexually active. Whether we're living with HIV or not, we all have a shared responsibility around HIV. This includes heterosexual women and men, trans and gender diverse people, gay and bisexual men, Aboriginal and Torres Strait Islander people, sex workers, people from culturally and linguistically diverse (CALD) backgrounds, people who inject drugs and people born overseas. Today, HIV is everyone's business.



HIV testing

IS EVERYONE'S BUSINESS

Anyone who is sexually active can contract a sexually transmitted infection (STI), including HIV. STI testing in NSW is free, confidential, anonymous and safe. It's time we offer HIV testing to everyone, including heterosexual people, women, refugees, and people from CALD backgrounds, and men who have sex with men. Some STIs are silent, without immediate symptoms and can damage your physical and reproductive health. If the test comes back positive, you'll be able to start treatment quickly and take care of your health and your partners. Testing is everyone's business.



HIV transmission

IS EVERYONE'S BUSINESS

Today, we all have a number of different strategies to prevent HIV transmission such as condoms, PrEP (pre-exposure prophylaxis), PEP (post-exposure prophylaxis), needle and syringe programs, and the use of HIV antiretroviral treatment by people living with HIV to reduce our HIV viral load and prevent onward transmission. Let's celebrate our shared responsibility in ending HIV transmission.



HIV stigma & discrimination

IS EVERYONE'S BUSINESS

Wherever and whenever stigmatising comments about AIDS or HIV or discriminatory practices go unchallenged, they impact people living with HIV and create risks to our lives, health and community. It's everyone's business to talk about HIV. Let's confront ignorance, dispel myths and misinformation about HIV together. HIV stigma and discrimination is everyone's business.

**Let's celebrate our shared responsibility to end HIV transmission.
There's no shame in getting tested for HIV.**

talkabout

Where we speak for ourselves

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Cover photo: Sydney Street Choir at the 2021 Candlelight Memorial, 16 May 2021.

Contributors: Robert Agati, Craig Andrews, Tina Angelo, Bruce Hamish Bowden, The Conversation, Jane Costello, Barry French, Yasser Ibrahim, Ulo Klemmer, Rob Lake, Steve Spencer, Liz Sutherland, Louisa Wright



The voice of all people living with HIV

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Letters should short (be less than 200 words) and may be edited.
All letters to be considered for publication must have a name, street address,
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Please specify if you want your details withheld from publication.

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Future use of information about that person's sero-status cannot be controlled by Positive Life NSW.

The greatest care has been taken to ensure the accuracy of information in this magazine at time of going to press, but we accept no responsibility for omissions or errors.

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PRESIDENT

On Sunday 16 May, Positive Life NSW hosted the annual Sydney Candlelight Memorial at the Eternity Playhouse with our partner ACON. This edition we hear from community member Ulo Klemmer, who shares his reflections and memories of decades of Candlelight Memorial celebrations (p8).

We held the second of our three community discussion sessions titled '*Beyond 2021: Ending HIV, Next steps*' in early June, where we examined the new NSW HIV Strategy 2021-2025 and what it means for all of us living with HIV in NSW. Now that the NSW HIV Strategy has been released by NSW Health, the Positive Life Board is close to publishing our 2021-2025 Strategic Plan, which has always been aligned with the state strategy. Keep an eye out for the release of our 2021-2025 Strategic Plan, as we would welcome your feedback on this important document.

To ensure that we fully support and represent the interests of all people living with HIV in NSW, we strongly encourage anyone living with HIV in NSW to take up membership of Positive Life. Membership is free (p25). At the same time, you'll be showing your support for the ongoing demand and need for the agency. As the voice of all people living with HIV in NSW, I strongly encourage you to get involved with Positive Life. Let us know how you're getting on, or even share your story in Talkabout.

Please contact me with any feedback or suggestions on how we can better support you and the needs of our members at president@positivelife.org.au

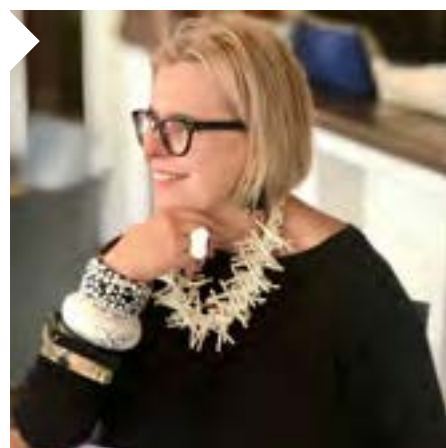
ROBERT AGATI

CHIEF EXECUTIVE OFFICER

By the time you read this, the Positive Life Office will have moved from our 'penthouse' position on Level 5 at 414 Elizabeth Street, down one level to take up a new location on the 4th floor. Our new space has a more user friendly and workable layout incorporating a separate, welcoming reception area decorated in our colourful refreshed branding. This will feature comfortable seating, lots of resources and information and will be accessible and accommodating for everyone in our community. When you're next passing by, pop in and say hello! Our efforts to be a more fully inclusive organisation and reflective of the diversity of our community living with and affected by HIV, is being recognised by community members like you, and our HIV sector partners.

In the next few months I invite you to keep an eye out for our next Community Consultation Engagement Forum (CCEF) which will start a community discussion around what we can do to record and protect our treatment and care wishes, within our own personal values, for peace of mind throughout life. Positive Life will develop resources to share with our community as part of our focus on living well with HIV. I invite your feedback on how we can do this more effectively.

JANE COSTELLO



TREATMENTS BRIEFS

This column offers health and treatments news in relation to living with HIV.

Interactions with antiretrovirals

The majority of people living with HIV today are extremely well managed by the antiretroviral treatment they are taking and there are many combinations available (one size does not fit all).

However, they ALL have the potential of interactions with other prescribed medications. These may be medications available to purchase in the pharmacy or may also be vitamin and herbal supplements. Even common supplements like a multivitamin or indigestion/heartburn medication can affect some antiretroviral medications.

Some interactions may have impacts on other medication you may be taking for cholesterol, asthma, depression, diabetes, erectile dysfunction or other conditions. These interactions can also alter the amount, effectiveness or levels of antiretrovirals in your body and change the effect your antiretroviral medication has in your body.

Some interactions may mean you have higher levels of the antiretroviral drugs than needed, and you are more likely to experience adverse effects or toxicities. Alternately, some interactions can result in you having insufficient levels of the antiretroviral drugs to control the HIV virus. This increases the risk of viral breakthrough and the development of resistance, which may compromise your HIV treatment options now and in the future.

Some medications or supplements may also affect the results of some of the regular blood tests that you have. An example is creatine which is a very popular sports supplement, which many people who go to the gym take. Creatine can affect the results of your kidney function

tests, so it is important to tell your doctor if you are taking these and ANY other supplements/herbs.

St John's Wort is a commonly used herbal supplement for anxiety/depression, and it is well known that this herbal supplement interacts with many antiretrovirals and should be avoided.

A useful website (and smartphone app) that is accessible to everyone with a mobile device (iphone, ipad, etc) is the University of Liverpool HIV Drug Interaction Checker. This app is a regularly updated database where you can enter the antiretroviral medication you are taking, and then other medications or herbs/supplements and see if there is an interaction.

It works on the traffic light system: green is good, orange means caution, and red means they definitely should NOT be combined. To note, this database is still somewhat limited for herbal medications and supplements, and some medications may be known by another name overseas.

There are far too many interactions to go into detail here, so before starting any new medication or supplement it is important to check with your HIV pharmacist or s100 prescriber to confirm the combination is suitable.

– **Bruce Hamish Bowden**
Clinical Pharmacist (HIV)

The *University of Liverpool HIV Drug Interaction Checker* is also online at www.hiv-druginteractions.org/checker or downloaded via your iPhone App Store or Google Play Store for Android.

unusual risks

Life Insurances for people living with HIV, diabetes and other complex health conditions

Stigma and discrimination free

unusualrisks.com.au





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) 9206 2177 or 1800 245 677 (freecall)
www.positivelife.org.au peernav@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 about what makes a culturally-safe model to support Indigenous people across NSW on telephone (02) 9206 2177, 1800 245 677 (freecall) or email contact@positivelife.org.au

THE ROLL CALL

CANDLELIGHT MEMORIAL

When Ulo Klemmer was part of ACON's Beats Outreach Project, the first in the world, his work patch in the late 1980s was the western suburbs. "There was a thirst for knowledge," he said. "They weren't getting information that we had closer in to town. We'd approach them at the beats, we went out in pairs for safety. Mobile phones had just started coming in, so we had this big heavy brick of a thing, in case something happened; some of the locations were very isolated." It was a role deeply embedded in the gay community: people distributing information to keep each other safe.

These days, Ulo is retired and living on a semi-rural block in the Liverpool area which his father bought many decades ago. Despite the arrival of neighbours, "the bush is still there," Ulo said, "and a creek, and platypus in the creek and snakes, and a dog and a cat." His distance from the city is a conscious choice. "For the past few years, I'm connected to the community in a way, but also not connected, living out there. When I choose to be I'm connected; I know a lot of people!"

Ulo's first Candlelight Memorial, in the early 1990s, was huge. "It started at Green Park and there must have been 30,000 people, a huge number of people, and it weaved its way down Oxford Street, twice actually, once ending in Hyde Park and the other time in the Domain.

"People in the march were carrying candles, people in the shops and bars along the way were holding candles, the Oxford Hotel had people on their awning holding candles, people standing watching us were holding candles, it was huge.

"It was very moving, a sort of sad Mardi Gras. It was solemn, but not depressing, because there were so many people doing this same thing; it made sense to all be together and to remember and be part of it together. It was still a frightening time,

things we'd never heard of, and the early drugs were terrible. Everything revolved around HIV.

"The crowd stretched almost the whole length of Oxford Street, just like Mardi Gras does, it was so big. And of course it was in the evening, in the dark. It was a glorious thing to see and watch and be part of, all those candles. It kind of took away the scaredness of the time, because we were all there together, you weren't alone. But that was temporary of course, it was only for that night.

"We got to William Street, and the traffic was piled up everywhere waiting for the march to go through. And in William Street, horns were blowing, beep beep, I remember this took me to a horrible place; one guy yelled out of his window, die you fuckin' poofers, and I thought, if you only knew what this was all about. It was so opposite to our purpose in being there. But being in such a big group, it was less horrible than it would have been otherwise."

"I went for a few years after that. And I started reading names at the Candlelight memorial five or six years ago; I found it easy, even when I knew some of the names on my list, I got through it. Before I did it the first time, I read through the names to make sure I would pronounce them right, and when I saw names that I knew, I thought, how am I going to do it? And surprisingly, I didn't waver. At the most recent one, one of the guys did waver, not because of names but he was just overcome with emotion, and I wondered why I don't get as emotional as that; but when I sat down, then that's when I get emotional.

"It's almost a ritual now for me; I'm honouring the community and I'm honouring friends who've gone. I keep doing it because I am honoured to be asked, and I'm honoured to name names, especially people I know. That's me there saying their name; and it means something, it means I'm connected still with that person in some way. I have even had the honour of reading Jon Sweeney's name. Jon and I were the first two to begin the Beats Outreach Project.

"At the time of reading, I'm not seeing their face, and I generally don't stay afterwards. Driving home, that's my thinking time; it's one of the reasons I like living out in the suburbs. That's when all the memories come flooding back and that's a time I treasure. I'll think about the person whose name I read, and I think about all the fun times I had

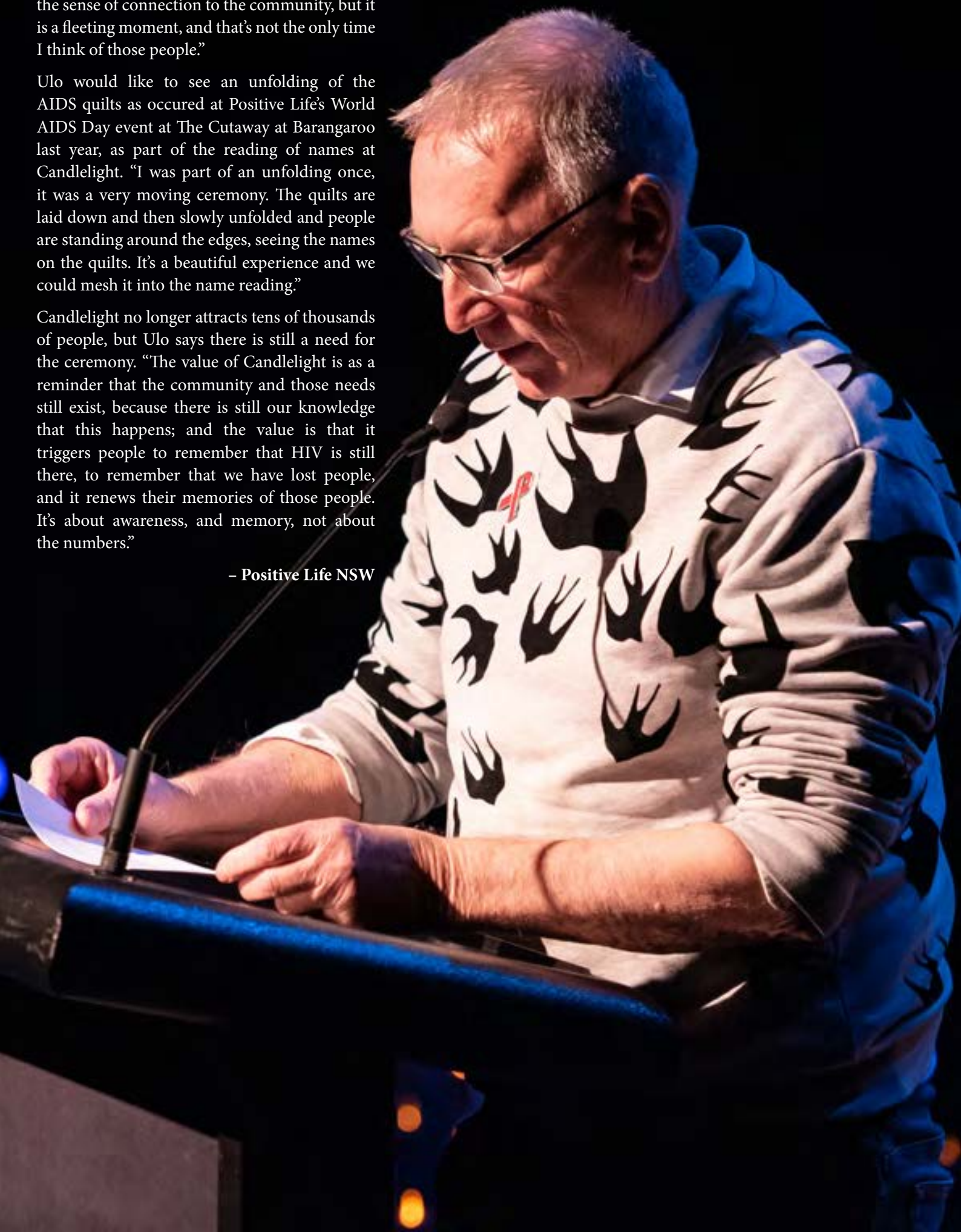
"It's almost a ritual now for me; I'm honouring the community and I'm honouring friends who've gone. I keep doing it because I am honoured to be asked, and I'm honoured to name names, especially people I know."

with that person. Reading the names reinforces the sense of connection to the community, but it is a fleeting moment, and that's not the only time I think of those people."

Ulo would like to see an unfolding of the AIDS quilts as occurred at Positive Life's World AIDS Day event at The Cutaway at Barangaroo last year, as part of the reading of names at Candlelight. "I was part of an unfolding once, it was a very moving ceremony. The quilts are laid down and then slowly unfolded and people are standing around the edges, seeing the names on the quilts. It's a beautiful experience and we could mesh it into the name reading."

Candlelight no longer attracts tens of thousands of people, but Ulo says there is still a need for the ceremony. "The value of Candlelight is as a reminder that the community and those needs still exist, because there is still our knowledge that this happens; and the value is that it triggers people to remember that HIV is still there, to remember that we have lost people, and it renews their memories of those people. It's about awareness, and memory, not about the numbers."

– Positive Life NSW





In My Own Words

We'd like to interview you for a new series 'In My Own Words'

**Tell your story,
share an experience about living with HIV
or call and have a yarn.**

Speak to Craig or Louisa
(02) 9206-2177,
1800 245 677 (freecall outside metro)
or email contact@positivelife.org.au

All published pieces receive a \$30 Woolworths Voucher



HIV Futures 10

A national survey of people living with HIV

hivfutures.org.au

TALK SHOP

The NSW Body Positive is represented across a range of NSW HIV/AIDS community partners. Below are brief details of advocacy issues impacting the interests of people living with HIV in NSW.

Access to health services in custody submission

In May 2021, Positive Life NSW partnered with the HIV/AIDS Legal Centre (HALC), Hepatitis NSW, and the NSW Users and AIDS Association (NUAA) in providing feedback to the Audit Office of New South Wales, who were conducting an audit to assess whether adults in custody have effective access to healthcare in a complex service environment.

The submission considered the demographic information available for incarcerated persons in NSW, including people living with HIV, people living with hepatitis, and people participating in Opioid Treatment Programs (OTP). A number of observations and recommendations were made, including the need for all incarcerated persons, including those living with blood-borne viruses (BBVs), to access an equivalent standard of healthcare as is available in the wider community.

Incarceration settings provide a unique public health opportunity to provide comprehensive and equitable BBV healthcare access to vulnerable and high-risk populations, including prevention, testing, treatment, and quality of life initiatives. Prevention initiatives need to target incarceration setting entrants, particularly those with a history of injecting drugs and those who are in an incarceration setting for the first time, to initiate prevention strategies including education, hepatitis B vaccination, hepatitis C treatment, and HPV vaccination and testing.

s100 Consultation Survey Report

In late 2020, the NSW Ministry of Health and Service NSW, along with Positive Life NSW, surveyed people living with HIV in NSW about our experience of the waiver of the Pharmaceutical Benefits Scheme (PBS) co-payment for s100 HIV medications in NSW.

This state-wide scheme enables people living with HIV who are eligible for Medicare to receive our HIV medication free of charge in NSW. The report provides a summary of the key findings, including the experiences of people living with HIV with s100 HIV medications in NSW including access, prescribers, collection, and experiences with ordering prescriptions online.

The report discusses respondents' reported awareness of the co-payment waiver, including their stated privacy concerns and associated issues, preferences when choosing a pharmacy along with sources of support to manage their health. Lastly, the report discusses respondents' responses regarding managing paperwork such as the s100 Patient Consent Form. Positive Life has offered some recommendations regarding the continuation of the NSW s100 HIV medication co-payment initiative, and options to improve the co-payment initiative in the future.

Heterosexual Workshop

Positive Life recently held a workshop for heterosexual people living with HIV in partnership with Pozhet. The event offered an opportunity for heterosexual people to meet others in a confidential and supportive environment, while gaining more detail and information about living well with HIV.

The workshop opened with a *Welcome to Country* by Ms Yvonne Weldon from the Metropolitan Local Aboriginal Land Council (MLALC), after which participants discussed what they hoped to get from the workshop, including their hopes and concerns about living with HIV.

A peer-based Advisory Committee had put together the agenda which included issues of resilience and self-empowerment, questions about legal disclosure, upcoming HIV treatments, complementary therapies and drug interactions, a timely discussion about COVID-19 vaccine hesitancy and valuable financial advice about planning for the future.

The full day included time for participants to socialise and discuss their own personal concerns and questions, both with each other and with various speakers outside the scheduled sessions. The workshop concluded with a group discussion about the day including ideas for future workshops.



STRAIGHT AND HIV+?

- Get the latest information on topics such as pregnancy, treatment and living well
- Find out about other useful services
- Connect with other heterosexual people living with HIV

WEBSITE

pozhet.org.au

EMAIL

pozhet@pozhet.org.au

FACEBOOK

[@pozhet](https://www.facebook.com/pozhet)

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

A place to showcase
our sector partners
who benefit the lives of

WORKING FOR ME

all people living with HIV

Community is close to Rob Lake's heart. As the Positive Life NSW CEO between 2007-2011, he's remained close to the NSW community sector ever since.

Today Rob heads up the Newtown Neighbourhood Centre (NNC) Aged Care programs. NNC has a strong focus on supporting boarding houses residents and homelessness people in general.

"The Neighbourhood Centre is really a front door," said Rob Lake. "It's a place where people can drop in, and find services that work for them and their needs. We try to support people who experience hardship in different ways. We do three main things.

"We work with people in boarding houses or who are insecurely housed. We work in community development, supporting Inner West families and residents dealing with disadvantage. And third we provide social support to older people. In addition, we try to support the community of Newtown, through the Newtown Festival, groups and services such as counselling and English language, as well as being an advocate for this community.

"There have been social support groups for seniors from the Greek or Yugoslavian communities for over 30 years at the Centre," said Rob. "We run a number of social support groups and also offer one to one support to older people living at home. We're also starting to engage more with social support for other communities, including older people living in boarding houses."

Despite having a population with 95% employment, Sydney's inner west has the highest number of boarding houses in Australia. A boarding house is an accommodation option where residents can rent a room quickly. These are usually furnished, with shared kitchen and bathroom facilities, however boarding houses can range dramatically in quality.

"People end up in a boarding house for all sorts of reasons and they live in a boarding house because they have to," said Rob.

"They either don't have money for a bond, or they can't afford a rental property. They're easy to get into and are affordable. However, it's also a very unstable option, and basically you're one step away from being homeless."

The NNC has run a Boarding House Outreach Service for over 30 years, supporting occupants and working with

owners of boarding houses across six Local Government Areas (LGAs) in Sydney. With a diverse inner west population, the NNC outreach team work daily with people facing financial hardship, housing insecurity, people living with a range of disability and health conditions including HIV, and people who are homeless or at risk of homelessness. NNC has always worked to support people living with HIV in boarding houses to access more secure accommodation, in partnership with the range of health and HIV-related programs and services.

Using an outreach model, people can meet up with Neighbourhood Centre staff in a variety of community settings, rather than an office or drop into the NNC. The team operate from a person-centered perspective, to resolve the underlying causes of the individual's housing insecurity with the aim to move towards secure housing.

In Sydney, homelessness is growing amongst older women," said Rob, "and this is due to a range of reasons like relationships ending, economic reasons, changes in the job market. Boarding houses are not really very safe for women. Often homeless women might couch-surf or try other things rather than living in a boarding house. Wherever possible, women tend to avoid being homeless on the street due to safety. Safe, secure, long term options for older women are harder to find and boarding houses are often not an answer."

"Boarding houses are one of the options that people living with HIV have turned to for housing, and this is where we can see negative impacts on health," said Rob.

"The main problem with boarding house accommodation for people living with HIV, like many other people with health conditions is the lack of privacy. It's a stressful environment, and bad for people's health. Insecure housing makes it really hard to keep everything on track. Managing health in these spaces is tricky, especially if you're juggling medications, money, doctors and managing your health and life..

"A secure place to live is a critical part of life," he said, "and it's no different for people living with HIV. Safety, privacy, human rights, are all better in secure housing. Sharing with strangers can make disclosure a risk."

"As we have known for a long time, all of these things together contribute to getting and maintaining good health, which is the goal for all people living with HIV. NNC is one of the housing and homelessness services that



work to help find a way out of insecure housing and into a secure place to live.

“The Neighbourhood Centre is open to everyone. We want people to feel welcome, and we don’t turn people away. Wherever you live we’ll either help or help find a service local to you to get help.

If you’re trying to find somewhere to stay, access housing, Centrelink, NDIS or aged care, navigating the system and understanding the process can be difficult.

For many people, the system can be too hard to access. It can be difficult to find your way into these services, which

is why people can end up homeless, jobless, isolated or unable to access services.

“People can make contact with the Centre in a range of different ways. Some drop in and have a conversation. Others come through the door and say ‘Can I get some help with...’ We’re open 10am to 1pm, four days a week or you can call us on 02 9564 7333 and we’ll try to help.

The Neighbourhood Centre will be moving from its current premises opposite Newtown Station to the Tom Foster Centre in Darley Street at the end of 2021.

– Positive Life NSW

halc

The HIV AIDS Legal Centre

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

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

For confidential legal assistance please contact us: Phone 02 9206 2060 or email halc@halc.org.au

Letters to the Editor

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

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

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

Please specify if you want your details withheld from publication.

Email Talkabout
editor@positivelife.org.au or

Post Talkabout
PO Box 831,
Darlinghurst NSW 1300

Calendar

COMMUNITY

The Social Club

A monthly get together for heterosexual people living with HIV in a safe, friendly and accepting social environment over a meal and discussion.

July and August 2021
6pm to 9pm

Peers Connect Online!

A safe, online meeting space for all people living with HIV in NSW, regardless of identity or sexuality. All welcome, especially people from rural and regional settings. Discussion facilitated by a person living with HIV from Positive Life. RSVPs are essential for each session.

THURSDAYS
8 July and 12 August 2021
6pm to 7.30pm

[+Connect]

An inclusive social event for all people living with HIV, our partners, family and friends.

THURSDAY
22 July and 30 September 2021
7pm to 9pm

Community Consultation Engagement Forum (CCEF)

A community discussion around planning for life and peace of mind.

SATURDAY
14 August 2021
10am to 4pm

Peer2Peer

An evening for all gay and bisexual men living with HIV to share experiences and build our networks, and discuss a range of issues relating to our health and living with HIV.

THURSDAY
19 August and 28 October 2021
6pm to 8.30pm

[+Connect]OutWest

An inclusive social event for all people living with HIV, our partners, family and friends at Western Sydney.

SUNDAY
17 October 2021
12oon to 3pm

For more information about any of these events or to RSVP call Positive Life on (02) 9206-2177, 1800 245 677 (freecall) or contact@positivelife.org.au

MONEY TALKS

A column focused on money matters in relation to people living with HIV in NSW

Financial Counsellors

For many people, talking about money is overwhelming.

Tina Angelo and Barry French are experienced Financial Counsellors based at the Bobby Goldsmith Foundation (BGF), where they say that every day they hear from people living with HIV who avoid paying bills so they can afford food, or avoid opening their mail in case it is another debt demand.

A Financial Counsellor can help you sort through all the worry and draw up a plan to get on top of the debt. Very often they can negotiate with your creditors and get the debts reduced. Getting support to sort through your financial anxiety and fears is easy. Pick up the phone and call 02 9283 8666 to make a time to talk to either Tina or Barry.

They're ready to sit down with you and talk about setting up your bank accounts, budgeting, the best ways to save, how to understand your Super statements and more. In fact, any financial questions are welcome. You'll be able to talk confidentially about your lived experience where you don't need to explain your health situation. And it's free!

Financial Tips for June

Government Co-contribution If you are under 71 years of age and receive employment income up to \$39,837 and make a \$1000 after tax contribution into your Superannuation by 30 June then when you submit your tax return the Government will deposit an extra \$500 into

your Super. You won't get 50% interest from any other investment! It scales down to zero at \$54,837. Ask your Super fund how to make a voluntary contribution.

Carry forward Concessional Contributions If you have a little extra cash to spare, you can make an even bigger difference by growing your Super and saving tax, by making an additional Concessional (pre-tax) Contribution. The Concessional cap is currently \$25,000pa which includes any Super your company has contributed. Since July 2018 you can carry forward any unused part of the \$25,000 for the last two financial years if your Super balance is under \$500,000. To do this:

1. Go to the Australian Tax Office (ATO) service online at <https://my.gov.au> under MyGov and look at Super/Information/Carry forward concessional contributions. This will tell you exactly how much extra you can add on top of this years \$25,000.
2. Make a voluntary contribution up to that amount to your Super fund before 30 June.
3. Before you submit your tax return, you can then notify your fund how much of the voluntary contribution you want treated as Concessional. This will reduce your taxable income. This process can be a little technical, so talk to us to make sure you get the maximum benefit from the process.

BGF Financial Counsellors

Free, confidential, independent and non-judgemental.

Barry French and Tina Angelo

T 02 9283 8666



HIV Vaccine

Why don't we have one after 37 years, when we have several for COVID-19 after a few months?

Smallpox has been eradicated from the face of the Earth following a highly effective, worldwide vaccination campaign. Paralytic poliomyelitis is no longer a problem in the U.S. because of development and use of effective vaccines against the poliovirus. In current times, millions of lives have been saved because of rapid deployment of effective vaccines against COVID-19. And yet, it has been 37 years since HIV was discovered as the cause of AIDS, and there is no vaccine. Here I will describe the difficulties facing development of an effective vaccine against HIV/AIDS.

I am a professor of pathology at the University of Miami Miller School of Medicine. My laboratory is credited with the discovery of the monkey virus called SIV, or simian immunodeficiency virus. SIV is the close monkey relative of the virus that causes AIDS in humans – HIV, or human immunodeficiency virus. My research has contributed importantly to the understanding of the mechanisms by which HIV causes disease and to vaccine development efforts.

HIV vaccine development efforts have come up short

Vaccines have unquestionably been society's most potent weapon against viral diseases of medical importance. When the new disease AIDS burst onto the scene in the early 1980s and the virus that caused it was discovered in 1983-84, it was only natural to think that the research community would be able to develop a vaccine for it.

At a now famous press conference in 1984 announcing HIV as the cause of AIDS, then U.S. Secretary of Health and Human Services Margaret Heckler predicted that a vaccine would be available in two years.

The problem is not failure of government. The problem is not lack of spending. The difficulty lies in the HIV virus itself.

Well, it is now 37 years later and there is no vaccine. The rapidity of COVID-19 vaccine development and distribution puts the lack of an HIV vaccine in stark contrast.

The problem is not failure of government. The problem is not lack of spending. The difficulty lies in the HIV virus itself.

In particular, this includes the remarkable HIV strain diversity and the immune evasion strategies of the virus.

So far there have been five large-scale Phase 3 vaccine efficacy trials against HIV, each at a cost of over US\$100 million. The first three of these failed quite convincingly; no protection against acquisition of HIV infection, no lowering of viral loads in those who did become infected. In fact, in the third of these trials, the STEP trial, there was a statistically significant higher frequency of infection in individuals who had been vaccinated.

The fourth trial, the controversial Thai RV144 trial, initially reported a marginal degree of successful protection against the acquisition of HIV infection among vaccinated individuals. However, a subsequent statistical analysis reported that there was less than a 78% chance that the protection against acquisition was real.

A fifth vaccine trial, the HVTN 702 trial, was ordered to confirm and extend the results of the RV144 trial. The HVTN702 trial was halted early because of futility. No protection against acquisition. No lowering of viral load. Ouch.

The complexity of HIV

What is the problem? The biological properties that HIV has evolved make development of a successful vaccine very, very difficult. What are those properties?

First and foremost is the continuous unrelenting virus replication. Once HIV gets its foot in the door, it's "gotcha." Many vaccines do not protect absolutely against the acquisition of an infection, but they are able to severely limit the replication of the virus and any illness that might result. For a vaccine to be effective against HIV, it will likely need to provide an absolute sterilizing barrier and not just limit viral replication.

HIV has evolved an ability to generate and to tolerate many mutations in its genetic information. The consequence of this is an enormous amount of variation among strains of the virus not only from one individual to another but even within a single individual. Let's use influenza for a comparison. Everyone knows that people need to get revaccinated against influenza virus each season because of season-to-season variability in the influenza strain that is circulating. Well, the variability of HIV within a single infected individual exceeds the entire worldwide sequence variability in the influenza virus during an entire season.

What are we going to put into a vaccine to cover this extent of strain variability?

HIV has also evolved an incredible ability to shield itself



from recognition by antibodies. Enveloped viruses such as coronaviruses and herpes viruses encode a structure on their surface that each virus uses to gain entry into a cell. This structure is called a “glycoprotein,” meaning that it is composed of both sugars and protein. But the HIV envelope glycoprotein is extreme. It is the most heavily sugared protein of all viruses in all 22 families. More than half the weight is sugar. And the virus has figured out a way, meaning the virus has evolved by natural selection, to use these sugars as shields to protect itself from recognition by antibodies that the infected host is trying to make. The host cell adds these sugars and then views them as self.

These properties have important consequences relevant for vaccine development efforts. The antibodies that an HIV-infected person makes typically have only very weak neutralizing activity against the virus. Furthermore, these antibodies are very strain-specific; they will neutralize the strain with which the individual is infected but not the thousands and thousands of other strains circulating in the population. Researchers know how to elicit antibodies that will neutralize one strain, but not antibodies with an ability to protect against the thousands and thousands of strains circulating in the population. That’s a major problem for vaccine development efforts.

HIV is continually evolving within a single infected individual to stay one step ahead of the immune responses. The host elicits a particular immune response that attacks the virus. This puts selective pressure on the virus, and through natural selection a mutated virus variant appears that is no longer recognized by the individual’s immune system. The result is continuous unrelenting viral replication.

So, should we researchers give up? No, we shouldn’t. One approach researchers are trying in animal models in a couple of laboratories is to use herpes viruses as vectors to deliver the AIDS virus proteins. The herpes virus family is of the “persistent” category. Once infected with a herpes virus, you are infected for life. And immune responses persist not just as memory but in a continually active fashion. Success of this approach, however, will still depend on figuring out how to elicit the breadth of immune responses that will allow coverage against the vast complexity of HIV sequences circulating in the population.

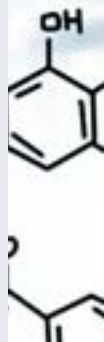
Another approach is to go after protective immunity from a different angle. Although the vast majority of HIV-infected individuals make antibodies with weak, strain-specific neutralizing activity, some rare individuals do make antibodies with potent neutralizing activity against a broad range of HIV isolates. These antibodies are rare and highly unusual, but we scientists do have them in our possession.

Also, scientists have recently figured out a way to achieve protective levels of these antibodies for life from a single administration. For life! This delivery depends on a viral vector, a vector called adeno-associated virus. When the vector is administered to muscle, muscle cells become factories that continuously produce the potent broadly neutralizing antibodies. Researchers have recently documented continuous production for six and a half years in a monkey.

We are making progress. We must not give up.

– **Professor Ronald C. Desrosiers**

Professor of Pathology, Vice-chair for Research,
University of Miami



OUTING the MYTHS

In the late 1940s, broader society learnt of research that demonstrated sexuality is not confined to only two categories: homosexual and heterosexual. This work by Dr Alfred Kinsey, ‘the father of the sexual revolution’ introduced the Kinsey scale, which is one of the first attempts to “acknowledge the diversity and fluidity of human sexual behaviour.” Since then we have also gained a modern and more holistic understanding of human sexuality. After the work of Kinsey in the 1940s came the Klein Scale in the 1970s from the American Bisexual Institute’s Dr. Fritz Klein, which has become another important guiding model for our understanding of human sexuality.

**...if you are
a bi+ person
living with HIV,
know that you
are not alone...”**

The Kinsey scale typically ranges from 0, meaning exclusively heterosexual, to 6, meaning exclusively homosexual. A common refrain is that “barely anyone is a 0 or a 6 on the Kinsey Scale,” which seeks to demonstrate that sexualities outside of homosexuality and heterosexuality are, in fact, the norm.

Today we are seeing increasing numbers of people identify other than heterosexual or homosexual. We are certainly seeing bi+ people (people who identify as bisexual, pansexual, fluid, bicurious, heteroflexible, homoflexible, and more) take their place in a society that has been dominated by monosexuality (hetero-, and homosexuality) for a very long time.

Yet within our predominantly visibly monogamous, bi-gendered society, discrimination and myths about bi+ people persist. While stigma and discrimination are systemic issues within our society, it’s the myths that feed fears, ignorance, even suspicion of bi+ people. I think it’s time to ‘out’ some of these myths.

One of the more pervasive myths surrounding bi+ people, is our sexuality changes (or was never true in the first place) because of the gender of our partner. A bisexual person is always a bisexual person, regardless of who we’re romantically or sexually active with. A bi+ man is not suddenly ‘straight’ because his partner is a woman. A bi+ woman is not suddenly a ‘lesbian’ because her partner is female. A bi+ orientation is not a button that just switches

on and off. It’s also not a reason for other people to have concern for the person’s partner. The ‘promiscuous bi person’ is a common myth that undermines an entire population of people.

This leads into another common, and sadly enduring myth. This is one about bi+ men in particular, and places us as the vector of HIV transmission into the heterosexual community. In truth, the transmission of HIV within the heterosexual community is due to a number of factors. In this myth, bi+ men are always suspicious at best, and dangerous at worst. We become convenient scapegoats and this unfortunate legacy lives on today.

I noticed that my bi+ male friends often lack the HIV education of their gay peers. In this way, we don’t get the same tools and knowledge as others and lack some of the best ways to engage with HIV prevention or combat HIV stigma.

It’s no secret that many of our community organisations and health personnel seem blindsided or confused when we show up in a waiting room or call for support. When we are engaged with HIV healthcare, we’re usually grouped in with the men who have sex with men (MSM) group. Worse still, bi+ women and non-binary people are usually forgotten completely or jumbled in with other groups. Female and non-binary partners of bi+ men are often thought to be misled or at-risk when they’re romantically or sexually active with this group.

Is it any wonder that my bi+ community feel a pervasive disconnect from mainstream society? We’re treated as either invisible or negatively queer. In LGBTIQ+ spaces, we’re super-conscious of the stigma of being ‘not-queer-enough’ depending on assumptions about our partner, or thought to be confused or lying if we’re with a same-gendered partner.

Is it any surprise that many of my community experiences atrocious mental health, impacts of drug use, high levels of loneliness, and worse HIV health outcomes than other priority populations? The reality is, bi+ people are ‘enough’. We’re whole people, and undeserving of distrust, suspicion, and ignorance.

As a bisexual man living with HIV, I see these myths and the elements that society has decided to assess bi+ people on, are grounded in exactly the same stuff of HIV stigma. Fear, ignorance, and sometimes hate. This is no way for



us to live, and none of us can stand by while we see others suffer from stigma. All stigma, whether HIV or bisexual stigma and discrimination, affects individuals as well as the community as a whole.

So how can I make a difference? I'm glad you asked!

You can reach out to bi+ people and make us feel accepted. I don't mean stand on a street corner with a sign saying 'hugs for bisexuals' or anything like that. I mean treat every person you come across in life that is bi+ with love and respect.

Could your friendship group or workplace offer bi+ people some recognition by hosting a small event on Bi Visibility Day (23 September)? Do you have a workplace newsletter that you can invite bi+ writers to write for? Can you encourage your friends to avoid stigmatising language against bi+ people, or steer conversations about queerness to be inclusive of bisexuality?

Let's create an environment that is accepting of diversity. One of my dreams for the next generation, is to foster a strong community in our mainstream society that treats bi+ people as equal, not as people that are confused, lying, cheating, or dangerous.

If you are a bi+ person living with HIV reading this, know that you are not alone, change is being made, and you are loved! If you want some extra information about these topics, contact local organisations like the Sydney Bi+ Network (SBN) as well as Positive Life NSW, who can provide you support and most importantly community.

– Steve Spencer

To contact the Sydney Bi+ Network (SBN), please find us on Facebook or email on syd.bi.network@gmail.com

MY JOURNEY OF RISK

At the age of twelve, Yasser started on a long journey. This was a winding journey to authenticity and self-acceptance, full of challenges, risk and even danger. In the midst of the uncertainty, there were also moments of joy and happiness, coupled with success and new life.

As an Egyptian person from a Muslim family embedded in the Arab culture, Yasser faced an early struggle. With a dawning realisation he was gay, he turned to his faith. “I was trying very hard to be a good Muslim. I was doing all the Islamic rituals, charity, fasting, praying every day and even the pilgrimage, Hajj. I was trying to be ok,” he said. “I really wanted to be accepted.”

After starting his studies in education, his university counsellor advised him his feelings were all ‘an illusion’ and marriage would solve his dilemma. After a number of arranged meetings, Yasser married at 27 years old. From the first night, he knew the marriage would not last. He began the divorce process.

While waiting for the papers to finalise, his new wife found out she was pregnant. This refocused Yasser to commit to the relationship, which “over 12 years brought three adorable and beloved sons into my life,” he said. “During these 12 years, I was on a long journey of understanding who I am, who God is and why I was created. I constantly asked myself, ‘what is the way to be loving myself and accepted by God.’ That journey took me so long.”

Soon he became involved with the United Nations Interfaith Dialogue Conferences, which provided him an opportunity to interact with people from other faiths and exposed him to different perspectives on life. “It was an open gate for me to study all the different religions,” he said. “Even though I was representing Islam in this work, I was constantly questioning my Muslim faith. It felt good to be able to step out of Islam to see if there was another way to understand God.”

As he began investigating different religions, the opportunity also meant he could explore his sexuality at his own pace. He searched “through the Baha’i faith, then Hinduism, Buddhism, Sikhism and finally Christianity.” After his Christian baptism, he said “I felt unconditional love. I have a relationship with God, and now I can tell everyone everything.”

Sometime during 2014, Yasser experienced the classic symptoms of a seroconversion illness. “I was feeling seriously ill. Sweating, dizziness, coughing.” Looking back, he reflects, “I know now, these are some symptoms of HIV. At that time, I didn’t know anything about HIV or AIDS. We are not educated about HIV in Egypt and I knew no-one with any awareness about it at that time.”

When his brother admitted him to hospital, he was close to death. He says, “The doctor diagnosed me with AIDS and told me, my sister and my brother together at the same moment. The only way to survive was to start medication.” Around this time, Yasser had also taken steps to disclose to family members including his wife, about his diagnosis, his religion conversion to Christianity and his sexual orientation! “My mother eventually could handle knowing I am gay, but she couldn’t handle me becoming Christian!” His wife initially had a similar response. “My wife couldn’t stand the idea that I had come out as Christian. She said, ‘you’re not Muslim and you can’t be living with me.’ So now I had to live by myself.”

In time, her concerns changed from a religious focus to his orientation. “She even started worrying about the impact on my sons. I felt deeply rejected and deeply disrespected by everyone.”

This sense of alienation was compounded at the time by the deep stigma and isolation experienced by the Egyptian community living with HIV. As Yasser recalls, “in all the time I was going to the Ministry of Health to get my medication, there would be around 40 people waiting in a queue, and I knew we were all HIV positive, but no-one talked to each other... Everyone was so closed up and scared in their struggle of accepting and understanding. The feeling of guilt was very strong. I even saw some people I knew, and we didn’t look into each other’s face or eyes. We just pretended like we didn’t know each other.”

In this climate of fear and intolerance, the police caught up with Yasser. “The police arrested me based on carrying Christian books, when I am carrying an ID that shows I am Muslim. As a Muslim-dominated country, it’s almost impossible to change this ID if you choose to follow another faith,” he explained. Technically adherents can’t be punished for being Christian; however, it was at least two weeks before Yasser was declared innocent.





During this time, Yasser experienced violence in prison and was also denied his life-saving HIV medications, which compromised his physical and mental health. His release brought him no peace. “I felt deeply depressed and my mental health was so bad. I went to the church and the pastor said they couldn’t guarantee I was safe from being arrested again. After he said this, he helped me apply for my humanitarian visa.”

Yasser felt encouraged with the speed of this process and care that the Australian Embassy staff demonstrated towards him. As he explained, his application was based on his Christian faith from a Muslim background, yet “the counsellor in the Embassy in the interview asked me directly, ‘are you gay’. I answered, ‘where is this coming from?’ She said, ‘because this persecution is severe and it’s not only because you’re Christian’... This very aware and knowledgeable woman approved my visa, even though the Embassy knew I was living with HIV.”

On arrival in Australia, medical tests showed Yasser’s CD4 count was 16. “I was taken directly to hospital for two weeks and I started a new medication.” With a climbing CD4 and a new lease on life, Yasser found time to reflect on his experiences of loss.

As he said, “Till today, the fact I did not want to leave my dear sons is the main reason of my depression. To come to Australia, I faced a lot of loss. I faced jumping into the unknown. I didn’t know where I am going, where I will live, how I would find work or make money or educate myself.” At the same time, Yasser still aimed to consciously focus on his new reality. “Very quickly I began to understand this is a huge chance and it’s the start of a new life.”

Yasser was particularly encouraged by Australia’s stance on anti-discrimination. He says, “One of the interesting things I remember when I had an introduction session to the Australian culture, the instructor said ‘here the law is above culture and religion.’ That statement made me so happy and I thought, here I can belong.”

“Back in Egypt when I was diagnosed with AIDS, doctors were advising me from a judgemental religious standpoint. They said things like, ‘you must have done something terrible and God is punishing you, so you need to repent and take the medication.’ I found it was definitely different here in Australia.”

As Yasser looks back on his experiences, he says “My journey from that young Egyptian teenager, trying so hard to fit in and be accepted by the Muslim community and Arab culture to who I am today, a proud Christian gay man living with HIV. Studying a Diploma of Counselling and volunteering in many organisations in the HIV sector, I have been on a huge rollercoaster ride.”

“I’ve had a double journey, one out to the world and another inside myself. But finally, my life story is encouraging and inspiring many youngsters here in Australia and also in Egypt, through Facebook and social media.”

“Today I don’t feel I need to ‘fit in with anything’. I am myself, and I love myself. I am a unique person and my pain and sorrow can be directed to serve others.

“No shame, no guilt and no regrets. I AM FREE.”

– Positive Life NSW

If you are living with HIV in NSW, you are eligible for Full Membership and can receive a free copy of Talkabout in the post. Please complete the following Positive Life NSW Membership Form and return it to **Positive Life NSW, PO Box 831, Darlinghurst NSW 1300**



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I wish to become a member of Positive Life NSW and I agree to abide by the Constitution of the Organisation at all times. I am applying for (please tick one box below)

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