

talkabout

Where we speak for ourselves

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

INSIDE

Let's talk about being Bi+!

Vaccine hesitancy

Review: It's a Sin

Spotlight: HIV/AIDS Legal 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.**

Visit us at positivelife.org.au

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Positive Life NSW

talkabout

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Cover photo: Supporter walking with Positive Life NSW in the 2021 Mardi Gras parade, 6 March 2021.

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The voice of all people living with HIV

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

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PRESIDENT

On Saturday 6 March, Positive Life NSW participated in the Mardi Gras Parade under the theme of ‘RISE up to HIV Stigma’ at the SCG. You can read an enthusiastic report from my fellow Board Director, Andy Heslop on page 8 about this year’s entry.

Soon after NSW Health published its new NSW HIV Strategy 2021-2025 late last month, Positive Life began engaging with members and community through a series of community discussion sessions titled ‘Beyond 2021: Ending HIV, Next steps’. Through the first half of 2021, we’ll be examining what the new Strategy means for all people living with HIV in NSW. If you’d like to join any of these sessions, please contact Craig Andrews our Communications Manager on the office number for more details.

On Saturday 10 April, Positive Life Board and staff met at Yaralla House for a BBQ in support of Yaralla’s long-term residents. Yaralla House in Sydney is the only public residential facility that provides high level care and support for people living with HIV and HIV-associated dementia and other neurological conditions. Not only was it great to socialise with Yaralla’s residents but also to show our gratitude to its nursing staff for the work they do.

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

Now that the COVID-19 restrictions in NSW have been eased, Positive Life resumed face to face events, albeit within COVID-safe parameters, which have been enthusiastically embraced by community.

We were pleasantly surprised with the overwhelming response to our first [+Connect] at Camperdown Commons. Places filled within 36 hours. Our [+Connect]OutWest event at Parramatta in April also proved extremely popular with 60 people attending. We expect our next [+Connect] event in Strathfield on Thursday 27 May, and our workshop for heterosexual people on Saturday 05 June will prove as popular, so make sure you are subscribed to receive advance notice.

On page 22, you’ll see an article detailing the Bi+ experience and living with HIV. Positive Life is especially aware of the diverse members of our community who may or may not neatly fit into the common definitions of sexuality, and we continue to advocate on behalf of all people living with HIV. I invite your feedback on how we can do this more effectively.

Free full membership is available to anyone living with HIV in NSW, with an added benefit of receiving Talkabout in the post free-of-charge. As the largest group of people living with HIV in Australia, get involved with Positive Life, share your story in Talkabout, and let us know how you’re getting on.

JANE COSTELLO



TREATMENTS BRIEFS

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

Generic Prescribing Now Mandatory

As of 1 February 2021, the prescriptions you receive from your doctor must list the name of the medication's active ingredient (drug) rather than the brand name.

For example, if you are prescribed Biktarvy®, the antiretroviral (ART) single tablet regimen, depending on the prescribing software that the medical practice uses, the new generic prescribing it can either look like this: "BICTEGRAVIR (AS SODIUM)/EMTRICITABINE/TENOFOVIR ALAFENAMIDE (AS FUMARATE) TABLET 50mg/200mg/25mg" or "Bictegravir 50mg + Emtricitabine 200mg + Tenofovir 25mg Tablets".

With many ART single tablet regimens containing two, three, or even four drugs, there is potential for the incorrect medication to be prescribed by your doctor, or dispensed incorrectly by the pharmacy.

Many of the single tablet regimens have the same two drugs, and only differ with the third drug. Incorrectly choosing from the prescribing or dispensing software can result in the wrong medication being provided.

So, if your medication looks different (different tablet size or colour), please double check with your pharmacy or doctor and confirm that what you have received is correct.

HIV & COVID-19 Vaccines

People living with HIV are included in Phase 1b of the COVID-19 vaccine roll-out, which commenced 22 March 2021. Some of you may have already accessed it through your GP or one of the vaccine hubs.

Common side effects of the vaccines may include injection site reactions (pain, redness, and inflammation) and also fever, fatigue, headaches and muscle or joint pain. These side effects are normal and signs that your immune system is building protection against future exposure to

the COVID-19 virus. For people living with HIV there is no indication of increased adverse effects compared to the general population, and there is not expected to be any interactions between the vaccines and your HIV ART medications.

There has also been no evidence to suggest that people living with HIV who are on effective treatment and have 'normal' CD4 counts (500-1200) have a different response to the COVID-19 vaccines than the general population. There is however the potential for those with low CD4 counts (below 200) to have a reduced immune response to the vaccine. For people living with HIV, COVID-19 vaccines bring the same benefits as they bring to all individuals and communities – that is the prevention of severe disease and death due to SARS-CoV-2, and potentially reduced transmission of the virus.

Even though I encourage everyone that can be, to get vaccinated, I understand that people have concerns, especially with recent reports of unusual blood clots with the AstraZeneca Oxford vaccine.

It is important to state that it is an individual decision to be vaccinated and you need to be 100% comfortable with the decision you make. Please ask your health care practitioners any questions you may have, as they will have the most up to date advice on the vaccines and the roll out.

CROI 2021 Highlights

The Conference on Retroviruses and Opportunistic Infections (CROI) is an annual scientific meeting devoted to the understanding, prevention and treatment of HIV/AIDS and the opportunistic infections associated with AIDS.

Once again this year, there was so much info at CROI, but my personal highlights were the following two items.

unusual risks

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

Stigma and discrimination free

unusualrisks.com.au



Continued safety data about the use of dolutegravir in pregnancy

Back in 2018, the Tsepamo Study (a large observational study of pregnant women in Botswana), reported concerning results that indicated that exposure to *dolutegravir* during conception or during the first trimester was associated with a higher risk of neural tube defects in infants. The risk was 0.94% for *dolutegravir* (4 out of 426 births) compared to non-*dolutegravir* regimens at 0.12% (14 out of 11,300 births) and 0.09% for HIV negative women (61 out of 66,057 births).

During 2019 more data emerged, which reported only one additional neural tube defect (in total now 5 out of 1693). This lowered the risk from 0.94% to 0.30%, and later in 2020, further analysis of the latest data showed the risk had reduced to 0.19%.

At CROI 2021 new data also showed that in pregnancy, *dolutegravir* based regimens were superior to *efavirenz* based regimens in terms of maintaining viral suppression.

They were also better tolerated with fewer discontinuations, and importantly lower infant mortality. It is reassuring that the new data shows the risk of neural tube defects has stabilised at around 0.2% pregnancies. Women living with HIV wishing to conceive should be provided with this information and discuss their available options with their HIV specialist.

Injectables for HIV

Many studies were presented on injectables for HIV treatment (and also for prevention). These include the latest data on *cabotegravir/rilpivirine* (ViiV/Janssen)

which should be available in Australia by the end of the year. It is currently approved in North America and Europe with a four-week dosing schedule, and in Europe also at an eight-week dosing schedule. Both schedules appear to be equally effective, with more than 90% of participants in the ATLAS and ATLAS-2M trials having an undetectable viral load at 96 weeks. Both regimens require an initial 2 to 4 weeks of oral tablets to ensure that both drugs are well tolerated.

The important point to stress with the *cabotegravir/rilpivirine* injectable, is that they require a commitment from the individual to attend regular appointments, every 4 or 8 weeks - which may be more frequently than they are now. Injection site reactions were the most common adverse effect in up to 20% of people, which is not surprising as the regimen consists of two intramuscular injections (in the buttocks).

Looking further into the future, a six-monthly injectable may be possible pairing *lenacapavir*, a Capsid Inhibitor (Gilead) with *islatravir*, a Nucleoside Reverse Transcriptase Translocation Inhibitor (Merck Sharp & Dohme - MSD). Both of these drugs are likely to be the first of their class to be approved.

Both drugs have performed well in studies, and *lenacapavir* has also shown to be effective against multi-drug resistant HIV and may be a useful option in heavily treatment experienced patients. Post CROI, Gilead and MSD announced a collaboration to develop this combination as a long-acting treatment option.

– Bruce Hamish Bowden
Clinical Pharmacist (HIV)

2021 Sydney Candlelight Memorial

Positive Life NSW will once again be hosting the Sydney Candlelight Memorial to reflect on and remember our loved ones, friends and family who have passed away from HIV/AIDS in partnership with ACON.

**Sunday 16 May 2021
3pm to 4pm**

**Eternity Playhouse
39 Burton Street
Darlinghurst NSW**

For RSVP or to submit names to be read out at the service, call Craig on (02) 9206 2177, 1800 245 677 or contact@positivelife.org.au



POSITIVE LIFE MARDI GRAS REFLECTIONS

The amazing tour-de-force spectacle organised by Sydney Gay and Lesbian Mardi Gras (SGLMG) was a stunning contrast to the year just past. Fears of a wash-out, and doubts and anxieties about the move from street parade to stadium were solidly trounced by what I can only describe as a thrilling queer-spectacular that showcased the immense talent and creativity of our communities.

If anything could beat the thrill of turning onto Oxford Street at the start of the parade, then it was the thousands of cheering audience members as we marched through the players tunnel on to the SCG, a moment both overwhelming and transformative.

I felt a profound sense of pride that Sydney, and specifically our communities could turn a year of despair into hope, change pandemic into pageant and put on a stonkingly good stadium party. The common ground between parade and stadium was that our community still managed to deliver the biting satirical floats that skewer our politicians; something for which Mardi Gras has become world renowned.

“This joyous and outrageous festive parade was a breathtaking celebration of life as people living with HIV.”

While this was very much a show in the SCG, it was *our* theatre. This was the difference between the Oxford Street parade and the ticketed event at the SCG. This year’s parade was less the symbolic protest platform and much more the physical stage for community organisations.

Year on year, Positive Life NSW proudly represents our friends, lovers and partners in the Body Positive by our presence in the Mardi Gras parade. Despite the pandemic, this year we felt more compelled than ever to participate in the parade. As the largest organisation of people living with HIV across Australia right here in NSW, we excitedly entered another parade as an enthusiastic opportunity to remind the broader community that HIV is everyone’s business.

Mardi Gras’ theme for this parade was **Rise** – a symbolic gesture perhaps to the phoenix rising from the ashes of a world turned upside down by a stream of emergencies. For our parade entry this year, Positive Life chose to **Rise Up** to challenge the stigma of HIV, to rise up and thrive, proving to our communities around the world and to ourselves, that as people living with HIV, we can strive forward as the vanguard of transformative change for all people living with HIV in NSW.

Positive Life did indeed rise to the challenge of creating something special for the parade above and beyond our usual annual participation. Our showstopper entry was passionately brought to life with the tireless help of many Positive Life volunteers and staff in the month leading up to the event. This year I was proud to participate in both the planning of the Positive Life presence and the parade itself.

We created huge 3metre x 2metre wings at the Mardi Gras Parade Workshop, to represent our community rising up, in the Positive Life new branding and colours. It was a true Mardi Gras representation of over-the-top pageantry which we combined with an old-school protest complete with placards to challenge the conventional thoughts on HIV such as *We rise up to defeat HIV*, *Positive people Rise Up*, and *Living with HIV and we rise*.

Others in our 40 strong group carried red ribbons above their heads, symbolic of the community we represent, and in memorial of those who were with us only in spirit. Our orange t-shirts were emblazoned with the defiantly uplifting message *We rise* and we wore Aboriginal themed COVID-safe masks made by an Aboriginal community member.

It was the time to celebrate the many sacrifices we as a community have made, particularly in the face of a pandemic which has ripped apart our social fabric. This joyous and outrageous festive parade was a breathtaking celebration of life, and ourselves as people living with HIV, vigorous and jubilant.

Congratulations to Positive Life NSW for a wildly successful parade entry and message, to the other community floats and parade entries, and the tireless efforts by SGLMG who managed to pull off an absolute triumph.

– Andrew Heslop



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.

Positive Life & Pozhet Heterosexual Workshop

This year on Saturday 5 June, Positive Life will be running a full day peer-led workshop for people living with HIV who identify as heterosexual, in partnership with Pozhet.

The interactive workshop will provide participants with the opportunities to connect with others also living with HIV, share their stories and lived experiences, and provide them with the support and up-to-date information, details of available activities, and referral services they need.

RSVPs will be essential, and to get involved and catch up on the latest news we recommend you call the office to claim your place as soon as possible!

National Day of Women Living with HIV

On Tuesday 9 March, Positive Life celebrated the lives of women living with HIV in Australia by holding an elegant afternoon high tea, which included an assortment of sweets and treats, and Devonshire teas along with 60 attendees in a COVID-safe arrangement.

The theme for this year's celebration was 'Taking control of our health' and aimed to encourage women living with HIV to ensure our own health is a priority and to remind us to have those all-important discussions with our specialists. After a year of dealing with COVID-19, many women living with HIV have postponed some of our usual regular tests, such as blood pressure and breast checks, cervical screening and initiating a sexual

health screen as part of our routine health check. It also aims to spread awareness about conditions that women living with HIV are statistically at a higher risk of developing, such as human papillomavirus (HPV)-related cancers, including anal and cervical cancer.

Aged Services Industry Training Products

Positive Life has responded to a consultation conducted by the Aged Services Industry Reference Committee (IRC) to provide input and feedback into Training Package Products, which include the qualifications and units of competency that provide the skills and knowledge for workers who may work in a residential or community care setting with clients who require personalised support due to ageing, disability, or other reasons.

Positive Life offered comments based on community concerns about the state of the aged care system in Australia as well as people who are living with disability and/or require individual support. Positive Life's comments can be read in our March submission "*Submission into Draft 1 of Certificate III in Individual Support, Certificate IV in Ageing Support, and Certificate IV in Disability Support Released for Consultation*". If you want a copy of the submission, please contact the office.

Reaching beyond 2021

In late March, Positive Life congratulated the NSW Ministry of Health on the release of the next NSW HIV Strategy 2021-2025. As a demonstrated world leader in the

response to the HIV/AIDS epidemic from its earliest days, NSW Health continues to build on the successes of the previous two Strategies.

As people living with HIV, we were pleased to see the acknowledgement from the NSW Chief Health Officer Dr Kerry Chant in recognising the exceptional partnership between people living with HIV, clinicians, general practice, researchers and communities at risk in NSW to maintain the momentum of striving toward the ambitious goal of virtual elimination of HIV transmission for all in NSW.

For the first time we see a fourth pillar of reducing stigma and discrimination positioned alongside the vital pillars of prevention, testing, and treatment. Positive Life is encouraged by this inclusion and recognition of the risk, impact, and barriers that stigma and discrimination poses for people living with HIV, and the general public when accessing HIV testing, treatment, and HIV prevention.

Throughout the first half of 2021, Positive Life NSW will be facilitating a series of community discussion and consultation sessions titled 'Beyond 2021: Ending HIV, Next Steps' to discuss and examine what the new Strategy means for all people living with HIV in NSW. The first of these sessions, held on Thursday 18 March in Camperdown, received a packed house of 60 attendees in a COVID-safe arrangement.

Please call the office to find out details of upcoming sessions in Austinmer and Liverpool, NSW.



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.

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.

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Please specify if you want your details withheld from publication.

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editor@positivelife.org.au or

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Darlinghurst NSW 1300

Calendar

COMMUNITY

2021 candlelight memorial

A time to remember our friends and family who we have lost to HIV/AIDS as we show our support of people living with HIV.

SUNDAY
16 May 2021

The Eternity Playhouse
39 Burton Street, Darlinghurst NSW
3pm to 4pm

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.

May and June 2021
6pm to 9pm

[+connect]

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

THURSDAY
27 May 2021
7pm 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
6 May and 3 June 2021
6pm to 7.30pm

[+connect]OutWest

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

SUNDAY
20 June 2021
12Noon to 3pm

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
24 June 2021
6pm to 8.30pm

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



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

Positive Life NSW

Ageing Support



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

Contact Positive Life NSW on (02) 9206 2177 or 1800 245 677 (freecall)



IT'S A SIN

It's 1981, the start of a new decade and Ritchie, Roscoe and Colin begin a new life in London. But a new virus is on the rise, and soon their lives will be tested in ways they never imagined.

When I first heard about *It's a Sin*, my initial thoughts were great; this looks like a lot of fun. Rollicking Gay London in the 80's, what's not to love? I knew there would be some references to HIV/AIDS and I thought I had prepared myself for any 'trigger' moments.

So, here I am at home, logged in to STAN and emotionally prepared ready to watch the first episode. Five hours and at least one box of tissues later, I found myself emotionally exhausted and yet exhilarated at the same time. I'd binge-watched the complete series!

Watching *It's a Sin*, reminded me of the first time I had heard of this mysterious cancer-like disease that there was no cure for and that no-one really seemed to understand. I was a teenager in the mid 80's at the time. I remember watching a 60 Minutes report by the BBC on Channel 9 and thinking how sad it was for these poor guys lying and dying alone in hospital wards and not even knowing what was wrong with them.

God! I thought, 'I hope I don't catch it!'

The trigger moments in *It's a Sin* hit me by surprise. Those triggers for the most part were negative. The sudden disappearances of friends from the 'scene'; the isolation positive people endured; the uncertainty of what was happening; the fear of dying; the hate and discrimination of this era from not only the world at large, but our own community; families denying their own children; the lack of dignity, the list goes on...

These triggers reminded me of the fear we all had of HIV/AIDS back in the 80's. It was not only the fear, but the disgust and stigma that came with it.

We all had friends who had died or were dying and we loved them and did what we could to support them. At the same time, we were also secretly glad it was not us, but them. Keeping someone's sero-status (and orientation) a secret back then, was just something we automatically did. We did this not only for the sake of our friends, but more self-protectively, because we didn't want to be associated with someone who had this disease.

God forbid, people thought we also had it!

I found myself wondering were we truly that self-centered and selfish? Was I? For my part, I have to admit, yes I was. I was motivated by my own self-survival.

It was seeing this kind of stigma and discrimination on the big screen that brought all of these memories and feelings back to me. The shame I felt for my younger self felt devastating.

Many of those triggers were also positive ones. I was reminded of the mothers and straight women, and in particular the lesbian community, who showed more compassion to our community than we did ourselves; the protests in the streets, the FIGHT that was eventually taken up across the world to combat this hideous disease; the love of our chosen families who sometimes were the only support that was available to us at the time.

If I was to choose one word to sum up my feelings after watching *It's a Sin*, it would be *Bittersweet*.

I feel bitter, that HIV/AIDS in the 80's happened the way it did. *Bitter* for those people who lost loved ones or those of our communities that didn't survive this epidemic and *Sweet*, because we have come such a long way since then.

Today we have good meds, we have PrEP, we have U=U, we have advocacy and we have much more community and peer support than ever before! There is still a long way to go in the fight against HIV/AIDS and *It's a Sin* certainly re-ignited my passion to do more.

Let's face it, even with all of the positive outcomes for people living with HIV these days, there is still a long way to go. Our fight is not over.

Did Russell T. Davies get it all right? Probably not.

Could some things have been done better? Maybe.

Did I love it and get value from it? Absolutely.

Would I recommend it to people? 100%.

If, for nothing else than the amazing soundtrack.

– Matt Cater

**God! I thought,
I hope I don't catch it!**

A GARDEN OF ONE'S OWN

SMALL PLEASURES

A place where people living with HIV long term share our realities and experiences.

“Life begins the day you start a garden” - Old Chinese Proverb.

My life has gone through many changes since COVID-19 came down upon us, not least being that my usual routines have been thrown into upheaval. The occasional lockdowns have also meant that many of the daily activities that were part of my life were put on hold, possibly indefinitely.

Yet, I have adapted to this new world. I have time to read a lot more, and became almost an addict to my local library's 'Click and Collect' way of getting new books. I learned new recipes, although not all of them were a success, and my local DVD shop saw me a lot more often. I watched and waited for vaccines to appear, and at last, they have, although I still haven't received my shots.

One continuing pleasure for me has been my garden, and small pleasures are a way of helping to survive in these trying times.

Gardens have long played an important role in bringing peace and happiness to humankind. Some are famous: the *Versailles Gardens* in France, the *Imperial Palace Gardens* in Tokyo, the *White House Rose Garden* in the USA, and our own *Botanical Gardens* in Sydney, all places of quiet and tranquility. Even history and mythology bring us gardens, everything from the *Hanging Gardens of Babylon* to probably the one we have heard most about, the *Garden of Eden*, from whence we are all supposed to have sprung.

So every morning when I wake up, I make a pot of tea, and then, cup in hand, I stroll out onto my balcony where I gaze around at the profusion of plants that welcome me. I wander around my garden; I see what new buds have opened, what needs pruning, what needs water, and wonder where the hell did those weeds come from!

Some of the plants I have had for decades. When I moved into my apartment about fourteen years ago, I needed two removalist's vans; one for my furniture and other effects, the other for my garden, all in pots. Still it was worth it – familiar souls travelling through life with me.

Variety is said to be 'the spice of life', and so I have a crimson flowering bougainvillea, two frangipani (one pink, one white), some tree ferns, a couple of bamboos (including a sacred bamboo), different-coloured geraniums, various succulents, a few dracaena, and a variety of lilies.

I also have native plants – some Bottlebrush, a few Grevilleas, a Strelitzia, and some Kangaroo Paws – and while the bees enjoy collecting their pollen, some of the flowering plants

also attract birds, and so I have constant visitors – mainly chattering lorikeets, often some noisy cockatoos, a magpie or two, and the occasional kookaburra.

I also have a fishpond, of sorts. It is very large ornamental Chinese pot, one I think they advertised as being for pidàn - 'thousand year old eggs' (although why anyone would want eggs that are 'a thousand years old' is beyond me). Some papyrus and duckweed grow there, and fishes and snails live their placid lives below the surface.

Sunny days are best, but even on miserable drizzly days there is always something to notice, to appreciate. And the garden changes its character during the different seasons.

After the heat of summer, some plants shed their leaves, others seem to shrink into themselves, while others slumber, awaiting the warmth of spring when suddenly everything seems to come to life again.

It would be hard not to enjoy, what a generous nature has given me. Eventually, at peace with the world, I go back indoors, and face a new day.

So, for me, during these COVID times, my garden has been like a Garden of Eden. Unlike the original Garden though, there are no snakes waiting to tempt me, although slugs and aphids give me a bad time, and I have the products to keep them under control. Well, mostly.

But, like the first Garden of Eden, when my boyfriend wakes up and comes out, we have a place where we can play at being Adam and Steve.

– Garry Wotherspoon





VACCINE HESITANCY

As a scientist and researcher in public health engaged with colleagues in the area of HIV, I thank our lucky stars for the concerted public health response that has allowed Australia to make it through 2020 relatively unscathed compared to the rest of the world.

The challenges that define us in an era of hope

The end of 2020 saw much hope and promise as news of effective vaccines started taking airtime from the usual doom and gloom of the COVID-19 pandemic.

Yet, here's the thing...while many people felt hope because they understood and/or trusted the science and the regulatory processes involved in rolling out vaccines, many others unfortunately did not. Recently, I've been part of a group of Canadian volunteer pharmacists, GPs, and scientists who offer jargon-free explanations and information to people who are anxious, hesitant or simply curious about vaccines.

For far too many people, the vaccines brought, and continue to bring, fresh anxieties. Many feared that the COVID-19 vaccines may be forced upon them.

We've all seen and read media articles that followed shortly after the news of the vaccine rollout which showed a nurse fainting (with no fault of the vaccine contents itself) after their shot, and articles that falsely linked deaths to vaccines.

Many of us have noticed the click-bait media reporting in our social media feeds of people contracting COVID-19 shortly after the vaccine, the fake articles of vaccines laced with tracking chips, and the false idea that vaccines are untrustworthy and skipped safety steps because they were made available in about a year.

These articles have meant that public health workers have had to fight two wars - the COVID-19 virus and the COVID-19 misinformation pandemic (infodemic). The misinformation and irresponsible click-bait headlines have unfortunately fueled vaccine hesitancy driving many vulnerable people into further vulnerability. For many countries around the world with high levels of community transmission, vaccine hesitancy has meant increased deaths among vulnerable and marginalised communities and also among those who have gravely misjudged their own vulnerability.

Fortunately for us in Australia, our stringent biosecurity laws, border shuts downs, and our hotel quarantine systems have meant that people who are vaccine hesitant will have some time to make their decision (thanking our lucky stars again).

To ease your mind...

#ThisIsOurShot has been a popular hashtag that healthcare workers around the world have been using to make their vaccine selfies accessible. We've noticed that these healthcare worker vaccine selfies have done wonders for people who are anxious about getting the vaccines.

Keep in mind, everything that happened in the past such as heart attacks, pregnancies, miscarriages etc. will continue to happen at the same rate that they did before COVID-19.

What is going to be a little different is that hundreds of millions of vaccines will be rolling out at the same time. So when the next click-bait headline pops up in your newsfeed with a condition 'linked' to the vaccine, it's important to remember that coincidence doesn't mean that the vaccine caused a particular condition.

Every adverse event after vaccination is reported by people like you and I, and thoroughly investigated to find out if they're directly linked to the vaccine. This is referred to as *pharmacovigilance* and for us Aussies it can be reported on this website or via your health care provider: www.tga.gov.au/reporting-suspected-side-effects-associated-covid-19-vaccine

This aspect of vigilance is built into all approved products so our public health officials are able to do their jobs of protecting us and alerting us of any issues that may arise really well (no click-baits here again!).

It is this pharmacovigilance that has allowed swift action and change in guidelines following reports of a rare (approximately 6.5 events per million doses according to the European Medicines Agency) but serious clotting event associated with the AstraZeneca vaccine. Pharmacovigilance also ensured that health care providers now know what to look out for and have access to appropriate treatment guidelines for this specific type of clot. For a lot of us, the news of the serious clotting events fed into hesitancy. However, it's important to

acknowledge this as a testament to how seriously our public health system takes our safety, *even* with such rare events, and how transparently the risks are communicated to us.

On a personal note...

I strongly emphasise the choice to get vaccinated is yours and yours alone. No health care worker with an ethical bone in their body would ever administer a vaccine without your consent.

Informed consent means being open and honest about what we don't know, and also understanding what the (very real) risks are of not getting vaccinated.

If you are hesitant about the COVID-19 vaccine for whatever reason, if you're feeling anxious, if you're feeling unsure about making a decision to get the vaccine, please reach out to your health care provider and talk to them about your vaccine concerns. It is your right to want to know more about the vaccines. It is your right to ask questions and it is your right to feel comfortable with the decisions that affect your health.

Your health care providers are best placed to articulate the risks of COVID-19 as they relate to your age, work, and any comorbidities that you have and are able to talk through the vaccine science and data. They will also be able to explain what we know because of the very generous people living with HIV who volunteered to participate in vaccine trials.

These conversations are also a great place for you to clarify any concerns you may have and receive factual verified information (no click-baits here!).

Despite these conversations, if you still decide that vaccines aren't for you, your decision to not get vaccinated today, doesn't have to be your decision tomorrow. It's important to keep a conversation going with your healthcare provider.

If you'd like to do your own research, you can safely learn more from the NSW Health website for trusted information. www.health.nsw.gov.au/Infectious/covid-19/vaccine/Pages/default.aspx

Other trusted sources of information include the Australian government health page: www.health.gov.au/initiatives-and-programs/covid-19-vaccines. Other reliable sources include the Centre for Disease Control (the CDC) which is US-based, and the World Health Organisation (WHO) based in Europe.

As many people around the world are getting vaccinated including many of your peers living with HIV, I sincerely hope at some point you will share the same joy and relief that I felt in December 2020.

Be safe my friends.

- Dr Prital Patel

WORKING FOR ME

A place to showcase our sector partners who benefit the lives of **all people living with HIV**

The HIV/AIDS Legal Centre (HALC) was formally established in 1992 after the ACON Legal Working Group and the AFAO Legal Project amalgamated.

HALC has grown from a team of two employed solicitors and volunteer solicitors and paralegals to currently employing six solicitors and a paralegal. We continue to rely heavily on our team of volunteers to be able to meet demand.

As well as assisting clients, HALC has always run community legal education programs to inform service providers, health care workers, and the general population of the legal issues people living with HIV face. We also work closely with other organisations, and ensure our clients are referred to the medical, housing, case management, and counselling services they need.

HALC has seen a change in legal issues from our origins in the 1990s through to now. At the time HALC was established, the life expectancy of a person diagnosed with HIV was significantly lower than today, and our focus was on assisting clients with end of life planning including drafting Wills, Power of Attorney and Enduring Guardianship documents, and also assisting clients accessing superannuation to make their final years more comfortable.

In 2001, 20% of our files were Wills and Estates matters. This has halved to only 10% in 2021. During our early days, HALC was running hospital outreach programs at Sacred Heart Hospice and St Vincent's Hospital for clients who were terminally ill and required urgent assistance in drafting their Will. For many of the gay men we assisted at this time, we provided specific advice on making provisions for same-sex de facto partners.

We are rarely called for an urgent Will requiring a hospital visit nowadays. We still assist in end of life planning for clients, but it is generally for clients who are planning for their longer-term future.

As antiretroviral (ARV) treatment progressed in the 1990s, our assistance in Superannuation and Disability Support Pension (DSP) applications declined dramatically as people remained employed following diagnosis, and doctors no longer advised patients that they should stop work following diagnosis. Discrimination in provision of services, health care, and employment based on a person's HIV status have always been an area we assist in and we will continue to do so in the future.

Today a significant portion of our work is immigration due to the Australian Government's health criteria for visas. Our work in immigration has grown exponentially from only 9% in 2000 to 57% of files in 2021. This is partly attributable to the change in health criteria and policy in 2009/2010 which increased visa options available for people living with HIV.

We have also seen a change in our client's demographics since the 1990s and are now assisting more culturally and linguistically diverse clients than in earlier years.

In Australia only 12% of people living with HIV are women, but at HALC 20% of our clients are women, and have been consistently since our service first started. This is because women have specific vulnerabilities and their circumstances are often made more complex because of factors such as domestic violence, societal pressures, and motherhood.

One of these clients was Suzie*. Suzie is from Uganda, she is a Finance Manager and was sponsored by an employer on a temporary work visa in 2013, and living in regional NSW with her Australian partner.

When she found out she was expecting a baby, routine prenatal testing showed that she was HIV positive. Her partner then left her and said he wanted nothing to do with the baby.

Distressed, Suzie confided in her close friend and work colleague.

Her friend said that they didn't want to be anywhere near her, they told her that she had better terminate her pregnancy as they incorrectly assumed the baby would be born with HIV, and then the friend told everyone in the work place about her HIV diagnosis.

She was treated terribly at work, and even though Suzie worked well, the employer refused to sponsor her for a permanent skilled visa, despite prior indications of their intention to sponsor her.

Suzie was terrified to return to Uganda, she had watched others in her community die from AIDS, including her brother. She didn't want to leave her baby in Australia without a mother.

Suzie called HALC and she asked for help – three years later, she was granted permanent residency through a complex Ministerial Intervention process. HALC also then assisted



her to bring her 12 year old daughter to Australia. Here is what Suzie has to say about the help she received from HALC:

I was introduced to HALC by one of the doctors at the clinic where I was receiving treatment as I needed assistance with a migration matter and a discrimination matter. I could not have afforded to pay a private lawyer. I called the legal centre I spoke to a lady and she said I could call her in case I needed someone to talk to. I had so many things to ask and every time she researched and gave me all the help I needed.

I grew up with a lawyer as a father and it was about winning and the money after that. I never once heard him talk about his clients and see him care. The HALC lawyers are true

heroes to so many who will not want to write in for fear of being exposed. But we could be many saying the same things about all of them. For me, I know that my future is bright because I got help when I was about to give up. HALC stood by me and showed me the possibilities. I'm here and strong because my lawyer gave her time, worked beyond her duties and supported me. My kids will always be grateful because today they could have no mother if she had not heard that phone and said the words that she said.

- Danielle & Niamh

*names of clients have been changed to respect and protect their confidentiality.

LET'S TALK ABOUT... being bi+!

March was Bi+ Health Month, which helped to draw attention to the unique experiences of the bi+ community and how these experiences affect our health.

This month also provided an opportunity to highlight the inequalities faced by this large and often-erased group of people, some of whom also live with HIV.

Bi+ is an umbrella term for personal identities that recognise the potential for attraction, romantically and/or sexually, to people of multiple genders. This might not necessarily be at the same time, not necessarily in the same way, and not necessarily to the same degree. The bi+ umbrella includes the sexual orientation labels of bisexuality, pansexuality, heteroflexibility, homoflexibility, and other sexual orientation labels. This umbrella term stands in contrast to monosexuality, such as homosexuality and heterosexuality which involves the attraction, romantically and/or sexually, to people of a single gender.

Visibility of bi+ people is important. Coming out as bi+ these days is still seen as something scandalous! We saw it on our television screens recently on *Married at First Sight*, we see it on our social media feeds, and you probably know more than a few people who are bi+ (whether or not they have come out).

For myself, coming out as bi was simply my way of putting out a singles ad. After having identified with the label 'gay' for most of my adult life, I thought it was important that my potential partners knew that I was attracted to multiple genders, and no longer identified as 'gay'.

Unexpectedly, the reactions I had from some parts of the community were mockery, disbelief, ignorance, and outright prejudice. I was dumbfounded by these responses but over time, I came to learn this is unfortunately the norm.

These distinctions are important to make and clarify. It's only by understanding the nuances of this human experience and fleshing them out, that we start to see the biphobia that is often driving these responses. *Biphobia is the prejudice and discrimination against multi-gender attraction and people attracted to multiple genders.*

Biphobia manifests itself in many ways. Bi men are often accused of being 'vectors of disease' especially in regard to introducing sexually transmitted infections (STIs) including HIV into the heterosexual community.

Biphobia is often expressed in dangerously common stereotypes about the bi+ community. Namely that we are promiscuous, confused, attention-seekers, or all of the above. The depth of biphobia runs from a macro level across society to personal levels of internalised biphobia where we minimise our own experiences and then externalise our own internal pain.

Sometimes this is externalised in self-harming ways, other times in ways that harm our loved ones, partners, friends and family. You can see how biphobia can emerge in a range of negative health issues in the bi+ community.


Another common form of biphobia is bi-erasure, this involves the invalidation and exclusion of the bi+ experience. It's easy to see how this becomes a problem in a health setting. When our healthcare providers either ignore our bi+ identity and practices, or we have no opportunity to disclose that we are bi+, or feel we would receive some kind of judgement of our identity, our full experience, health risks and health needs are unmet. Even today, we don't know how many bi+ people are living with HIV because this identity isn't sought out or acknowledged in our surveillance data.

Many people in the bi+ community also have intersectionalities with other parts of our lives, identities or experiences. These can include cultural intersections, gender, language, and disability to name a few. While these make our community incredibly diverse and rich, intersectionality also highlights the complexity of the bi+ community.

One of the biggest barriers to addressing these issues is the lack of research on or involving bi+ people. We are often merged or jumbled into other groups in a research setting. We recognise that most of the information we can glean about bi+ people living with HIV comes from bi+ men living with HIV.

A recently released paper from Associate Professor Jennifer Power explores the experiences of Australian

...what does it take for a bi+ person living with HIV to feel comfortable to talk about our lived experience..”



bi men living with HIV and we can now point to data that shows that bi men experience higher levels of internalised HIV-stigma and poorer emotional wellbeing than gay men, and significantly less connection with other people living with HIV and less connection with LGBTQ communities. While we suspect the situation for bi+ women living with HIV and bi+ trans and gender diverse people living with HIV is almost certainly as concerning, this lack of knowledge highlights the significant gaps in research on bi+ people.

In the next few editions of Talkabout, I hope to unpack a little more about the bi+ experience and about how we can make our society a little safer for bi+ people, to feel more confident to be ourselves, especially bi+ people who are living with HIV.

What does it take for a bi+ person living with HIV to feel comfortable to talk about our lived experience, especially with our healthcare providers? How can we support each other, straight, gay, or bi+, and challenge stigma and discrimination including phobia in all forms and perhaps even validate bi+ attraction as a real, healthy, and extremely common sexuality orientation?

Let's start to talk about bi+ experiences and perhaps we'll find our commonalities, unpack some shared experiences and make our communities more inclusive for all of us who are living with HIV.

– Steve Spencer

CELEBRATE! WOMEN LIVING WITH HIV

The National Day of Women Living with HIV is held annually on the 9th of March. This is a celebration of the lives of women living with HIV in Australia.

All women from around the country are invited to celebrate the day by holding a special event. This day not only establishes and maintains connections with other women living with HIV, but also raises awareness that HIV can affect all women within the broader community as well. It is an opportunity to highlight conversation topics that relate to our lives and initiate discussion surrounding our needs and how we might be best supported to create better health outcomes for women living with HIV and achieve a good quality of life.

The theme for this year's celebration was 'Taking control of our health'. This theme aims to encourage women living with HIV to ensure our own health is a priority and to remind us to have those all-important discussions with our specialists.

After a year of dealing with COVID-19, many of us have postponed some of our regular tests we would have had with our doctors, such as blood pressure and breast checks, cervical screening and initiating health screen as part of our routine health check. It also aims to spread awareness about conditions that women living with HIV are statistically at a higher risk of developing, such as human papillomavirus-(HPV) related cancers, including anal and cervical cancer.

Positive Life celebrated the National Day of Women Living with HIV by holding an elegant afternoon high tea, which included an assortment of sweets and treats, and Devonshire teas.

Several speakers attended the High Tea:

Jane Costello, Positive Life CEO opened the event and invited Michelle Tobin, Positive Life Aboriginal Health Program Officer and proud Aboriginal woman of the Yorta

Yorta Nation who has lived with HIV since 1990, to deliver an Acknowledgement of Country.

Jane introduced Associate Professor Kathy Petoumenos from the Kirby Institute next, who gave us some valuable insights into the paucity of research about women and highlighted the importance of doing co-designed research for women living with HIV.

Kathy explained a new research study, the Cohort of australian hIv wOmen or CLIO study, that is currently being undertaken to gain insight and a greater understanding of how HIV affects women's bodies. It is important for women living with HIV to participate and have our lived experiences included in studies to ensure our voices are heard and respected in the HIV response.

The next part of the presentation included a viewing of the Gilead video HIV – Just a part of Me which was produced in partnership between Gilead, the National Association of People living with HIV Australia, and Positive Life NSW.

The three women living with HIV who spoke at today's event, Jane Costello, Michelle Tobin, and Natasha Io were all featured in this short video. They each recounted their inspiring stories and lived experiences to camera as an artist created artworks, while listening to each speak. Their strength and resilience shone through, and their words were an inspiration to everyone in the room.

Our final presenter Natasha, who is a Positive Life Board member and Positive Speaker Bureau (PSB) speaker, touched on her video and shared some moving experiences and insights from her own journey living with HIV.

It was an enjoyable afternoon with women catching up with old friends and making new ones, and we will look forward to meeting together again next year.

– Kim



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**

Positive Life NSW Membership Application Form

The voice of all people living with HIV

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)

FULL Membership

I am 18 years or over, and a NSW resident living with HIV.
As a person living with HIV, I understand that I am entitled to full voting rights.

ASSOCIATE Membership

I am a NSW resident affected by HIV, i.e. a partner, family member, carer, healthcare worker/ or under the age of 18 years living with HIV (subject to the consent, where appropriate, of his or her parent or guardian), and resides inside or outside New South Wales.

I consent to receive information from Positive Life: (please tick one box below)

- By post only** (in a plain unidentified envelope – postal address is below)
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Signature _____

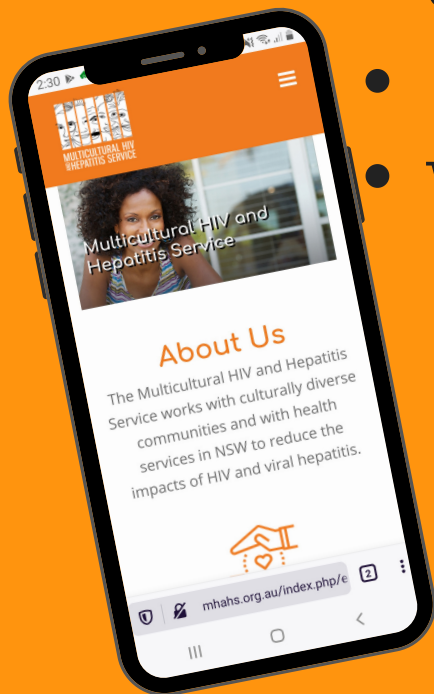
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Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and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

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