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# POZLITE

The best of 2018

**A COMPILATION OF THE YEAR'S  
MOST POPULAR ARTICLES**

*Invisible women living with HIV*

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*HIV stigma: The social disease pandemic*

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*Is it time for a medication review?*

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It's with great pleasure that we present the fourth edition of PozLite as we head into the 2019 Mardi Gras celebrations.

This year we're making 'HIV Noise' with our strong and powerful voices, as people living with HIV (PLHIV). As 2019 begins, the diversity of our voices needs to be heard more than ever with no one being left behind or silenced. Out and proud, shouting it from the streets, shouting it from the roof tops. HIV affects us all, from all walks of life, no matter what age, gender or sexuality we identify with.

This PozLite carries the most popular stories of 2018 and highlights the very real effects of HIV stigma and discrimination within our communities, within our everyday lives. HIV stigma and discrimination negatively impact on our right to knowledge, agency and choice about our health. Our health outcomes, quality of life and life expectancy are on par with the general community, provided we know our status, start treatments sooner rather than later, and remain engaged in our own health and with the health system.

Even so, the burden of unjust HIV stigma and discrimination can act as barriers in our access to adequate health services, testing and treatment

adherence as well as our quality of life. Our voices must continue to raise awareness of the intersections of racism, sexism, homophobia and silencing of trans and gender diverse PLHIV, all of which can double the effects of discrimination for us.

In this edition of PozLite, we also address a range of health options available today for PLHIV, including combination complimentary treatments, medication reviews, drug/drug interactions, phylogenetics, treatment as prevention (TasP), as well as considerations of HPV vaccination and Digital Ano-Rectal Examination (DARE).

We sincerely hope you enjoy this edition of PozLite and look forward to hearing more of your strength and rich diversity and lived experience of HIV throughout 2019. We'd like to thank all the PLHIV that have shared their stories and contributed to the 2019 PozLite edition.

For now we wish you all a happy and safe Mardi Gras!

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**CRAIG COOPER**

*CEO, Positive Life NSW*

**ROBERT AGATI**

*President, Positive Life NSW*

# CONTENTS

---

## **HIV STIGMA**

The social disease pandemic

---

## **HIV IS NO BARRIER**

to love or lust

---

## **HIV TESTING:**

Is for everyone

---

## **(IN)VISIBLE WOMEN LIVING WITH HIV**

National Day of Women Living with  
HIV Australia 2018

---

## **WHY HOOK-UPS = CHECKUPS!**

---

## **TasP**

The unspoken game changer

---

## **ON BEING TRANS AND POZ**

---

## **HIV CURE FOR HELP OR HARM**

---

## **PHYLO-WHAT?**

---

## **SWITCHING IT UP**

Is it time for a medication review?

---

## **PSB SPEAKERS**

Out loud & proud

---

## **HPV & ME**

Vaccinate or not to vaccinate?

---

## **POLYPHARMACY, DRUG INTERACTIONS**

... WTF?

---

## **BREAKING DOWN STIGMA**

one barrier at a time

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# HIV STIGMA



Treating someone differently based on their race, culture, language, ethnicity or national origin is never okay, yet is a daily reality for many of us living with HIV in Australia. When we asked culturally and linguistically diverse (CALD) people in NSW who are also people living with HIV (PLHIV), about their experiences, HIV stigma was deeply linked with their experiences of racism. It was impossible to separate them. Experiences of HIV stigma and racism result in discrimination, which meant that many CALD PLHIV in NSW felt they don't belong in the community and can even keep them from accessing healthcare.

Dai, an Asian gay man living with HIV described this in terms of feeling like a 'second class citizen', which affected his self-esteem when dealing with his doctors. He shared a personal example of the difficulty he had with a doctor who was impatient with understanding his accent and finding emergency health care. 'Tanh', an Asian gay man also spoke about a similar experience where a "GP outside my usual clinic avoided his routine examination of my operation wound" on account of his HIV status. Tanh went on to explain how he found he was also dealing with racism over the language barrier. He said, "I usually understand basic English and recognise the act of stigma and discrimination against me, but I became doubtful and could not react promptly by myself." As a result of the intersection of HIV stigma along with language barriers, both men described a "decreased confidence" in medical practice in Australia. Tanh felt this double layering of discrimination "caused more stigma and discrimination against me." Dai concluded that "while HIV doesn't kill us today, stigma does."

This discrimination is real and present within our society. It's so real we have CALD PLHIV community members who are saying discrimination affects how they feel about going to the doctor. 'Chibale' an African heterosexual man said, "it feels like having to go to the headmaster's office to explain why I have been naughty." People shared the effects of this combination of racism and HIV stigma. African born 'Akeyo' shared that HIV was an isolating factor in her experience. "It makes me not have an open conversation in my community. I feel excluded from participating in several different functional areas of society."

Cultural connection is a core social support for many people in CALD communities, and particularly important for those living away from family, culture and country of birth. Without this support, HIV discrimination and racism can divide CALD PLHIV and can further isolate us from both healthcare services

and cultural communities. Chan, an Asian woman in her 50s explained, "In my culture and community, this status is one of the most serious stigma and discriminations." She went on to share her fears of leaving Australia, "I often imagine how much more severe stigma and discrimination I will face when I return to my own country."

When we discussed support from cultural communities for CALD PLHIV, the most common answer was many CALD PLHIV are choosing not to disclose to our cultural communities in order to avoid further discrimination and isolation. Many CALD PLHIV are hiding their HIV status in order to retain acceptance within their own cultural groups. PLHIV from CALD backgrounds face considerable cultural obstacles when it comes to disclosure.

Many said the same thing, "I do not disclose to anyone" or "I cover my status strictly." Chibale said, "I avoid contact with other people as much as I can, to not have to face people and stigma." It was common to hear this narrative interlaced with internalised stigma from those of us who are CALD PLHIV. HIV disclosure and support in the face of racism is more than a two-edged sword. It's harder to shield yourself from racism than it is to conceal your HIV status. And this is how many CALD PLHIV are managing, without disclosing with little support and further isolation.

While overall notifications have been dropping in NSW, there has been an increase in the number of overseas-born men and women diagnosed with HIV. PLHIV from CALD backgrounds not only deserve genuine support, but acknowledgement of the doubling effect of racism and HIV stigma. Dai described an experience of interlinked HIV stigma, discrimination along with language and cultural barriers which contributed to his acquisition of HIV. And we wonder why overseas born HIV notifications are on the rise and CALD PLHIV have difficulties accessing health care!

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Sections of this article are based on interviews undertaken by Multicultural HIV and Hepatitis Service (MHAHS) with people living with HIV from culturally and linguistically diverse backgrounds who access MHAHS services. If you are living with HIV and need culturally diverse community support, please contact MHAHS on (02) 9515 1234.

If you would like to talk to a peer, who is another person living with HIV, you can contact a treatments officer at Positive Life NSW on (02) 9206 2177 or [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

## THE SOCIAL DISEASE PANDEMIC

# HIV is no barrier to love or lust

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**CRAIG ANDREWS**

*Communications, Positive Life NSW*



For anyone, the negotiation of relationships can be tricky. For people living with HIV we usually find an extra layer of complexity. Nearly 60% of people living with HIV (PLHIV) in Australia are in a HIV-different (or 'sero-discordant') relationship.

Over eight years after the first Sero Disco, where we asked *Why let HIV get in the way of a good relationship?*, the division between HIV positive, negative or unknown has transformed to a gradual erasure of the 'sero-divide' in sexual relationships for all of us as lovers, friends and fuck-buddies. *HIV Difference* takes up this evolving story of sex, health, love and HIV, through our personal stories living in HIV-different relationships (where one partner is HIV positive and the other is HIV negative) as we negotiate and navigate love and lust.

From the days when we relied on a range of HIV prevention strategies, such as serosorting, strategic positioning, viral load monitoring and other negotiated sex safety options, today's strategies rest on the benefits of immediate treatment commencement along with long term adherence to treatment and viral load monitoring. Treatment as Prevention (TasP) is an acceptable and powerful HIV prevention strategy. PrEP has also delivered another powerful blow to the 'sero-divide' reducing fear and anxiety and opened up a new freedom between partners of all HIV sero-status. HIV-difference need not stand in the way of emotionally and physically rich relationships, 'no strings attached' fun or love.

In *HIV Difference?* you will read the stories of a range of 'silent warriors' who boldly tackle the biggest killer of all, HIV stigma. As we cross the boundaries of fear, culture, gender, disclosure and sero-status on our way to freedom, excitement and adventure, we enter a 'brave new world' full of desire, pleasure and acceptance. *HIV Difference?* normalises living and loving in today's social and sexual spaces as we all start to realise what it means to be Ending HIV.

Visit [www.hivdifference.positivelife.org.au](http://www.hivdifference.positivelife.org.au) to read more and go forth, love, lust and live positively.



# HIV TESTING IS FOR EVERYONE

I'd heard of AIDS. I'm too young to have seen the Grim Reaper TV adverts but my grandad told me that "there was a lot of AIDS fear back in the 80s." HIV today is drastically different from what is back then. It's no longer a death sentence.

Today people living with HIV (PLHIV) have access to medications which allow for a normal lifespan. As a 22-year-old queer woman I hadn't really given much thought about HIV until I started working for Positive Life NSW, an organisation that represents people living with and affected by HIV.

I've quickly learnt that HIV is a risk for anyone who's sexually active or anyone who injects drugs. HIV is transmitted through unprotected anal and vaginal sex, blood to blood contact. Regardless of whether you're gay, straight or anything in-between or who and how you fuck, anyone who has sex can get a sexually transmitted infection (STI) including HIV. That includes me and you!

In Australia HIV notifications have declined in Australian-born gay men. Yet in 2017 one in every four people diagnosed with HIV contracted HIV through heterosexual sex. HIV doesn't discriminate who is at risk. It doesn't just affect men who have sex with men. Since joining the HIV sector, I've met many women, men, trans and gender diverse people living with HIV who identify across a range of sexualities.

What concerns me is that anyone who is not a gay man, like me, are less likely to ask for a HIV test. I don't think I've ever had a doctor recommend a HIV test. Yet, nearly half (48%) of all new HIV diagnoses among non-gay male people are known as 'late presenters' meaning they have been living with HIV for four or more years without knowing

it. In that time, their immune system has been under attack and everyone they've had sex with was at risk of acquiring HIV.

Once they start on HIV treatment, (usually one pill a day) their viral load falls, they aren't infectious and can't pass HIV to anyone no matter how much sex they have. Condoms are an effective barrier to HIV. Today we also have PrEP and PEP. Like the contraceptive pill, PrEP is a daily pill that prevents HIV transmission for people that are at high risk. PEP on the other hand is a four-week treatment to stop HIV taking hold if you've already been exposed to it.

If you're sexually active, think about making STI and HIV testing

In Australia HIV notifications have declined in Australian-born gay men. Yet in 2017 one in every four people diagnosed with HIV contracted HIV through heterosexual sex.

a regular part of your sexual health check. Regular sexual health screens don't include HIV, so it's something you need to specifically ask for, especially for women. As someone who enjoys sex with anyone, I now go for a full check at least every six months.

If you have any questions or concerns about your sexual health, you can call the Sexual Health Info Link (SHIL) anonymously on 1800 451 624. They can also help you find your local (free!) Sexual Health Clinic. You can also call Positive Life on 02 9206 2177.

**BELLA BUSHBY**

Communications and Policy Officer,  
Positive Life NSW



# INVISIBLE WOMEN LIVING WITH HIV

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**JANE COSTELLO**

*President, Positive Life NSW*

**LIZ SUTHERLAND**

*Title?*



## NATIONAL DAY OF WOMEN LIVING WITH HIV AUSTRALIA 2018

Let's start having honest conversations about the systemic silencing of women within our society, particularly when it comes to the medical sector's pervasive disbelief of women's experiences of pain and right to bodily autonomy.

New HIV diagnoses in gay, bisexual and other men who have sex with men (GBMSM) continue to decline in NSW and indeed Australia-wide, while new diagnoses in heterosexual men and women, particularly from aboriginal and culturally and linguistically diverse (CALD) backgrounds is climbing. Nearly half of all heterosexual PLHIV are diagnosed with late stage HIV infection, meaning they likely acquired HIV at least four years prior to diagnosis. They are referred to as 'late presenters', but often they are presenting time and again (i.e. 'frequent presenters') to various medical professionals who simply won't consider an HIV test, even on request.

I recall having to see a different GP than my usual doctor while she was on holidays, for my standard yearly sexual health check-up. As I was in this appointment requesting a full suite of tests, including specifically asking for Hepatitis C and HIV, this GP said to me "why would you need those tests? You don't need those." The GP then went on to question whether I had eaten any food shared by someone living with HIV, as if this could put me at risk of infection (which it most definitely cannot!) This is the sort of misinformation that is prominent even in inner-Sydney medical practices, and it needs to be quashed. I'm aware of at least two Australian women who have been knocked back from requesting an HIV test from GPs numerous times over the course of years, only to be diagnosed in hospital years down the track with advanced HIV infection.

Every person who is sexually active or who injects is at risk of HIV. HIV doesn't discriminate, people do. The earlier HIV is detected, the earlier it can be taken under control, and managed for our own health, and to prevent transmission to the people we love. This can only start with a test; knowledge is power.

This NDWLHIV, let's educate ourselves, empower ourselves, and open our eyes, ears and hearts to the approximately 3,000 women living with HIV (WLHIV) in Australia. This isn't about "us and them", there is no "us and them". She is the 57-year-old mother and grandmother of African descent, HIV positive, terrified to tell her community. She is also the 26-year-old bisexual woman studying full time, out and proud to friends. She could be your 40-year-old neighbour married to an abusive man who threatens to out her to her colleagues and restricts her access to medication and doctors' appointments. These women are not only our neighbours, but our friends and family. They are us. Go get an HIV test. Talk to your friends and family about sexual health. Educate yourself about the transmission routes, demographics, terminology to use, and the lived experiences of PLHIV in our community. Challenge the stigma, discrimination and invisibility that still surrounds WLHIV in Australia today. Know your status!

Whenever we talk about feminism and women's issues and rights; the LGBTQIA+ community's struggles and rights; HIV in Australia; and chronic health conditions, WLHIV are perpetually left out of the conversation. We must address the intersectionality that faces WLHIV, as well as our own privilege and opportunity to empower all women with good health, autonomy, quality of life, and freedom from discrimination.

## WHY HOOK-UPS = CHECKUPS!

Recently, my friend “Peta” rang me in a panic. She’d hooked up with a guy she met off Tinder and didn’t use a condom. Being on the pill, pregnancy wasn’t her worry. It was the thought that she’d “caught something” from her hook-up.

As a 20-something year old woman having casual sex in Sydney, I’ve noticed that many of my friends aren’t regularly having Sexually Transmitted Infection (STI) checks. Young people are recognised as a high-risk group for contracting STIs, including HIV. I’m wondering what’s the hold-up in getting tested?

STIs are on the rise across Australia. Peta may have ‘caught something’ from her hook-up date. Between 2012 to 2016, gonorrhoea notifications jumped 63% and 75% of new notifications of Chlamydia in 2016 were found in young people aged 15-29 years old. Reality is most of us aren’t using condoms.

To all the Millennials out there, let’s raise our sexual pleasure, get it on and get it tested!

What’s more, we’re having way more sex with way more people across a range of different sexualities and genders. We’re no longer straighty-180’s. Young people are pursuing diverse sexual partners as well as multiple or poly relationships. With the growing popularity of hook up apps like Tinder, Bumble and Grinder, casual sex and online dating is the norm.

As sexually liberated millennials, most of us are highly educated with the internet in our pocket to answer

all our questions. Yet I know from my own experience that STI testing is not really that high on my health radar. I’m curious why we’re not more involved in our sexual health with routine testing, especially seeing most of us have sex positive lives.

Unless my friend Peta has an STI test, she could have picked up an infection without knowing. Not all STIs have obvious symptoms. While most STIs are curable or manageable with medications (such as, HIV), if left undiagnosed and untreated they can pose significant health risks to ourselves and our sexual partners. Untreated, STIs can affect fertility or lead to other longer-term health complications that are harder to treat.

Condoms are good protection against STIs (you can even get them for free!), though many of us don’t use them which puts us at an increased risk for STI transmission. If you’re having regular condomless sex, then your best safeguard is routine STI screening, which is free, easy and confidential. Regular testing for STIs is an important part of maintaining your health and the health of your partners.

I’m proud to be part of our sex positive generation with more of us feeling comfortable to embrace and experiment with our sexuality. We also need to feel comfortable taking care of our sexual health. As we move towards normalising sex (and having lots of it!), let’s normalise STI testing and taking care of our sexual health and in turn our partners we care about. There’s no fear, stigma and shame in getting tested regularly.

The main issues for my friend Peta was she didn’t know where to

get tested, she was worried about the cost and she didn’t know if she was at risk. On top of all this, she was embarrassed. I offered to go get tested with her and a group of us ended up going together. It’s easier to do something when you have a pal with you.

Testing today is simpler, easier and less embarrassing than ever. It usually involves a pee in a cup and a blood test. If it involves any genital swabs, you can usually do these yourself. Be open with your doctors and nurses about types of sex you are having, whether that be oral, vaginal or anal sex. It means you get the STI test you need.

Let’s start raising awareness of regular STI testing and changing these attitudes of shame, fear, stigma and embarrassment. The best way to do this is to spread the word. When we talk about sex, let’s talk about STI testing. To get tested you can go to any GP (it’ll be free if you go to a bulk billed practice), any sexual health clinic in NSW or these Aboriginal community health services. It’s recommended to get tested every three months if you have multiple partners (e.g. 3–5 a month) otherwise getting tested every six months is a good rule. At the very least it’s recommended to get tested once every 12 months even if you are in a monogamous relationship.

To all the Millennials out there, let’s raise our sexual pleasure, get it on and get it tested!

If you have any questions you can ask anonymously and get answers from the NSW Sexual Health Infolink (SHIL) line on 1800 451 624, or call Positive Life NSW and chat to one of our Treatments Officers on 1800 245 677.

Without a doubt, PrEP is a game changer in the HIV epidemic and has led the charge in this space. PrEP is an effective HIV prevention tool that promotes choice, and supports many HIV negative people to protect themselves against HIV and take control of their sexual health. With over 5,000 people in NSW taking PrEP as prescribed, it's definitely set to significantly slow the transmission of HIV in this state.

I remember when PrEP was the new HIV preventative kid on the block. This pharmaceutical strategy challenged many people's opinions and beliefs about responsible and acceptable protected-sex practices. Early adopters of PrEP who were barebacking, were slut-shamed and flamed with stigmatising comments and branded irresponsible for not using condoms. This early backlash against PrEP polarised the community. Ultimately science won in the end. Now that PrEP has an overwhelming level of support in the whole community, both HIV positive and HIV negative, there's equally exciting news about people living with HIV (PLHIV) who are using TasP or Treatment as Prevention to prevent HIV transmission.

Just like PrEP is used by HIV negative people who take it as prescribed to prevent contracting HIV, TasP is a strategy used by HIV positive people who take their HIV treatments as prescribed to prevent HIV transmission. TasP is just as effective (if not more so) at preventing HIV because PLHIV are no longer infectious when we use TasP to maintain an undetectable viral load (UVL).

Science spoke again with the Partners Study, when the success of TasP was proven. This study tracked 58,000 occasions of 'bareback' or condomless sex between 848 sero-discordant (one positive, one negative) couples globally. There were zero instances of HIV transmission. Not one negative partner contracted HIV from their HIV positive partner. ZERO!

Again stigma fuelled backlash made an appearance when the recently crowned Mr Gay New Zealand, an out and proud HIV positive activist

Charlie Tredway was publically shamed about his views on condomless sex. The sensationalist stigma-fuelled fear-mongering about Tredway's comments were a missed opportunity to provide informed detail on the latest and safest sexual health strategies of TasP and PrEP which are supported by the World Health Organisation, UNAIDS and many other health promotion NGO's including Positive Life.

The landscape about protected sex has definitely changed. Together TasP and PrEP have reduced the sero-divide in the community. Together TasP and PrEP are opportunities for HIV positive and HIV negative people to share equal responsibility for sexual health.

As we work towards 100% of people diagnosed with HIV being offered treatment immediately, for the newly diagnosed this can be an empowering experience during a difficult time. Immediate treatment not only halts onward HIV transmission, but it puts PLHIV in the driver's seat of our health immediately for better long term health outcomes.

As community awareness and understanding about TasP grows, the realisation that TasP is not just for positive people also tells HIV negative people that PLHIV who have an UVL are a safe bet in the sexual landscape. HIV positive or negative, there are new ways for all members of our community to care about each other and make safer, more informed sexual health choices.

As we celebrate this Mardi Gras, let's take a new informed look at our sexual freedoms, choices and responsibilities in the light of TasP and PrEP. Let's encourage and support our peers to take control of our sexual health and talk confidently and openly with each other about our testing practices and sexual health without fear.

# TasP

the  
unspoken  
game  
changer

—  
**NEIL FRASER**  
*Positive Life NSW*





# ON BEING TRANS



# AND POZ

For several years I have been giving talks on living with HIV and being Transgender as an out Positive Speaker to schools, health professionals and business organisations.

The ice breaker I like to use is, *'I'm Trans, over 50 and Poz; not a winning trifecta in the relationship market place.'* While this little piece of self-depreciating humour may be seen for just that, like all humour there is a kernel of truth in it.

I was diagnosed HIV+ in 2008, and my partner the week before. Both of us skipped HIV and had AIDS-defining illnesses. She died, I lived and with that came the beginning of a new life. Living as a HIV positive Transwoman I would go on to discover that I don't exist. Here I mean in the statistical cascade of people living with HIV (PLHIV). HIV+ Transwomen have only ever existed as an 'other'; an invisible subset of gay. This has been the case for years. It is symptomatic of the overt and covert stigma and discrimination that Trans people face daily.

It can be as subtle as a misused pronoun to verbal abuse. Remember the hate and prejudice unleashed during the marriage equality plebiscite? Negative stereotypes of transgender women like we are 'easy', drug addicts, sex workers, or a combination of does not help. 'Tranny' porn only fuels this misrepresentation where we are relegated to fetish objects of male sexual fantasy. I'm here to tell you, there are positive Trans role models out there, if you look beyond the noise.

Detractors dismiss the emerging visibility of Transgender people in the media and popular culture as a 'fashion' or cultural anomaly. No, we aren't an aberration, we have always been here. Transgender rights and recognition are about a decade behind the rest of the gay community. As we gain our voice there is movement here in NSW with the opening of T150 clinic at the Albion Centre, the coming opening of the first Transgender Legal Service at the Inner City Legal Centre and the supportive voice of Positive Life NSW.

For me, being Transgender cannot be separated from my living with HIV. For anyone who is HIV+, disclosure remains a major anxiety. To disclose or not to disclose; that is the question? For years I carried the survivor guilt of somehow being responsible for the AIDS related death of my partner while I survived. Nothing good comes from such a negative self-perception. Then the realisation; being Poz is only a small part of who I am as a person. This led me to an openness about my undetectable status when appropriate.

The 2008 HIV+ diagnosis took away everything from me including the love of my life. Out of this came a choice; be the victim of life's misfortunes or look for the opportunity to be found in adversity. I choose the later. Today I view being HIV+ as one of the best things to every happen to me. As to the why? That's another story.



**NATASHA IO**

Community member



# HIV CURE FOR HELP OR HARM

It seems that at least once a week I read a sensationalised story in the media about the end of HIV or finding the HIV cure. Today, thanks to modern anti-retroviral medications, we actually have a functional cure already. However, I can't help wondering if our seemingly endless quest to find the mythical Excalibur of HIV does us all more harm than good? This was the question leading a circus in my head this morning at 5am. Sure, my old foe anxiety had woken me with a head full of thoughts about the subject but I suggest these issues weigh up against other considerations that we trade-off or ignore, to our detriment. Why are we so obsessed about a one-size-fits-all-fix?

I hadn't given much thought to the subject of cure until the other day when I was chatting with a mate about hep C. He had gone through the hep C treatment but hadn't been able to clear the virus. Some people are lucky and hep C anti-retroviral meds have a minimal impact on their body, but my friend had a reaction to one of the drugs. Fortunately he is resilient and well educated about the virus and knows he still has plenty of options available. Besides being aware of the physical effects, I caught a glimpse of the mental health impact this could be having on my friend when he mentioned he hadn't cleared the virus. Treating hep C once again will test his resilience. As he goes for more tests to explore some of the newer treatments that may be more

effective for him, it means another round of treatment and side effects which pose trade-offs he will be considering very carefully.

When I was first diagnosed with HIV five years ago, I was eager to start anti-retrovirals (ARVs) as soon as possible. I placed more weight on my decision to start because I needed to feel in control of the virus. I was frightened because I felt different to the norm now that I had to factor my diagnosis into life's big decisions. I believed that by taking a pill, it would somehow change the way I felt about myself. It was my own way of dealing with the diagnosis.

Despite the evidence back then and still today that while HIV is a chronic and manageable condition, my diagnosis took an unnecessary toll on me because of stigma and discrimination, both perceived and actual. I spent many hours back then dreaming of a cure because I was fearful of what living a life with HIV would mean to me. I still remember what that fear felt like, and my own false expectations of an unnamed impending doom.

If I had the opportunity today to have a cure that may or may not work or just continue with my treatment as I have taken it for a number of years now, I believe I would be less inclined to allow my post diagnosis anxiety make an emotional decision for me. We know treatment works, so if it ain't broken why mess with it? Also, now that I have had an undetectable viral load for some time,

today I wonder if my life would be that different if we found a cure?

When talking about a cure for HIV or hep C, the language we use builds up expectations on what this could mean to us. I've been asked this question by kids many times whilst speaking at schools about living with HIV. I love their directness. What would a HIV cure mean to me? Speaking honestly, the only area of my life this would have any real impact on would be my career since I work in the HIV sector and the number of pills I take at night before bed. When I think of a cure, to me this would be the eradication of the virus from my body. I am still going to be left with whatever damage already done.

I'm not suggesting we stop looking for a cure, but I think we must challenge our assumptions about these medical conditions. HIV and hep C are health issues, not moral dilemmas. Today, people are still needlessly showing up to the hospital emergency room with opportunistic infections or AIDS-related illnesses. Why? Because of fear. They are too afraid to test regularly, if at all. It's clear to me that the effect HIV or other blood borne viruses have on our health starts with our mental health long before we even contract the virus. That is the lasting effect of stigma, much of it internalised. A HIV cure won't help any of us feel more normal, or more attractive or just more socially acceptable. At the end of the day it's a virus. A treatable one. It doesn't change who we are.

In our journey to find the holy grail of HIV cures, today we have a functional cure. ARVs allow most of us access to treatment in NSW to live long and fulfilling lives. I feel the more important trade-off in the discussion of cure, like undetectable viral load, is the fact it applies to only some of us. What does this mean for those of us who will never achieve an undetectable viral load?

We must ensure another generation of PLHIV are not left behind.

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**NEIL FRASER**

*Positive Life NSW*



# Phylo-what?

If you're like me, the first time you saw the word *phylogenetics*, it probably made your brain swim. Phylogenetics is coming and it has impacts for people living with HIV (PLHIV). It will play an important part with in our community and it has several different impacts on our lives as PLHIV.

While our bodies are made up of DNA, HIV is made up of RNA. HIV is a single virus, but it also has different strains (aka subtypes) of RNA. Researchers can classify HIV from sub-type M through to sub-type P. Looking at these different strains a researcher can tell where the HIV virus originally came from because HIV can be different between people. This is *phylogenetics* and it's used to understand how some viruses are related to each other.

The main aim of the NSW HIV Strategy is to reduce HIV transmissions by 2020. Phylogenetics can help researchers to do this by understanding how new HIV infections are acquired and also work out if a certain HIV infection came from people living with the virus or from someone who has not yet been tested and diagnosed. It can also mean people with undiagnosed HIV can get better medical care and treated early.

When a person is first diagnosed with HIV, this diagnosis is collected by the NSW Public Health Unit as a *notifiable infectious disease*. While this is carried out confidentially, it does not include the person's full name and address. Doctors can tell from the blood test result, what sub-type of HIV virus the person has and whether or not it contains any resistant mutations. By doing this, it's possible to agree what antiretroviral medication is best for the PLHIV. This is where phylogenetics becomes

important. It helps researchers and medical staff understand how HIV is being transmitted from person to person and can also help put treatment strategies in place for the future prevention of HIV.

Researchers are also able to use this unidentified information or *data* about HIV diagnoses to link up the different sub-types across NSW and gain a better understanding of the key features about HIV in NSW. This linking process includes what the proportion of HIV transmissions are from newly acquired HIV infections versus untreated long-standing infections, the rate of the HIV drug treatment resistance in NSW, what the common sub-types of HIV are and in which area they originate from.

This collection of unidentified data can do a number of different things like help inform and educate PLHIV about the best treatments available, informs ways to better educate the public and people at risk of HIV as well as the ways we can improve and implement prevention strategies.

Sharing the work of researchers in different research settings like the Kirby Institute offer PLHIV and our community an understanding of the various research studies that contribute to understanding how HIV is transmitted, better strategies for diagnosis and prevention as well as improved treatment for PLHIV.

If you would like more information about phylogenetics or the studies being carried out, you can call our Treatments Officers on (02) 9206 2177 or 1800 245 677.

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**DAVID CRAWFORD**

*Treatments Officer, Positive Life NSW*

# SWITCHING IT UP

## Is it time for a medication review?

Around a third of us living with HIV (PLHIV) change our drug regimen each year. Sometimes this could be something we've asked for because we've heard of a new antiretroviral on the market. It might be part of a routine medication review with our doctor, or even initiated by your pharmacist. As increased HIV treatment choices become available and our knowledge of how to manage HIV and other health conditions continues to grow, it's reasonable to ask, "is this the very best treatment for me at this time?"

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It's always good to consider the options and take control!

When we're first diagnosed with HIV, we usually don't know the questions to ask about medication to find the treatments that suit our routine. 9-5 work life, night shift, gym bunny or party animal. Different lifestyles, along with our daily routine

considerations, such as, medications that need to be taken with food affect your medication regimen. At the same time, our doctors usually don't know us all that well either, so it's not until we have a closer partnership

with our doctors can we talk about what's important to us and what suits us best.

There's a few reasons for changing treatments or asking for a medication review. Sometimes it's because of some undesirable side effects, or work commitments get in the way. Some medicines need to be taken with food and irregular meal times can mess with this. More of us are working full time now and juggling full schedules. Travel across different time zones can complicate things and changing meds to a simpler regimen or taking combination treatments (several medications in the one pill) might make more sense.

For many of us who live with several health conditions, a treatment review could benefit you by reducing the number of pills you're taking. When you start a new medication, sometimes your body goes through some adjustments. There might be some temporary side effects. These usually resolve within a week or two of starting a new medication. If you're having unpleasant side effects, bring these up with your doctor, sooner rather than later. It's important you always talk about any side effects with your doctor or pharmacist.

Asking for a medication review



could mean a welcome change of medication and bring relief. Ask your doctor to talk through the side effects the new medication might be, what the signs and symptoms would be and what you could do if you experience any. If you bring up the topic with a doctor and feel you've been dismissed or unheard, and this has happened on more than one occasion it's probably a sign to seek an alternate HIV doctor and ask for a referral. Friends living with HIV are often only too happy to share names of doctors they're confident in and feel understood by. Your HIV doctor should always take you seriously and be able to listen and understand what you're feeling or experiencing.

Sometimes your HIV doctor is the one recommending a change or medication review especially if they see changes in your test results. Sometimes HIV can develop resistance to a particular antiretroviral. In this case, most of us can easily change to another effective and tolerable HIV antiretroviral. Co-infections like hepatitis C, hepatitis B or medication for another medical condition can also interact with some HIV medications. This is why some people will be on different medication combinations.

Some of us who have had HIV treatment over many years, develop further health conditions on top of what we previously had. Examples of this can include altered kidney function readings or high blood pressure or Type 2 diabetes. Additional medications may have been added over time, resulting in a larger overall 'cocktail' of medications often referred to as polypharmacy. Multiple meds can increase the likelihood of drug interactions especially if you have four diagnoses or more. This kind of 'pill burden' is often a strong reason to ask for a medication review with your doctor. The time to have a

review of your meds is whenever you start a new medication or at least every twelve months if you are taking a number of pills.

Medical advances happen all the time, and HIV antiretrovirals are constantly being refined and altered. These can lead to improved treatment options that manage inflammation better and other age related conditions. Perhaps a new formulation may be available, to reduce your pill burden, side-effect profile or interactions.

Some of us also take complementary therapies such as multi-vitamins, fish oil tablets, glucosamine or calcium for example and it's a good idea to include these in a total medication review. Talk about these natural health products (NHPs) or complementary therapies with your pharmacist or general practitioner – not just your HIV meds. Sometimes there can be unexpected interactions with some NHPs like calcium, St. John's wort or Echinacea and some fish oils and it could mean you just need to take these at a different time to your HIV meds. If you are on a limited budget given the expense of supplements, fresh fruit and vegetables have shown to be as beneficial, unless your doctor or dietician specifically recommends the supplements.

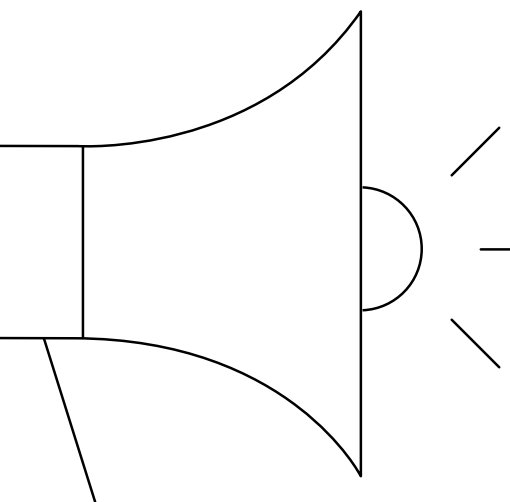
All of us have individual circumstances. There is no 'one size fits all' approach to achieving the best outcome for each and every one of us. Raising these issues with your doctor and checking out if there's some better options to juggle your meds mean you're the one in control. You could find you feel a whole lot healthier with a switch to meds that do the job better. A real change for the better!

If you want any support or need to talk things over before talking with your doctor, you can call the Treatment Officers here at Positive Life on (02) 9206 2177 or freecall 1800 245 677, to run through any questions or thoughts on your mind.

#### DAVID CRAWFORD

*Treatments Officer, Positive Life NSW*





## PBS SPEAKERS OUT LOUD & PROUD

On 1 December 1994, Positive Life NSW launched the Positive Speakers' Bureau (PSB). This is a dynamic program of Positive Life NSW which offers your agency, school, organisation or group the opportunity to hear the first-hand experiences of people living with HIV (PLHIV). The program is still running strong today, with a small team of passionate trained members of the community who actively put a human face to living with HIV.

PSB speakers are a diverse team, and come from a range of cultural backgrounds, ages, genders, time diagnosed with HIV and life experiences. They openly share from personal experience as PLHIV to address HIV stigma and ignorance, dispel myths about HIV, and communicate a deeper understanding of what it is like to live with HIV today. Many of the speakers also offer powerful secondary messages of resilience, bullying, and mental health and more.

The PSB team regularly share their key messages of safer sex, harm reduction and HIV prevention woven into each speaker's story. The entire team undergo regular training to upskill their public speaking skills and ensure they keep pace with the ever-changing landscape of HIV information, treatment and prevention.

Our speakers are an experienced team who speak from the heart to a range of people from secondary and tertiary institutions, youth services, to corporate, clinical and community-based audiences throughout NSW. The PSB team regularly present in secondary schools under the NSW Department of Education Life

Ready curriculum. Increasingly our speakers are complementing the training offered in the health sector at mental health and AOD units (alcohol and other drugs), HIV and sexual health units, accident and emergency units including allied health and aged care.

Now as we all are living longer with HIV and more engaged than ever in life, work and love, we seek people who are willing to be open about their experiences of living with HIV. PSB speakers are remunerated for their time by Positive Life, and coached and supported by their PSB peers and the PSB Coordinator to articulate their experiences of resilience and empowerment.

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**Many of the speakers also offer powerful messages of resilience, bullying, and mental health and more.**

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In many ways, as *Ending HIV* is in sight, and PLHIV are more invisible than ever before. As HIV warriors, PSB speakers give a great deal through their willingness to stand and have their voices heard.

To discuss your requirements or to book a speaker, please call the PSB Coordinator on (02) 9206 2177 or visit [www.psb.positivelife.org.au](http://www.psb.positivelife.org.au). If you live with HIV and are interested in undergoing training to become a PSB Speaker please call the PSB Coordinator on (02) 9206 2177



# HPV

Vaccinate or not to vaccinate?

# & ME

—  
**JOEL MURRAY**

*Associate Director,  
Positive Life NSW*

For a few years now, Human Papillomavirus, or HPV as it is more commonly known as, has been on my radar because of the link between some types of HPV and cancer. As a queer man who has fucked a lot of men (cis and trans) and most of it bareback, I'm at a higher risk of HPV because there are higher rates of HPV and HPV-related cancer among gay, bi and queer men. Living with HIV also places me at higher risk of cancer.

I haven't been vaccinated for HPV. At 34, I was too old to have received the vaccine in high school. Recently the vaccine has been recommended for gay and bisexual men. There's talk about the potential protective effects of a vaccine for people living with HIV (PLHIV) who're already sexually active.

With over 100 different types of HPV, it's possible that many of us have been exposed to HPV through sex (oral, front hole and/or anal). While only some of HPV types could lead to cancer, I wondered what I can do to reduce my risk of HPV-related cancer, and explored my options for a vaccine?

Sexual health clinics in New South Wales are giving gay, bi and queer men aged 34 or under free vaccines using the quadrivalent, which protects against the four most common cancer-causing HPV types. Earlier this year, a new nine-valent vaccine was made available in Australia which protects against nine most common cancer-causing HPV types. Unfortunately, the nine-valent is not subsidised and costs about \$170 per injection (a total of three injections are required over a six-month period, like the hepatitis B vaccine).

I had a conversation with my HIV-specialist about my thoughts and I asked for a digital anorectal examination (or DARE). A DARE is about checking for irregular lumps or bumps in my anus. This is one practical thing I can do myself or ask my lover, GP or HIV specialist to do on a semi-regular basis to check for any changes. If detected early, any lumps that could lead to cancer are easier to treat and less invasive compared to later detection.

Last week I started the nine-valent vaccine – what I consider a small investment in my future health. I'll have the next shot in two months' time and then the final shot four months after that. I am glad to have decided to put my health first and consider how living with HIV could impact upon my health in the long-term.

If you want to speak to a peer to explore your options to look after your health, you can always call Positive Life and speak to our Treatments Officer or one of our Peer Support team on 9206 2177 or 1800 245 677 (freecall).

# Polypharmacy, drug interactions ...

# WTF?!

Many of us who are either recently diagnosed or living longer with HIV, are taking extra off-the-shelf medications, supplements, vitamins and minerals for a range of reasons. Which is great, because we're prioritising remaining healthy. The question is: how does the additional medications and supplements impact on our health as people living with HIV (PLHIV)?

Recently at an 'In the Know' evening focused on research updates on HIV experiences and treatments, A/Prof Limin Mao from the Centre for Social Research in Health at UNSW and Dr John Rule from the National Association of People with HIV Australia presented results from a research study, PAART, led by Dr Krista Siefried and Prof. Andrew Carr at Sydney St. Vincent's Hospital. This study looked at the use of five or more medications at the same time (polypharmacy) by PLHIV who had one or more extra medical

conditions (comorbidities). For example, this might be someone living with HIV and high blood pressure or HIV and diabetes, or HIV and hepatitis C as well. In providing a research report back to our community and peers, A/Prof Mao spoke about what this means for our health over time, based on the research.

For those of us diagnosed with HIV before 2000, or before *Highly Active Antiretroviral Therapy* (HAART) combination therapies were available, many of us live with the permanent side effects of these early first or second-generation HIV drugs. Unfortunately, some of us also developed resistance to certain HIV medications so effective HIV treatment today might look like several HIV pills a day. When we take HIV medications along with other medicines for high blood pressure, hep C, depression, or diabetes (among other conditions), this becomes an issue of polypharmacy.

For those of us diagnosed after-2000, or after combination therapies were available, effective HIV treatment is usually one pill a day. Today, nearly half of us who live with HIV are over the age of 50 and have the usual age-related conditions like cardiovascular disease, arthritis, hypertension, osteoporosis, or type 2 diabetes. While, many of us might be taking only one or two pills a day for ART, the PAART study showed we're popping on average an extra six pills a day for non-HIV meds, and this is also polypharmacy.

Co-medications among PLHIV are for blood pressure medication, non-prescription medication like low-dose aspirin for inflammation, cholesterol medicine, antidepressants, herbal/alternative medications,



extra supplements, vitamins and minerals like omega-3, probiotics or niacin and a vitamin B complex. Most of these non-HIV meds are taken for a variety of reasons: some of us are taking a supplement for preventive purposes (e.g. lowering lipids) or treating ourselves for ART side-effects, low-level pain, attempting to treat a co-morbidity etc.

At the end of the day, polypharmacy puts a burden on our digestive system and gut health, in particular our liver and kidney functions. Concurrently, the study found that polypharmacy was associated with an increased risk of medication side-effects like fatigue and diarrhoea that might be due to non-HIV drugs. Some non-HIV drugs, even those as common as micronutrients, can interfere with our ART drugs by diminishing its potency in our body (our bodies ability to absorb and digest the medicine) or it might be harmful (*contra-indicated*). Some remedies for acid reflux also interact badly with some HIV treatments.

A well-known example is St. John's wort. This herbal supplement is usually taken as an anti-depressant or mood stabiliser and is contraindicated for PLHIV whose antiretroviral combination contains a protease inhibitor (e.g. indinavir, nelfinavir and saquinavir). Garlic supplements have been shown to reduce the body's ability to process protease inhibitors and lowering the amount of HIV antiretroviral in the blood. There are some indications that supplements containing magnesium or calcium, DHEA, ginkgo biloba, liquorice, milk thistle and valerian are *contraindicated* as they interfere with HIV antiretrovirals.

Other risks of polypharmacy, is a greater potential for a drug-drug interaction especially if newer medications are prescribed to manage or treat the side-effects of earlier medications or other 'adverse events'. Adverse events are an unintended and sometimes harmful occurrences associated with the use of a medicine. For PLHIV an adverse event can be as simple as a fever, rash, dry mouth, nausea and vomiting or something more serious like optic neuritis, anaemia, treatment failure or drug resistance.

If polypharmacy is your experience, there's likely to be a lot of information to keep up with so you can assess your own situation. There's a few different strategies to use to make sure you've got the latest details about the pills you're taking. There's an online app available through [www.hiv-druginteractions.org](http://www.hiv-druginteractions.org), which can be download onto your smartphone for free and use to check drug-drug interactions which the University of Liverpool (UK) regularly updates.

If you don't have a smart phone, or can't use this technology for any reason, you can easily find a nurse practitioner, usually connected to your GP or your HIV doctor or talk to your local pharmacist to review all the medications (HIV

and non-HIV) you're taking to see if there are any problems.


Pharmacists are funded by Medicare to do your medication review for free and they are more likely to have the time to research and access to the very latest literature regarding drug-drug interaction compared to your GP or HIV specialist who is usually running to a tight appointment schedule. You'll need to make sure you let the pharmacist know all the medications and supplements you're taking. Keep in mind, if you go to different pharmacies for different medications; have a complete record of all the drugs, medications and supplements you take with you.

If you're uncomfortable with either the nurse practitioner or pharmacist for any reason, you can still ask your GP or HIV doctor to do a medication review at your next appointment (book a 'long-appointment'!) or you can also call the Positive Life Treatment Officers who live with HIV themselves for advice on (02) 9206 2177. Peer Treatment Officers are available for support to discuss options to reducing your pill burden and/or to navigate medication considerations.

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**CRAIG ANDREWS**  
Positive Life NSW

When we take HIV medications along with other medicines for high blood pressure, hep C, depression, or diabetes (among other conditions), this becomes an issue of polypharmacy.



# BREAKING DOWN STIGMA ONE BARRIER AT A TIME



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MATTHEW HALL

Matthew Hall was diagnosed with HIV as a 23-year-old in 1995. Given effective antiretroviral treatment was yet to become available, HIV was considered a death sentence at this time. Devasted by the news, Matt struggled with his own fears of dying as well as the worries and anxieties about HIV from other people.

In retrospect, 1995 was a transition year for people living with HIV. The Olympic gold medal diver Greg Louganis, announced he was living with HIV having come out about his own sexuality the year before. By 1996, triple anti-retroviral (ARV) combination therapy and viral load testing began in Australia and with the rapid increase in ARV uptake, deaths from AIDS defining illness began to drop.

After starting combination therapy also known as HAART (highly active antiretroviral therapy) in 1997, Matthew's own viral load quickly fell to 'undetectable'. When his HIV specialist, Dr Darren Russell advised him that his undetectable viral load represented "zero risk" to others, Matthew's sights were set on registering with the (VAFA).

VAFA disagreed and banned him based on his HIV status. This was despite 1992 Australian Federal legislation which made it illegal to discriminate against a person due to HIV or AIDS.

VEFA's thinking at the time was, "We should be catering for the 10,000 uninfected players rather than the couple (with HIV) who want to play."

Not one to accept this intolerance, Matthew challenged the ruling in the Victorian Civil and Administrative Tribunal (VCAT). This high-profile case took on the football establishment and risked the scorn and derision of his team mates as well as the football-mad public of Victoria.

This was a personally traumatic time for Matt, even with the support from his HIV specialists, members of the HIV sector and his wife Amanda.

"It was overwhelming, confronting, and hurtful," he says. "I felt bullied. The media was in a frenzy and every report was negative."

Courageously along with Australian anti-discrimination laws, Matthew Hall not only successfully challenged the ruling in 1999 but changed the hearts and minds of many in the community. The case raised the standard of the 'blood rule' in Australian Rules Football and set a precedent for athletes living with HIV on the international stage. (The 'blood rule' in sport, is if a player is bleeding, or who has blood on them or their clothes, must immediately leave the field to receive medical attention.)

Matt also engaged strategically with public media outlets to offer education, during which he declined to sit behind a screen to hide his identity. He openly offered a face of a healthy, average Australian man living with HIV on *A Current Affair* and *The Footie Show*.

"I know the power of standing up against ignorance and discrimination," said Matt. "When I've called it out for what it is, I've seen barriers come down."

Even the solicitor for the Collingwood Football Club and former member of the VAFA conceded that after looking at the medical evidence and provided the 'blood rule' was followed, he had changed his initial response about players living with HIV being on the football field.

Still, Matthew Hall didn't stop there.

After the uncomfortable lessons of battling HIV stigma and discrimination head on, he put them to good use in the next chapter of his life. Inspired by Ian Roberts' example as an openly gay rugby player in 1997, Matt followed in those footsteps in 2002 as the first openly gay Australian Rules Footballer player. This time his focus was on battling homophobia in sport and the need for gay masculine role models in sport.

"Sport is part of Australian culture. By coming out and putting a human face to what it's like to be a gay man in today's sporting culture, I showed we're ordinary blokes having a go playing the game we love, like anyone else does."

"Sport is part of Australian culture," says Matt. "By coming out and putting a human face to what it's like to be a gay man in today's sporting culture, I showed we're ordinary blokes having a go playing the game we love, like anyone else does."

"While there's been some spectacular medical advances over the years for HIV," Matt says, "negative social attitudes and stigma still comes up."

"Physically, we've come a long way. These days living with HIV is easier than living with diabetes or heart disease. It's a pill a day for most of us," said Matt.

"My battles against stigma and discrimination have been hard, but also very powerful for me personally. I've had some very sweet successes and met amazing people through it all. I love that I've been able to create the change I have in my time."

Today Matthew works as a Lifeline counsellor and as a speaker living with HIV for the Queensland Positive Speakers Bureau.

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This article acknowledges contributions from *Anyone for football?* by Douglas Barry in Talkabout June 1999 and *Positive and Proud* by Jess Jones in the Star Observer December 2017.

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Positive Life NSW is a non-profit community-based organisation. We work 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 and targeted referrals, and advocate to change systems and practices that discriminate against people with HIV, our friends, family and carers in NSW.

**Phone** 02 9206 2177 **Freecall** 1800 245 677 **[www.positivelife.org.au](http://www.positivelife.org.au)**

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