

# talkabout

Where we speak for ourselves



REMEMBERING  
MATTHEW  
WOOD

IN MY  
OWN WORDS  
PAUL MAUDLIN

ONE OF THE  
FIRST 400

5 THINGS  
BEFORE  
PARTNERING UP



# TALKABOUT

WHERE WE SPEAK FOR OURSELVES

## EDITION #202

### CONTRIBUTORS

Brian Attard, Drew Browne,  
Bruce Hamish Bowden, Jane Costello,  
Barry French, Andrew Heslop, Rhiannon Hopley,  
Ellen Kipper, Jane Marriott, Paul Maudlin,  
Priscilla Njeri, Frances Parker, David Polson,  
Emma Reid, Eric Riddler, Steven Spencer,  
Louisa Wright, Sebastian Zagarella, Kim.

### EDITOR

Craig Andrews |  
[editor@positivelife.org.au](mailto:editor@positivelife.org.au)

### CONTRIBUTING EDITOR

Louisa Wright |  
[louisaw@positivelife.org.au](mailto:louisaw@positivelife.org.au)

---

### CURRENT BOARD

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**Treasurer** Neil Fraser | **Secretary** Sebastian Zagarella  
**Directors** Tim Bishop, Greg Horn, Natasha Io, Frances Parker  
**Ex Officio** CEO Jane Costello, Staff Representative Craig Andrews

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**Communications Manager &**  
**Positive Speakers Bureau Coordinator** Craig Andrews  
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**Peer Support Officer** Priscilla Njeri  
**Health Promotions Officer** Reuben Matheson  
**Peer Support Projects Officer** Tyler Marks  
**Administrative and Project Officer Support** Ellen Kipper  
**Consultant** Simon Wilson

Printed by SOS Print + Media Group

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# Positive Life NSW

The voice of all people living with HIV

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Simon Wilson |

[simonw@positivelife.org.au](mailto:simonw@positivelife.org.au)

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[editor@positivelife.org.au](mailto:editor@positivelife.org.au)

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

Cover photo: 2022 Positive Life NSW Mardi Gras Parade Group.

Photographer: Rhiannon Hopley /

RH Photography & Design

*A bumper edition this April 2022, thanks to new and familiar voices who shared their thoughts, wisdom and insights.*

Talkabout runs an interview with David Polson that explores the experience of 'one of the first 400' (page 22). This is a phrase used to refer to the small group of gay men who were first tested for HIV antibodies in Australia as part of the Sydney AIDS Project in 1984.

**This study and the time were both pivotal moments in the history of the HIV/AIDS epidemic in Australia, and Positive Life NSW would like to interview members of this group who are willing to share their thoughts. If you were diagnosed in 1984 and part of the study, or if you know someone who was, please contact Positive Life.**

Steve Spencer puts pen to paper once again, broaching the topic of sero-discordant relationships (page 10). He shares five important points to consider as you head into the dating and mating dance as someone living with HIV.

Talkabout introduces you to three more faces behind Positive Life NSW, two Board Directors (page 7) and a staff member (page 20). A community supporter shares a snapshot of a little known, but not forgotten community member Matthew Wood, along with an evocative reflection on Matthew's life and fleeting presence in life (page 30).

Hamish Bowden offers some tips and guidance on working with a particularly crucial healthcare provider, your

pharmacist (page 28). Today, as we're making use of a variety of different pharmacies, hospital-based and local community pharmacies, there are some basic suggestions on how we can make the most of this significant relationship. Last but not least, Paul Maudlin shares part 2 of his story (page 12). With opportunistic infections never far away, Paul offers another episode of his lived experience. This chapter straddles the time just before the protease inhibitor moment in 1996 which was full of research trials and experimental testing to the remarkable 'Lazarus' period that many of us today will never fully appreciate.

Once again we call on the membership to get in touch if you have any contacts who might be interested in advertising in Talkabout. We only need a couple of small advertisements to ensure Talkabout is sustainable, so let us know if you have any suggestions we can approach.

If you have a story in mind, or want to explore how you might be part of Talkabout, please get in touch. We can also interview you as part of 'In My Own Words' to make it easier than ever to share your story in Talkabout. Call us on (02) 9206-2177 or 1800 245 677 or by email on [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

I look forward to hearing from you in the near future.

**CRAIG ANDREWS**  
**EDITOR**

**EDITION 3 JUNE - #203**

**SUBMISSIONS AND ARTWORK: FRIDAY 27 MAY 2022**  
**DISTRIBUTION: WEDNESDAY 15 JUNE 2022**

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**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](mailto:contact@positivelife.org.au)

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Ageing Support



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

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# DIRECTORS' PROFILES



## Frances Parker - PLNSW Director

I am a woman living with HIV, in a serodiscordant relationship with a wonderful man who accepts who I am unconditionally, a mother of three daughters, and recently welcomed my 7th grandchild! I am new to the Board of Positive Life and like many women living with HIV, I am a strong independent intelligent woman who has survived extraordinary life events.

Initially my HIV diagnosis in 2004 paralysed my life with fear. I was grieving the loss of a future, a relationship, happiness and sexual freedom, friends, family and jobs. I was in isolation living with threats of HIV discrimination and stigma. The diagnosis almost destroyed me. My self-worth and self-esteem shattered until I was introduced to other people living with HIV, and Positive Life NSW literally saved my life.

The challenges I have faced both internally and externally are a testament to my resilience, commitment and strength. We all have our story of HIV stigma and discrimination, and now I have skills and knowledge to support others going through their own challenges. Every day, I strive to find the positive in being Positive.

As a Positive Life Board Director, and a positive heterosexual woman from a regional area, I have a platform to represent the interests of women living with HIV through my lived experience. I am passionate about the needs of women living with HIV. We make up 10% of the positive population and yet we are underrepresented in medical trials and social research. We often face significant issues associated with isolation and lack resources and support related to our unique health issues. I love that I can use my voice to fight for issues that are close to my heart.

Today I have found my power through owning my truth. I run a successful business working as a beauty therapist in Newcastle. I have friends and a community that supports me. I have truly authentic friendships, conversations and support in a safe space. I am proud of my status as a woman living with HIV.



## Sebastian Zagarella - PLNSW Director

I was diagnosed in 2002 and consider myself very fortunate to have lived with HIV for the past 20 years with no ill health related to my status and have not had any negative impact as a result of my medication. I've been on the Pos Life Board since 2017, and over the past five years I've learnt the most valuable thing I bring to the table is my point of view, my lived experience and that of people I know who are positive.

I've been actively out on the Sydney scene since the mid 90s and, like most gay men at the time, I had lost friends to AIDS, knew lots of men who were positive and in the late 90s was also in my first sero-discordant relationship. Keeping abreast of what was happening with transmissions and medications was part of my life. It was during this time that I picked up my first copy of Talkabout which then became a regular read. Keeping up with advances in medicine became even more significant once I seroconverted in 2002. By 2014 I began to work on an art installation ([www.insideoutexhibition.com.au](http://www.insideoutexhibition.com.au)) centred on my experience of being positive. It also turned into my 'coming out'.

It was through my interactions with the then-President, now CEO, Jane Costello, and the then-CEO Craig Cooper and Pos Life that I gained the strength and confidence to be authentic and be able to speak openly and without shame about being positive and it was at this time that I discovered the real value of peer to peer support, speaking with people who have been through similar experiences, and could relate, was so very important to my healing and growing process.

I feel the focus should always remain on the current needs of the body positive. Remaining current allows the team at Pos Life to ensure they are advocating for the body positive where it matters most to them but also provide relevant information and services. While I always felt that being on a Board meant you needed a certain skillset or range of capabilities, what I've learnt from the Pos Life Board is that the value is in the richness of each lived experience.





## After a crazy few pandemic years and a terrible summer of floods, our colleagues and clients in the Northern Rivers are selflessly assisting the

many people affected by the floods. It reminds me how the community helps itself.

And the importance of having an emergency fund. It's never too late to start saving now, however little!

We are also reminded that people living with HIV outside the queer community also need our love and support. Cars are a big burden to people on low incomes but as our community ages they are often vital.

One of our clients, 'Ada', is from a culturally and linguistically diverse (CALD) community, and her HIV status was leaked to her community. The discrimination was subtle but eventually she could no longer work. As well as, Ada is having serious health problems with a possible HAND diagnosis and she fell behind on her car payments. After careful analysis with one of our financial counsellors, it became obvious that the only way out was to surrender the car and get a fresh start. Her journey from financial distress to survival is only just beginning but she needs support and for her voice to be heard.

We were approached by a client, 'Jack', who had been talked into a terrible car loan with unreasonable conditions and extra fees. Unfortunately, this was a First Nation person at a vulnerable point in their life being exploited by the many so-called 'financial services' out there eager to 'help'. With legal advice we were able to determine that the loan was issued without meeting the criteria for responsible lending and as Jack really wanted to keep the car, we negotiated a final settlement amount which meant everything paid to date was counted against the loan in full. The car now belongs to Jack and he's rebuilding his life.

'Jonathan' has an early HAND diagnosis, and he's struggled on his disability support pension (DSP) each fortnight. The biggest hurdle was every time he used his card to pay for items or services, he could never be sure there was enough money. We assisted Jonathan to set up his banking app on his phone and transfer a fixed amount into his spending account weekly. Now that this potential stress has reduced, Jonathan can check each time and know there will be enough money each time, one week at a time.

Financial Counselling isn't just one thing. We can listen to your personal situation and help you identify where you might change just one action or decision, and get a better outcome.

Get free advice and talk with someone who is non-judgemental, confidential and independent to help you break the cycle of financial stress

Contact us by calling (02) 9283 8666 or email us at [fc@bgf.org.au](mailto:fc@bgf.org.au).

– Barry French and Emma Reid,  
Bobby Goldsmith Foundation (BGF)  
Financial Counsellors

# GOING SERODISCO

Sitting down to indulge in the guilty pleasure of watching *Married At First Sight* or *First Dates Australia* has become a ritual for many of us over the past couple of years of COVID-19 lockdowns, where we have nothing but time to gawk at the awkwardness of dating.

As we come out of our long COVID slumbers and we start going out more, it is inevitable many of us will take part in our own clumsy social dances. Yet for people living with HIV, we have more than just small talk and a chat about what we do for work, to discuss with potential partners. Every time we date someone, we consider disclosure and how we might navigate talking about HIV. Do we open ourselves up to full scrutiny from people who may know little to nothing about HIV, let alone the lived experience of it in 2022, and if we do, how do we go about this?

If we are lucky, we might just be sitting across from someone who is also living with HIV. I will never forget my first hookup from a dating app after I was diagnosed with HIV and received my first undetectable viral load result. I turned up, fully prepared to have a long-winded conversation. I had a photo of my results on my phone, and from what I had learnt in my recently diagnosed workshop for people living with HIV and from friends living with HIV, I had to be prepared for any outcome. "I need to tell you, I am HIV positive, I'm undetectable, and this means that..." and he stopped me and said "that's cool I'm undetectable too." Easy!

That was lucky chance, more likely than not we will end up with partners (whether for one dance, one night, or your whole life) who are HIV negative and don't necessarily understand what it's like to live with HIV. Serodiscordant relationships

(where at least one partner is HIV positive and the other/s are HIV negative) will be more common. Although they don't come without challenges, any relationship or connection we can make with other people improves our quality of life.

So here are my top five things to look out for as you embark on your own search for love and lust in a time where people living with HIV face fewer barriers to serodiscordant relationships, thanks to PrEP, U=U (also known as TasP or treatment as prevention), and HIV education, yet still experience HIV stigma.

## **1. Be open to possibilities and do what you need to safely navigate serodiscordant relationships.**

Our HIV status shouldn't be a barrier to our romantic lives, no matter where we are at in our journey of living with HIV, we all approach relationships differently. Being prepared for any outcome, as I was warned to be, doesn't just mean be prepared for negative outcomes. While it is important for us to be aware of potential rejection and stigma, it is also important to be open to positive experiences! The fear of negative outcomes and also the internalised HIV stigma many of us face can stop us from venturing out. This limits us and can affect our quality of life. Imagine the possibilities that are out there if we face some of our fears.

However, what is most important in all of this is your safety and happiness. If there are situations that make you

uncomfortable, do not feel bad for avoiding them or removing yourself from them. We can find the right resources that are relevant for us, and the support systems that work for us to build our confidence. A serodiscordant relationship is just a relationship. While living with HIV and dating may require some extra effort, it's usually well worth it.

## **2. If you face HIV stigma, you can control how you react.**

HIV stigma in serodiscordant relationships may show itself in many, sometimes unexpected ways. It may not even be between yourself and your HIV negative partner, it could be stigma from friends or family, it could be discrimination in healthcare settings, or from somewhere else. While stigma is incredibly hurtful, there are ways you can use these encounters to build your own resilience and confidence. In my own long-term relationship, HIV had never reared itself in a negative light until I experienced a very minor viral blip. My doctor treated me like I was a threat to my partner even though I was still undetectable. This experience was stigmatising and incredibly frustrating for me. Yet it showed me that HIV stigma can come from unexpected places. I realised I had the knowledge to reassure myself that I am normal and safe. I also had the power to leave these stigmatising situations. After this experience, I found a more informed doctor who understood 'viral blips' were part of my life, and not a health crisis.

### 3. Be prepared to offer some HIV 101.

As tedious as it might be, those of us living with HIV are often expected to be educators. Whether it's with friends, family, partners, or random hookups who are not living with HIV, we're often called on to share our own HIV knowledge. Managing other people's expectations of what amount of information we can provide is an important way to keep sane.

Some of us find ourselves as advocates and can talk endlessly on the topic, but the rest of us just want to get on with life. While HIV negative people don't have a right to our private medical history, if we share it, it is offered as a kindness and an invitation to be part of us. Every time we disclose, we open ourselves up to scrutiny and possibilities. I like to think of disclosure as bringing that person along on my journey. Some people will ask for way too much information. I've had potential lovers ask for statistics, my own sexual health history, and my viral load data from the last 24 months, when really this is completely unnecessary and they have no right to be so invasive. People living with HIV who use reasonable precautions during sex to prevent HIV transmission are completely within the law. When you've had an undetectable viral load for at least six months, you're physically unable to transmit HIV to another person.

These detailed questions about facts and figures simply shows the incredible stigma and anxiety that exists in the broader community. While it might feel awkward to shut down someone's line of questioning about HIV, I think it's more worthwhile to respectfully and

firmly say while they have this level of anxiety around the topic, they might need to find someone else, such as a clinician to settle their fears. Stay confident, in control and sure of yourself. This shows me just how important it is for us all to access relevant information on HIV for ourselves and for our partners. Knowledge is power.

### 4. Your undetectable viral load is enough and will prevent HIV transmission alone even if your partner isn't on PrEP.

There has not been a single recorded case of HIV transmission from someone with an undetectable viral load to someone who is HIV negative. The science is in on this people! When we take our HIV medication as prescribed, we use HIV treatment as prevention (TasP), also called 'U=U'. An undetectable viral load for at least six months means HIV is untransmissible.

A person who believes they are HIV negative, but hasn't been tested, is more likely to pass on HIV than someone who knows they are HIV positive, on HIV medication with an undetectable viral load. Serodiscordant relationships are safe relationships, no matter what other HIV preventatives are used, so long as we are using U=U. My own HIV negative partner decided to stop using PrEP when I became 'undetectable', but they said to me that they were happy to continue with it so that the burden of HIV prevention doesn't fall solely on me.

I said, "Don't be silly, my medication is enough for both of us", and here we are three years later, safe and happy. To hear an HIV negative person acknowledge that HIV positive people have carried the HIV prevention burden

for decades, not just medically but socially, was one of the most eye-opening experiences for me. To be trusted, to have the science, and to have my HIV negative partner embrace all of it was a gift. We all bear the responsibility for the prevention of all sexually transmittable infections including chlamydia, gonorrhoea, syphilis, lymphogranuloma venereum, hepatitis B and HIV. Today we have a range of HIV prevention tools, such as condoms, PrEP, PEP, and other strategies, including the scientifically proven reliability of our undetectable viral loads.

### 5. HIV is not our only experience of life.

We bring our whole selves including all our other experiences into our serodiscordant relationships. Today HIV is a manageable chronic health condition which we all experience differently. Here in NSW, we're privileged to have access to incredible medications and support systems that make HIV just a footnote in our life rather than a giant exclamation point.

At the end of the day, you may find that in a serodiscordant relationship, your HIV status has no impact at all. It's often everything else in our complex, diverse, well-lived lives that we bring into a relationship that shape that relationship. How we communicate, how we respectfully acknowledge each other's lived experiences, how we embrace our intersectionalities, even how we kiss (still something I'm no good at!) are more important things than our HIV status. All of this is pretty obvious to us, so let's bring our HIV negative partners along on the journey. I reckon everyone benefits from this.

– Steve Spencer



## 1994-1998: Growing stronger, wellbeing and disclosures

Before 1993 had ended I achieved several things which I needed to do for my health, wellbeing, and mental health after such an emotional time three months beforehand. These included completing the ACON HIV peer support facilitator's training for gay men. I went on to facilitate seven groups (including two groups for newly diagnosed men) over the next six years.

It was also through the peer support programme that I first heard about PLWHA (NSW) (now Positive Life NSW), and its proposed new project called the Positive Speakers Bureau (PSB) which would commence planning in May the following year, in time for the project's launch in late 1994. I made enquiries and was accepted as a volunteer to work on the project's small group to formulate training, policy and generally assist with getting things off the ground. The rest of that as you know is history (see February 2022 edition).

I also attended two of ACON's series of information night seminars which were run for several weeks learning about the early prevention treatment programme for people living with HIV and how to appropriately disclose our HIV status. As a result, I had a much better understanding about disclosure, health, wellbeing, and lifestyle things that I could use to potentially prevent the onset of worse health and possible progression to an AIDS-defining illness. These included diet, nutrition, exercise, relaxation, and meditation. I was 38 years old at the time and had never been a great fan of sport and exercise. However, I soon found myself attending positive pump classes at Bondi Olympic Gym and then later aerobic sessions for the LGBTI community at Waterloo. I also contacted the dietician at the

Albion Street Centre to have an assessment done for muscle tone and diet. While I did not maintain exercise activities for very long, they set the scene for more gym work at Pride's Fitness Network, hydrotherapy classes at the Royal Prince Alfred (RPA) Hospital in Camperdown, and participating in St. Vincent's exercise programme four years later.

I was still attending Sydney Sexual Health Clinic (SSHC) for ongoing follow-up HIV monitoring and counselling when I thought I needed it. I was concerned about the need to disclose my new HIV status to friends, family, and much later, work colleagues. I soon felt comfortable and much more at ease, and before year's end disclosed to twenty-five people that I felt needed to know. This included my parents and siblings but at that stage that did not include my newly divorced ex-wife and children, for another fourteen months. Most of my disclosures were to straight friends and therefore in effect I was doing double disclosures (sexuality and HIV status). I am happy to say that nobody rejected me and that I received nothing but love, support, and ongoing friendships. The only odd thing is that nobody to date has ever mentioned the state of my HIV health, nor have I wanted to bring it up.

Dr Andrew Pethebridge was my first GP who also specialised in HIV medicine. In early September 1993, after having a sudden onset of laryngitis, my long forgotten upper back and chest acne returned, flaring up with a vengeance. Throat swabs returned negative results for any infections including gonorrhoea or chlamydia. I was given antibiotics which resolved the first of many throat issues over the coming years together with Retin-A (Tretinoin) Liquid which temporarily relieved my cyst-like acne. I later self-

referred myself to an acupuncturist in Darlinghurst who prescribed a twice daily course of Chinese herbs together with three sessions of acupuncture which were very relaxing. These worked well until I got quite sick with diarrhoea and needed to quit. In early December I saw a dermatologist in Bondi and that relationship lasted for six months while taking the very toxic drug Roaccutane which could affect my liver or cholesterol levels if not correctly monitored. I needed additional regular blood tests to ensure that did not happen. Roaccutane was successful despite my liver function tests (LFTs) becoming slightly elevated at the end of the treatment. Unfortunately, it was not long before I was regularly returning abnormal LFTs which were causing my doctors and myself a lot of concern. I then needed several ultrasounds and five liver biopsies over the next ten years.

The last thing I did in 1993 was complete the co-purchase of a 100-year-old federation house on the St Peters flight path with the biggest avocado tree I had ever seen in its backyard (I hated avocados at the time).

### 1994-1998: Research trials and tribulations

Work, social life, volunteering, the new house and frequent doctor and specialists' appointments kept me on my toes, and I tended to throw myself whole heartedly into these activities while trying to not overly think about HIV until it was suggested I was eligible to participate in a HIV research trial.

In early February 1994, I met Nicholas who moved in, and we became lovers for the next five years until breaking up during the first week of our six-week European holiday with friends Jon and Tony. In March, my home co-owner Brandon mysteriously

disappeared and moved out, and this then caused the very nasty and stressful process for me needing to re-finance to purchase his share of the property.

In late April 1994, after deliberating for some time after discussions with Andrew Pethebridge and Alan Walker from the Community HIV AIDS Trials Network (CHATN) over the previous couple of months, I decided to participate in the year-long research trial using an experimental therapeutic vaccine called P24, with or without Zidovudine (AZT), to assess the safety of the vaccine in humans as a future treatment option. This required my attendance at Andrew's surgery in Bondi at regular intervals (a total of fourteen visits over the year) to having six immunisations at four weekly intervals and taking two capsules three times daily over the next six months.

Additionally, I had to have six cell-mediated immunity (CMI) skin tests bi-monthly to monitor my immune response. Alan used a disposable plastic applicator consisting of eight sterile test heads (little needles) preloaded with seven delayed hypersensitivity skin test antigens. The trial commenced in June 1994, two weeks after the Roaccutane experience, and was the first of my participation in fourteen more research studies/drug trials over the next twenty years. P24 was a huge commitment which resulted with nothing more than boosting my immune response and not increasing my CD4 count or viral load (VL). My CD4 count at the beginning of the trial was 780 and at trial's end had dropped to 299.

After much anguish, the hardest double disclosure was to my children, Julie (13) and Phillip (11) in mid-October 1994 while they were playing competition baseball in Campbelltown. The location and timing were not ideal, but it was the best choice at the time.

Both kids were visibly upset and shocked at my news. Julie told me that it was obvious to them that I was gay because of the friends I associated with, my change of hair colour and earring. When I asked them if they knew what HIV/AIDS was and its possible health

outcomes, their response was they understood what I was telling them, and they were taught about sexuality and gender issues including sexual health/HIV as part of their Personal Development Health and Physical Education (PDHPE) curriculum at school. Their mother, Elaine, phoned me later that night to ask if I had good support, and to also say I should not hesitate should I need any help in the future as she and the kids would always be there for me (it was the nicest she'd been to me for three years) She was also happy about my coming out. The kids and I (and their families) remain close to this day. Unfortunately, Elaine was tragically found dead after being home alone with her two dogs for three days in 2014.

In February 1995 I wanted to also provide support to somebody with HIV who needed emotional support of the sort I received in 1994, and then applied to do the Ankali training which was conducted over six days and nights. I found myself disclosing to forty-three people at this training on the first day and their response to that was amazing. I went on to provide emotional support to two clients.

In July 1995 I commenced monotherapy with AZT and by the end of November 1997 my HIV antiviral drug regimens were changed ten times due to experiencing a variety of side

effects while becoming resistant to most HIV medications available at the time, while my LFTs continued to rise alarmingly with ongoing investigations failing to find a cause. Three weeks later, I had a minor procedure to excise a small wart which had grown on the bottom of my uvula in the back of my throat. This turned out to be my first and only ever incidence of discrimination by the staff involved in the procedure. I did all the usual things that occur when visiting a service for the first time, including bringing the referral letter, completing personal particulars, and providing medication information.

What occurred next was nothing short of bizarre. The specialist discarded the referral letter before the procedure and did not read it until the procedure was fully completed. He then asked, "What are you taking AZT for?" I replied, "I am HIV positive." At that point staff attending to me went into panic mode with both nurses flying out of the room with the specialist calling after them telling them to make sure they correctly wash their hands and sterilise the instruments.

**In the adjoining room I overheard somebody whispering to other staff "He's HIV positive".**



PLWHA (NSW) Xmas party '98 (L-R, Antony Nicholas CEO, Luke Smith (Finance Officer) with me

I remained where I was sitting without any further verbal contact with anyone, and was made to feel very embarrassed and humiliated. To make matters worse, the specialist did not practise universal precautions during the procedure. To save face, the specialist told his receptionist not to bill me.

### **1996-1998: Community, health and protease inhibitors**

My GP referred me to Dr Andrew Carr at St. Vincent's Immunology Department in May 1996 to assess me for compassionate access for the HIV antiretroviral drugs 3TC and D4T. This was approved and became my fourth regimen change in six months. My first ever viral load test that day revealed a high count of 116,700 copies with a CD4 count of 190 which Andrew explained meant that I was a mid-range HIV progressor, not progressing fast, but not slowly either.

At the end of June, I resigned from the French defence company where I had been employed at for four years due to their world-wide sonar merger with GEC-Marconi. I took up another position with a North Sydney information technology business, but this didn't work out and I left this job after a week without another job to go to (something I'd never done before).

For the first and only time in my life I was unemployed for three months until I took up an inventory control position at the Australian Red Cross Headquarters in the Sydney CBD. Two weeks before starting, I did a one-day course at the National Centre in HIV Epidemiology and Clinical Research (now The Kirby Institute) to be able to conduct interviews on their behalf for the Sydney Men and Sexual Health (SMASH) Periodic Survey Project. My first interviewee was a young gay man who said he was in a monogamous relationship and had never had sex with a woman, further stating that he was very vanilla.

In June 1997 I began working as the PSB Co-Ordinator for PLWHA (NSW), and at that time my health was up and down while dealing with annoyingly odd medical issues that cropped up frequently, as well as navigating varying treatment difficulties. I thought I dealt very well with all of this and had the attitude that if something was wrong with my health, then I wanted to know exactly what it was so that I could get on with whatever needed to be done to fix it.

I was very successful with this approach and had it not been for the ongoing assistance and support of the organisation's Board, staff and clients, I most likely would have thrown the towel in. I had the privilege to be on the Board as Treasurer from August 1996 to January 1997. I will talk more about the PSB and some of the project's highlights in the June Talkabout edition.

Sleaze Ball in October 1997 was a total disaster for me, after bumping my left knee while putting together a new bed earlier in the day. Nick, Jon, Tony, and I ventured off to the showground as planned; however, my knee became painfully hot and after several hours was badly swollen. I was unable to walk (or dance) and was forced to sit the rest of the event out on the sidelines trying to capture my friends enjoying themselves. The next morning, I was carried out to a taxi and taken to St. Vincent's Emergency where several needle biopsies failed to draw any fluid from my knee. I was admitted to Ward 17 South because I was HIV positive and not allowed home for two weeks. Nine days after being admitted, pathology results revealed that I had a Staphylococcus G infection called Patella Bursitis with Cellulitis. The day prior to my discharge Dr Andrew Carr came to see me, because he was not happy with my current antiretrovirals and wanted to arrange a blood analysis test from RPA and then review

my medications. Two weeks later I had an appointment with Andrew in his clinic at St. Vincent's, and was told to stop taking all antiretrovirals immediately as the RPA test had not come back and he was considering repeating the analysis test again. Another two weeks later, Andrew wanted me to recommence the medication regime which I had been on four months previously.

By November 1997, despite the best care and good intentions of both Doctors Carr and Pethebridge, I felt I needed a new doctor who could provide me with a more radical approach and a new treatment direction so I transferred my care to Dr Cassy Workman in Surry Hills.

My first appointment with Cassy lasted two hours. My initial medication burden was 37 pills a day and I was worried what that would do to my liver. Cassy assured me that my LFTs were high but not abnormal, and I would be able to reduce my medication burden once my viral load dropped to undetectable levels. While waiting for a break from declining viral load results, I had the opportunity to volunteer for several months making the float and props for the PLHWA (NSW) 1998 Mardi Gras entry called Dick van Dykes on bikes with Mary Poppin' Pills. I was also one of the thirty Dick van Dykes on Bikes who participated on the night. While moving up Oxford Street, Mary who was sitting atop a makeshift chimney would proclaim:

**“A spoonful of protease inhibitors makes the viral load go down, the viral load go down.”**

The night was a huge success and a lot of fun (Talkabout Cover No. 85, April 1998).

On 25th May 1998 Cassy told me that I had an undetectable viral load, but sadly the decrease in medications never eventuated. Despite that, I was over the moon and remained on this huge medication regimen until the end of 1998.

Eight days later, my joy was short-lived due to receiving a diagnosis for my first AIDS-defining condition, progressive cutaneous Kaposi's Sarcoma (KS). I knew three people that had this nasty cancer, and secretly hoped it would not happen to me. So, when I discovered the first purplish blister type lesion in my groin, the second week into my six-week European holiday earlier in the year, I instinctively knew that I had developed KS.

By the time I arrived back in Australia I had sixteen lesions in my groin and on my torso, and could not wait three more weeks for Cassy's return

from holidays to have my suspicions confirmed. Professor Michael Kidd therefore arranged for skin tests and biopsies, which unfortunately then confirmed KS.

A follow-up chest x-ray thankfully confirmed that my internal organs were not affected. I considered this to be a blessing, as that would have been potentially fatal. I was then placed under the care of Dr David Goldstein at the Prince of Wales (POW) Hospital Oncology Unit, who suggested systemic chemotherapy treatment with Stealth Liposomal Doxorubicin (Dox-SL), which at that time was an experimental drug, and only available to patients as an investigational drug under the Special Access Scheme for compassionate use. After being advised of potential side effects and the process for proceeding with Dox-SL, I gave my signed consent. This was my second

experimental form of treatment after the P24 research trial in 1994, and so in June 1998 I began the first round of chemotherapy (eight cycles) over the next three months, after which I had severe bruising on both legs and smaller lesions on my right leg.

Two months later, an ultrasound revealed deep vein thrombosis (DVT) in the femoral vein of my right leg. Dr Goldstein thought that the clot was associated with KS in my lymph nodes which was causing the bad bruising on my lower right leg, and I spent the next three months doing my own subcutaneous injections to thin my blood.

In the next edition I will write about the period 1999-2004, and struggling with lipodystrophy, more KS and Thalidomide, not going on my Poland and USA trip, PSB highlights, and how I thought I was going to die.

## IN MY OWN WORDS / PAUL MAUDLIN

# 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](mailto:halc@halc.org.au)



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

Have questions about HIV treatments?  
Need to talk about your HIV and health?

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

Positive Life NSW



**Treatments Support for all people living with HIV**  
- Call Positive Life NSW (02) 9206 2177, 1800 245 677 -  
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## FOR MORE DETAILS

Call (02) 9206 2177 or 1800 245 677 or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

Subscribe by email on our website to get our regular updates about all the latest on events, forums, activities, and other ways to participate in Positive Life NSW. Event details are correct at time of printing.

PULL OUT  
FOR THE FRIDGE!

APRIL	DATE	TIME	EVENT	LOCATION
	20	12.15pm-2.15pm	<b>Digital Mentors</b> A peer-based workshop supporting all people living with HIV to build your skills and confidence using computers, mobile devices and the internet.	Sydney
	21	6pm-8.30pm	<b>Peer2Peer</b> For all gay and bisexual men living with HIV	Sydney
	26-29	TBA	<b>Regional Visit</b> Western NSW/ Nepean Blue Mountains	
MAY	DATE	TIME	EVENT	LOCATION
	06	6pm to 9pm	<b>Social Club</b> A monthly meetup in Sydney over a meal for people who identify as heterosexual	Sydney
	10	6.30pm-8.30pm	<b>For Women</b> An online moderated discussion forum every second month for women over 45 years of age living with HIV	Online
	15	3pm to 5pm	Sydney Candlelight Memorial	Sydney
	17	6pm-7.30pm	<b>Positive Conversations</b> A monthly online moderated discussion forum for anyone living with HIV in NSW	Online
	18	12.15pm	<b>Digital Mentors</b> A peer-based workshop supporting all people living with HIV to build your skills and confidence using computers, mobile devices and the internet.	Sydney
	19	12.30pm-2.30pm	<b>Peer2Peer</b> For all gay and bisexual men living with HIV	Newcastle
	23-26	TBA	<b>Regional visit</b>	Hunter-New England/ Central Coast
JUNE	DATE	TIME	EVENT	LOCATION
	03	6pm-9pm	<b>Social Club</b> For all heterosexual people living with HIV	Sydney
	05	Noon-3pm	<b>[+Connect] OutWest</b> For people living with HIV, partners, friends & family	Liverpool
	07	6pm-7.30pm	<b>Positive Conversations</b> A monthly online moderated discussion forum for anyone living with HIV in NSW, over 18 years of age	Online
	14	6.30pm-8pm	<b>The Women's Room</b> A monthly online moderated discussion forum for young women living with HIV	Online
	15	12.15pm-2.15pm	<b>Digital Mentors</b> A peer-based workshop supporting all people living with HIV to build your skills and confidence using computers, mobile devices and the internet.	Sydney
	16	7pm-9pm	<b>[+Connect]</b> For people living with HIV, partners, friends & family	Sydney
	23	6pm to 8.30pm	<b>Peer2Peer</b> For all gay and bisexual men living with HIV	Sydney
	27-30	TBA	<b>Regional visit</b>	Mid-North Coast/ Northern NSW

THIS 2022

# LET'S LEAVE NO ONE BEHIND!



As HIV affects more communities than ever, let's

**LEAVE NO ONE BEHIND!**

The HIV pandemic is not over. HIV is moving into the margins and affecting many communities, including people from culturally and linguistically diverse (CALD) backgrounds, heterosexual people, people born overseas, people from diverse genders and sexualities, and women of all ages. It's time to talk about HIV in all communities, dispel myths, confront ignorance and misinformation about HIV together, so we leave no one behind.



Using Treatment as Prevention, means we

**LEAVE NO ONE BEHIND!**

When newly diagnosed people access HIV treatment as soon as possible, we can't pass it on. Early treatment also improves our health outcomes and quality of life, and reduces our risk of long term health issues. Let's encourage all people living with HIV to use treatment as prevention and leave no one behind.



Let's make HIV testing easier for everyone, and

**LEAVE NO ONE BEHIND!**

With 90% of people who are living with HIV in NSW diagnosed, let's strengthen the awareness of HIV testing and treatment. Anyone who is sexually active can contract a sexually transmitted infection (STI), including HIV. STI testing in NSW is free, anonymous, confidential, and safe. About 10% of people live with HIV for many years without knowing they have HIV. Whether it's fear of finding out or they just haven't had a test, when testing and treatment is delayed, HIV can severely damage the immune system and a person can develop advanced HIV disease (AIDS). It's time we offer HIV testing to everyone to ensure that no one is left behind.



Speak out about HIV stigma and discrimination, so we

**LEAVE NO ONE BEHIND!**

Whether we're living with HIV or affected by HIV, it's time to shine a light on HIV stigma and discrimination. Jokes about AIDS, or comments about 'being clean' are signs of HIV stigma and discrimination, as well as discriminatory assumptions about who is at risk of HIV. We normalise HIV when we remove the barriers to HIV testing, prevention or treatment. Eliminating HIV stigma and discrimination means everyone can make informed choices about their health and no one is left behind.

- + Ask 'could it be HIV?' and test for HIV
- + Leave no one behind, because HIV is everyone's business

- + No shame in getting tested for HIV
- + #NoOneLeftBehind

Visit us at [positivelife.org.au](http://positivelife.org.au)

Positive Life NSW

# POS LIFE IN YOUR AREA?\*

In 2022, Positive Life is planning to travel to the following regional and rural areas as we return to our usual engagement in partnership with NSW Local Health District HARP Units, NSW Sexual Health Services and state-wide services. We run a minimum of four rural outreach sessions per year to meet with people living with HIV throughout NSW.

This will be an opportunity to meet with a peer (someone else living with HIV) to discuss the latest HIV information, and to talk about your needs and experiences living in your regional or rural area.

If you live in these areas or would like to meet when we're in your region, please register with us as soon as you can. This will ensure you receive all the details about the location and times closer to the relevant dates, as well as any updates.

## NEPEAN BLUE MOUNTAINS

26 - 29 APRIL 2022

## WESTERN NSW

26 - 29 APRIL 2022

## MID NORTH COAST

27-30 JUNE 2022

## NORTHERN NSW

27-30 JUNE 2022

## HUNTER NEW ENGLAND

23-26 MAY 2022

## CENTRAL COAST

23-26 MAY 2022

## SOUTHERN NSW

26-29 SEPTEMBER 2022

## MURRUMBIDGEE REGION

26-29 SEPTEMBER 2022

Please call to register with either Andrew Heslop or Craig Andrews on (02) 9206 2177 or freecall 1800 245 677 or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

\* pending covid restrictions or other unforeseen changes

## INTRODUCING ELLEN KIPPER:

Ellen Kipper is the Administrative and Project Support Officer at Positive Life NSW. This crucial position spans across many of the programs at Positive Life, with community support at the heart.

Ellen came to Australia on a work/study visa to expand her English studies for six months after which she decided to study for a Diploma and Advanced Diploma in Business. She comes to Positive Life with a background as a lawyer in Brazil working with mergers and acquisitions for multinational companies, and with a number of languages, fluent in Portuguese, speaking Spanish and English, and learning Italian.

Shortly after COVID hit, Ellen's world turned upside down with the death of her father. "This experience completely changed my outlook in life," she said. "Before I was focused on making money in the corporate world, and getting ahead professionally. After I lost my father, I discovered that life is too short. You know, life's too short to just work for money. I decided to find a meaningful job that could connect with my soul purpose.

"I started to think more about what is satisfying to me, and I realised making a difference to people's lives over the long term, gives me a bigger sense of accomplishment. Through various friends of friends in my studies, I met Jane. From there we had some conversations, and I started to think about my life.

"Being here at Positive Life, I can help in a very meaningful way. Given I speak a number of different languages, I have something very strong to offer Positive Life NSW. When I can translate things for Positive Life into the person's language, I am sharing knowledge with someone. It makes a difference. This is the way I can change the world a little bit.

"For example, I can help other people who need assistance with accessing their medication. With my international student experience I understand the barriers that other people coming to this country experience, and I can help them navigate through the barriers much more easily.

"As a heterosexual woman, I also support our work with women, and groups related to women, and I am also a point of contact and support for heterosexual people."



"In my role as an Administrative and Project Support Officer I work alongside my colleagues to organise events, like [+Connect], forums, workshops and support groups. I ensure we have appropriate venues, I organise the catering and make sure the community is going to be comfortable," Ellen said.

"Positive Life NSW has a wide range of community engagement, support groups and social inclusion events. It's important I ensure we utilise the right spaces and things go smoothly, so people can relax, be happy and enjoy a moment to be socially connected. I work to organise these arrangements so people have a positive experience, build some memories and enjoy their time with each other. I enjoy the opportunity to impact positively someone's life."

Since mid-2021, Positive Life NSW is offering an expanded program of support and social inclusion groups to heterosexual men and women living with HIV, gay and bisexual men living with HIV, and specific supports targeting the needs of women living with HIV. For more details call Positive Life NSW on (02) 9206 2177, or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

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HIV in the Hunter-New England region

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The early days of the HIV epidemic in Sydney was a frightening time. A lethal illness silently targeting and striking down young, healthy promising young men. In this terrifying and dire time, we knew so little about the condition. Who was at risk? Who was next?

A young David Cooper, on a travelling National Health and Medicine Research Council (NHMRC) Fellowship, had already witnessed similar alarm in Boston. It wasn't long after his return to Sydney in 1983, that he was leading the charge to slow or halt the new retrovirus called Human Immunodeficiency Virus.

A year later alongside seven colleagues and allies, as the newly minted Director of the NHMRC Special Unit in AIDS Epidemiology and Clinical Research, Dr David Cooper established one of the world's first prospective studies of HIV in gay men.

The Sydney AIDS Prospective Study (SAPS), also known as the Sydney AIDS Project, ultimately recruited more than 1000 participants drawn from six enrolment centres in Sydney. All were anonymous. There's no list of names.

 Dan Luke Photography



David Polson was one of 386 gay men in the study, who was already HIV positive. He was among the very first group of people tested for HIV antibodies in Australia. As one of the most vocal proponents of 'the first 400' today, David was surprisingly unaware of the significance.

"I wasn't aware of it to be very honest. I was part of the study in 1984 when I tested positive. But I wasn't aware of the notion."

He shared how he first heard the phrase 'the first 400':

"I was at a World AIDS Day function at the Powerhouse which had a timeline which started at 1985. Professor Andrew Carr was there, and I said, 'Andrew, this is wrong, this timeline is wrong. And you know it. You know, I was diagnosed in 1984.'

"He said, 'Polly, you are part of the study, and you are part of the first 400 people who were diagnosed in 1984. That's why it's not counted, because the HIV test was only really approved in 1985. So the study you were on in 1984 hadn't been finalised.'

ONE OF THE FIRST 400

That's why I only found out about that years later. I've been using that phrase ever since. I knew I was in that study, but it was only then that I realised that I was one of a group of 400 at that time."

Despite being part of this pivotal point in history, David knows no one else in person with this shared history, "because none of us knew who we were. No one. Okay. I don't know anyone. The only person I did know started the study up and he's long gone. But who else knows who they are? And how you would find out because this was anonymous. I don't know how you would find out."

He describes a chance meeting again at a 2021 Positive Life World AIDS Day event with another Positive Life community member who disclosed he had also participated in the Sydney AIDS Project study. "I said, 'Oh, you're one of the first 400.'

"I've been told that there are only 28 people who've survived since then, but that could be an approximation even though it came from a knowledgeable voice. There could be more, there could be less."

Reflecting on the anxiety of that earlier time, David says: "at that time, they knew nothing else about it except it was a certain death sentence."

### A Diagnosis

"I was 29 at the time, and it was devastating. I just felt like I'd fallen down this big black bottomless pit. I use the phrase suffocating terror because that's what I felt it was. It was just suffocating. It was just unbelievable.

"At first, I didn't believe the doctor when he said it, yet I knew it was correct. And there was nothing. But it was worse than that. I was told I was HIV positive, but I was also told not to tell anyone else. This was because of the hatred, the vitriol, the fear, and the discrimination. My doctor said I should maybe tell two very close, trusted friends. Just don't let it get out there.

**"So at the age of 29, I was told I was dying. I had this terminal illness. I couldn't tell anyone. There was no counselling. There were no psychiatrists, no support, there was nothing. I walked out of that surgery on my own. I felt dreadfully alone.**

"I actually told four people. My cousin and her husband, they were both actors, in the business. They lost dozens and dozens of friends. I told my very close friend at the time and another female friend who died of breast cancer ten years later. So those are the four people I told, but there was no one else.

"Two weeks after I was diagnosed, my doctor rang me and said, 'there are two medical students who are doing a study about the effects of HIV on people during the seroconversion process. Would you be interested in being in it?' I said, 'Yes, of course! Anything that will help improve the knowledge of this disease!' That study ultimately became one of the most longstanding behavioural surveillance programs among gay men in the world, the Gay Community Periodic Survey."

By 1990, David's CD4 count had fallen from a robust 800 down to 220, just shy of the then-200 marker for an AIDS-defining illness. Brett Tindall, a researcher on the Sydney AIDS Project and a personal friend, encouraged him to seek advice from David Cooper.

"David was wonderful. He was very proficient, very warm. But he was just the doctor until I said, 'Well, I'm Brett's friend, and he said, 'Ah! you're Polly!' And then the dynamic changed from there, the friendship grew and grew.

"He had the most amazing sense of humour. I mean, it was a obviously a very serious time, going through all those drug trials. Still through all the drug trials and until he died, he had the most wonderful sense of humour. So many times we would be falling about with laughter."

### Drug Trials

"First of all, I went on AZT. I was really worried about that, because there was so much negative press about it at that time. David was adamant, he said, 'look your CD4 count is so low, you've got to try this.'

"So I thought, 'Okay'. And I took it home and I looked at it. 'Okay, I'm going to have to take it.' So I started taking it, and it was fine. It was fine for about six months, and then slowly but insidiously, some of the side effects started.

"Until one day, I got to work, and I really honestly thought I was dying. I was so sick. I rang David, and said, 'David, I'm really really ill. I'm think I'm dying.'

"He said, 'Stop AZT, stop, stop, stop it'. So I did. But there was nothing then, until 1991 when DDI came. All the trial drugs were vile, but DDI was the first of the vile ones.

"It came in a tablet the size of probably a 50 cent coin, and it was twice as thick. You had to take two twice a day. There were only two ways you could take them. They were that huge, and you had to put them in your mouth and chew them and swallow them.

“I did it once. It was unbelievably vile in taste. The taste was indescribable. Or you could crush it up with a mortar and pestle and mix it up with a little bit of water. There was a catch with that, because once you’d taken it, you couldn’t eat or drink anything for two hours afterwards. And the rub with that was, because when the two hours had evolved, I’d think ‘Oh, good, I can go and eat something’, but I’d feel so sick and so nauseous with just the smell of food, I couldn’t eat. Consequently for the entire time I was on that trial, I existed only on lunch. Eventually I stopped that because I developed peripheral neuropathy, and the nausea was just too much. So David said, ‘okay, that goes’, and I stopped DDI.

“My CD4s stopped plummeting for a while. I did end up getting down to a CD4 count of 32, so at the time, the drugs didn’t actually help me much. A lot of us who were in the trials simply didn’t make it through, because they were way too sick before they even started. Ultimately I ended up doing 28 drug trials. That was because of my absolute belief that I had to do it. That was my obligation.

“Not every HIV positive person did that. There’s no reflection on them for that. There was a cohort of us who wanted to do them. For 20 years I was on the trials every day. For every trial I suffered nausea every single day, because the drugs were so toxic. They were absolutely vile. Nausea was the most minor of the side effects, although it was horrible. It was so dreadful.

“Still today, I have really bad peripheral neuropathy, so that’s permanent. I also have lipodystrophy. That’s permanent. Some of these side effects like the nausea stopped, once I stopped the trial drugs. When I went off ritonavir, the migraine headaches stopped, the vomiting stopped. Every single drug had its different side effects. But the peripheral neuropathy, and the nausea stayed with me the whole time.”

### **Surviving and being a Survivor**

As a member of the first 400, David Polson is a survivor. He puts his endurance down to a personal gritty desire to reject the conventional medical diagnostic conclusion.

He speaks of a “little voice in my head, that said to me, ‘no, no, you’re not going to die from this. It won’t kill you.’ I don’t know where it came from, but it was there.

“So I said to my doctor, ‘I’m not going to die from AIDS! it will not kill me!’ He pounds the desktop emphatically.

“I literally hit the desk like that. I think that immediate, positive response to the diagnosis set up a strong mindset to help me through. Then I backed that up with a health plan I had. Given the doctors couldn’t give me anything, to my naive, layman’s mind, it made sense, that if the virus attacked the immune system, I had to keep my immune system as strong and healthy as possible.

“I went on a healthy diet. I exercised. I meditated with a meditation phrase, my immune system is strong and healthy. I did visualisation, supplements and minerals, I gave up alcohol, and I kept that regime going right through to the trial drugs.

“I made a very positive effort to survive. I was determined to survive, I was not going to die from it. I can’t say that determination got me where I am today, the drugs did, but I think the two things combined made a very strong recipe for me still being here.

“As a survivor, I feel an obligation. I feel an obligation to tell my story, to educate people, and to persuade as many people as I possibly can to test for the virus. That way we can work towards ending HIV transmission. Getting as many people tested, getting them on medication and those at risk of HIV and not on medication, to be taking PrEP.

“I’ll be very honest. As the opportunity came to jump onto the trials, it was done for a selfish motivation, because I wanted to survive, and it was also done with altruism. If the drugs didn’t help me, I wanted them to be part of medical history that could go on, and the knowledge to help others down the track. So it was 50/50. I wanted the drugs to help me, of course, who wouldn’t? But I also wanted to be part of medical history that could help others, that was another part of the survival thing.

### **HIV stigma and discrimination**

One could be forgiven for assuming David has been inoculated against the haunting impacts of HIV stigma and discrimination. As a well-known figure in the NSW HIV sector, an out gay man, and a potent survivor, he presents a formidable character unbowed to public opinion. Somewhat reticently, David disclosed that he experiences HIV stigma and discrimination more readily in clinical environments than any other.

“I have experienced discrimination. Unfortunately. Even right up to 2015. Let me share three examples. The first one was fairly early on, probably around 1990. I had to go into hospital for something that wasn’t HIV related, and it was in a private hospital.

“I had to tell them that I was positive. As I was being wheeled to the operating theatre, they had six large red labels on my body with a big red, ‘HIV positive’.

“As I was wheeled down the corridor, I was asked probably five or six times, ‘are you HIV positive?’ This wasn’t a corridor full of people, but at the time, it was pretty horrible. Anyway, after the operation I woke up my room, because I heard this noise. I was still pretty groggy and I thought it must be the nurse coming in. I looked up, expecting to see the nurse looking down at me. There was nothing there. But the noise continued, and I wondered, ‘what the hell is it?’ I looked over and noticed my door has been opened, and my food tray had been slid across the floor, and the door closed.

“For three days, that happened every single meal time. My room wasn’t cleaned for three days. The only person I saw was the nurse, and she was heavily gloved up and gowned. I didn’t mind that obviously, but I saw none of the cleaning staff or any of the ancillary staff. That was the first one.

“There were other incidences, but the last one was the most disturbing because it was 2015. I was going in for an endoscopy and colonoscopy. I was in the prep room. The anaesthetist came in and said to the nurse, ‘close and lock that door!’ She said ‘why?’ He said ‘I don’t want anyone coming in and bumping me, and me getting blood all over myself and getting AIDS.’ I just couldn’t believe what I was hearing.

“This from a doctor, my anaesthetist! I couldn’t believe it. I told my doctor, and he said, ‘Oh Polly, you’ve got to report that,’ so I did. But there were other doctors along the line who have said similar things.

“The third example, was this particular incident in 1992. My friend John had AIDS and he was dying. He had the horrible AIDS look, the gauntness, the grey. He was obviously very sick. I had had my appendix taken out, and was recovering, so I was also gaunt, grey, and looked like I had AIDS as well.

“We had a favourite restaurant in Bondi Junction that we used to go to. We went there to have lunch one day. When we got there, the restaurant was packed. The girl at the reception just sort of looked at us. ‘Table for two?’ and so she took us in.

“Everyone in that packed restaurant, there would have been about 200 people, everyone went silent, put their knives and forks down, their glasses down, their coffee cups down, and just looked at us. They stared and stared, as we were taken to a table. They

stared and stared. Eventually, conversation started up again. But you could hear, ‘AIDS...’, ‘...AIDS’, and we couldn’t wait to get out of there. It was just a horror. That’s the worst experience I had.

“But other than that, with my friends, my family, I’ve been extraordinarily lucky with all my colleagues and in all the jobs I’ve had, where they did know I was positive. In the beginning no one knew, of course, but when I did start to come out and disclose, I never had any trouble with anyone ever. I know people who weren’t as fortunate. Personally I’ve been very lucky even though my discrimination came from the medical field, which was very sad.

“It’s so different today. I would like to quote a doctor from St. Vincent’s Hospital. He is one of the leading specialists.

“He said to me, ‘Polly, if I had a choice of a disease, I would take HIV over diabetes or over anything else. The research, the medication, and the treatability of HIV is so good, that is the disease I would choose.’ But it’s not something you could say back in 1984. Couldn’t even think of it!”

### **Planning to live**

Today in his late 60s, David Polson remains active, independent, engaged and warm. He tenaciously and enthusiastically embraces the observation that he’s a man who is very much planning to live, rather than preparing to wrap up a full life.

“It is basic to ourselves, it’s ingrained in our brain. This sense of survival seems stronger in some people. Again, I don’t know what drives it. I don’t have all the answers. I’ve been someone who was relatively well off to being someone who was absolutely penniless.

“I made a definite plan to be where I am today with deliberate choices to build my life. I’ve planned for my present, and I plan for longevity.

“I didn’t plan all the things that had happened, but I plan to be here.”

If you’re one of the first 400 people who were diagnosed with HIV in 1984 and enrolled in the Sydney AIDS Prospective Study (SAPS), also known as the Sydney AIDS Project, please get in touch!

Call Positive Life NSW on  
(02) 9206 2177, 1800 245 677 or  
email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

# SENIORS RIGHTS

**When an older person no longer has the ability to make decisions that affect daily life, such as life changing decisions like whether to have surgery or**

to go into residential care, they can appoint a person or trustee organisation to act on their behalf in managing their assets and making financial and legal decisions. Ideally, this person acts on behalf of the older person, and should not have a conflict of interest in carrying out the decisions. This creates what is known as the “principal-agent relationship”.

A Power of Attorney can be set up which can be either general or enduring, with the point of distinction resting upon capacity. A person can lose and regain capacity. Capacity is fluid, and can change throughout the day.

There are three forms of Power of Attorney. A general power gives the attorney power over finances up until the principal loses capacity, during this time the principal may also redraft or cancel the power granted. An enduring power, however, lasts past the principal's capacity up until they are deceased, and requires the NSW Civil and Administrative Tribunal (NCAT) to remove the attorney. A Power of Guardianship grants the legal right to make healthcare, lifestyle, and medical decisions on behalf of the principal. The agent in this case is known as a Guardian and gives them a wide range of powers over the principal's life, and so the choice of person must be carefully considered. When creating the power, it is important to know the difference between general and enduring, and which one you think is best suited to your situation.

Unfortunately, Seniors Rights Service has seen an increase in elder abuse, more specifically when the agent is abusing their powers. While an agent is legally required to act in the principal's best interest, abuse does happen.

For example:

We recently were contacted by a concerned friend, after a Guardian had sent the principal back to Vietnam, then cancelled the return flight ticket, and placed the principal's house up for sale. We had to apply for an immediate injunction and apply to NCAT to have the Guardian immediately removed. During this time, the principal was stuck in Vietnam. Even with the application being rushed through it took some weeks to have the Guardian removed, and a new one put in place.

Another example was where an Attorney (who was the daughter of the principal) had misappropriated funds up to the amount of \$40,000 from the principal. This was only discovered when bills could not be paid, and one of the other daughters contacted us. We had to make an application to NCAT to have one daughter removed with a suggestion that the other daughter be named Attorney. This took several months to complete.

At Seniors Rights Service we emphasise the importance of choosing someone you trust, as abuse can happen. Unfortunately when it does happen, many people are too ashamed to come forward to seek help. It is still important to come forward and seek help. A good solicitor doesn't judge, and stays focused on helping or resolving the situation. To discuss your specific situation or question, please contact Seniors Rights Service on 1800 424 079 or visit our website at <https://seniorsrightsservice.org.au>





## 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

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[pozhet.org.au](http://pozhet.org.au)

### EMAIL

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[pozhet@pozhet.org.au](mailto:pozhet@pozhet.org.au)

### FACEBOOK

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

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

**You may think of your pharmacist simply as the person who fills your prescription. However, pharmacists play a really important role as a member of your healthcare team.** Pharmacists are medication experts who love to solve medication related problems, and whom you can turn to for guidance on your medications. They can help you understand your medications and the treatment decisions that are being made by your healthcare team. Taking your medication properly is an important part of taking care of yourself. By working with your pharmacist, you can be sure you take your medication safely, effectively, and appropriately to maintain your good health.

Pharmacists can also provide advice on your medications such as how to take them. This will include how frequently and at what times of the day are best, whether to take them with or without food, and also how to store your medications.

For your information, your bathroom medicine cabinet is not the best place to store your medications. Being in your bathroom, it's often a moist and relatively warm place. Ideally, medications need to be stored in a cool, dry place and out of reach of children. Pharmacists can also provide advice on what to do if you miss a dose of your medication. Please check with your pharmacist as this will vary depending on the medication.

Your pharmacist will also be able to advise you on what side-effects you can expect and how to mitigate them; including which side-effects are normal, and what side-effects may be serious and need further investigation.

If you are taking multiple medications, it can become difficult to keep track of them all, and quite overwhelming, confusing and also time consuming. Your pharmacist can provide hints and strategies to help with managing your medication. Taking daily medication can become so routine that you may not specifically remember whether you've taken it or not. Your pharmacist may suggest using pill boxes or dosettes, and may offer to pack all your medication in a Webster-Pak or similar. These devices not only help you organise your medications more effectively, they allow you to easily check whether you have taken your medication. Forgetting to take medication or taking too much can have severe consequences.

Drug interactions are particularly prevalent with HIV medication. Your pharmacist will check for any potential interactions with other prescribed and non-prescribed medicines, vitamins and supplements and also any other medical conditions. This is particularly important for those who take multiple medications and see multiple doctors. Your General Practitioner and your specialists may not always know all the medications the other has prescribed. They may also not be aware of the non-prescription medicines/supplements you may be taking.

One of the best things that you can do is have a list of all the medications you take, and have that on hand for your medical appointments and also show that to your pharmacist when having a prescription filled. This is particularly important if you collect your medications from different pharmacies. Ideally, I recommend clients collect all their medication from the one pharmacy.



While many people living with HIV now collect their HIV medication from community pharmacies, others continue to use specialised services like The Albion Centre, Sydney Sexual Health Centre, Clinic 16 or other hospital-based pharmacies. These services may not have a list of all your medication, and likewise your community pharmacy may not know you are taking medication for HIV. At least one of your healthcare providers should have knowledge of all the medications you take. This is why a list of all your medications is vitally important.

The list can be simply written in a notebook or on your phone and there are now a number of smart phone apps available to help. The NPS 'MedicineWise' app is one such helpful phone app ([www.nps.org.au/consumers/medicinewise-app](http://www.nps.org.au/consumers/medicinewise-app)) It not only records your medications, but can also be used to set medicine and appointment reminders, record allergies, access information on medications and more. It also provides a section where you can write down all the questions you may want to ask your doctor, your pharmacist or your nurse.

Please do not be afraid to ask questions of your pharmacist, whether at your local pharmacy or a specialised service. All pharmacists undergo extensive training and have access to support and more specialised pharmacists, to be able to offer you the expertise and knowledge you need.

Community pharmacists are the most easily accessible healthcare providers to the general public. Pharmacists are bound by a Code of Conduct which protects your confidentiality and you should hopefully feel comfortable in discussing any health-related matters, including but not limited to your HIV status.

Most pharmacists want to be an active member of your health care team, and they can be a huge advocate for you and your health. While you may only see your doctor a few times a year, you hopefully see your pharmacist at least every month or two and they are there to intervene and refer when needed and liaise with other health care professionals.

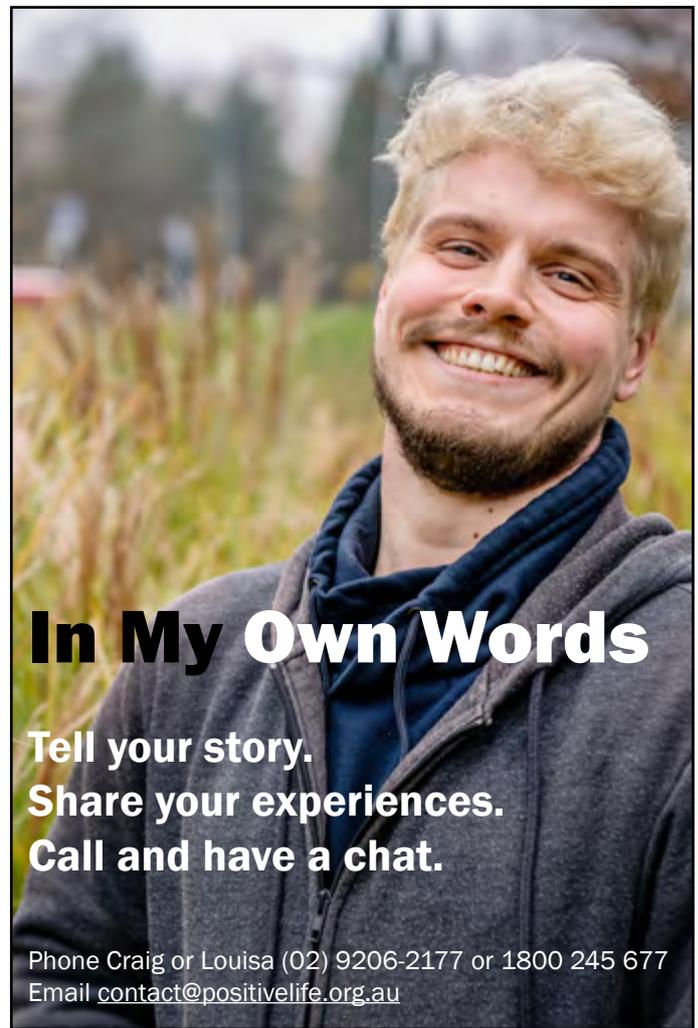
Building a strong relationship not only with your doctor but also with your pharmacist will result in better health outcomes for you.

As a pharmacist, I want to be a partner in your care. I want to see you as healthy as possible and I want you to help me to take the best care of your health and wellness.

So next time you go and pick up a prescription at your pharmacy, whether at a community pharmacy or at one of the specialised Sexual Health Services, have your medication list on hand, stop and have a chat.

And please, ask those questions!

– Bruce Hamish Bowden  
Clinical Pharmacist (HIV)



## In My Own Words

**Tell your story.  
Share your experiences.  
Call and have a chat.**

Phone Craig or Louisa (02) 9206-2177 or 1800 245 677  
Email [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

## Emails to the Editor

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

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

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

Please specify if you want your details  
withheld from publication.

Email Talkabout  
[editor@positivelife.org.au](mailto:editor@positivelife.org.au) or

Write to Talkabout  
PO Box 831  
Darlinghurst NSW 1300

# REMEMBERING



I first became aware of Matthew Wood in the spring of 1986. Our Western Sydney high schools had booked the same venue for the Year 12 formal and, amongst the suburban fashions of the day, the tall blond goth from North Rocks stood out. We met properly a few months later in the Penrith studios of the then-Nepean College of Advanced Education's School of Visual Arts.

Matthew's fashion sense as an art student was less gothic than his high school days, as painting and sculpture required the more durable approach of t-shirts and jeans. The colourful knitted jumper, which would be, far too soon, sewn into his AIDS Memorial Quilt panel, came into its own in the bitterly cold winter of 1987.

As we progressed through the first few semesters of art school, his natural performative nature guided him. He once took a midnight-to-dawn shift at a 24-hour restaurant to hone his Basil Fawlty impersonation on difficult customers; another time, bored with the painting he was working on, he took to it (and, to the chagrin of the lecturers, the studio wall) with an axe.

We had a difficult friendship at times; me, the sensible one, mind set on working out everyone's place in art history; him, the ever-questioning risk taker; but that friction could be inspirational too. After taking snapshots of one of Matthew's temporary installations in the studio's front lawn, I began planning a collaborative project: an artists' book documenting his performances and installations with etchings or lithographs based on my photographs.

The book idea expanded when the second year three-dimensional art class students' were offered a two day exhibition at the experimental Kelly St Kollektiv Gallery in Ultimo in April 1988. With an excessive number of cameras in my backpack, I began to document the exhibition as the works were installed and the performances began. My presence, however, wasn't necessarily appreciated by the other students and, finally, Matthew in mid-performance, blindfolded, grew impatient with the distraction of footsteps and shutters nearby and asked me to stop. End of a promising project.

It wasn't long afterwards that Matthew took an extended break from his studies. I only saw him a few times after that. The last time we spoke was a pleasant conversation when we ran into each other one morning in Albion Street, Surry Hills. The location didn't seem significant at the time. He returned to art school about the same time but his health began to fail.

Matthew Wood died in 1992. His art school degree was awarded posthumously.

PHOTO: Matthew Wood's shadow during a performance at Kelly St Kollektiv Gallery, Ultimo, NSW, 5 April 1988. Photo by Eric Riddler.

# WOMEN'S SPACE

**On Wednesday 9 March, we celebrated the lives of all women living with HIV at the 7th National Day of Women Living with HIV (NDWLHIV).**

The event comes the day after the International Women's Day (IWD), and was created as annual event to celebrate all women living with HIV in Australia as part of an opportunity to highlight conversation topics that relate to our lives and initiate discussion surrounding our needs. It's also an opportunity to come together with our sisters and supporters to make new friends and share our life experience.

Our theme this year, 'Living Well, Beyond Stigma' as explained by Positive Life NSW CEO Jane Costello "provides an important opportunity to shine a light on women living with HIV and the focus on particular issues faced by and of concern to women. *Beyond Stigma* speaks to that exactly. While today many of us are living well with HIV, staying happy, healthy and connected and being proactive in managing our wellbeing, women continue to be largely invisible in our HIV response and live with inequality, in silence and secrecy. Those in turn feed an insidious climate of stigma and discrimination."

We were presented with the latest research findings from three impressive female researchers. Dr. Skye McGregor from The Kirby Institute's Surveillance Evaluation and Research Program provided a presentation on HIV surveillance in Australia, Associate Professor Kathy Petoumenos from The Kirby Institute, Biostatistics and Databases Program spoke about the Cohort of australIian hIv wOmen (or CLIO study) and gave a background rationale on research participation among women and Professor Carla Treloar of the Centre for Social Research in Health, gave us a presentation on stigma.

One thing highlighted from the research and through the presentations was the inequity in the participation of women living in HIV research. Hence the ongoing call for all women living with HIV, to continue to join hands with researchers to overcome gender-specific stigma and discrimination. We encourage all women living with HIV in NSW, to willingly participate in research and surveys like HIV Futures 10, to have our voices heard and included.

To conclude with a quote from Jane Costello, Positive Life NSW CEO:

"Today we have the opportunity to join together as a community to improve the public's understanding of HIV, demonstrate our support for all women living with HIV and look beyond stigma to empower us all to reduce stigma and discrimination and above all to celebrate women's lives, strength and resilience."

At Positive Life NSW, we have a range of bi-monthly online peer groups meeting, specifically tailored for women living with HIV throughout NSW. These are The Women 's Room (women living with HIV under 45 years of age) and For Women (women living with HIV over 45 years of age).

For more details on any of the events or groups in the Women's Space, get in touch with Positive Life NSW by phone (02) 9206 2177, 1800 245 677 (freecall) or email [contact@positivelife.org.au](mailto:contact@positivelife.org.au) to speak to another woman living with HIV.





## Gut bacteria, gut bugs, gut microbiome...no matter what you call it, no doubt you've heard of it. What exactly is gut microbiome?

The gut microbiome is an ecosystem of tiny microorganisms such as bacteria, viruses, and fungi that live in our gut like the insects, animals and trees found in a rainforest. The large intestine, or bowel, has the greatest number of microbiota in our body. Click here to watch a YouTube video and learn more about the human microbiome ([www.youtube.com/watch?v=YB-8JEo\\_0bI](https://www.youtube.com/watch?v=YB-8JEo_0bI)).

Why is it so important? Gut microbiome play an important role in digesting the food we eat and assisting our body to change food into energy and other nutrients we need. They also help balance the immune system and maintain a healthy body weight.

Is my gut healthy? Many factors like poor eating habits, some medications, illness, or stress can compromise gut health. If you are experiencing any uncomfortable gut-related symptoms, get checked by your doctor before you make any changes to your diet.

What can I do to keep my gut happy? A healthy lifestyle is the best first step you can take towards a happier and healthier gut.

To give your friendly bacteria a helping hand:

1. Eat a diverse range of foods.
2. Take part in regular exercise.
3. Get enough sleep. Achieving between seven and nine hours of sleep per night for adults is the goal.
4. Try to manage your stress as much as you can e.g. try mindfulness meditation.
5. Drink around eight glasses of water a day, and more if it is humid or if you've been sweating.

Can I increase the diversity of the good bugs in my gut? The answer is yes! Here are several simple ways to keep your good bugs happy and improve your gut health.

- Eat plenty of plant foods and fibre. Include a rainbow of fruit and vegetables, nuts, seeds, whole grains, lentils and beans in your diet.
- Include prebiotic foods that feed your 'good guys', like chickpeas, lentils, baked beans, brussels sprouts, artichokes, asparagus, garlic, onion, leek, barley, rye bread, oats, and green slightly unripe bananas.
- Get your daily dose of probiotic foods (live 'friendly' bacteria) these include fermented dairy foods like yoghurt, kefir and certain cheeses, and some naturally fermented foods such as sauerkraut, kimchi, miso, and tempeh.

If you have any questions, or need any specific advice on obtaining prebiotics and probiotics for your own specific health needs, or would like to chat to a dietitian, especially if you have gut issues, then please call The Albion Centre on (02) 9332 9600 to make an appointment. Right now, we're offering telehealth (video and phone) appointments.

– The Albion Centre nutrition team

# UNUSUAL RISKS

## One of the most common questions Unusual Risks hears from people living with HIV is, *can I get Life Insurance as a person living with HIV?*

The good news today is, yes you can.

Life Insurance (also called term life or death cover) is designed to protect against the financial impact of your unexpected death by paying out a specified amount of money to your beneficiaries. Unusual Risks has worked with people with a range of specialised medical conditions including well managed HIV and diabetes, and these no longer need to be a barrier to taking out Life Insurance.

People set up [life insurance](#) for a range of reasons. **The possibilities are as individual as you.** Life Insurance can help you be certain your loved ones are provided for, your child's educational needs are taken care of, or the needs of frail aged loved ones or others with higher care needs can continue to be met. Life insurance is also for the living. Most people don't know over 30% of all life insurance payouts are made for terminal illness claims.

If you're in business, business debts can be paid out rather than forcing a fire sale of a business and a loss of its value. It can mean you or your business partners have options around continuing business. You can even take out life insurance if you have unrelated medical issues in addition to your HIV.

In Australia, if you have well-managed HIV and are on HIV antiretroviral medication, you can also now qualify for Crisis/Trauma Recovery cover, Income Protection, and Total & Permanent Disability (TPD) cover.

- [Crisis Recovery](#) insurance is designed to pay an immediate lump cash sum to help offset unexpected medical expenses and help you maintain your financial liquidity in the event of an unforeseen (and usually expensive) medical crisis specified in the policy. This can help stabilise your debt obligations and boost your personal cash flow at a time when you are focused on recovery. There are currently 40+ specific medical conditions covered from heart attacks to strokes and cancers.
- [Income Protection](#) insurance is designed to protect up to 70% of your income after a waiting period of your choice, while you cannot work due to sickness or injury.
- [Total & Permanent Disability](#) insurance is designed to protect against long-term disability and can pay a lump sum after a six-month wait if you become permanently disabled, as defined in the policy and you can no longer work in your current occupation.

The next steps

- *Take action now while you're still insurable.* Waiting for just another year might mean the risk of adding another unforeseen medical event to your list that tips the balance out of your favour.
- *Put a number on it* – having an amount of cover in mind forces you to know what you're working with, not 'just something in case.'

To explore your options, [click here to take the Unusual Risks pre-assessment](#) and [email](#) or call Drew Browne on 1300 137 403.

– Drew Browne





**The 2022 Conference on Retroviruses and Opportunistic Infection (CROI), was held online on February 12-16, for a second year in a row. The 29th CROI brought together leading researchers and clinicians for one of the most important international HIV conferences, with a focus this year on human retroviruses and infectious diseases.**

The main themes at this year's conference were emerging science and advances in treatment and prevention, HIV and ageing, and progress toward a cure for HIV. Results of the Anal Cancer/HSIL Outcomes Research (ANCHOR) study were presented. Findings established that screening for precancerous anal cell changes, and treating them early, lowers the risk of progression to anal cancer in people living with HIV by 57%. The lead researcher, Joel Palefsky, MD, Professor of Medicine at University of California, San Francisco said that the data supported a recommendation for screening and treatment to be included in the standard of care for people over 35 years of age who are living with HIV.

Researchers from the National Institute for Infectious Diseases in Rome presented findings from a cross-sectional analysis of the neurocognitive profiles of 1365 people living with HIV and taking HIV antiretroviral therapy, to evaluate the impact of therapy on their neurocognitive deficit. Findings from the study demonstrated there was a marked reduction in the overall prevalence of HIV-associated neurocognitive disorder (HAND) among people living with HIV. These lower rates of HAND were associated with the use of dual HIV therapies and integrase inhibitor-based regimens.

ViiV Healthcare presented data demonstrating further evidence that administration of the long-acting injection of Cabenuva (cabotegravir and rilpivirine) every two months was just as good at maintaining viral suppression as those who received it every month, even though the less frequent schedule appeared more likely to experience treatment failure. The regimen involves two separate injections. One is the integrase inhibitor cabotegravir, and the other a non-nucleoside reverse transcriptase inhibitor rilpivirine, both of which are administered into the buttocks.

Gilead Sciences presented the latest results for the new long-acting injection Lenacapavir that could potentially be administered every six months. While the Lenacapavir study is quite small (n=182) and still in a research phase, findings after one year continues to show good viral suppression both in people newly diagnosed and people with multidrug resistant virus.

CROI also heard of the widely reported case of the women whose HIV was cured through a stem cell transplant from a donor who had the rare genetic mutation which is immune to HIV (CCR5), and another strategy dubbed 'kick and kill', in which memory cells are kicked awake followed by a broadly neutralising antibody to stimulate the immune system to kill off the now-awakened infected cells.

The ever-present COVID-19 also made an appearance in the research profiles, with the news that COVID vaccine non-response appears more likely in people with advanced HIV disease. The good news was that COVID severity may be somewhat reduced among older people living with HIV who are taking tenofovir disoproxil fumarate (TDF), relative to other NRTI treatment regimens.

# CONFERENCE FINDINGS



The voice of all people living with HIV

Positive Speakers Bureau

Employment + Vocational Support

HIV Health Promotion

Advocacy + Policy

Peer Navigation + Support

Talkabout Magazine

Housing Support

a[STARTx]

Ageing Support

Treatments Information + Support

Social Support

Aboriginal Health Program

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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.

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

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