

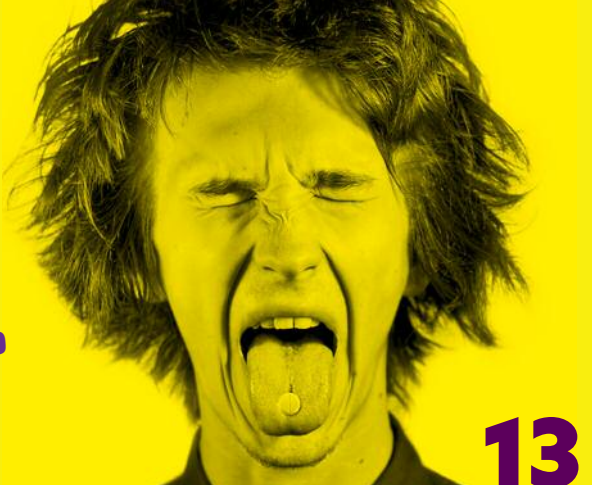
positiveliving

FOR PEOPLE LIVING WITH AND AFFECTED BY HIV | SPRING 2018



THE QUEER
REVOLUTION

WHILE I WAS
INITIALLY
HAPPY TO BE
GIVEN AZT,
I SOON
DISCOVERED
THE NASTY
DOWNSIDE TO
TAKING IT.



13

4 TIPS
TO CONQUER
LONELINESS

18

Taking that first pill

POSITIVE VOICES 16-17

TRENDING NOW
HEMP SEEDS

18



OKAY TO HATE 5



REALITY CHECK

The epidemic is far from over

PLUS

PERSONAL
IMPRESSIONS

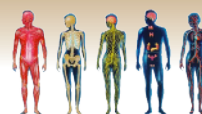
6-9

THE INFLUENCERS
CHARLIE
TREDWAY

18



The SKIN



HIV+THE BODY 12

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Concerns grow over MHR

Amid community concerns — particularly among vulnerable populations such as people with HIV, sex workers, and injecting drug users — the federal government's digital health database, My Health Record, has been referred to a parliamentary inquiry to examine potential security weaknesses and third-party access to sensitive information.

While federal health minister Greg Hunt has vowed to implement legislative changes that will ensure government and enforcement agencies will need to obtain a court order before accessing people's electronic data, serious privacy concerns remain — not least of all the revelation that a person's e-record can store their DNA.

In an effort to allay fears, the Australian Digital Health Agency said — much like any other health information stored on the system — users would be able to choose whether or not they wanted genomic data uploaded to their My Health Record account. Meanwhile, privacy experts voiced outrage. “Why didn't we know about this?” asked Bruce Arnold of the University of Canberra. “The lack of information only fosters fear and distrust.”



Indeed — according to a survey — 90 percent of sex workers are planning on opting out of the My Health Record scheme due to fears of stigmatisation and criminalisation. “Sex work is

criminalised in a number of states; working as an HIV-positive sex worker is criminalised in a number of states,” said Cameron Cox, CEO of the Sex Workers Outreach Project. The message is clear: the risk of prosecution is real.

To further compound people's concerns, the My Health Record privacy framework has been linked to a failed UK model which was cancelled after it was revealed that drug and insurance companies were able to buy data. Describing the similarities

between the two schemes as “extraordinary”, UK privacy expert Phil Booth said: “The parallels are incredible ... almost like a rewind or a replay.”

Although the My Health Record system allows users to block data from being accessed by third parties, Booth said the same protections were touted in the UK. “I can say that any safeguards that are promised will be routed around or ignored. On the basis of the evidence of what happened in England, it's not worth the paper it's written on.”

Australians have until 15 October to opt out of the My Health Record scheme — if an individual fails to do so, a record will be created automatically.

Read the pros and cons of My Health Record [here](#).

HIV rates rise among indigenous

Researchers have called for immediate action to address a spike of new HIV diagnoses among Australia's indigenous population.

Latest data shows a 33 percent rise in new cases of HIV among Aboriginal and Torres Strait Islander communities. Meanwhile — among non-indigenous Australians — rates of HIV have decreased by 22 percent.

In a statement, the researchers said: “There is a general consensus that [HIV] could rapidly transition to a concentrated epidemic among Aboriginal and Torres Strait Islander people, as has occurred among First Nation people in Canada.”

According to data, a higher percentage of Indigenous people are unaware that they are living with HIV than their non-indigenous peers. Also, a higher percentage of diagnoses are being presented among injecting drug users and heterosexuals than in non-indigenous communities. Women in particular are being disproportionately affected, with rates of HIV three times higher than those for non-indigenous women.

Calling an immediate response a “national priority”, the researchers said: “It is clear that the current approach needs strengthening and modifying in terms of reach, potency and sustainability to connect different groups within the Aboriginal and Torres Strait Islander population.”

Spitting story slammed

Queensland's *Courier Mail* newspaper has been criticised by HIV advocates for its lazy and stigmatising reporting of a spitting incident during which the alleged offender claimed he was HIV-positive. The incident occurred during an altercation between a patron and a security guard outside a Brisbane hotel.

The Courier Mail's coverage of the case — which included the headline “HIV-infected man spits in security guard's face” — was subsequently slammed on social media. Through Twitter, activist Joshua Badge said, “Shame on *The Courier Mail* for this stigmatising hack piece. It is impossible to acquire HIV through saliva.”

Replying to the author of the article, Mary Rose wrote: “You need to become basically informed about HIV and infection. This is shockingly irresponsible.”

Meanwhile, Ian Mackay wrote,



“Shame on *The Courier Mail*” — Joshua Badge, one of many activists to condemn the coverage

“Why on earth publish such a confusing headline instead of one that clarifies the man's claim as wrong?” And Harry Cook wrote, “Enough of this fearmongering, lazy bullshit. It's lame.”

The case follows the [Expert Consensus Statement](#) presented at AIDS 2018, through which some of the world's leading scientists put forward the view that — in the era of U=U — there is no scientific basis to criminalise HIV (see page 6).

“Prosecutions for non-disclosure, exposure or transmission of HIV frequently relate to sexual activity, biting, or spitting. This includes instances in which no harm was intended, HIV transmission did not occur, and HIV transmission was extremely unlikely or not possible. This suggests prosecutions are not always guided by the best available scientific and medical evidence,” the statement reads.

Despite the fact that the virus cannot be transmitted through saliva, there are still some Australian states and territories that require people who spit on or bite police officers to undergo an HIV test.

Asian men at greater risk

Increased access to PrEP and targeted education is urgently needed, say experts, to stem the rise of HIV among Asian gay men in Australia.

While rates of HIV among Australian-born men are on the decrease, diagnoses for gay men born in Southeast Asia have risen sharply in recent years. NSW data, for example, shows there were 29 percent more new HIV cases among men born overseas in the first quarter of the year than during the previous five years.

Criminalisation of homosexuality in migrants' native countries — such as Indonesia — is cited as an underlying causation for the trend (see page 5). "You're going to have a very different perspective about accessing healthcare, particularly to get a HIV test or talk about



sexual health for fear of some sort of reprimand," said ACON CEO Nicolas Parkhill.

Medicare ineligibility is also a factor in the rise in rates among Asian-born gay men. "We're really keen to work with all governments on what might be an access scheme for people who we certainly know are high risk and who can't afford or get access to things like PrEP or treatment," said Parkhill.



Fewer deaths from Hep C

Groundbreaking, affordable treatment has led to a 20 percent decrease in deaths from hepatitis C, new data from the Kirby Institute reveals.

The dramatic decline — based on NSW data — is the first large-scale evidence of the impact new hepatitis treatments are having on liver-related deaths in Australia. "This decline reflects the high uptake of direct-acting antivirals (DAAs) among people with hepatitis C, particularly those with more advanced liver disease," said the Kirby's Professor Greg Dore. Since 2016, around 60,000 Australians have been treated with the highly effective DAAs. "For the first time, we are seeing fewer people dying of hepatitis C-related causes," said Dore.

With DAAs listed on the Pharmaceutical Benefits Scheme,

Australia is one of only a few countries in the world to offer hepatitis C treatments at low cost. People who inject drugs are a key population for hepatitis treatment and among this group Kirby research shows a decline in infection rates from 43 percent to 25 percent. Hepatitis NSW CEO Stuart Loveday described the decline in the numbers as "truly fantastic news". "We now need to raise awareness levels and mobilise the people who are hard to reach and hard to engage."

Melanie Walker, CEO of the Australian Injecting and Illicit Drug Users' League, agrees. "It is no time for complacency. With only 30 percent of people living with hepatitis C in Australia having been treated, we will need to focus on making treatment more accessible to marginalised and at-risk groups."

MyLife+ app scores upgrade

Two years since its launch, MyLife+ is now recognised as the go-to app for people with HIV in Australia.

The app's core goal is to empower people with HIV to take control of their health and wellbeing, and more easily manage their overall quality of life.

Feedback from users collected since September 2017 shows 82 percent of respondents agreeing that the app has helped them to proactively manage their health and wellbeing; 75 percent said that it has helped them better understand HIV and treatment options; while 70 percent agreed that it has helped them have better conversations with their healthcare professional.

The success of MyLife+ is largely attributed to the involvement of the positive community in the development process. Focus group participant Craig Burnett told PL: "It was empowering to be invited to contribute to the MyLife+ app. I believe it is important for positive people to be involved in shaping initiatives within the positive community."

It was empowering to be invited to contribute to the app. It's important for positive people to be involved in shaping initiatives within the positive community.

The latest version of MyLife+ includes a new home screen with intuitive in-app reminders, optional data protection, and fingerprint or Face ID login. The upgrade also includes Australia's first short quality-of-life scale. Called PozQol, the scale allows users to receive a quality of life score by answering just 13 questions.

Download MyLife+ today through Google Play or the Apple App Store, or find out more [here](#).

Transmission is still zero

The Australian-led Opposites Attract study continues to contribute to global evidence, demonstrating that when an HIV-positive partner is on daily antiretroviral therapy and has an undetectable viral load, the risk of sexual transmission to the HIV-negative partner is effectively zero.

"Opposites Attract shows that HIV treatment as prevention works," said the Kirby Institute's

Dr Benjamin Bavinton, the study's project leader. "Not only is this information vital to inform HIV prevention in gay, bisexual, and other men who have sex with men, it provides strong evidence to help dismantle some of the stigma still associated with HIV."

Researchers tracked the sexual behaviour of 343 couples in Australia, Brazil and Thailand over a four-year period — specifically acts of condomless

anal intercourse — along with testing the HIV-negative partner for HIV, and the HIV-positive partner's viral load. Despite more than 12,000 acts of condomless anal intercourse over the length of the study where the HIV-negative partner was not taking PrEP and the HIV-positive partner was virally suppressed, there were no new HIV infections due to sex between partners.

Since it was first presented in

Paris at last year's International AIDS Society Conference on HIV Science, the Opposites Attract data has added to a previously limited body of evidence in this area. "These results form a significant part of the evidence base for the international community-led U=U campaign, which highlights the fact that people living with HIV can now live long and healthy lives, with effectively zero chance of sexually

transmitting the virus to others, provided their viral load is undetectable due to effective antiretroviral treatment," said Professor Andrew Grulich, the study's chief investigator.

The study has also been cited in the Consensus Statement endorsed by HIV global leaders and organisations on the risk of sexual transmission of HIV from a positive person who has an undetectable viral load.



TOP LEFT The atmosphere for LGBT people in Indonesia has become increasingly hostile BOTTOM LEFT Men are arrested for attending a 'gay party' RIGHT A young man is publicly caned

Okay to hate

Indonesia's LGBT population is under attack. As Christopher Kelly reports, forcing the community into the shadows is having a devastating impact on the country's HIV response.

On 28 March 2017, neighbours forcibly entered an apartment in the Aceh province of Indonesia. Inside were two young men. They were abducted and taken to the local police station. Two months later, the men were caned in front of a jeering crowd of more than a thousand people. They received 83 strokes each. Their crime? Engaging in consensual sex.

While Aceh is unique in that it is under ultra-conservative Islamic rule, systemic persecution against the LGBT community has become commonplace across all of Indonesia over the past couple of years. In 2017 alone, at least 300 people were targeted by police because of their sexual orientation and gender identity – the highest number recorded.

As well as acts of vigilantism, LGBT spaces are raided on a regular basis and social media accounts of those suspected of being LGBT are monitored by

police. Authorities forcibly test gay men for HIV and release the results, and members of the LGBT community face public humiliation and widespread shame. All the while, politicians stoke the anti-gay hysteria by calling for criminal penalties for LGBT activities.

"The government and the police have made it abundantly clear that it's perfectly OK to hate LGBT people and to act on it," said Kyle Knight, an LGBT researcher at Human Rights Watch (HRW). According to a recently released [HRW report](#), the hate campaign being waged against the LGBT community is proving catastrophic for public health.

Figures from UNAIDS back up the claim: HIV rates among men who have sex with men (MSM) in Indonesia have rocketed five-fold in recent years, from five percent in 2007 to 25 percent in 2015. In major cities such as Denpasar and Jakarta nearly one in three MSM are living with HIV. Meanwhile, HIV prevalence among transgender women in 2015 was 22 percent. This spike in HIV diagnoses, says the HRW report, "can be traced to a nationwide anti-LGBT moral panic".

Cultivated for cynical political purposes, the witch hunt of Indonesia's LGBT community has forced people underground and into the shadows. "Stigma and discrimination against populations at risk of HIV, as well as people living with HIV, have discouraged some HIV-vulnerable populations from accessing prevention and treatment services," says the report. Indeed, only 50 percent of gay men in Indonesia have tested for HIV and – of those diagnosed – only nine percent are on antiretroviral drugs.

Many of the LGBT spaces that have been raided were used for outreach purposes. Their closure has already had a detrimental impact on the local response. "It is devastating that clubs have closed – they were the only places where we could find the community," an HIV outreach worker in Jakarta told HRW. "Clubs were hotspots for us because we knew that even the discreet guys felt safe about their sexuality inside, so we could do HIV testing and they wouldn't be scared to participate."

Another outreach worker told HRW that "over the past two years, MSM have started distancing themselves from us"

and also noticed that "we see more and more [MSM] waiting to get really sick before they seek help or even ask questions about HIV". An HIV counsellor at a community health centre in Yogyakarta confirmed the disturbing trend. "Most of the MSM we see these days have at least mild symptoms when they come in for their first HIV test."

Since mid-2017, it has become increasingly difficult for outreach workers to conduct even the simplest conversations about HIV. "It's becoming more and more work to convince them of the basics – condoms, testing – because of the moral panic," said an outreach worker in Jakarta. Such is the climate of fear that condoms have become illicit items that – if discovered by police – can be used as evidence that "deviant" sexual activity has taken place. "People refuse condoms these days. They tell me that keeping them in your private room is dangerous."

As a result of the draconian measures, HIV organisations and sexual health clinics are operating in secrecy. Jakarta's main sexual clinic has no website and its existence is spread by word of mouth out of fear it will be attacked by vigilantes. "We like

to keep [the clinic] known for only those who need it," said its chief doctor.

In the conclusion to its report, the HRW urges the highest ranks of the Indonesian government to display "the courage to confront the anti-LGBT moral panic". While Indonesian President Joko Widodo has publicly defended the rights and dignity of LGBT Indonesians, his statements have not been followed through with moves to stop discrimination and abuse. President Widodo, for example, has yet to take any steps to deter senior government officials from engaging in hate speech or to stop the police from conducting discriminatory raids on LGBT venues.

If the present climate persists, it is feared that the HIV epidemic among Indonesian MSM and other marginalised groups will become unmanageable. "Unless certain steps are taken, this will spin out of control," said Knight. "The Indonesian government's failure to address anti-LGBT moral panic is having dire consequences for public health. The government should recognise that its role in abuses against LGBT people is seriously compromising the country's response to HIV."



A REALITY CHECK

MORE THAN 16,000 DELEGATES FROM 160 COUNTRIES GATHERED IN AMSTERDAM FOR THE BIGGEST HEALTH-RELATED EVENT IN THE GLOBAL CALENDAR – THE INTERNATIONAL AIDS CONFERENCE. REBECCA BENSON PROVIDES AN OVERVIEW.

Another even-numbered year, another International AIDS Conference — the 22nd to be precise. Held amid the canals and bikeways of Amsterdam, AIDS 2018 featured nearly 3,000 abstracts, dozens of satellite sessions, pre-conference programs, demonstrations, and community events. The theme — **Breaking Barriers, Building Bridges** — alluded to the core message of this year's conference: **we're not done yet.**

The stats speak for themselves: there were 1.8 million new cases of HIV in 2017. Combine these spikes in new cases in key populations with a dramatic fall in funding and you have what has been described as an “epidemic in

crisis”. A rising tide of populism, and questionable political commitment and leadership are also causes for concern. “Relying on the current pace is insufficient,” said President of the International AIDS Society, Linda-Gail Bekker. “We are not seeing the downturn that we need to be able to reach the goal of ending the global pandemic by 2030.”

More than half of major donor governments decreased their funding commitments in 2017, leaving a US\$6 billion shortfall that could lead to millions of unnecessary HIV infections and deaths, experts warned. Predictably, the groups most at risk are those on the fringes such as the LGBTI community, sex workers, people who inject drugs,

and young people — women in particular. “They aren’t getting proper services because of policy, prejudice and stigma,” said Bekker.

The gloomy forecast turned minds to formulating a prevention agenda. With PrEP proving effective in reducing rates of HIV in North America, Western Europe, and here in Australia, discussions were held about the feasibility of rolling the anti-HIV drug out in low-income countries. Meanwhile, findings of a French study presented at conference strongly suggested that PrEP is highly effective at preventing HIV whether taken daily or intermittently. But of course PrEP on its own won’t end HIV. A broad range of interventions needs to be considered and numerous barriers overcome if we are to curb the epidemic, delegates were told.

One major barrier is criminalisation. Recognising this, 20 of the world’s leading scientists used AIDS 2018 as a platform to refute the rationale for laws that criminalise HIV

transmission. In an **Expert Consensus Statement**, it was argued that laws that criminalise non-disclosure, exposure or transmission ignore the science around HIV, i.e., (and repeat after me) a positive person on effective treatment with an undetectable viral load cannot pass the virus on through sex. “HIV criminalisation laws are ineffective, unwarranted and discriminatory,” said Bekker. “In many cases, these misconceived laws exacerbate the spread of HIV by driving people living with and at risk of infection into hiding and away from treatment services.” (See page 5)

Here at home, HIV orgs applauded the move. “The National Association of People with HIV Australia (NAPWHA) welcomes the release of the Consensus Statement and hopes that the document will persuade prosecutors and courts to carefully appraise current scientific evidence when considering criminal prosecution of people with HIV,” said NAPWHA



PL’s man on the ground, Adam Ehm (left), with Swiss Statement co-author Pietro Vernazza

President Cipri Martinez.

The comprehensive health and wellbeing needs of people with HIV were also much discussed at AIDS 2018. Integration, delegates were told, was key. As WHO Director-General Tedros Ghebreyesus told delegates attending the opening session: “We have not truly helped a child if we treat her for HIV but do not vaccinate her against measles. We have not truly helped a gay man if we give him PrEP but leave his depression untreated. We have not truly helped a sex worker if we give her STI screening but not cancer screening. Universal health coverage means ensuring all people have access to all the services they need, for all diseases and conditions.”

Perhaps responding to growing criticism over recent years, organisers were keen for young people to take centre stage at this year’s conference. Indeed, they accounted for more than one-third of the submissions presented at AIDS 2018. And for good reason: young people are disproportionately affected by HIV/AIDS globally. AIDS is the number-one cause of death for individuals aged between ten and 24 years in Africa, and the second leading cause of death worldwide. Young women have double the chance of acquiring HIV than young men, and – between 2000 and 2015 – young people remained the only key population group experiencing increases in AIDS-related deaths.

In order to highlight youth and HIV, multiple platforms were provided for positive young people to share their stories. Dozens of youth-focused programs and events were held, allowing young people from around the world to network and collaborate. “I lost count of the number of up-and-coming positive young leaders that I heard speak with passion and conviction,” said Australian delegate – and PL’s man on the ground – Adam Ehm. “Their voices and actions are crucial to ending HIV.”

The PARTNER 2 findings were also warmly received and reconfirmed that the chance of an HIV-positive person with an undetectable viral load transmitting the virus to a sexual partner is scientifically equivalent to zero. The second phase of the PARTNER study recruited only gay men in serodiscordant relationships (one HIV-positive, one negative). Out of 77,000 acts of condomless sex, PARTNER 2

recorded no transmissions of HIV. “We looked so hard for transmissions,” said chief researcher Alison Rodger. “And we didn’t find any.” Further proof – if any was needed – that undetectable equals untransmittable.

The U=U message loomed large at AIDS 2018, evidence that the campaign has energised advocates around the world. At the opening of a U=U pre-conference, world-renowned immunologist

associated with undetectable status is following six months of consistent adherence to ART.

- Nothing in life is risk-free. It’s up to individuals to weigh up the cost-benefit ratio of various activities in an evidence-informed way.

Also at the U=U event, Dr Pietro Vernazza – one of the authors of the Swiss Statement –

Guide for Clinicians to Discuss U=U, which aims to provide information to healthcare providers about how HIV treatments prevent sexual transmission of HIV. “This document needs to be disseminated as widely as possible to PrEP prescribers, sexual health physicians, HIV clinicians and other health professionals,” said Ehm. “HIV-positive community members cannot be expected to be the sole educators working to

rights, treatment access for all, and against HIV criminalisation. “I felt privileged and humbled to be among them,” said Ehm. “I felt a profound connection to my community, and knew that I was part of something very special in Amsterdam.”

Meanwhile, someone very special was honoured at AIDS 2018 – Professor David Cooper, who passed away earlier this year. On behalf of Australia’s community organisations, NAPWHA’s executive director, Aaron Cogle, was among those to pay their respects. “David’s personal devotion to the people most affected by the virus was extraordinary,” said Cogle before a packed hall. “Patients were his focus. They gave him much inspiration over the years – and much humility. For that, we loved him.”

Of course, no International AIDS Conference is complete without the bling of celebrity and AIDS 2018 was no exception. Bill Clinton pleaded with the world not to abandon the fight to end HIV/AIDS; Conchita spoke of the stigmatisation of people with HIV; Charlize Theron spoke passionately about the devastating impact the epidemic has had on Africa; while Elton John and Prince Harry united to launch a billion-dollar project aimed at delivering effective HIV/AIDS services for men who have sex with men.

And once again the Global Village proved to be a diverse and vibrant space where communities from all over the world gathered to hang out and share life experiences. As well as a networking zone, the Global Village provided a hub for cultural activities, live performances, and art exhibits. A highlight was the Disclosure Sofa, a cultural engagement platform where people – regardless of HIV status – spoke out against stigma and discrimination.

While previous conferences have ended on a congratulatory high, AIDS 2018 closed with a reality check: if barriers – such as stigma, discrimination and criminalisation – are not urgently addressed, and if key populations continue to be sidelined, then progress will be further undermined. To avoid catastrophic outcomes, the global response needs to be recalibrated and governments re-engaged. Delegates were told in no uncertain terms that when it comes to ending HIV: we are far from there and the epidemic is far from over . . .



Anthony Fauci outlined all of the data to date associated with undetectable viral load and risk of transmission:

- U=U . . . but only when U really is U (undetectable). Achieving and maintaining an undetectable viral load is key for positive individuals.
- There is some risk of HIV transmission throughout the first six months following ART initiation. The message of effectively no risk

received the Lifetime Achievement in Health and Human Rights award. “The room erupted into a standing ovation,” said Ehm. “Ten years after the Swiss Statement, and following extensive global criticism, we now know that the information contained in this document was accurate and ahead of its time. It was such an incredible privilege to meet him in person.”

The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine launched a

get the U=U message out into the wider society.”

After all, having people with HIV understand U=U is all well and good; the next step is to take the message out on to the streets. Which is exactly what happened on the day of the protest march. “Hundreds of people gathered at Amstelvelld square where the bright colours of the U=U T-shirts immediately stood out for all to see,” said Ehm. As well as promoting U=U, activists made their voices heard for sex workers’



NO INTERNATIONAL AIDS CONFERENCE WOULD BE COMPLETE WITHOUT COMMUNITY ENGAGEMENT. FOUR AUSTRALIAN ACTIVISTS AND ADVOCATES SHARE THEIR

IMPRESSIONS

TOBIN SAUNDERS

As an HIV-positive man of 27 years I temporarily felt in the majority in Amsterdam and my self-esteem was given a lovely boost. Myths, misunderstandings and ignorance often mean HIV-positive people feel like damaged goods. To feel welcomed and validated is life affirming.

A pre-conference event I attended — which focused on the developing, innovative solutions to the challenges faced by young gay and bisexual men around the world — served as a reminder of the huge challenges LGBT people face under the spectre of criminalisation, and how the **UNAIDS 90-90-90** goals cannot be realised while human rights and structural barriers remain in place.

Another highlight — the Global Village — saw thousands of people sharing their work, stories and strategies to bring an end to HIV. The high visibility of

sex-worker advocates from around the world was a reminder that the fight for legal frameworks and protections is complex and protracted. The art exhibits — especially Condom Couture — were a winner; as was the Disclosure Sofa, a community cultural engagement activity that provided a platform for people — regardless of HIV status — to speak out against stigma and discrimination.

CONFERENCE TAKEAWAY
At AIDS 2018 I was reminded that affordable HIV treatments are not universally available. I feel privileged and lucky to live in a country that subsidises my life-saving antiretroviral drugs.

CHARLIE TREDWAY

The AIDS 2018 theme was “Breaking Barriers, Building Bridges”, and two years out from failing the lofty first goal of the UNAIDS 90-90-90 targets, what

has become alarmingly clear is that we will continue to be a long way off turning the tide of this global pandemic until we are able to ask ourselves whether we are truly breaking barriers or creating more of them?

Expressing thoughts on how we would be unable to end HIV transmissions without including those people that can very easily be left behind, Ted Cook of the transgender advocacy group PASH.tm told me: “One of the chilling statements out of the discussion about 90-90-90 was that someone said, ‘Actually, I think it has been decided that we are already the 10-10-10.’ And that spoke volumes to me — it’s okay for trans people to be left behind.” Such thoughts were echoed among other delegates from vulnerable populations. “I attended some sessions where the communities most affected were not at the core of the discussions. It’s the same story time and time again,” said Sergio Lopez of SOMOSGAY.

And then there was the moment a plenary moderator called a passionate speech delivered by a positive woman a “polemic” before going on to say, “now for something less dramatic” as he introduced a session on HIV criminalisation! That’s when you look at your neighbours seated around you with your jaw open aghast and realise just how far off course we are to meaningful engagement and equity. Building bridges indeed.

That’s not to say that some tremendously important news didn’t come out of the 22nd International AIDS Conference. When the results of the **PARTNER 2 study** were announced, the buzz around U=U reached fever pitch. Here we are with yet more incontrovertible evidence that there is nothing to fear and zero risk of sexual transmission from a HIV-positive person with a sustained undetectable viral load. Rightly so, it was a cause for celebration.

As was the **Expert Consensus**

Statement signed by leading HIV researchers and public health officials worldwide declaring HIV criminalisation laws “ineffective and unwarranted”. “Rather than reducing HIV infection or protecting anyone, these ill-conceived laws most likely make the epidemic worse by perpetuating stigma,” read the statement. This truly is good-quality, high-profile stuff. Of course, for people at the coalface of HIV, working in the community, this was confirmation of what we have been saying for years.

Another hot topic of conversation at AIDS 2018 was AIDS 2020, which America is hosting. In a time when the Trump administration is rolling back rights and placing restrictions on marginalised communities, it leaves a sour taste in the mouth that — due to US visa restrictions — our most vital advocates and activists will be shut out of the San Francisco and Oakland AIDS Conference.



LEFT Young people with HIV are our future leaders ABOVE Feeling the joy in the Global Village ABOVE RIGHT The buzz at AIDS 2018 around U=U reached fever pitch

Sex worker and advocate Paul-Gilbert Colletaz had this to say: "It is unacceptable for the conference to move to a place that excludes sex workers living with HIV and people who use drugs with HIV."

These conferences are a strange beast. And AIDS 2018 was no exception — inspiring and invigorating with one breath, and wholly frustrating in the next. Reflecting back on my week in Amsterdam, I suppose that this sentiment sums up the history of the broader HIV movement: global activists and advocates and people working in the trenches of the communities most at risk, struggling to be heard or demanding more than tokenism. We're over three decades into this battle and still people with HIV

are having the same conversations around equity, amplification and how human rights violations drive and exacerbate new transmissions. Is it any wonder that tempers are flaring?

CONFERENCE TAKEAWAY

What I discovered at AIDS 2018 is that true engagement is found in the community sessions in the Global Village, and at the protest actions, or during the conversations held in corridors or in transit as you traverse the conference venue.

ADAM EHM

There was a considerable amount of hype surrounding the AIDS 2018 U=U pre-conference, and

considerable interest from delegates. I attended the event believing it would simply reinforce what I already knew about this global campaign, but was pleasantly surprised with the content presented — and extremely grateful to be present among some of the world's greatest and most respected individuals working within the HIV sphere.

Many countries around the world currently criminalise HIV, injecting drug use, sex work, homosexuality, and remain hostile to key populations. During my week in Amsterdam, I met community members who spoke of the violence they'd faced in their countries and the fact that often they need to choose between their lives and their

identity. One trans individual from Uganda explained that — through being an activist — it's possible to be arrested and simply disappear. Other community members explained that they can be forced out of suburbs where they live and work when individuals find out they are seeking out HIV services, and that it can be increasingly difficult to find landlords who will offer HIV health providers space.

I also engaged with many young people at AIDS 2018. What became clear was that appropriate services for HIV-positive youth improve overall health outcomes — including quality of life. Young people commented that they expect services to be accessible, acceptable, appropriate, effective, non-judgemental, and confidential.

These inspirational young people stressed that peer support is critical. This made me think about what that means for HIV-positive young people in Australia. How do we ensure that services these young people get to access are appropriate to their needs? How do we get HIV-positive young people to meaningfully engage at all levels of the response as we work towards future goals?

CONFERENCE TAKEAWAY

Community organisations need to create space for our future leaders, and to encourage young people to be the best activists and advocates they can be.

BILL PATERSON

I had the immense privilege of being part of the Trans Action pre-conference. To hear that several women who had scholarships to attend AIDS 2018 were refused visas was a sobering reminder of the daily struggles of the trans and gender diverse communities (TGD) — struggles of such significance that we cannot dislocate them from the HIV response.

A strong and persistent message calling for the meaningful involvement of the TGD communities in a HIV response — with concrete examples of how this truly works — was a delight to experience, but the most delightful of all was the emergence of the transman voice into the forum. I have been involved in the HIV response for all of the decades, and it never fails to move me when I see and hear the lived experience stepping boldly forward to be heard. I was both humbled and uplifted by the experience.

The meaningful involvement of affected communities in all of their diversities is essential; the idea that communities are hard to reach is a fallacy and what it really means is that there are strategies lacking to engage TGD communities. If we are to truly leave no one behind, we must first of all include TGD communities.

CONFERENCE TAKEAWAY

While we can rightly celebrate the journey so far, there are lots of signs we have a long way to go.



LEFT Art at AIDS 2018: Condom Couture

RIGHT The meaningful involvement of affected communities in all of their diversities is essential



THE U=U REVOLUTION

GROUNDBREAKING, GAME-CHANGER, REVOLUTIONARY. THESE WORDS HAVE ALL BEEN USED TO DESCRIBE THE DISCOVERY THAT UNDETECTABLE HIV IS SEXUALLY UNTRANSMITTABLE. BUT WHAT GOOD IS GROUNDBREAKING SCIENCE IF PEOPLE DON'T KNOW ABOUT IT? **BRUCE RICHMAN, THE DRIVING FORCE BEHIND U=U, DESCRIBES TO *POSITIVE LIVING* HOW THE CAMPAIGN GAINED CRITICAL MASS.**

When my HIV doctor told me in 2012 that I could not sexually transmit HIV because I had an undetectable viral load, it changed my life. I was elated. For years I'd been so afraid of passing on HIV that I hadn't opened myself up to love. Now I felt free. But it struck me that nobody seemed to be talking about this earth-shattering news.

HIV information sites were saying that there was a risk of transmission — even when you're undetectable. I started talking to researchers, heads of clinics and some HIV-positive community leaders. They knew about the research, but it seemed to be a big

secret in the field. Most people weren't being told that when you have an undetectable viral load, you cannot transmit HIV sexually. It was known to only a privileged minority. Millions were left in the dark, especially people already marginalised by the

healthcare system.

I felt that I had to do something to get the word out. So, in the summer of 2015, I began organising with other activists and researchers to launch the **Undetectable=Untransmittable (U=U) campaign** to make sure that the breakthrough science of HIV transmission would reach the people it was meant to benefit.

I had developed cause-related campaigns for high-profile people and brands before, but this was the first time I was to embark on something so close to my heart, with so much potential to help people and the field. I gave up my income from previous clients, moved into a studio apartment in New York City and had absolute faith that truth and science would be my guides.

LAYING THE GROUND

It's mind-blowing to look back at how much the global U=U community accomplished in such a short time. Just over two years ago, a small group of us started drafting the **U=U consensus statement** with researchers from groundbreaking treatment as prevention studies such as HPTN 052, PARTNER, the Swiss Statement and Australia's **Opposites Attract**. We planned to use that statement as an advocacy tool to secure influential endorsements to support the overwhelming evidence confirming U=U. When we issued the consensus statement in the summer of 2016, we felt we had the Holy Grail. It was a life raft in a sea of HIV stigma.

Now we needed to find champions. U=U was brought to life when the pioneering Dr Demetre Daskalakis from New York City's Department of Health signed on that summer and Terrence Higgins Trust led the way in the UK. But even after New York City and several powerhouse US organisations joined a few months later, there was a frustrating lack of acceptance of the science, or even an understanding as to why the message was so important. Quite often, I felt the life raft sinking.

RESERVATIONS AND RESISTANCE

The initial response was mixed. Few recognised that U=U was true. We found visionaries who stepped up, but most of the established HIV organisations worldwide were telling our advocates that we were wrong — and even a danger to public health.

People worried about the Pandora's Box that might open up if people with HIV stopped using condoms and about the rise in STIs that could ensue. Some worried that people might not realise that they need to take their meds every day to stay undetectable. In other words, they worried about whether people living with HIV would understand that meds only work if you take them. We were told this would be a disaster in places where people don't have access to treatment and regular viral load testing. People who doubted the science felt we were being unethical and dishonest. Essentially, we were told to stay silent.

THE CANADIAN CONNECTION

The campaign picked up momentum in January 2017, when the executive director of Canadian AIDS Treatment Information Exchange (CATIE), Laurie Edmiston, was unequivocal in her support of U=U: "All of us here at CATIE, and indeed around the world, are celebrating the most significant development in the HIV world since the advent of effective combination therapy 20 years ago: people living with HIV with sustained undetectable viral loads can confidently declare to their sexual partners, 'I'm not infectious!'"

When Bob Leahy, a leading Canadian U=U advocate sent me CATIE's endorsement, I couldn't speak. I was sobbing. CATIE's credibility and reach helped set the message on an international trajectory. CATIE's statement and ongoing advocacy and education paved the way for other organisations in Canada and abroad to embrace the message. These organisations now recognise that U=U must be a headline — not an asterisk.

Canadian organisations are engaging in open and challenging dialogue to explore the complex issues related to U=U — such as the social determinants of health, the criminalisation of HIV non-disclosure and women's reproductive health. U=U is a leading topic at Canadian HIV and sexual health conferences

that set the priorities for the field and at conferences led by and for people living with HIV throughout the country. Every time I've gone back to Canada, I'm moved and inspired by the trailblazing work of our Canadian partners.

INTERNATIONAL MOMENTUM BUILDS

Soon after CATIE signed on, other globally respected HIV research and HIV/AIDS service organisations joined, and we

science really does verify and validate U=U". Later that month, because of the groundswell of data and our community's activism, the US Centers for Disease Control and Prevention (CDC) confirmed that there is "effectively no risk" of sexual transmission of HIV when the virus is undetectable.

That update to the CDC's messaging had a transformative impact not only in the US but around the world. U=U and similar messaging is now being

simple but hugely important campaign based on a solid foundation of scientific evidence. It has already been successful in influencing public opinion, causing more people with HIV (and their friends and families) to comprehend that they can live long, healthy lives, have children and never have to worry about passing on their infection to others. The clarity of the message will make it easier to promote the undeniable benefits of treatment, which will encourage more and more people with HIV to seek treatment, bringing the HIV community one step closer to achievement of the UNAIDS 90-90-90 target by 2020 and to complete elimination of the entirely unfair and outdated stigma still faced by many people living with HIV today."

U=U has now been widely accepted by the global medical and scientific community. More than 600 pioneering community partners, including research associations and public health bodies from 75 countries have joined the campaign. In Eastern Europe and Central Asia: H=H; in Vietnam: K=K; in Brazil: I=I; in the Netherlands: N=N; in Turkey: B=B.

THE TRANSFORMATIVE IMPACT

Saying U=U, or any version of it, is still revolutionary. The message is the most radical challenge to the status quo since we learned 22 years ago that antiretroviral therapy can keep us alive. U=U is transforming the social, sexual and reproductive lives of people with HIV. Our partners are using the message as a powerful public health argument for access to treatment and viral-load testing, and to promote treatment uptake, adherence and retention in care. They are dismantling stigma in an unprecedented way by changing what it means to live with HIV.

I am continually moved to hear about the impact this information is having on people's lives. A man who attempted suicide after his diagnosis now feels human again and has become an educator, letting others know about U=U. An HIV activist who isolated herself from relationships for more than 15 years because she feared passing on HIV is now dating and open to love. A woman finally feels she can be intimate with her husband after more than 20 years of feeling unsafe and worrying a condom would break. People talk about feeling freedom and hope — and that means everything.



LEFT Founder of the U=U campaign, Bruce Richman, taking U=U to the airwaves

BELOW Spreading the message in Melbourne earlier this year



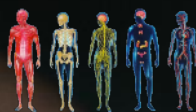
U=U is the most radical challenge to the status quo since we learned 22 years ago that antiretroviral therapy can keep us alive.

started gaining critical mass. It was a glowing validation that the message we were shouting from the rooftops was not only factual, but a game-changer for the field.

In September 2017, history was made at the United States Conference on AIDS (USCA) when one of the world's preeminent immunologists, Dr Anthony Fauci, declared that "the

integrated into policy and communications in many parts of the world, including China, Uganda, Kuwait, Malaysia, England, South Africa, Australia, Guatemala and Vietnam.

U=U has been featured in national and global media and was even lauded by the editorial board of the leading medical journal *The Lancet*: "U=U is a



HIV+THE BODY

EXPLAINING THE EFFECT HIV HAS ON PARTICULAR PARTS OF THE BODY

Skin's the thing

Think of the skin as a kind of Bubble Wrap that protects and keeps in place our internal organs. Without it, we'd literally be all over the place!

Available in all shapes and sizes, the skin is the body's largest organ. It's made up of three layers: the epidermis (the outer layer); the dermis (which lies beneath the epidermis); and the subcutis (an area under the dermis containing collagen fibres and fat cells), which cushions the body from knocks and bumps, and insulates us from the cold.

Crucially, your skin is a first line of defence for the immune system. When the skin is broken, your body becomes vulnerable to infections. There are many underlying causes behind skin problems such as bacterial infections, viral infections, fungal infections, skin cancer, psoriasis and allergies. Most people with HIV will develop a skin condition at some time. Indeed, a skin condition can be an early warning sign that HIV is active in

the body and is often viewed as a barometer of the virus's progression.

One of the most common skin conditions among people with HIV is dermatitis which can occur on various parts of the body including the feet, ankles, hands, wrists, neck, eyelids, and inside the knees and elbows. Warts are also common among people with HIV. Caused by the human papillomavirus, warts are small growths located on the top layer of skin. They are usually found on the back of your hands, your nose, or on the bottom of your feet. HIV makes it difficult for your immune system to get rid of warts, and outbreaks can be ongoing. They can be easily treated, however, and are relatively harmless.

Some HIV medications can also produce skin conditions — especially immediately after starting treatment, with rash a fairly common side effect. The rash typically appears as a red, flattened area on the skin that's usually covered with small red bumps. A common symptom of the rash is itchiness. It can show up on any part of the body but

most often occurs on the face and chest, and hands and feet. Skin conditions may also be associated with inflammation caused by an overactive immune system. The good news is advancements in viral control have made skin problems among people with HIV less severe and less common.

Non-HIV-related causes of skin conditions include:

A LACK OF HYDRATION. Your skin cells are made of water and need to be regularly replenished in order to keep the skin healthy. Water is therefore the best sustenance for the skin.

SMOKING. As well as all the other detrimental effects of smoking, it also dries out the skin and leads to premature ageing.

THE SUN. UV rays are extremely harmful to the skin and overexposure can cause skin cancer (Australia has one of the highest rates of skin cancer in the world).

JUNK FOOD. The skin needs various nutrients to stay healthy.

Feed it the right food and it will glow with appreciation.

So, how best to maintain healthy skin?

SLATHER ON THE SUNSCREEN.

It isn't the sun itself that's the problem. Sun is crucial for good health; a lack of rays leads to vitamin D deficiency. It's overexposure that you have to be careful of — too much sun can cause skin cancer. So limit the amount of time you're in the sun and, when you are, slap on the sunscreen. And it shouldn't just be a summer ritual: whatever the season, sunscreen should be applied. Other protections include wearing a hat, sun-protective clothing, and sunglasses. Wear gloves and long sleeves if you're cycling, motorbiking or driving.

MOISTURISE AND EXFOLIATE.

While moisturisers do not add a great deal of moisture by themselves, they do lock in any present moisture and help hydrate the skin. Exfoliating the face is also recommended as it will rid the facial skin of dead

cells and clear the skin of toxins.

EAT WELL. Fruit and vegies rich in vitamin C are good for the skin — vitamin C produces collagen that is responsible for keeping the skin firm. It is also an antioxidant. Sources of beta-carotene (such as red, orange and green leafy vegies) are necessary for cell formation and will help keep your skin smooth. Nuts are also good for healthy skin, as is fish with omega-3. Tomatoes, too, are great for the skin.

EXERCISE. Physical activity leads to greater blood flow which is essential for oxygen to travel throughout the body. All cells require oxygen for optimal functioning — including skin cells. Oxygen also soothes inflammation and irritation by creating a calming effect to the skin and is crucial for healthy cell development.

SEEK HELP. If you develop a skin condition, discuss the symptoms with your doctor. They will reconsider your HIV medications and prescribe a treatment plan to relieve any discomfort.

**WHILE I WAS
INITIALLY
HAPPY TO BE
GIVEN AZT,
I SOON
DISCOVERED
THE NASTY
DOWNSIDE TO
TAKING IT.**



A BITTER PILL

Thirty years ago, AZT became the first drug to show some hope to treat HIV. But, as David Menadue recalls, its debilitating effects proved too much for some.

Desperate times call for desperate measures. And the 1980s were indeed desperate times. With deaths from AIDS skyrocketing, HIV activists pushed governments and pharmaceutical companies to come up with something — and fast. That something was zidovudine, better known as AZT.

AZT was a failed cancer drug which had sat on the benches at Burroughs Wellcome laboratories since the 1960s. When scientists at Burroughs Wellcome discovered AZT worked against HIV in mice, they began clinical

trials in humans. However, during the trial, AZT was found to cause extreme side effects, including severe intestinal problems, anaemia, nausea, diarrhoea, vomiting and headaches. Aware that AZT was all there was, the researchers concluded that the drug was relatively safe.

To test its effectiveness against HIV in humans, scientists next began a trial of AZT on 300 positive people — half on the drug, half on placebo. When there were 19 deaths in the placebo group but only one in the AZT group, the trial was immediately discontinued and the drug sent to the US Food and Drug Administration (FDA) for approval. Because of the enormous pressure to stop the tide of deaths, the FDA fast-tracked its drug approval processes for AZT. A novel drug like this might spend ten years in safety trials. But as there was no time to lose, the FDA gave AZT the green light in March 1987 — a mere two

years after the initial trial.

Meanwhile in Australia, the wait for AZT was agonisingly slow. As the Therapeutic Goods Administration didn't accept clinical data from the US, we were told that AZT would have to go through years of trials before the drug could be approved here. It was only after massive pressure from HIV activists that, in 1988, AZT was released to people thought to be at greatest risk of developing AIDS. With a CD4 count below 200, I was one of those people. While I was initially happy to be given this new drug, and hopeful that the hype around its efficacy might prove true, I soon discovered the nasty downside to taking it.

Within a few weeks, I had lost my appetite, was often nauseous and found myself so lacking in energy that I would rush to the sick bay at work to catch a nap during lunchtime. I started to lose a lot of weight and to experience significant muscle wasting from the arms and legs,

and fat from the face. My CD4s continued to dwindle regardless and I developed my first AIDS-defining illness, pneumocystis pneumonia, in 1989.

To this day, I still don't know if AZT contributed to the deterioration of my health and to developing AIDS sooner than I might have, or whether, in fact, the drug may have helped a little. Certainly, plenty of my friends with HIV at the time thought AZT made things worse (indeed, it established such a bad reputation amongst the HIV-positive community that many people were put off taking any HIV antiviral drugs for some years afterwards, even as treatments began to improve).

It was later realised that we were all being put on much too high a dose. Some of us were on 1,500mg a day — two-thirds more than necessary. It was also discovered that the drug became resistant to HIV fairly quickly when used by itself and that other antivirals were needed to get HIV

under control.

By 1996, new potent classes of antiretrovirals had at last been discovered and were being used in combination to maximise their effectiveness in treating HIV. This approach was termed Highly Active Antiretroviral Therapy (HAART). HAART saved many of those who'd managed to survive those early toxic regimens. Me included.

The activism that was generated over AZT continued to have a long-lasting impact on treatment access protocols in Australia and helped forge the HIV community's relationships with government, doctors, pharmaceutical companies, and researchers. Relationships still in play today.

For me, AZT and that period is an experience I will never forget. After all, I only have to look in the mirror to be reminded of it . . .

● Thanks to Bill Whittaker and Ross Duffin for help with this story.

WTF is polypharmacy?

Many of us living with HIV are taking extra off-the-shelf medications, supplements, vitamins and minerals for a range of reasons. Which is great, 'cause we care about staying healthy! The question is: how do these additional medications and supplements impact our health as people living with HIV?

Recently, at a Positive Life 'In the Know' research update evening, Associate Professor Limin Mao from UNSW and Dr John Rule from the National Association of People with HIV Australia presented results from a [study](#) that looked at the impact taking five or more medications at the same time had on people with HIV who also lived with one or more extra medical conditions.

When we take HIV treatments alongside non-HIV medicines for other conditions — such as a low-dose aspirin for

inflammation, or medications for high blood pressure, hep C, depression, or diabetes — this is called polypharmacy. These medications may include non-prescription remedies taken for preventive purposes or for HIV treatment side effects, such as herbal/alternative medications, probiotics and extra supplements, vitamins and minerals.

Today, nearly half of us living with HIV are over 50 years of age and living with typical age-related conditions such as cardiovascular disease, arthritis, hypertension, osteoporosis, or type-2 diabetes. Even if we take only one or two pills a day for HIV, we're popping on average an extra six non-HIV pills a day. Polypharmacy puts extra burdens on our digestive system, including liver and kidney functions, and is associated with a higher risk of side effects such as fatigue and diarrhoea. Some

non-HIV drugs can also interfere with our HIV antiretrovirals (ARTs) and our body's ability to absorb the medicine.

Also, when taken with HIV meds, some other medicines may be harmful (contraindicated). For example, some remedies for acid reflux interact badly with some ARTs. As does the herbal supplement St John's wort — usually taken as an antidepressant or mood stabiliser — which is contraindicated for people on protease inhibitors (e.g. indinavir, nelfinavir and saquinavir). Other supplements which contain magnesium or calcium, garlic, DHEA, ginkgo biloba, liquorice, milk thistle and valerian can also interfere with HIV treatments.

Other polypharmacy risks include complications from newer medications which are prescribed to manage or treat the side effects of earlier medications

or other adverse events. Adverse events are unintended but sometimes occur when taking certain medicines. For positive people, an adverse event can be as simple as a fever, dry mouth, vomiting, optic neuritis, or perhaps drug resistance.

If polypharmacy is your experience, there are a few different strategies to stay on top of the pills you're taking:

- There's a free online app called [HIV-Drug Interactions](#) for iOS or Android to use to check drug-to-drug interactions.
- No smart phone? You can always talk to a nurse practitioner, usually connected to your GP or your HIV doctor, or speak with your local pharmacist to review all your medications (HIV and non-HIV) to see if there are any problems.

- Pharmacists are funded by Medicare and provide medication review for free. They can research and access the very latest literature regarding drug-to-drug interactions, and they often have more time to do this compared to your GP or HIV specialist with tight appointment schedules.
- If you're uncomfortable with either the nurse practitioner or pharmacist, you can still ask your GP or HIV doctor to conduct a medication review at your next appointment (book a long appointment!)
- Or you can call the Positive Life Treatment Officers who live with HIV themselves for advice on (02) 9206 2177 or (freecall) 1800 245 677.
- Click [here](#) to read this story in full.

Immediate Start survey report now available

In June 2017, people living with HIV and HIV-negative people across Australia generously shared contributed attitudes and views on the benefits and concerns of starting HIV antiretroviral treatment at the time of an HIV diagnosis. This survey report has been published and we would like to acknowledge and thank the HIV-positive and HIV-negative community for your valuable support and time taken in completing the survey.

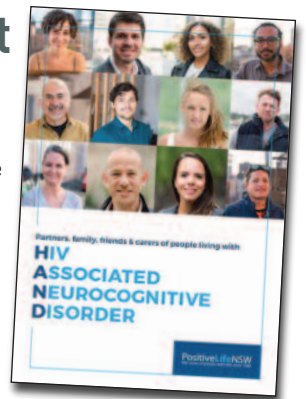
- Click [here](#) to download your copy and [here](#) to learn more about the benefits of starting HIV treatment at diagnosis



HAND companion booklet out

Positive Life has published a companion booklet to support partners, family and friends (including carers) of people living with HIV Associated Neurocognitive Disorder (HAND). The resource contains practical advice on living with HAND and information on where to seek more assistance.

- For a copy of the booklet, please call (02) 9206 2177 or email contact@positivelife.org.au or download it [here](#). There's also a booklet available aimed at those who support people living with HAND, which can be downloaded [here](#).



PositiveLifeNSW
the voice of people with HIV since 1988

Housing
Support



If you're living with HIV and require support with housing issues, we can help you:

- find crisis or temporary accommodation;
- complete a housing application;
- apply for a transfer to another property;
- address maintenance or tenancy issues;
- lodge a complaint; or
- attend a tribunal hearing.

Positive Life NSW provides peer led support and can help you access, achieve and maintain stable accommodation.

Contact our Housing Support Officer, to discuss your needs
Phone 02 9206 2177 Email johnc@positivelife.org.au

With the tagline "Where we speak for ourselves", Talkabout is an online magazine for and by

people living with HIV. Talkabout shares the personal stories and experiences by and for PLHIV, to express our views and to represent ourselves.



- Share your story in Talkabout or call to have a chat with the editor to brainstorm an article or story

you might have to share on (02) 9206 2177 or email editor@positivelife.org.au

- To read others' stories click [here](#) or to subscribe to Talkabout Online click [here](#).

New CEO as we move into 30th year

At a pivotal time for the organisation, Living Positive Victoria is pleased to announce the appointment of Richard Keane as its new Chief Executive Officer.

Richard has been a champion of the HIV community for more than 25 years and will bring this experience along with his passion and natural leadership to the organisation at a time when there is still so much to be done in support of people living with HIV.

Living Positive Victoria President, Christabel Millar, is "delighted to welcome Richard to the organisation in such a pivotal role. We know with confidence that the organisation is in the capable hands of a seasoned and cultured individual," said Millar. "Living Positive Victoria was born out of the passion and dedication of people living with HIV. Richard will preserve that legacy while pursuing an exciting new vision

for all people living with HIV in Victoria."

Richard's passion for the HIV community allowed him to take on a diversity of roles within the HIV response over the last 25 years. Some of his previous engagements include being a member of the AIDS Ministerial Advisory Committee, a facilitator of the Positive Leadership Development Institute Australia/New Zealand, and former president of Living Positive Victoria.

"I am honoured to have this opportunity to lead an organisation



Richard Keane

whose people and culture has enabled me and countless others to build skills and resilience over the last three decades," said Keane. "In my role as CEO, I will continue to champion the meaningful involvement of people living with HIV as central to an effective community-led response."

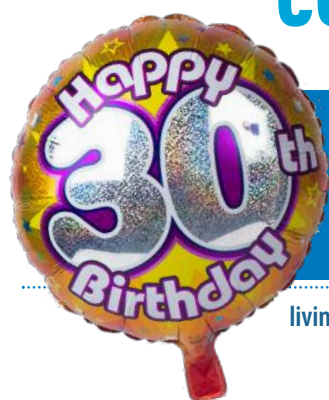
The role of CEO attracted international candidates and was followed by a rigorous recruitment and selection process. Richard was selected as the candidate with the right mix of passion, vision and leadership needed to lead Living Positive Victoria into the future.

Richard's appointment as CEO comes at a time when Living Positive Victoria launches into its

30th year — a time for both reflection on the past and planning for future growth and engagement. A series of events are planned over the next six months to mark the milestone. These events will trace the journey that Living Positive Victoria has travelled since its formation in 1988 while acknowledging the people who have helped guide and inform that journey.

The 30th anniversary will also be a time to reflect on the achievements made in response to the advancements of the human rights and wellbeing of people living with HIV. It is also an opportunity to focus on the further empowerment of all people affected by and living with HIV in Victoria, as we seek an end to the HIV epidemic and do everything we can for positive people to live their lives to their full potential, in good health and free from discrimination.

RICHARD In my role as CEO, I will continue to champion the meaningful involvement of people living with HIV as central to an effective community-led response.



Keep an eye on livingpositivevictoria.org.au for 30th birthday news and updates.

When you begin treatment for HIV, taking that first pill is a big deal. Here, five positive people recall the experience.

JOSEPH

I lost my partner to AIDS in 1994. I was still negative. I volunteered for AIDS organisations and lost so many friends. I saw all the experimental medications come and go, and the toll it took on all their lives. So the day I was diagnosed as positive I just became numb.

I was numb for about two weeks. Then I heard that everyone diagnosed as positive regardless of T-cell count should start medication immediately. Well, my count had dropped that month from 650 to 475. I guess it was time to start anyway.

Every night for three nights I tried to take the pill. I would open the bottle and stare at it or hold it in my hand. How could I take a pill that would seal my fate? If I took that pill, I would be admitting there was something wrong with me. The fourth night, a friend came over for dinner. How could I take the pill in front of him? Tears were rolling prior to dinner, and then he arrived. We sat down and I heard my partner's voice in my head, "Just take the damn pill will you!" I did. I've not missed a dose yet. I have never had one side effect. My count is over 750 each visit, and the viral load is undetectable.

I remember picking up my first prescription. I was on Eviplera. It was probably about 8pm and having eaten a pretty chunky-looking sandwich (cos the blurb said I had to have at least 500 calories), I took out the tablet, put it in my mouth and . . . hesitated. That bloody inner voice. "What exactly is this the start of? What is actually going happen to me when this hits my stomach? Is this the right thing to do?" GULP. I swallowed.

And that was it, really. I've been taking Eviplera (almost) religiously ever since. Yes, I've missed a couple of days. Yes, I've had a bit of trouble locking it into my routine: do I have it at dinner and struggle with the occasional social exposure or

cells. He said I needed to start right away. But I had friends on AZT and they had terrible side effects. I listened to my gut and said, "No". Instead, I waited and watched my T cells drift down.

Finally, I got to the point where I had to do something. It was 1988 and I wasn't dead yet, but I was symptomatic. I agreed to start AZT, but I told my doctor at half the dosage. We argued, but this is my body. It made me sick, but I could stand it and I could continue to work. I watched more friends on the full dose get sick and die. I did all I could to stay healthy: I ate right and worked out. Eventually, I stopped AZT and started on the notorious D drugs. (Thanks for

165,000. I didn't know what those numbers meant, but she explained everything to me and told me how advanced the condition was. I was devastated; tears came down my cheeks. She looked at me and said, "Cry all you want, and vent your pain, but it is not a death sentence like everybody thinks. There are new medications and none of my patients has ever died."

She put me on a pill called Atripla because she was completely sure it would work well on me. Atripla has been my main medicine since then and I have not planned on changing it because I get basically no side effects. Three months after taking Atripla I was undetectable and my CD4 count had increased to 350. Currently, my CD4 count is 875 and I am still undetectable, so I am happy and I live like a normal person. I don't even think about being HIV-positive. I totally forget about it and try to live my life as any other person. I exercise; I go to parties and clubs. HIV is not stressing me. If you are positive, be positive about your life, take your medication on time and forget about HIV.



JOHN

My first pill was accompanied by a whirlwind of emotions: anger, depression, happiness, denial and sadness.

The idea that, before this, I had never taken any pills other than over-the-counter medicines took me so long to get over. I remember telling myself that I didn't have to take the medicines if I didn't want to, although I knew deep down I had to. I called my doctor and told her that I was having problems with taking the pills. She assured me that I would be OK and that my numbers were not the best due to the years of not knowing my status so my body had a lot of catching up to do (my viral load was 101,500 and I had a CD4 count of 51). Before taking my first pill, I had mentally defeated myself into believing that I was just delaying the inevitable. After hours of fighting I managed to take my medicine. For anyone who's having trouble with their meds, it's an inner battle. But don't give up. Don't give in. It will get better!

BETH

Oddly enough, the question of whether or not I would go on medication wasn't really that big of a deal.

Officially, at that time, there were still restrictions about when I could actually start treatment. You had to have a fairly low CD4 count (although this restriction has since been removed). But my GP made it perfectly clear that — while it would always be my choice — he was very pro-treatment as prevention and would support me starting meds, regardless of my current health status. And to be honest, for me, it felt like there really was no question.

potential questions? Or do I have it at lunchtime? Symptom-wise? A bit of an upset tummy for a couple of weeks (and the very occasional sporadic diarrhoea) but nothing earth shattering or life threatening!

BOB

I took the HIV test because I was dating someone who was the man of my dreams and he shared his positive status with me before we had sex.

I went to my doctor, one of the HIV specialists at the time. He said I should start on AZT because I had just 236 T

neuropathy, medical science! My feet and hands just love you!) I am still here though. My doctor isn't. He died in 1989.

MARIA

It was 2007 when I got my HIV test results from my doctor. He said to me, "I'm sorry, but your HIV test came back positive."

My life was destroyed, I felt like I just got a death sentence and I was thinking about how many more days or months I had left in this world. I went to visit a specialist and she told me that I was actually an AIDS patient because my CD4 count was only 140 and my viral load was

With [research](#) showing that loneliness is a problem for people with HIV (especially those over 50), here are four



TO CONQUER LONELINESS

- 1 Employ mindfulness.** Loneliness can cause people to dwell on negative thoughts and feelings. Adopting mindfulness encourages people to observe them without judgement and to learn to release them.
- 2 Connect with community.** [Finding likeminded people](#) can reduce the sense of isolation and can act as a reminder that there are people out there who understand how you're feeling and what you're going through.
- 3 Tap into tech.** There are some extremely useful online forums and orgs — such as [TIM](#) — that can offer peer support to people with HIV regardless of where you live in Australia.
- 4 Reach out.** Sometimes feelings of loneliness can become overwhelming. Mental health professionals can assist people who may find themselves unable to find their way out of an emotional head space.



The global AIDS response is at a precarious point — partial success in saving lives and stopping new HIV infections is giving way to complacency.

UNAIDS Executive Director **Michel Sidibé**

THE INFLUENCERS CHARLIE TREDWAY

When Charlie Tredway was diagnosed HIV-positive in a Sydney sexual health clinic 13 years ago, he was so taken aback by the news that he refused to accept it. He also refused treatment. "For me, starting treatment made it real." Instead, Charlie took to drugs and anything else that would block the reality of the situation. "It took seven years for that precarious denial to crash around me." During that time, his CD4 count dived into single digits and his viral load went into overdrive. It was the wake-up call Charlie needed.

He decided to head home to New Zealand and take ownership of his HIV status. Not long after, Charlie participated in an awareness campaign for the New Zealand AIDS Foundation. Following this, he was offered a job as an outreach worker. "I'd already been putting my face to HIV, living openly, discussing it with everyone, so it just seemed the next logical step." Then, in a concerted effort to challenge stigma (which he describes as "the bitterest pill to swallow as a person living with HIV"), Charlie entered the Mr Gay NZ contest . . . and won.

The spotlight prompted a backlash. And Charlie found himself having to defend comments he made about engaging in condomless sex. In response to negative media reports, Charlie said: "We live in a time when there are scientifically proven and highly effective [preventative] options. Whether that means TasP, regular testing, condoms, PrEP — or many of those in tandem — they are all very, very important. If all we needed were condoms and moralistic judgment, we would've ended HIV decades ago."

Today, Charlie remains a committed activist and a role model to thousands of young positive men around the world. "If you had told me that I would be devoting my life to HIV awareness and advocacy all those years ago, I would have laughed in your face but it has turned out that HIV does, in fact, define me — for the better."

Follow Charlie on [Twitter](#) and friend him on [Facebook](#)



TRENDING NOW HEMP SEEDS

First up, eating hemp seeds will not get you high. Though hemp is a variety of the *cannabis sativa* plant, it has very low levels of the psychoactive compound THC, the cannabinoid most known for its psychoactive properties. Secondly, after years of investigation and lobbying, Australia and New Zealand finally joined the rest of the western world and legalised hemp for human consumption late last year. So, why not add this true superfood to your diet?

Hemp seeds are rich in essential fatty acids, and have a healthy 3:1 ratio of omega-3 to omega-6. Hemp is also one of the few sources of the hard-to-get gamma linolenic acid — a healthy, plant-derived omega-6, which is metabolised differently than other less healthy omega-6s — and which has been linked to a reduced risk of heart disease. As well, hemp seeds are a very good source of arginine, which has been [shown](#) to reduce the levels of

C-reactive protein, an inflammatory marker linked to heart disease. They've also been shown to improve fatigue, to have positive effects on the immune system, to improve dry skin and skin diseases, including eczema, and may reduce symptoms associated with premenstrual syndrome and with menopause.

Hemp seeds are an excellent protein source, too, with at least 20 amino acids, including the nine essentials, making them a complete protein source. About 25% of the calories in hemp seeds come from protein; by weight, that's similar to beef and lamb. Hemp protein is very digestible — better than protein from many grains, nuts and legumes — and contain high amounts of vitamin E, phosphorus, potassium, sodium, magnesium, sulphur, calcium, iron and zinc.

You can add hemp seeds and hemp protein powder to smoothies, breakfast cereals and porridges, protein bars, muffins, brownies, cakes, waffles and ice cream. For some recipes, visit this [site](#).



QUOTE / UNQUOTE