

# poslink

The Newsletter of **Living Positive Victoria**

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**AIDS 2014 Edition: *STEPPING UP THE PACE***

This special issue of *Poslink* is dedicated to the diverse activities, events and experiences that took place around the 20th International AIDS Conference in Melbourne this past July.

We have collected a range of articles to present AIDS 2014 from the perspectives of different people who took part in the conference through a variety of ways. Inside you will find an account of John Manwaring's AIDS 2014 experience, an exploration of activism around the conference by Richard Keane, a reflection by Sara Graham and Sarah Feagan of the Women's Networking Zone as well as a range of other personal voices from around the community. AIDS 2014, and the months preceding, were monumentally exciting, busy and unique for Living Positive Victoria and the wider Melbourne community. In this issue of *Poslink* we have aimed to capture some of that essence and are greatly appreciative of the contributors who shared their stories.

This is the last issue of *Poslink* that I will have worked with the team on and it is fantastic to have been a part of such a dynamic and engaging publication. As always, please contact the *Poslink* editors at [poslink@livingpositivevictoria.org.au](mailto:poslink@livingpositivevictoria.org.au) if you would like to suggest some content, offer feedback or get involved.

We hope you enjoy the *AIDS 2014: STEPPING UP THE PACE* issue of *Poslink*!

Simon Bailey

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# Note

from the

## President

*Ian Muchamore*

The community of people living with HIV was centre-stage during the recent International AIDS Conference in Melbourne. It is important to acknowledge and celebrate the efforts, activities and contributions of the positive voice across so many areas. We should also reflect upon our successes and learn from the experiences so that there is an ongoing local legacy.

Living Positive Victoria led, supported, sponsored or participated in almost 30 different events during AIDS 2014.

Anyone who was involved in these activities will have had their own special experience and hopefully they also experienced several of what I coin 'AIDS 2014 Moments'.

Recognising these memorable moments highlights and why they matter helps us understand the bigger picture of how we can make a difference. There are so many steps to take to make progress in improving the lives of people living with HIV and towards bring the HIV epidemic to an end in Australia.

I know I had multiple AIDS 2014 moments and here are just three.

Thursday morning coffee break during a preconference meeting with Australian social and medical researchers. We check our mobile devices for emails and updates and the latest global news drama is the

lost passenger plane over Ukraine. Some delegates in the room fear they know and have worked with those who are missing. The reality now dawns, MH17 will impact AIDS 2104 and beyond. Whilst shocked, we commit to honouring those lost and to making our actions count to improve the lives of people living with HIV.

Early rise on a Sunday morning and months of work is bearing fruit at the Beyond Blame international meeting on HIV criminalisation. Leading local and international speakers will highlight some shocking cases where the law has failed people living with HIV. Locally, we have been advocating to change unfair laws for many years. The Victorian Health Minister is formally welcoming delegates to Melbourne and no surprises are expected. However I start to sense he is going beyond the warm words and somewhere quiet specific. For the very first time we all hear a public commitment from a major political leader to reform those local unfair laws.

A brisk winter evening at Federation Square and thousands of local and international supporters have congregated for the Candlelight Vigil. This keystone event is crafted to include musical performances, moments of remembrance and also uplifting personal speeches from our community. Opposite Flinders Street Station I can't but notice the parked



queue of television outside broadcast vehicles, representing all the major Australian TV News. That evening the voices of our community and the clear message that HIV has not gone away will be reaching into the homes of millions of Australians.

# Full disclosure

John Manwaring

***UNTIL LAST  
MONTH, I  
WAS A  
VIRGIN.***

I'm fairly certain that elicited a loud guffaw from many of you. To clarify, until last month, I was a virgin to the circus that is the International AIDS Conference.

My experience with HIV, aside from living with it for the past eight and a half years has been limited to some volunteer work and a brief time on the Board at the Victorian AIDS Council. Going into the conference, having been asked to speak at the closing session, I was tabula rasa. I didn't know what to expect, and

approached the experience with an open mind. However - being the foolish optimist that I am - I hoped to be inspired and uplifted.

The conference was a condensation of the myriad experiences of people living with HIV and those affected by it, writ large. In the Global Village - the public space for people and groups from around the world - I encountered individuals from parts of the world that had previously been to me nothing more than bylines in a news article. Standing face to face

with them took their wants, their needs, and their lives out of the realm of the hypothetical and intellectual. They were immediate and tangible. They were real.

Hearing these individual experiences humbled me. Considering my own experience in the broader context of the lives of others, reminds me how deeply fortunate I am to live in a developed country with universal healthcare. The fact that I can walk into a full-service sexual health clinic and get a four-month supply of top-





line ARVs without the slightest hassle or expense seemed remarkable to me after the bureaucratic nonsense I experienced the United States. For many, the fact that they had access to medication at all was remarkable, to say nothing of the difficulties they endured in accessing and adhering to it. I don't mean to suggest I feel guilty for how good I have it. Rather, I realised that viewing my own experience in isolation is to do a disservice to the epidemic as a whole. Progress isn't won when we divide ourselves and fight for crumbs. It's achieved when we base our efforts on the idea that we are all in this together.

Though most of my time at the conference was invigorating and inspiring, I saw a great deal that was disheartening and downright frustrating. The common factor I observed underlying these instances was ego. It was behaviour that was unmistakably self-serving. Many people, some of whom I knew personally, were painfully blatant in their disregard for sense of community that the effort against HIV absolutely requires. They stigmatised other positive people for having the audacity to respectfully disagree with their motives and methods. They outright belittled some of the strongest partners in the sector for the mere fact that they were HIV-negative, or straight. They used their moments in the spotlight not to draw attention to any of the countless issues we face, but to further their own reputations and careers.

Frankly, much of what I saw was stereotypically catty bullshit. Part of me had believed the sector got past this nonsense after the Dr. Bob Gallo debacle in the early 1980s - yet here it was, many times over - played out in the pettiest of ways.



In his speech at the closing session, Sir Bob Geldof called out the entire sector on all this. In no uncertain terms, he dressed us down for bickering and infighting, for letting ego trump our goals, for failing to call out the extraordinary prejudice that inhibits progress. His words were received, to be generous, tepidly. Many were offended by his words, still more were dismissive. One person with whom I spoke offered a simple critique: *"Where does he get off saying shit like that? He doesn't know what he's talking about."* Without consideration or elaboration, this person ignored what, to me, was an incisive and necessary

*"Progress isn't won  
when we divide  
ourselves and fight  
for crumbs."*

assessment of what needs to be done to help end HIV.

It's not easy or pleasant to hear, especially for those of us who live with HIV. Many of us carry our diagnosis as a sort of noble cross, something that elevates us above others, whilst simultaneously weighing us down. We like to think of ourselves as both saviour and victim. We want acclaim for our individual efforts and achievements, yet are affronted when it's suggested to us that perhaps our aims are misdirected.

Ultimately, the conference was inspiring and uplifting, but not in the way I'd anticipated. It was a reality check. It showed me that HIV isn't necessarily a life-changing or eye-opening experience for everyone. We are, after all, still human, and susceptible to the same inclinations and shortcomings as everyone else. Rather than discourage me, it reminds me that there is work to be done on ALL fronts. It's critical that we continue to identify and call out stigma and discrimination wherever we see it. This includes the stigma and discrimination that exist in our sector and our community. Again, being the foolish optimist, I believe there is extraordinary energy and strength among us, that the end of HIV is truly within sight. The pursuit of this goal may occasionally require us to subsume our individual egos, interests, and ideas. When HIV is gone, it will prove we are something we've always claimed but never fully embodied: a community.

# Activism at AIDS 2014

## *In solidarity?*

RICHARD KEANE

I was employed by the International AIDS Society to be the local Australian representative on the Activist Liaison Committee for AIDS 2014 along with my team leader Andy Velez (formally ACT-UP New York) and Fred Baldou (ACT-UP Paris).

It was 8:30pm on Friday the 17th of July, the day before registration when we were invited to attend a meeting at the Crowne Plaza Hotel. I walked into a conference room where there was a huge circle of chairs and around 45 international activists from all over the globe who were keen to engage around local issues.

I talked about themes around the mobilisation rally, criminalisation of HIV and the repeal 19A from the local statutes, the ENUF campaign, as well as access to PEP and PrEP and to new treatments for those co-infected with hepatitis C.

A woman sitting next to me from India leaned in and quietly said to me *"We can't even get regular viral load testing or guaranteed ongoing access to treatment. People never disclose their HIV status due to very real fears of physical violence and persecution from authorities and even family members."*

Through this prism the conference seemed to split into two: first world HIV issues and the issue of AIDS in developing nations.



There seemed to be a spotlight on OUR 'good story to tell', and then the very real horror that millions across the globe continue to endure. A lack of structural, political, cultural and financial capacity and regressive punitive laws around HIV in so many countries are still creating barriers to testing and treatment access, adding to the ever mounting death toll of this pandemic. This might seem worlds away from our 'Lucky Country', but in reality, this story is played out just a few hundred kilometres off our shores in places like PNG and across much of the Asia Pacific region.

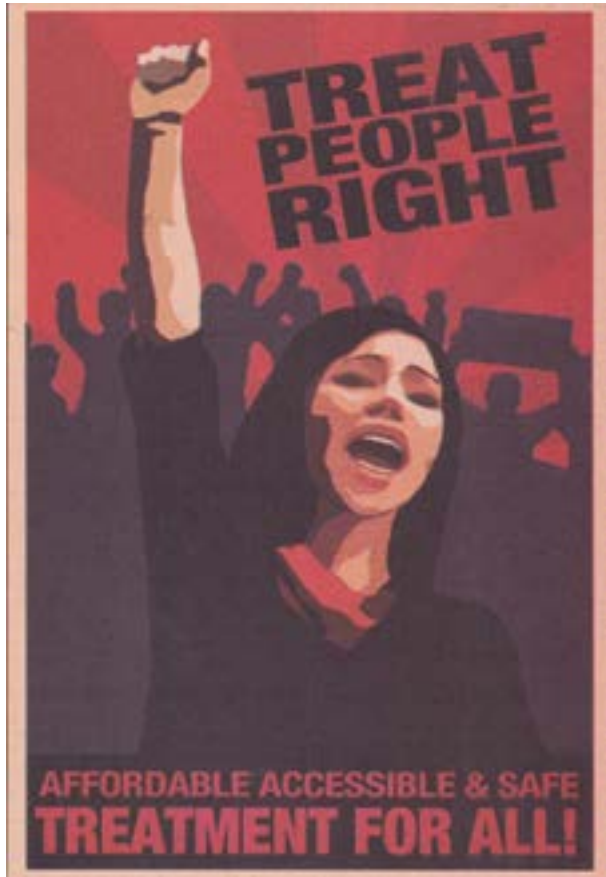
There were plans made at this meeting to shadow UNAIDS leaders around at the conference to attempt to have them verbally commit to fully funding the Global Fund through a Robin Hood tax (an action also directed at President Clinton and the media that follow him) on financial transactions over 10 million USD, and to challenge extended patents on effective treatments like Truvada.

The sex workers' organisations drew attention to the fact that less than 1% of global funding goes to prevention programs for sex workers.

The largest action came from the Hep C coalition and was directed towards Gilead Pharmaceuticals who have developed Sofosbuvir to treat this chronic disease. *"PILLS COST PENNIES. GREED COSTS LIVES"* was the chant as a liver was presented on a platter to the President of Gilead as a die in occurred. They then marched to the Gilead stall and continued their action. The only time I felt like things were unscripted and might get out of hand was when I was jostled and elbowed among about 250 people, in a frenzied rush toward the action with their smart phones held out to record it.

Had it all just become part of the show? Had the bureaucrats of the AIDS industry machine decided through reluctant pragmatism to co-opt tightly controlled demonstrations and discord to ensure that the serious business conducted by those VVIPs, PHDs and multinationals could go ahead largely uninterrupted? Maybe, but without them, would I still be alive? Would there be any chance of effective treatments ever becoming accessible in developing countries as they are for us here today?

I got to meet, observe and speak with many of the movers and shakers. To be honest they spoke with much the same sense of purpose that we do. Their determination, dedication and passion to work towards an AIDS-free



world is genuine. They too are acutely aware that lives are being lost and much more needs to be done.

So what of the Australian activists? Was there any sense of urgency here around fighting for an issue, for finding a voice? Was signing the Melbourne Declaration as radical as we can get? Is local activism simply now a historical footnote, some retrospective hardback 30th anniversary edition full of nostalgia and pictures of the dead and the decorated?

The facts are that the effectiveness of our national political response allowed many of those AIDS activists to become part of the solution. They became stakeholders, volunteers, community services workers, management committee participants, board members and leaders - developing and implementing targeted and innovative programs designed with and aimed at specific key populations. These people being 'of' the community not only gave us the ability to react - but through that engagement - to identify emerging issues. This, I believe, is at the core of our comparative success. Being able to source funding, gain bipartisan political support and participate in a way that has built up local organisations. It is something that deserves to be honoured and celebrated.

Do those obligations and professional responsibilities mute or inhibit our ability to challenge and dispute the very bodies that have funded our organisations? Are we now forever tied by single source funding to the ebbs and flows that dominate the broader community services sector and often leave agencies competing against each other, fighting to protect their 'patch'? Do we remain silent when positive voice organisations in smaller states collapse and peak national bodies have no guarantee of ongoing funding allocations? Have we also been co-opted?

Activists can light fires from within and from outside formal structures. The current example of this is The Institute of Many (TIM) where people can engage outside of official existing frameworks and create their own communities. Here, issues can be raised and discussed in peer based forums via social media, remaining unencumbered by political influence or interference.

There is a growing sense - which feels irrational, but is evidence based - that we have all but overcome AIDS in this country. There is now but one thing left for us to do. The final call to arms. NOW is the time to 'Step Up the Pace'. Not to feel guilt about our privilege, but rather use it to put our foot firmly on the throat of this virus. To use that hard-won social capital and again foster the necessary political and community resolve to refocus and reshape what we do and how we do it. We must direct that same passion working together towards ending HIV.

And finally, just maybe, lose that inward-looking island mentality for a bit and not be afraid to think outside ourselves about how we can work with others in our region to promote leadership and peer based support - prevention and education models that we know are effective and can be supported with political will and efficient resource allocation.





LIVING POSITIVE VICTORIA

# ANNUAL GENERAL MEETING

15 OCTOBER 2014

*At the Positive Living Centre  
51 Commercial Road, Prahran  
6.00pm for a 6.30pm start.*

RSVP: <https://lpvagm2014.eventbrite.com.au>

A postal ballot has been introduced in 2014 to increase member participation. No voting for election of board members will operate at the Annual general meeting.



living positive victoria

PEOPLE LIVING WITH HIV/AIDS VICTORIA REG NO. A0039027B



# How do I put into words the impact of AIDS 2014?

Marg Hayes

Challenges aplenty, encouragement and affirmation.

Day 1 of conference attending began with the tragedy of MH17 and the deaths of friends of friends and also the support of many Melbourne people. At the Intefait and Catholic Preconferences on that day I could feel a pall of sadness over the event, so we set up a remembering space and we prayed. We were also encouraged by the many messages of sympathy and support.

Stepping up the Pace whilst Remembering the Loaves and Fishes were the themes of the two conferences held at the Catholic Leadership Centre in East Melbourne. There, 200 people gathered. We reflected on the Gospel story of the loaves and fishes - reminded that often in our work we are confronted with situations just like the apostles on the hillside. Feed 5000 people with five loaves and two fish, confront the prejudice and discrimination in the village, encourage the person who is unable to obtain the necessary

antiretrovirals and Lord - I only have five loaves and two fish, nowhere near enough for the task at hand and I learn it's not about what I have, but what Jesus can do it with it if I allow him into my world. I am reminded too, that it does not mean that I can abdicate from my role in working for a world with zero new infections, zero discrimination and zero AIDS related deaths. Rather, I use the transformed loaves and fish to work at my tasks.

Then to the Convention Centre and such a buzz and so many good things happening - the meeting up with people I have not seen in a long time, observing that that is the case for many, the sadness of the loss of friends on MH17 and in all, a sense that God is here amongst us.

Tuesday night and people march to Federation Square for the Candlelight Vigil, so cold but so important to be there. We remember and we are yet again propelled to act for justice, to continue to advocate for medication for all, for an end to stigma. And as people of faith we cross the road to

the Cathedral and the warmth. Rev Phumzile Mabizela launches into the most beautiful and haunting African song and then tells us that like the founders of our faith communities, our mission is to "*comfort the distressed and to distress the comfortable*" as we provide health services and work to ensure justice and dignity for everyone living with HIV.

The Global Village - what a wonderful place for connecting with people - learning about the many initiatives being undertaken to give life and dignity to people living with HIV, to combat stigma and discrimination. I felt privileged to be able to talk about an initiative of Catholic HIV/AIDS Ministry in Melbourne. To prepare for the conference and to educate people in our parishes and schools we produced a book - *Angels in Disguise: Stories from Catholic HIV/AIDS Ministry, CatholicCare*. In this collection we have the human face of people living with HIV and our hope is that through meeting people who live with HIV, prejudice and stigma will disappear.

Copies of *Angels in Disguise* can be purchased from Catholic HIV/AIDS Ministry, CatholicCare for \$15 + postage. Contact Marg or Anthony at [am23@ccam.org.au](mailto:am23@ccam.org.au)







# Are we getting older faster?

*David Menadue*

I knew that heading would get your attention! No one wants to think about ageing too much but if someone was to suggest that you might get older by doing certain things, most people would want to find out about it and try to stop that happening.

For some time, we have been hearing at AIDS conferences, that some people with HIV might experience premature or accelerated ageing due to the inflammatory effects of the virus and possibly from long-term side-effects of some treatments.

In a session that I participated in at AIDS 2014 on HIV and Ageing, Dr Peter Reiss, co-principal investigator of the AGEHIV cohort in Amsterdam examined this issue. In his study, he said that it is clear that people with HIV experienced a wider range of co-morbidities than his HIV-negative cohort. Diseases such as hypertension (high blood pressure) and chronic obstructive pulmonary disease (COPD) were higher in HIV-positive people, even after adjusting for lifestyle factors. Having multiple conditions was

mostly seen in people who were 60, 65 or older, said Reiss. Many of these people have lived with HIV for many years, including periods where it was untreated or poorly treated and if they had ever experienced a T-cell count of less than 200 (and particularly, if over a long duration), were likely to be at increased risk of these conditions later in life. Other factors including smoking, family history of disease and waist-to-hip ratio played a role.

However there is still some conjecture about whether HIV causes accelerated ageing, whether PLHIV might get ageing conditions earlier than the general population or not. Reiss said even well-controlled HIV is associated with chronic inflammation which contributes to the ageing of the immune system. But it is still too early for his research to claim that HIV itself - or some of the treatments we take (or have taken in the past) directly affect the biological mechanisms of ageing.

As someone who has lived with the virus for thirty years and experienced several AIDS-defining

illnesses, I was asked to present on my views on HIV and ageing after Reiss. I started by thanking Reiss and other researchers who are interested in this area, because I know that people with HIV want answers to these questions.

Those of us who are experiencing multiple co-morbidities as we have gotten older, want to know if the virus and/or treatments are to blame - but more importantly, if we can do something about these risks for ourselves but also for the younger generation who seem to be doing so well health-wise currently.

To illustrate my own situation I had to list my current co-morbidities: diabetes, renal problems, high cholesterol, osteoarthritis, HIV wasting and a lymphoma in remission. I fit the model Reiss was referring to as being of highest risk - I'm 61, have had HIV for 30 years and had a five year period where I had less than 60 T-cells (at one stage, zero!). I was treated with inferior and often toxic drugs until the proteases came along in 1996 - but even they brought toxicities such as high cholesterol and I think,



contributed to my insulin resistance problem.

I see similar problems in my 'generation' - people who have lived for a long time with HIV (although some for considerably less time than me, as well) and are usually at least in their fifties or older. I have friends who have had strokes, heart attacks, cancer, osteoporosis, fractures or live with debilitating conditions such as peripheral neuropathy or a neurocognitive condition called HAND. My HIV-negative friends in this age group usually don't have any co-morbidities - or if they do, it might be one problem - not several like my positive friends.

To confound things though, I also have friends who are long-term survivors who have minimal health issues despite similar histories - although most have not had AIDS-defining illnesses.

So what can we do about it? The first and most obvious thing that Reiss mentioned in his talk was that people with HIV should really try to give up smoking. People with HIV are several times more likely to get lung cancer and some other cancers and more likely to develop cardiovascular disease, (particularly after the age of 50) according to some studies Reiss cited. It is the single most

important thing people can do to protect their health as smoking is more likely to shorten a person's lifespan than HIV.

Our doctors do need to pay attention to the potential for side-effects from HIV antiretrovirals which might be contributing to conditions associated with ageing. We know that long-term use of Tenofovir can affect kidney function in some people - my doctor took me off the drug after I developed proteinuria, a precursor to kidney disease. Abacavir has some question marks about its involvement in cardiovascular problems over the long-term and some protease inhibitors are known to raise lipids and contribute to insulin resistance (although much less so with the current regimens).

*"If I'm not aware enough of what my treatments are for, when to take them and to remind doctors when to refill scripts, I can seriously endanger my health."*

This is not to say that we should stop taking the regimens we are on as there are undoubtedly good medical reasons to do so, but close monitoring by your doctor of your blood results will help prevent problems. And if you see your doctor regularly you are making sure this monitoring takes place. While on that topic, I mentioned the need for PLHIV to be 'HIV literate' in my presentation. My point is that it is important that we learn what our various drugs are for, particularly when it comes to side-effect management. There are times I have been given the wrong doses of certain drugs because my prescribing doctor has made a small mistake in writing a script or I have forgotten to take a particular script to my pharmacist. If I'm not aware enough of what my treatments are for, when to take them and to remind doctors when to refill scripts, I can seriously endanger my health. It might not be such an issue for people with HIV who only have to take one or two pills (unlike the more experienced PLHIV like me who has to take about 20!) but even then, I think it's important that you take note of the names of your antivirals and follow any items of research about them that you might want to discuss with your doctor.

The more 'experienced' you are in terms of time with HIV and on





treatments, the more likely you are going to need to see specialists for various conditions. This care needs to be well coordinated and your primary doctor (usually a GP) needs to be able to get reports and results in a timely way. My ID specialist happens to also be an expert on HIV and bones and, once I reached the age of 50 and had certain risk factors for falls (weak knees and ankles from HIV wasting), I was given a DXA scan to observe what my bone mineral density (BMD) was. As my doctor said, just going on antiretrovirals will reduce your BMD anyway and there are certain regimens that are less likely to contribute to this than others (e.g. Truvada is more likely to increase risk than Abacavir and 3TC; Ritonavir-included protease regimens are a higher risk but changing to regimens with Raltegravir lowers the risk). I supplement my diet as a result with Vitamin D supplements and daily serves of dairy foods for calcium.

There are many other conditions that we can develop over time and having a good relationship with your doctor and feeling able to discuss any health concerns, no

matter how trivial they may seem, is a vital thing for PLHIV. Like with depression, a very sensitive matter for most people. Raising this issue with your GP can be extremely important if you are HIV-positive. Apart from standard depression that we might get from difficulties in our everyday life, there is a possibility that people can develop a condition called HAND (HIV Associated Neurocognitive Disorder). Being tested for this, if you have any concerns about cognitive changes, can help with early interventions.

My presentation at AIDS 2014 also went into a couple of other issues associated with HIV and Ageing. I spoke about the importance of our HIV-positive organisations advocating for older PLHIV. We need to advocate for their specific service needs and do outreach to older groups of HIV-positive men and women who can more easily feel isolated because of their feelings about body-image and previous issues with HIV stigma and discrimination.

Last but not least, I spoke about a subject we don't particularly want

to think about either: nursing and end-of-life care. While positive people in Victoria await the establishment of a committee at Alfred Health to review the HIV services provided there, including the future of Fairfield House, we need to continue our advocacy for appropriate care for people needing respite and more extended nursing with serious chronic illnesses. There is also the need for education of staff in nursing homes as a number of HIV-positive people have been admitted to these services - and will undoubtedly continue to be in greater numbers in the future.

The Living Positive Victoria *Senior Voices Project* will soon see trained HIV-positive speakers talking to staff in these nursing homes and in services delivering home care to the aged, about treating people with HIV with the dignity, respect and understanding required.

If you are interested in being involved with *Senior Voices* and are an older person living with HIV, contact *Senior Voices Project* Officer Don Harris at [dharris@livingpositivevictoria.org.au](mailto:dharris@livingpositivevictoria.org.au) or phone 03 9863 8733.



*"The key issues facing people living with chronic health conditions are the same, whether it's HIV or another serious chronic condition. These issues include isolation, stigma, employment and financial issues, reliance on the health system, high rates of depression and fears about their care and service providers." Paul Ostrowski, CEO CARECONNECT*

Living Positive Victoria's *Senior Voices Project* seeks to challenge stereotypes associated with older People Living with HIV (PLHIV), by:

- Providing quality training to older HIV positive people to become public speakers in the community and aged care sectors.
- Providing education around HIV-related issues (including stigma, discrimination, sexuality and sexual health) to aged care service providers.
- Establishing social and educational networks for older PLHIV.

If you are interested in learning more about the *Senior Voices Project* or becoming a PLHIV speaker and help make a difference to the lives of senior PLHIV, please contact Don Harris at Living Positive Victoria.

EMAIL: [dharris@livingpositivevictoria.org.au](mailto:dharris@livingpositivevictoria.org.au)

TELEPHONE: +61 3 9863 8733



# ***An AIDS Activist's Memoir in Music***

*a response from  
Joel Murray*

Presented in the gorgeous surrounds of the Melbourne Recital Centre's Salon, the audience sat in an arch around the four players of the Acacia Quartet, the composer Lyle Chan standing to the right of the quartet. For those of you unfamiliar with the structure of a string quartet, it comprised first and second violin, viola and cello. The 'success' of any quartet is to present to the audience a cohesive, almost singular organism - not only making it impossible to tell where the musician ends and the instrument begins - but also the individual contributions of each instrument. But I get ahead of myself. Let me first explain the piece.

*An AIDS Activist's Memoir in Music* comprises 13 movements each connected or relating to a person or moment in the composer's lived experience as an AIDS activist - first in Madison, Wisconsin - and then in Sydney, New South Wales in the six years between 1988-1994. The piece serves as an honorarium for those who fought, those who lost their lives doing so and acts as a time capsule to forever echo the political activism that was happening at the time. But is also about so much more.

***“The intellectual, emotional and artistic connection of the musicians to this piece was clearly evident.”***

As a young person living with HIV, a child of the 1980s, I was unaware of the measures ACT UP took to bring both politicians and the general public's attention to the AIDS crisis in Australia. I was unaware of activists storming parliament house, of singling out the homes of politicians so that activists could picket their homes or of the

buyers clubs that operated out of Sydney, facilitated by the composer himself.

At the beginning of each movement Chan introduced the music, scene and person we were about to hear about, providing a living narrative of related stories that constructed a metaphorical frame for the picture that was about to be painted with the broad and specific brushstrokes of string music. I was conflicted - I was extremely grateful that Chan was providing the context for our listening - filling in my own history of those who had fought for me and others like me. But on the flip-side I longed to hear the piece without interruption, played through for its 90 minutes of entirety. Even though the music prompted a strong emotional response in me, so much so that I found myself suddenly in tears during one movement, I was ultimately grateful for the composer's narrative. Without which I would not have been able to begin to understand the raw energy and passion behind the activist movement in Australia, nor know the names of those who had fought for irreversible change in the way HIV/AIDS was viewed in Australia.

The Arcacia Quartet were an extremely competent ensemble, achieving a rich and uninterrupted cohesive sound. It provided reason to believe that the composer had worked closely with the ensemble during rehearsals and that because of the scale of the event of the AIDS 2014 Conference allowed the audience a glimpse into this work that would not have been made possible in ordinary circumstances. Some weeks later the piece still resonates on an emotional level with me. I feel forever changed as a result of being witness to such a gorgeous piece of music from what was such an important history of AIDS activism in Australia.

*An AIDS Activist's Memoir in Music*

**Lyle Chan (1967- )**

**Arcacia Quartet**



# WOMEN'S NETWORKING ZONE

**Sara Graham and Sarah Feagan**

*"The week inspired me to go into professional advocacy. I have been living with HIV for 12 months, but I was dying with it for 5 years. Living in Australia, I have everything I need to be healthy and well, and now I need to make sure others have that. Now feel I have a responsibility and owe it to the people who fought before me."* – Sarah Feagan, Australia

The Women's Networking Zone (WNZ) was at the centre of women's HIV organising at AIDS 2014. It was a community-led forum - a vibrant, inclusive, exciting space for the promotion of dialogue, networking and raising the visibility of issues directly affecting

women living with HIV. The WNZ was both a safe space for women and a place for learning, sharing, advocacy and the global exchange of experiences and knowledge. For many local Australian women the WNZ provided a rare opportunity to engage with passionate women leaders from around the world and to reinvigorate their efforts, both globally and locally, in fighting the HIV pandemic and improving the lives of women living with HIV. It also gave local researchers, policy makers, medical professionals and community health workers new insights into the impact of HIV on the lives of women in the Australian community and around the world.



The WNZ ran a full program of workshops, daily dialogues, films, presentations, and dance performances by women living with HIV and leading activists, policy makers, researchers working in the HIV field. The sessions within the WNZ were organised around four central themes: access to antiretroviral therapy and healthcare; sexual and reproductive health and rights; discrimination and violence; and criminalisation and justice with a final session devoted to women living with HIV in Australia. What became clear as the week progressed was how artificial the distinctions between these themes are in the real world. It is impossible to talk about improving access to antiretroviral therapies without addressing sexual and reproductive health and rights, gender based violence, stigma and discrimination, and the criminalisation of certain key populations affected by HIV or behaviours.

The daily dialogues, based around each theme, were very popular and particularly insightful. Women living with HIV from all over the world joined together with the audience in wide ranging discussions on how HIV affects them personally and the work they are doing in their own countries or regions to prevent HIV or improve the lives of women and children living with HIV. Although women came from vastly different regions with varying responses to the HIV pandemic there were many common experiences. As one female activist from the Asia-Pacific region noted, *“the issues are the same in many parts of world, especially when it comes to sexual and reproductive health and rights and the law”*. Forced and coerced sterilisation and abortion, denial of access to routine sexual and reproductive healthcare, discrimination experienced in the healthcare setting, and the lack of coordinated services were common experiences for many women all over the world.

Gender inequality and gender based violence compounded the difficulties faced by women living

with HIV in both prevention and access to healthcare and ART. Gender based violence increases a woman's risk of exposure to HIV. Furthermore, women living with HIV are at greater risk of violence. Fear of violence and discrimination was also shown to be a barrier to healthcare access.

Women comprise over fifty percent of people living with HIV globally yet they do not have adequate representation on HIV advisory bodies and their voices are rarely heard. While the needs of women living with HIV in some ways mirror those of men, there are important differences. A central theme that ran through the presentations and discussions in the WNZ was the role of stigma, discrimination and criminalisation of HIV, and the intersection of gender and poverty as barriers to women living with HIV leading full, satisfying and productive lives.

Furthermore, they hamper treatment access and prevention efforts. What is also clear is that there can be no simple medical solution to HIV. While people living with HIV yearn for a cure and a vaccine, to get to zero new infections a human rights-based approach that addresses stigma, discrimination, and criminalisation of the key affected populations is essential. As the largest affected population, women's voices must be a part of the conversation - and addressing gender justice must be a part of the solution. The WNZ program was truly inspiring. As one female activist and researcher from Namibia living with HIV noted, *“the WNZ is our platform to raise our issues”*. The WNZ was at the heart of women's rights organising and movement building at AIDS 2014 and strives to carry that learning beyond the conference and into communities affected by HIV globally.

There will be no getting to zero without women.

Photography thanks to Vicci Tallis



# AIDS 2014 Candlelight Vigil

The AIDS 2014 Candlelight Vigil was held on 22 July at Federation Square and provided global, regional and local PLHIV speakers who shared unique perspectives reflecting the realities of living with HIV. The themes for the Vigil were remembrance of those who have died from HIV and AIDS, hope for the future of everyone living with HIV and celebration of the achievements and successes in the global HIV response.

With Richard Taki as the Master of Ceremony, the Vigil commenced with a minute of silence to remember the tragic deaths on the Malaysian Airlines flight. Musical performances from the cast of Wicked, Dani Sib, the Melbourne Gay and Lesbian Chorus and the Melbourne



Gay and Lesbian Youth Chorus resonated with the 2000 strong audience.

The visual effect of seeing 2000 candles held aloft during the one minute's remembrance for everyone who has died from HIV and AIDS was very poignant. A brilliant team of 34 volunteers assisted in the roles of distributing candles, guiding the Vigil audience into Federation Square and collecting donations.

Photography by Andrew Follows - Blinkie Photography

The volunteers handing out the candles - with little encouragement - collected a total of \$2833 in donations over the space of one and a half hours. We acknowledge the Vigil speakers, performers and sponsors at [www.aids2014candlelightvigil.com](http://www.aids2014candlelightvigil.com) and express our thanks to all involved, especially the Event Producer Jennifer Pitson.

## Global Planet Positive

Global Planet Positive was held on Sunday 20 July at the Collingwood Town Hall, 400 people attended arriving on the ENUF Buses which transported guests from the Melbourne Convention and Exhibition Centre and also dropped them off at Sircuit for the after party. This unique event brought together our Planet Positive faithful local regulars and delegates from around the world who were attending the conference. This events success was due to the collaboration of the funding partners which included Living Positive Victoria, NAPWHA, GNP+, Positive Life NSW, The Yarra Social Hub, Sircuit and the City of Yarra. It showcased the importance of providing a social space that people living with HIV and their friends and family can connect with others in a safe space.

Tobin Saunders was our wonderful MC who made everyone welcome and relaxed with his witty humour. Guest speakers from the key partner organisations reminded us all of the importance of the positive voice which is a powerful tool in the fight to end HIV stigma. The crowd was kept entertained by our DJ Colin and artists Yirmal, a young Indigenous Australian singer songwriter who had the most beautiful voice and Stella Angelico and her band who increased the volume with Stella's soulful voice and violent hip shaking rhythmic performance. We have to thank our amazing volunteers and also the team at Sircuit and the City of Yarra.



Photography by DEANation - Dean Arcuri

# **RACISM.** **IT STOPS** **WITH ME**

## **RACISM. IT STOPS WITH ME**

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ALL AUSTRALIANS TO REFLECT  
ON WHAT THEY CAN DO TO COUNTER RACISM  
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# AIDS 2014 VOLUNTEER

# VOX POP

“

*It's not every day you are given the opportunity to take part in one of the most important conference events in the world where the topic that you have great passion for is discussed for an entire week; and so when I was told two years ago that there was a chance for me to take part in the International AIDS Conference - I jumped at it. Volunteering at the 20th International AIDS Conference was truly an unforgettable experience and being situated in the Global Village at the conference made it extra memorable. Not only was I able to bask in global music, dance, art and performances; but being in the Global Village also gave me an otherwise impossible opportunity to interact with delegates from around the world who have vast knowledge beyond belief and a never ending passion to find a cure as well as prevent the spread of HIV/AIDS. In addition, through volunteering, I was able to meet and make lasting friendships with other volunteers (a number of whom were Melbourne-based, but an even larger number were from other corners of the world) with diverse backgrounds ranging from research and medical to prevention and NGOs. I may not get another chance to do this again - but if I did - I would most likely jump at it again. Guess we'll just have to wait till 2016 and see what happens.”*

**Josie**

“

*The conference was preceded by the downing of MH17, a heartbreaking event that dealt a blow to the global AIDS research effort. However, the tragedy pushed our conference, and the topic of HIV and AIDS, into the spotlight. The media gave it extensive coverage and people started talking. AIDS 2014 was my first experience as a volunteer, and I talked to many members of the general public - most of whom had been unaware of the conference, its importance, and the need for more research. MH17 got people talking, thinking, and reflecting - myself included. I enjoyed being part of the conference, and hope I helped in some small way in our fight against HIV and AIDS.”*

**Tim Chainey**

“

*Whilst volunteering in the Positive Lounge I said hello to a woman from South Africa on my second day as a volunteer. After our initial introduction she went on to tell me she was HIV as was her mother and seven of her siblings. Although I have heard about entire families being infected with the HIV virus I didn't realise the profound impact it had on people until I listened to her amazing story. She was not looking for sympathy, she was simply trying to help other people. It helped put my individual struggle into perspective. I was proud and inspired to be a part of the conference and especially being able to represent Living Positive Victoria and ENUF in my home town Melbourne. Thank you to all for making it happen.”*

**Will Vials**

“

*I had the pleasure of volunteering for Living Positive Victoria events over the period of the 2014 AIDS Conference. As a community outsider and a university student studying Public Health, I felt the conference opened my eyes to the medical advances in HIV treatments. It also demonstrated that community education is also lagging far behind the science. I met some amazing people during the conference who have been supporting Living Positive Victoria for many years. These people gave me an insight into the struggles through difficult years to the point now where there is strong public support for the HIV community. I would like to honour these people and the amazing Living Positive Victoria staff who have supported the organisation through the lean times and helped it flourish.”*

**Andonios Souliotopoulos**

“

*Seeing so many people from all over the world coming together to share their research and knowledge for AIDS 2014 was awe inspiring, and the city of Melbourne was an amazing host! A highlight for me was being able to help out at the Outrage Film Festival where I was lucky enough to meet the curator and see a number of the films addressing discriminatory laws and policies surrounding HIV/AIDS and how they contribute to the stigmatisation and disempowerment of those affected. The films were fascinating and the people involved are inspirational. Volunteering at AIDS 2014 was an experience I won't forget.”*

**Pip Courtney-Bailey**

“

*For me, the International AIDS Conference, hosted by my beloved city of Melbourne, holds memories of hugs, appreciation and laughter. There are many stories I could share about my time in the Positive Lounge, but there is one that is never far from my thoughts when I think of AIDS 2014. He'd lost his luggage and therefore had no ARVs to suppress the HIV in his body. He also approached me - tall, weak and dehydrated. I agreed, Melbourne was an expensive place to eat and drink. I ushered him into the Positive Lounge and told him to take as much food as he could carry. We were mainly offering pieces of nutrition - fruit and packets of nuts - things like that. I told him the options regarding sourcing ARVs as soon as possible, left a voicemail with one centre and encouraged him to go to ED at the Alfred that same evening. I followed up with a nurse from the ID Clinic at the Alfred who said he'd presented and been given two weeks of medication - it was a difficult combination to source but they wanted to maintain his same prescription. It was one of those hugs with meaning. With commitment to holding on and tears in his eyes. He'd approached me fast and I wasn't expecting to see him again, which made it all the more special for me. It's so heart-warming to be thanked, especially when you are just doing your job.”*

Well done, Melbourne, well done.

**Vicky**



# *The POSITIVE LOUNGE* at AIDS 2014

On behalf of the board, staff and volunteers of Living Positive Victoria and AIDS 2014 we would like all the supporters whose generosity helped to make the Positive Lounge at AIDS 2014 such a success. The space would not have been so comfortable, functional and attractive without this community support.

The Positive Lounge opened on Sunday 20 July and provided an exclusive space for the next six days to delegates living with HIV from around the world. Over the course of AIDS 2014, 3712 people were recorded visiting the Positive Lounge – a figure greater than we had anticipated and a testament to word of mouth recommendations of the space that occurred during the conference.

Thanks to the generosity of a range of businesses, we were able to provide complimentary massages, rest spaces, magazines, newspapers, fruit, beverages, yoghurt, a range of dry snacks, entertainment and IT services to delegates using the Positive Lounge. This is in addition to the quality furniture, decorations, flowers, transportation services and cosmetics/toiletries we received as donations. The diversity of businesses who got on board with the supporting the Positive Lounge has allowed us to nurture ongoing partnerships, and at the same time foster new relationships with other businesses that we look forward to working with in the future. A total of 30 volunteers (recruited from the boards, staff and volunteers of Australia's major organisations for people living with HIV) provided their time and care to ensure that the Positive Lounge ran smoothly.

The Lounge's designer Tony Harding - in collaboration with the Positive Lounge working group - formulated a space that captured Melbourne's vibrancy whilst remaining restful. Together, a blank canvas was turned into a special space for people living with HIV.

We have collated evaluations on the Lounge from visitors, volunteers and other key stakeholders. Responses were overwhelmingly positive, and we would like to share with you overleaf some comments received.





***“Well done to all involved. It was a highlight which provided many opportunities to build relationships and engage in community dialogue.”***

***“Wonderful place to meet people and feel empowered. A highlight of AIDS 2014.”***

***“Keep having these – so valuable for wellbeing during the conferences.”***

***“I have been to seven IAS conferences and this lounge was tops. A place to rest, reinvigorate and enjoy the buzz of my poz brothers and sisters.”***



### **THANK YOU TO THE SUPPORTERS OF THE POSITIVE LOUNGE AT AIDS 2014**

- |                                        |                                     |                         |
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# HEX

## a response from Joel Murray

Writing about contemporary dance is not easy - neither is watching, for some. Unlike other forms of dance, this style is not necessarily driven by a strong linear narrative storyline. So in my best attempt to give as much credit to the work, which I thoroughly enjoyed, I will explain some of the scenes along with my accompanying thoughts and emotions. This is not to make a definitive interpretation of the choreographer's intent nor to make invalid any differing emotions or thoughts stirred up in other audience members. Our responses are our own.

The Grim Reaper appears on stage, a menacing and confronting image made more real by the physical manifestation before us. The Grim Reaper has hunted those old enough to remember the shock advertisement campaign around HIV/AIDS awareness. But for those of us born in the eighties and later (the infamous Y-Generation) the Grim Reaper has been either a story, a myth, something you found on YouTube or completely unknown... until now. Disco music begins to play and choreographer James Welsby, as the Grim Reaper, begins to dance along, the audience laughs and two more dancers wait in the wings.

It's a party and everyone is invited - it was a delicious montage of pop, music theatre, music video gay camp queer iconic choreography of the 1980s - the playground for Y-Generation - Welsby's generation, my generation. Was that Bob Fosse? All three dancers shone warm rays of fun and happiness from their eyes, mouths, faces and bodies - the personification of fun footloose and fancy free. Invincible and untouchable but completely naive.

Nothing lasts forever - the choreography starts to weave back upon itself presenting variations on a theme. The dancers looked as though they were getting bored to it all, a routine, a farce, a merry-go-round that is impossibly to get off.



This is our queer party culture - one that can become all consuming - it was at this point that I questioned the time setting for *HEX*. Were we reflecting on the 1980s, placed there by Grim Reaper, or are we in the early adult years of Y-Gen'ers - twink on the dance floor of the Market or the Exchange - pop another E, party a little longer?

The disco turns into a lovely little trio of arms and bodies, over and under - playful, caring, intimate - symmetrical with the two young gentlemen on the outside and the very attractive lady on the inside. I ponder on this over and over - it was 'pretty', flirty and a little tongue-in-cheek. It makes me feels romantic. It is an interlude, a moment in time that can be looked back upon as that moment before everything changed forever.

The two men sit on the floor, their bodies intertwined but not touching. This scene is erotic and slightly sterile. The two men begin to sing into each other's mouths (still not touching) "ahhhhhhh", softly at first and then louder and louder. The woman stands by as a spectator and is then invited to join in. I don't know what is going on - are they infecting each other with HIV? This is very intense. A single dancer inflates a pink

rubber glove (think the washing up kind), and then lets it go. I expect the glove to take off into the air, but it doesn't. The single pink rubber glove falls to the ground, limp, lifeless, dead. The other two dancers join in and slowly walk around the stage inflating pink rubber gloves, each one falling to the ground. I am reminded of stories I have heard about nurses 'double gloving' for those unfortunate victims in the early days of Gay-related Immune Deficiency. I don't know if this is a specific reference. I get a sense that everyone is infected and people are dying.

A sharp piercing whistle blows, the audience is now watching a riot. All three dancers play perpetrator and victim. The violent physical blows trebled in the perpetrator's shadows animated across the three walls of the space. I feel every punch and kick the victim receives. Who are the perpetrators - police, homophobes, people responding to fear of the unknown - fear of being infected by HIV?

We return to the trio (a love triangle?) but I see the dancers awash with a newfound sense of resilience. There is a quiet confidence in the symmetrical sequences we are already familiar with.

This scene's beauty balances out the intensity of what we have witnessed moments before. The Grim Reaper's scythe is leaned up against the back wall. All three jump into the air, breaking the symbol of death, cracking and splintering the scythe in two. The audience cheers. Three dancers leap and bounce around the space with gymnastics ribbons. Celebration and triumph. Welsby is left dancing by himself, he pulls his pants down around his ankles as he spins around and around, before bending over and using his lovely arse hole to lip sync the words to the song playing and the lights fade to black.

James Welsby's *HEX* presents a series of vignettes, images and symbols to convey ideas around the theme of the HIV epidemic and the ignorance of Y-Generation of this important part of queer history. Welsby uses this mechanism successfully, allowing individual audience members to have these images wash over them and stimulate a memory response. Through layering of differing movement sequences, *HEX* not only leveraged a response in me based on the aesthetics of the piece, but also penetrated to achieve a much deeper emotional response.





# THOSE OF US WHO ARE NOT TRADITIONAL ALLIES IN THE HIV DEBATE MUST STEP UP

Ian Smith - ENUF Ambassador

In this edition of *Poslink* we offer you the inspiring speech delivered to the crowd gathered at the launch of the *ENUF Voices* exhibition by ENUF Ambassador Mr Ian Smith of Bespoke Approach.

*ENUF Voices* was a multimedia exhibition staged for AIDS 2014 that engaged PLHIV through a creative, inclusive and collaborative artistic process using a range of artistic media to portray real experiences of HIV-related stigma and discrimination.

Joining other speakers, Brent Allan, Executive Officer of Living Positive Victoria, Cr Jackie Watts, City of Melbourne and Richard Keene, *ENUF Voices* participant, Ian Smith provided a different perspective in tackling HIV stigma...

*“Ladies and gentlemen, it is a privilege to be here tonight to help launch the ENUF Voices Exhibition. It is an accident that I am here in many respects.*

*Given I am viewed as a crusty old Tory with embedded old-fashioned values, thanks to middle-class conservative parents from the cosseted stockbroker belt of Surrey in England, some say to me how did you get involved with ENUF and the efforts to remove HIV stigma?*

*“HIV stigma is the single most important barrier to public action”*

*Well, ENUF’s real target was my wife, one of Australia’s most loved people – Natasha Stott Despoja. Natasha is now Australia’s Ambassador for Women and Girls and Chair of the National Foundation to end violence against women and their children.*

*18 months or so ago Natasha was asked to be an Ambassador for ENUF. She accepted and in the discussion was told that the campaign needed heterosexual men, preferably from senior levels in business, to help challenge HIV stigma and take a role in pushing to end the isolation that many with HIV feel.*

*So here I am - playing a very small but passionate part in working with other Ambassadors and the superb team at Living Positive*

**Victoria to remove the fear of disclosure for those living with HIV.**

**What I have learned and from the many conversations I have had, I have become passionate about playing a part to change attitudes. HIV stigma is the single most important barrier to public action because people are so concerned about the disgrace or humiliation of talking about it or taking available precautions.**

**It remains an undeniable fact of life that many people think those**

**welcome positive steps. Indeed our government has recently determined that people living with HIV do not face an automatic exclusion, or unequal treatment when applying for entry, stay or residence visas.**

**HIV is obviously regarded as something that is most prevalent among gay men, but it is wrong to see the challenges of HIV, which is once again increasing in numbers, through such a generalised prism.**

**Most people deal with HIV and lead**

**It is not for the 'Gay Community' to lead the charge alone. Indeed, I often feel we must stop dividing 'community' as it is better when we work as one.**

**Those of us who are not traditional allies in the HIV debate must step up.**

**What my conservative father always taught me was to try to show respect to others. He could have his streak of mirth, sometimes misguided but never malicious, but he would always be**



**"Indeed, I often feel we must stop dividing 'community' as it is better when we work as one."**



**with HIV should be excluded from so many aspects of modern life.**

**Thankfully that number of people is reducing – thanks to the leads set by individuals such as you and me, to companies to governments. The lead from the ENUF pledge so people do not sit by and take action when others gossip about, reject and/or promote negative stereotypes about people living with HIV.**

**The lead from 40 of the world's leading CEOs who signed a pledge in 2012 opposing HIV restrictions, calling them discriminatory and bad for business.**

**Even the lead from governments – and while we are quick to criticise, we should also be open to**

**normal, healthy lives. But some do not.**

**Many men and increasing numbers of women are infected by men who often knowingly have contracted HIV from a previous sexual encounter.**

**That makes me incredibly angry and can be justifiably regarded as cowardly and weak behaviour. But anger does not deal with the challenge of changing the behaviour of these men.**

**Making these men understand they must talk about HIV, seek treatment and protect others when they have sex is the goal we must focus upon. Changing attitudes should not be the domain of sectoral or sexual interests alone.**

**respectful to others not like him even if he viewed himself as 'normal'.**

**So perhaps it is no surprise that I am part of the campaign.**

**Respect must be our bond – straight, gay, male, female, HIV or not.**

**Just as we have removed the stigma of so many problems in society – depression being a prime example – so we can remove the stigma of HIV.**

**But to do so we must all talk about it, understand it and deal with it."**

Photography thanks to Peter Curnow





# Positively Fabulous+ at AIDS 2014

KIM DAVIS

The *Positively Fabulous+* Miss HIV Universe Pageant took place on the Global Village Stage in front of a packed house. Mistresses of Ceremony were Ma'Dam Kim and Bollywood superstar Laxmi Narayan Tripathi.

The *Positively Fabulous+* documentary was shown as 17 Miss HIV contestants took the stage. Each was looking 'positively fabulous!' The attention did not overwhelm them as they have over 5000 followers on Facebook. Ethel - the mother of one of the contestants - shared some of the HIV awareness and insights she had gained from being part of the *Positively Fabulous+* adopt an HIV-positive mannequin campaign and Miss HIV Universe pageant.

Ross Anderson performed on the Global Village stage for the pageant audience. At voting time it was a close call, but the Fabulous Joyce Familia-Quinn - our indigenous representative from JOY 94.9 - was

crowned the winner. She is *Positively Fabulous+* Miss HIV Universe 2014. Two years of conceptualising, developing and creating went into *Positively Fabulous+* as we travelled throughout Southeast Asia and Australia documenting the stories of women living with HIV, hunting for mannequins, partnering with families, NGOs, businesses and communities whilst collaborating with artists, craftspeople, musicians and performers. All involved were passionate to learn more about HIV and create an environment that entices new audiences to pose questions, enter into dialogues, share new knowledge and make changes.

Last year, GloballyAware took a *Positively Fabulous+* film crew to Thailand. The HIV Adoption Centre was installed at ICAAP and the crew documented Ma'Dam Kim in conversation with women leaders from all over Asia living with HIV. Meanwhile, we went hunting around Bangkok for HIV-positive mannequins.

During World Aids Day 2013 weekend, the *Positively Fabulous+* Adopt an HIV Mannequin Centre was installed at Federation Square. We met with UNAIDS Executive Director Michel Sidibé and attended Government House with Aung San Suu Kyi for the lead up to AIDS 2014.

The 20th International AIDS Conference was held in Melbourne - my hometown. I'm 20 years positive at the 20th AIDS conference - 20 years of working and co-creatively enabling the voices of PLHIV to change lives. For AIDS 2014 and the City of Melbourne I've directed and produced 8 events: *Positively Fabulous+* Women's Voices documentary, Babbling Boudoir, Junkies' Pool, Kitchen Chatter, POS FAB Touring Caravan, Mannequin Rescue, Miss HIV Universe pageant, Ma'Dam Kim and worked with over 180 volunteers. I am exhausted thinking about it. I need to breathe, ponder, evolve, re-energise and savour the moment. International AIDS conferences always bring together the most amazing people from all over the globe. You can only be inspired and overwhelmed by the passion of others living with HIV. Their knowledge is vast and their compassion is humbling. I have been attending AIDS conferences





***“You can only be inspired and overwhelmed by the passion of others living with HIV. Their knowledge is vast and their compassion is humbling.”***



since the mid-1990s and without prejudice, this year in Melbourne was the best thus far. Firstly, the Global Village was the place to be. It is ours - the community space where our stories can be told without fear and with a sense of autonomy that we then share with the broader public. This includes who we are, what we once were, who we fight the fight for and to whom our stories need to be told. The space had many zones for women, human rights, harm reduction, sex workers, MSM, trans\*, youth, art and more art, as well as zones for JOY 94.9 and activists from right across the globe all with a story. The Global Village was vibrant and a must for all delegates to experience. The inner sanctum of the main conference rolled on, as always, with one difference - more of the experts were now openly positive, thus breaking the mould of tokenism. There was an air where we, the people living with HIV, have the answers to lead us all through this journey. Amazing vision Melbourne - a job well done.

My thanks goes out to the amazing people, groups and business who have supported *Positively Fabulous+* including the Australian Arts Council, Living Positive Victoria, English Family Foundation, Ferals, Change Media, Coles, City of Melbourne, Victorian College of the Arts, Academy of Design Australia, International AIDS Society, Marisa Quigley, Darren Christie, Gavin Henderson, Terry Standfield, Brent Allan, Suzy Malhotra, Murray Sayer, Fran Kerlin, Roxanne Peters, Alyson Campbell, Ross Anderson, the 33 amazing bands and musicians who performed in the Global Village, Positive Lounge and City Square and to all of my volunteers. Thank you for supporting GloballyAware's *Positively Fabulous+* Changing Lives campaign for the last 2 years.

A *Positively Fabulous+* art auction at Sotheby's will take place in 2015. Please visit <http://globallyaware.com.au/> for more information on the campaign.

# HealthMap: *A new way to manage your health*



## **Why was HealthMap developed?**

People with HIV are living longer, healthier lives since the advent of combination antiretroviral therapy (ART). While advances in ART make it easier to control the HIV virus, people with HIV are more likely to have other conditions. These conditions include heart, bone and liver disease.

Health professionals have known for many years that people are healthier and happier when they are supported to take greater control of their own health. Self-management programmes can now be made more accessible through technology. However, we are only just beginning to understand the best ways to design these programmes. As yet there is no programme available for people with HIV.

## **Why is HealthMap important?**

Healthmap is a dynamic programme that uses ground-breaking technology and is at the forefront of improving healthcare. It is the first to combine successful research from many different areas into one complete programme. It involves leading researchers with many areas of expertise, as well as HIV organisations around Australia. Healthcare is changing rapidly and HealthMap is keeping people with HIV at the centre of this change. Your involvement is important in helping to shape the future of healthcare for people with HIV around Australia.

## **What is HealthMap?**

HealthMap is a health programme of interactive health plans and self-management support. The HealthMap programme provides:

- access to health coaches,
- access to a confidential, anonymous peer-moderated online support group and
- a secure online health record.

The health record can be used during doctor visits to discuss lab results and health priorities and plan goals. It can also be used at home by patients.

## **The aims of HealthMap**

The overall goal of HealthMap is to improve the health status of people living with HIV in Australia. The aim of the project is to develop a self-management tool that can be accessed via smartphone, tablet or desktop. The tool will help patients manage their medications, health goals and connect them with health care providers.

## **The HealthMap study**

The HealthMap platform has been developed and piloted over the past two years. The programme is being rolled out as a research study across 14 clinics in Victoria, NSW and SA with 70 doctors as 1200 patients. The doctors together with their consented patients will be randomised to either receive immediate access or delayed access (in 12 months) to the programme.

If you are interested in finding out more about the study or would like to sign up for the study, you can:

- visit our website, Facebook page for more information and to send us a message;
- follow us on Twitter and Facebook to see which clinics have been recruiting;
- or contact us directly by phone or email.

We look forward to hearing from you.

Contact us to find out more:

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# ***STATUS - a response from Dean Camilleri***

*STATUS* is an insightful piece of verbatim theatre which is sometimes joyous, sometimes heartbreaking, but always truthful in its depiction of the stigma that has plagued HIV over the decades since the 1980s. I was in fact one of the 30 people whose stories contributed to this play, which is compiled from interviews with HIV-positive people, as well as people who knew and worked with HIV-positive people throughout various stages of the epidemic. I can honestly say that it is a very honest and raw theatrical production. The interviews are extremely powerful, and the realism is so accurately maintained by the fact that they have not changed a single word of the storytelling, so much so that not an "um" or an "ah" have been removed, in an effort to truly capture the sentiment and emotion of the interviewee.



There is an incredibly diverse mix of stories in the play, some heartbreaking and some extremely funny. Some of the more poignant moments come from hearing stories from people that had to watch their friends be euthanised back in the late 1980s and early 1990s when HIV was still a death sentence.

*STATUS* is an honest portrayal of real life stories that are pieced together in a way that truly captures the stigma of HIV, and the ever changing idea of what it means and feels like to be living with HIV.



*In the Loop is a free workshop for carers, partners, friends and families of people living with HIV (PLHIV).*

It is recognised that people who look after, or are close to PLHIV may often feel silenced by the virus and this can make it harder for them to access support for themselves. This therapeutic workshop aims to provide information about support services available in the community and seeks to explore the constraints that carers may experience and how they might overcome these.

*The workshop runs twice a year.*

# MY INTERNATIONAL AIDS CONFERENCE EXPERIENCE



*Cath Smith*

The 2014 Melbourne IAC was my first ever. Being in my home state, I was very fortunate to receive a complimentary registration allotted by the Department of Health to Positive Women Victoria.

In preparation, I trawled through the conference program to work out what was of interest to me (to augment my knowledge and skills as an activist and advocate for women living with HIV in Australia) and booked and paid for tickets to all the social events I wanted to attend. I had planned on attending both the opening and closing ceremonies, as well as attending sessions relating to my health concerns like ageing, inflammation and in particular a session on sustaining myself in HIV Activism and Advocacy Work. And most importantly, I wanted to see Bob Geldof speak.

My experience started with an opportunity to meet some amazing young women living with HIV from around the world through the Young Women's Christian

Association on the Thursday prior to the conference starting. I spoke to these young women about my experiences of living with HIV in Australia after which I got to speak to some of them one on one and hear their courageous stories; these young women and their amazing "Mum" Hendricka from World YWCA, became an anchor for me during the conference. However, like everyone connected to the conference, the downing of MH17 and the implications it had for the worldwide HIV community, completely changed the landscape of the IAC2014. Whilst I didn't personally know any of the people lost in the tragedy, I was acutely aware of the impact on their colleagues, some of whom had worked with the victims since the start of the epidemic, and the loss of the collective passions and knowledge these wonderful people had shared.

All that I had planned to attend changed, and I found myself having to take actions to 'sustain' my emotional and physical health.

I became overwhelmed by the stories of many of the people I met living with HIV, in particular women, who face such adversities like enforced sterilisation after an HIV diagnosis. It was reinforced to me over and over again, just how lucky I am to be HIV-positive in Australia and the guilt I felt around this was very consuming. I soon realised that in order for me to physically and emotionally survive the conference, I would need to pace myself better. I ended up not attending many of the social events related to the conference and I even took a day off from attending, something which many of my peers who work in the HIV sector in Victoria did not have the liberty to do.

Whilst my conference experience was not what I planned, it was a once in a lifetime opportunity that I will never forget. I have made new friends, I have found new passions and I have a renewed sense of my reality and my future of living with HIV.



# HAVE YOU BEEN EXPOSED TO SYPHILIS?

GAY MEN LIVING WITH HIV ARE MORE LIKELY  
TO EXPERIENCE REINFECTION WITH SYPHILIS.  
GET TESTED FOR SYPHILIS EVERY THREE MONTHS IF YOU ARE LIVING WITH HIV.

## EVERYTHING OLD IS NEW AGAIN

# Treatment News

Dimitri Daskalakis - Health Promotion Officer - Living Positive Victoria

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## Triumeq

Triumeq (dolutegravir/abacavir/lamivudine) is an investigational drug indicated for the treatment of adult and adolescent patients (minimum age of 12 years and with a minimum weight of 40kg) affected with human immunodeficiency virus (HIV).

The drug has been developed and manufactured by ViiV Healthcare. It is a single-tablet, triple-combination antiretroviral (ARV) regimen, as a first-line therapy to treat HIV. The tablet is comprised of the integrase inhibitor Tivicay (dolutegravir – which was approved in the Australia in April 2014) plus Epzicom (abacavir and lamivudine). The Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) granted a positive opinion on the Marketing Authorisation Application (MAA) for Triumeq on 26 June 2014. Regulatory applications are also being evaluated in other markets worldwide, including Australia.

## Studies

In the 'SINGLE' study, the primary clinical trial leading up to its approval in the U.S, Triumeq was found to be virologically and immunologically superior to Atripla, and was better tolerated.

A number of studies - the SPRING-2 study, which put Tivicay (dolutegravir) up against Isentress (raltegravir); and the FLAMINGO study, in which dolutegravir bested Prezista

(ritonavir-boosted darunavir), have also suggested that dolutegravir has a more favorable resistance profile than other currently approved integrase inhibitors - not only in terms of its activity in people with resistance to other integrase inhibitors, but also in terms of the extent to which people develop drug resistance when therapy with a dolutegravir-based regimen fails. According to Benjamin Young, M.D., Ph.D., the chief medical officer of the International Association of Providers of AIDS Care, "The lack of observed emergent drug resistance is a key attribute" of Triumeq. However, the tablet is not recommended for individuals with a history of resistance to the component drugs. To date, no resistance has been seen in people starting dolutegravir as an initial regimen. Only time will tell whether its barrier is as high as that of boosted protease inhibitors (PIs), where we never see resistance in people who didn't have PI resistance to begin with. Dolutegravir is also well tolerated and has relatively few drug interactions.

## Adverse Reactions

The most commonly reported (<2%) adverse reactions of at least moderate intensity in treatment-naïve adult subjects receiving Triumeq were insomnia (3%), headache (2%), and fatigue (2%).

## Approval in Australia

An application has been made for registration with TGA (Therapeutic Goods Administration) in Australia

and is awaiting approval. If approved, it will be the first single-tablet regimen available that does not contain Truvada (tenofovir/emtricitabine). ("Tenofovir's attendant risks of kidney and bone toxicity are of increasing importance among an aging HIV population," Young notes). Consequently, Triumeq is also an option for those who have impaired kidney function, thus making it an important step forward for antiretroviral therapy. Despite its many attributes, Triumeq is not for everyone. While dolutegravir itself has no discernible disadvantages, the pairing with abacavir can be a deal breaker in some cases. Pre-treatment HLA-B\*5701 testing is required, and those who test positive can't take it because of the high risk of the abacavir hypersensitivity reaction.

## Sources

Please email [ddaskalakis@livingpositivevictoria.org.au](mailto:ddaskalakis@livingpositivevictoria.org.au) for a full list of references.



**STAMP OUT**  
**SYPHILIS** in VICTORIA



**HAVE YOU**  
**HAD YOUR 3 MONTHLY BLOOD TEST?**

**SEE YOUR HIV SPECIALIST  
OR GENERAL PRACTITIONER**

**EVERYTHING OLD IS NEW AGAIN**

# Imagine the quality of life you could have if you quit smoking...

Queensland Positive People (QPP) and  
Living Positive Victoria (LPV)  
are providing a **FREE** 6 week online quit course  
for people living with HIV in Queensland  
and Victoria

**Commencing November (weekly 6-8pm)**

**Register your interest now**

**Queenslanders:** Peter Watts on 07 3013 5555 or [pwatts@qpp.org.au](mailto:pwatts@qpp.org.au)

**Victorians:** Vic Perri on 03 9863 8739 or [vperri@livingpositivevictoria.org.au](mailto:vperri@livingpositivevictoria.org.au)





# MEMBERSHIP AND SUBSCRIPTION FORM



**living positive victoria**  
PEOPLE LIVING WITH HIV/AIDS VICTORIA

Join online at [www.livingpositivevictoria.org.au/members](http://www.livingpositivevictoria.org.au/members)

## Living Positive Victoria Membership

Membership of Living Positive Victoria is **FREE** and is open to any person in VIC/TAS living with or affected by HIV.

Members receive a free subscription to Poslink, an Annual Report and occasional mail/email updates.

For more information, visit [livingpositivevictoria.org.au](http://livingpositivevictoria.org.au)

- ☐ **Full member** (I am a VIC/TAS resident living with HIV)  
As a person living with HIV, you are entitled to full voting rights. You must tick the Privacy Information Statement at the bottom of this page.
- ☐ **Associate member** (I am not living with HIV eg: a partner, family member, carer, healthcare worker).
- ☐ **Affiliate member** (I am authorised to represent the organisation/business applying for membership).

**Note:** Applications for membership must be approved by the Living Positive Victoria Board of Directors. Full members may be asked to provide verification of HIV status. The Rules of the Organisation are available online at [livingpositivevictoria.org.au](http://livingpositivevictoria.org.au) or can be requested by contacting 03 9863 8733.

## Privacy Information Statement

Living Positive Victoria collects your personal information in accordance with our Privacy Policy ([livingpositivevictoria.org.au/about/privacy](http://livingpositivevictoria.org.au/about/privacy)).

Your details are strictly confidential and only used to add you to our membership database. We will send you information about Living Positive Victoria, our newsletter and email updates.

We store your personal information in hardcopy and or electronically. Access to your information is strictly limited to Living Positive Victoria and will not be shared with any other organisation or individual.

You can access and correct your personal/health information by contacting us on 03 9863 8733 or [info@livingpositivevictoria.org.au](mailto:info@livingpositivevictoria.org.au)

- ☐ I have read the Privacy Information Statement and consent to my information being collected and stored by Living Positive Victoria.

**Please return the completed form to:**

**Living Positive Victoria**

**Reply Paid 87634**

**Southbank VIC 3006**

*No stamp necessary.*

**Please tick and complete the following:**

☐ **New Membership** ☐ **Update contact details**

Name

Address

State

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Contact Number

Email

Date of Birth

Gender

Signature

Date

## General Correspondence

I/we wish to receive correspondence from Living Positive Victoria about the latest HIV news, information, events and campaigns.

Post/Mail ☐ Email ☐ Do not wish to receive ☐

## Poslink Newsletter

Members can receive Poslink, we produce four copies of Poslink each calendar year.

I/ we would like to receive Poslink via:

Post/Mail ☐ Email ☐ Do not wish to receive ☐

Living Positive Victoria (People Living with HIV/AIDS Victoria)

ABN 67 049438341

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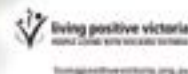
# PHOENIX



WORKSHOPS FOR PEOPLE WHO HAVE RECENTLY BEEN DIAGNOSED HIV-POSITIVE



Take the first step to living well with HIV.  
To find out more email [info@livingpositivevictoria.org.au](mailto:info@livingpositivevictoria.org.au) or call 03 9563 8733.



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*EXPRESS*

is here!

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