

# poslink



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Education, Information  
& Representation

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## Coventry House volunteer positions available



Are you interested in volunteering for a not for profit organisation?

Would you like to be a part of an energetic team that is dedicated to improving the lives of people affected by HIV?

Great opportunities currently exist for volunteering within the supportive environment of Coventry House.

To express your interest or for more information please contact PLWHA Victoria on 03 9863 8744 or email [info@plwhavictoria.org.au](mailto:info@plwhavictoria.org.au)

## Note from the President Sam Venning

Being open about living with HIV and sharing personal experiences help raise awareness, address anxieties and support people to test for HIV.

A couple of years ago my partner and I discussed with a friend how being HIV positive impacted upon dating, relationships and sex. Our friend revealed he had engaged in sexual activity that significantly increased his risk of acquiring HIV – yet he had never been tested for HIV. Until that conversation he didn't know of anyone in his circle of friends living with HIV. He avoided learning about HIV and deferred testing in an effort to reduce his anxiety. The consequence of this is potentially quite damaging. If he was HIV positive and did not monitor the state of his immune system and start treatment before his immune system was compromised, he risked serious illness. Fortunately our friend later received a HIV negative result.

Does the two week wait between drawing blood for a test and obtaining the result deter people from testing regularly? Do you think people would be more inclined to test more regularly if it was possible to complete the test and get the result at the same appointment?

The period between drawing blood and obtaining the result can be a very anxious wait for some people. Reducing this from two weeks to 15 minutes would remove a significant barrier to testing for some people in Australia.

Offering rapid HIV screening services in Australia has the potential to address issues of HIV stigma and testing and support those newly diagnosed. It is estimated that about 20% of people who are living with HIV don't know their status.

As a result, individuals who don't know they are living with HIV will not be offered routine services to monitor the health of their immune system; they are also less likely to start treatment before their immune system is significantly compromised.

Rapid HIV antibody tests, which provide results within 15-60 minutes, can help reduce the number of unrecognised infections by improving access to testing facilities and increase the number of people testing.

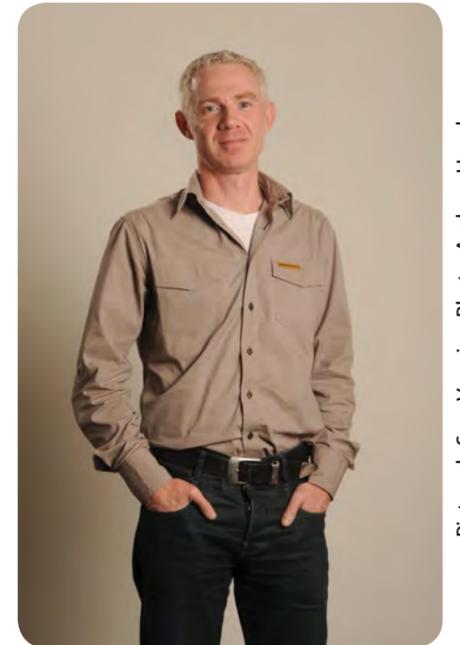
A positive result to a 'rapid HIV screening' should prompt a follow-up HIV test that looks at a broader set of indicators to look for HIV infection.

Rapid HIV screening technologies have obvious benefits in settings that aim to screen a large number of people in a short space of time, and where screening is conducted in remote locations far from pathology services or in countries where health resources are limited.

A great example of this service is from the BCN Clinic in Barcelona which offers 'rapid HIV screening' as well as other sexual health services, to men who have sex with men.

This model also provides an opportunity for appropriately trained PLHIV to work in a health promotion setting supporting people to stay HIV-negative or supporting those diagnosed HIV-positive with advice and information to maintain good health. Meeting people face to face and learning about personal experiences is often more engaging than messages in text and photos in brochures, posters and web sites. It is another opportunity to present PLHIV as confident, empowered individuals able to affect their own health and wellbeing as well as helping others.

The novelty of introducing 'rapid HIV screening' to an Australian setting would no doubt raise considerable



Pictured: Sam Venning Photo: Andrew Henshaw

interest and discussion in the community and provide a new angle to promote testing and deliver health promotion messages.

If the cost of providing 'rapid HIV screening' is not prohibitive and appropriate protocols are in place for pre and post-test counselling 'rapid HIV screening' this will encourage people to test regularly, know their status and be in a better position to either avoid acquiring HIV or take steps to avoid passing it on.

# Any questions for Brent?

James May

Brent Allan came on board as the new Executive Officer with PLWHA Victoria in April 2012. 'I'm loving it,' he says. 'It's a challenging and exciting role and the staff are great. I've never worked with such an amazing crew who are so keen to get things done.' Brent is full of energy himself. He's enthusiastic about his work and he's got a great sense of humour too.

He started volunteering in the HIV sector in 1989, in his home town of Edmonton, Canada. 'There were no treatments back then. I was a newly 'out' gay man and many friends and colleagues were sick and dying.' Brent says he wanted to contribute to the response so he got involved in volunteer outreach, handing out condoms in bars. 'They were scary times,' he says. 'There was a lot of camaraderie and unified action but it was tough.'

Brent's first professional role was coordinating gay men's outreach programs in Edmonton. He finished his Education degree and moved to Ottawa to head up National HIV Education programs in Canada. This was followed by a stint in Vancouver in a similar role. He then travelled to Warsaw, Poland to work with the United Nations. 'It was mostly volunteer coordination, on the ground stuff. It was a great experience and gave me the opportunity to come to Australia.'

Brent arrived in Australia in 1997 and took up a job at ACON in Sydney, managing Peer Education programs. He also managed Regional Development and Community Health programs during this time. 'Antivirals had just come on the scene and we were uncertain what the medication would do. People were taking handfuls of pills back then. We were concerned the meds wouldn't be all they were cracked up to be, but thankfully they exceeded

expectations. The epidemic we're living through now is so different.'

Brent moved to Melbourne in 2004 to work with VAC/GMHC. He managed HIV Service programs while maintaining his position on the board of NAPWA as Vice-President. Brent says his passion is to support HIV-positive people to come to terms with living with the virus and to develop the skills to be resilient. 'I'm passionate about involving HIV-positive people in all levels of the response. I want them to have the skills and capacity to be on our board of directors. I want them to have input into our education and peer support programs. I want to put the GIPA principles into practice.' (the greater involvement of positive people).

He believes we're in a new era in our response to HIV which affords us an opportunity for positive people to play a more active role in engaging and delivering programs. 'It's the on-going stigma that holds people back more than anything. Although discrimination is well addressed in law, stigma still exists in our community, among family, friends and partners.' Brent says it is stigma which diminishes the capacity of positive people to believe they can contribute to the response to HIV/AIDS. 'Stigma has to be addressed in order for positive people to realise their potential.'

Many people with HIV still feel like they have a tremendous emotional burden to carry, Brent says. 'This leads to anxiety and depression, and diminishes one's personal agency.' He points out that recent studies on stigma in Australia reveal that just about everyone living with HIV has experienced stigma in one form or another. 'I can often blend into a crowd but I still have to sense if it's safe to say I'm HIV-positive,' Brent says. 'It's the same burden as coming out as a gay man, only we have to do it again and again.'

The early and coordinated response to the epidemic in Australia has been a big success but also created its own challenges, Brent says. While the virus has largely been maintained to the gay male community, it's made it very difficult to be an HIV-positive heterosexual man or woman or someone who identifies with the CALD community. 'I want to acknowledge that if you're a woman or heterosexual man living with HIV in this country, it's very isolating and challenging. I firmly believe in the existence of Positive Women and Straight Arrows to serve their communities. They're a minority within a minority and extra effort needs to go into their communities.'

PLWHA Victoria are launching a new campaign to fight stigma and discrimination called 'ENUF'. The PLWHA Victoria team have been putting it together since May and they want people to get involved any way they can. 'The goal is to get partners, businesses and organisations behind the brand 'ENUF'. We're all tired of stigma and



Pictured: Brent Allan Photo: Andrew Henshaw

# ENUF

Resist HIV stigma and promote resilience

'we want help to break it down,' Brent says. The soft launch of the campaign kicked off in Washington in the US in July. Badges were passed around to get people thinking about what HIV stigma means to them. 'We'll be collecting stories from people about stigma and pulling out quotes that we can display on billboards, bumper stickers, anywhere we can. People who haven't been able to share their stories till now can do so without feeling like they're outing themselves or committing more energy than they can.'

According to Brent, this campaign is different in that the content will be decided by the people involved. 'It'll be the real voices of positive people that we're displaying. It's a community owned and operated campaign, calling on businesses and organisations to sign a declaration to stand up and say they're against HIV stigma.' A website has already been created for businesses to link to: [www.enuf.org.au](http://www.enuf.org.au). 'The most shocking thing about HIV stigma is that it's mostly experienced in a person's own community. If you're a gay man, it's in the gay community. If you're a woman from a CALD community, it's often

most pronounced in that community. It's really unfortunate.'

Brent firmly believes that reducing stigma will also see a decline in new infections. 'One of the biggest barriers to getting tested is the fear of being HIV-positive. If someone doesn't know their status, it's harder to take precautions. It all goes back to HIV stigma.' According to Brent, positive people are also less likely to seek support if they think they'll come up against prejudice. 'Fear is a great motivator,' he says.

Brent is proud of the team at PLWHA Victoria and the great personal development services the organisation offers like Phoenix and Quit. He says he wants to take it a step further and provide tangible skills and leadership development to members. 'If we believe that positive people should have a vital role to play in leadership, then they need the skills to do so. Too many positive people are held back personally and professionally and we need to think of way to build resilience. This is the key to changing this.'

Brent would love to see PLWHA Victoria build its membership base.

'Our member numbers demonstrate the commitment we have from across the community. It's important to build on this as well as the diversity of our member base.' Brent is excited about the current rebranding exercise taking place, regarding the organisation's name and logo – and the 2014 International HIV/AIDS conference and the opportunities it will bring. He's also thrilled about the move to Coventry House and the great opportunities that will stem from PLWHA Victoria and its partner organisations working closely together.

'There's more than enough to keep me busy,' Brent says. 'I'm easily bored. I have to be doing multiple things simultaneously. There's always stuff to do in this role. The staff here have such a can-do collective attitude. Everyone is on board all the time. They want to work together, get ideas into motion. It's amazing to have a team of people who see opportunity everywhere.'

## We can help if you think you are being **DISCRIMINATED** against

If you think you are being discriminated against but aren't sure what to do, call us at the Victorian Equal Opportunity and Human Rights Commission. Whether it is your age, disability, race, sex, status as a carer or parent, or other personal characteristic, discrimination is against the law.

We run an informal resolution service that is fair, free, and flexible – we can help.

Know your rights  
[humanrightscscommission.vic.gov.au](http://humanrightscscommission.vic.gov.au) | (03) 9032 3583

1300 292 153



# Respect and Dignity: Representing PLHIV at police recruit training

Eric Glare

Glenn Filbin and I have been doing public speaking in HIV with the Positive Speakers Bureau for over seven years and we both agree that representing PLHIV at Victoria Police recruit training has been among the most enjoyable and rewarding presentations we have given.

We get to speak to Protective Security Officers (PSO) and Police Recruits within the first two weeks of their training in a session called Community Encounters. It brings together a diverse range of volunteer community representatives in a question and answer format resembling speed dating. The community reps rotate every fifteen minutes between tables of 4 – 6 recruits over a 2.5 hour period. Recruits are instructed to develop a biography of the community volunteers through questioning with an emphasis on how they and their community interact with police. Like speed dating where you have to earn the person's phone number, the recruits have to work out which community we represent through questions without asking us directly. They are warned that people are multi-dimensional and we are likely to represent more than one community. Glenn and I both secondarily represent the gay community and I also talk about having been mentally unwell.

People with mental illness are also represented by speakers from Mind Australia. Other communities represented at Community Encounters include Aboriginal, gay, lesbian, bisexual and transgender people (GLBTI), youth, sex workers, refugees and migrants from Africa and South East Asia and various religious groups such as Muslims, Sikhs and Jews.

Recruits put into practice skills they have learnt in cultural competency

and professional conversation and just prior to the session they have heard how the various communities have interacted with police in the past. The recruits tell us they were surprised that many communities do not trust the police but they understand why when told by police trainers of their history of brutality, discrimination and neglect toward GLBTI members.

For me this mistrust was realised when I was involved in the fraudulent raid by Victoria Police on the gay Tasty Nightclub in August 1994. The recruits have been educated about the raid on Tasty and I get to put a face to the story. I usually say "I sued and I won but did not feel like I had won" because the police were recalcitrant to reform at that time, strung out the legal process and the offenders were allowed to stay in the force.

"What changed to enable you to volunteer here", they ask? We talk about the Police's gay and lesbian

liaison officers (GLLO) building relationships with community and I tell my story of resisting the excitement of Chief Commission Christine Nixon marching in the Pride March for the first time. I was waiting to march with PLWHA Victoria when a roar went up from the crowd and I turned to see the Police had started to march. Christine was leading them a few metres out in front with a massive grin on her face. I saw then that she was leading change.

Recruits typically say they do not know much about HIV and AIDS or the difference between them. It is an opportunity to say HIV is a less stigmatising label than AIDS and that most people with AIDS are well because their AIDS-defining illness was some time ago but conversely, most people ill as a consequence of HIV do not have AIDS. They all want to know how we coped when we were diagnosed with HIV. "What happened to your relationship then? Was it too much for your relationship to bear?"



Representatives at Community Encounters: Greg Adkins, Anti-violence Project, Rob Mauger, Mind Australia, Glenn Filbin, Positive Speakers Bureau, Sally Goldner, Transgender Victoria, Eric Glare, Positive Speakers Bureau, Sgt Scott Davis.

they ask. They want to know about treatments, maintaining health and being unwell but still having hope for the future.

After one discussion about the diversity of wellness of PLHIV and mental health, a young woman lent back into her chair and looked me squarely in the face before making a comment. "She's practising", I thought. She said "you're not just trying to get us to understand you. You are trying to get us to understand what you might be like if we saw you at your worst." She was so right even though I hope my worst is behind me.

I remember a PSO recruit who similarly had in mind his future role patrolling railway stations and the like. He wanted to know if using public transport made me more anxious when I was not well and how would he know if I was distressed and anxious. I told my story of being unwell on a train and not being able to find my ticket in my bag because

I was too anxious that I might lose it. Later, I found it was there all the time. At points like this someone will always ask "what could we do to help, what could we do to make things easier?" That is the spirit of community policing.

The session concludes with a short sum up but most afternoons by the last rounds the groups are saying their own sum up message: "people just want to be treated with respect and dignity". Glenn says "they are always very thankful and grateful". A telling sign is the applause has changed from a respectful welcome to an appreciative and enthusiastic thank you.

The recruits often say Community Encounters helps them see their responsibility to work with equality. Sgt Scott Davis, who runs the sessions, takes the opportunity to tell the recruits that "equality is not about treating everybody the same. Equality is about giving everyone an equal

opportunity for the same outcome," he says. "You might need to treat people differently. You might have to do more with some people to achieve equality."

Glenn says Community Encounters "is simple and effective. It is forward thinking and very progressive because it brings the human element into policing", he says. "If they can take that philosophy into policing, putting their moral judgements aside, they can be more effective police officers."

## PLWHA Victoria Joins Ritchies Community Benefit Card

### Here's how it works!

- Ask for your free Ritchies Community Benefit Card at your nearest Ritchies supermarket or liquor store.
- Enter the name People Living with HIV/AIDS Victoria and number 90561 on the form.
- Your Ritchies Community Benefit Card will be issued and can be used, immediately!
- You can choose to have a key tag to place upon your key ring or you might prefer the convenience of a plastic card to place in your wallet or purse. You might prefer one of each. The card or key tags are free and the choice is up to you!
- Your completed application form is returned to Ritchies Head Office,

where your Community Benefit Card number and 90561 for People Living with HIV/AIDS Victoria is entered into Ritchies computer.

- Every time you shop you will be asked by one of Ritchies friendly cashiers to present your Community Benefit Card!
- Your card will be scanned at the register, which will automatically allocate 0.5% of the money you spend to People Living with HIV/AIDS Victoria on your behalf.
- There are also hundreds of weekly specials that have extra discounts for Ritchies Community Benefit Cardholders. These 'CB' specials are clearly marked with red shelf tickets

bearing the Community Benefit logo.

To find your local Ritchies Store visit [www.ritchies.com.au/vic\\_stores](http://www.ritchies.com.au/vic_stores)

\* Ritchies reserves the right to change the terms of any of its cards, programs or clubs at any time.

Help yourself to savings and help People Living with HIV/AIDS Victoria at the same time with your free Community Benefit Card.



# Looking ahead to AIDS 2014 in Melbourne

## Brent Allan and Suzy Malhotra

The International AIDS Conference is a unique opportunity to bring together people working in the response to HIV/AIDS from around the world into a single place to talk, to think, to debate and to network.

Although much of the content is available online, it is the dynamics and the enormity of this event that makes it more than just a "talk-fest" or a junket. But like any of these events, it's as much about what you put into it as what you get out of it.

Our attendance at the conference was about looking at the logistics and coordination and being critical and aware that Melbourne will be hosting this event in two years' time. What worked well? What could be improved? How do we ensure that the public has as much access as possible? And what are the issues we want to profile in 2014 that leave a lasting legacy for PLHIV in Victoria, Australia and the region?

### The top ten issues for Melbourne 2014:

#### *Make the Global Village truly publicly accessible*

This conference hosts a section called the Global Village and it is open to the general public so they can experience the conference including panel discussions, art projects and community exhibitions and stalls. The village focuses upon topics and issues which hold relevance to the general public and provide an opportunity for delegates to mingle with the general public. It also provides an insight into the reality, the experiences and the passions of those who are living with HIV.



Brent Allan and Sam venning supporting the "Keep the Promise" rally in Washington DC 22 July 2012.

#### *Make HIV justice a major theme in 2014*

The issues of criminalisation, discrimination, stigma and failures of human rights that enable the epidemic to continue to spread are increasingly being recognised as something that needs to be tackled head on. HIV justice is an umbrella term to group these issues together and explore how these issues intersect with good public health, prevention, care and support.

#### *Bring Melbourne into the conference*

The conference never lacks quality content, but often it is the experiences outside the conference facility where the networking and deep conversations happen. The conference can provoke intense debate and questioning and debriefing of the day should never be underestimated. The cultural aspects of Melbourne can and should be promoted to provide delegates an opportunity to reflect upon the

conference, but also to understand the framework, within which we live, work and play.

#### *Harness the fuller capacity of volunteers to add value*

Volunteers are integral to the conference. The conference simply could not run without their dedication and involvement. We need to not just recruit volunteers, but make them valued, engaged and supported by providing them with the full conference experience through thorough training, and by providing access to sessions and affiliated events.

#### *Make the Positive Voice the centre piece*

Whether you work in a lab, at a hospital, at a university or in a community setting, we all work with one thing in mind - helping people living with HIV or at risk of acquiring HIV. The effect of all of our actions on HIV positive people needs to be considered from the perspective of HIV positive people and hosting "talk-back" sessions where HIV positive respond to the science needs to become a part of the conference.

#### *Activate Activism*

Many of the achievements in the response to HIV and AIDS have come about through political and social activism and the conference provides a platform to highlight what still needs to be achieved.

Even in our own backyard, we need to be aware that HIV positive people still face barriers and hurdles in their everyday lives such as the criminalisation of HIV transmission, mandatory testing of sex workers, lack of condoms as well as needle and syringe programs in prisons, the continued marginalisation of women living with HIV and the constant fight to maintain innovative and effective social marketing campaigns for gay men.

#### *Highlight the world's indigenous cultures*

The world's first nation cultures continue to be profoundly and disproportionately affected by HIV due to various social disparities. The fight against HIV can best be measured by the communities and populations worst affected. How we treat our indigenous cultures reflects our

failures and our successes as society. We must do more to protect and support our first nation's people and the conference and global village are both key places to raise these issues.

#### *Reaching out beyond the HIV sector*

The partnership which is the hallmark of the response to HIV in Australia has to expand. It is high time to bring businesses, other community agencies, media and mainstream cultural and sports groups into the response to HIV. As the lives of PLHIV continue to improve for many, it is vital that all of the community becomes aware of PLHIV in their workplaces, social spaces and amongst their friends and families. The conference will provide an opportunity to bring a vast array of new partners into the response to HIV.

#### *'Nobel-ise' being positive*

At one of the conference sessions, someone spoke about "nobel-ising" being HIV positive. What this means to us is twofold. First, we need to break down the stigma and shame that keeps HIV positive people from talking about being HIV positive. Secondly, it is about creating a community that instead of judgement and discrimination opens its arms to HIV positive people as valued leaders - not as simply vectors of a disease.

Being HIV positive is not a death sentence. It is a life sentence and we must live.

#### *Highlight the Asia/Pacific response to HIV/AIDS*

The lack of content and participation from the Asia/Pacific region was overwhelming. Where were the speakers, the program successes and our brothers and sisters from the region? If the 2014 conference is going to be a success it must reflect the work and the voices from the region. Our task is to ensure that this is truly a regional conference albeit held on Australian soil - it must speak to the challenges and successes of the world's most populated region.

**Help take the first step towards eradicating HIV**

Are you HIV positive? Live in Melbourne? Aged between 18 and 60?  
 Had an undetectable viral load for at least three years?  
 Had a CD4 count above 500 for at least six months?  
 And on ARV treatment?  
 We need you for a new trial into an agent that may be the first step towards eradicating HIV from the body.  
 The drug is called Vorinostat and the study involves taking it for 14 days.

**Call 03 9076 6908**

OR EMAIL: [clinresearch@alfred.org.au](mailto:clinresearch@alfred.org.au)



**TheAlfred**  
Ethics Project Number 308.10

Talk to **Michelle Boglis** or any member of the Clinical Research Team at The Alfred, today.

## Heart Foundation & HIV

Max Niggl

PLWHA Victoria attended the launch of the Heart Foundations new resource along with many representatives from other agencies at the Positive Living Centre in July.

The resource was developed with an unrestricted educational grant from Gilead.

The National Heart Foundation consulted widely and set up the Cardiovascular Disease (CDV) and HIV working group to develop the resource over a 12 month period.

As PLHIV are living longer due to more effective medications the resource is timely. It allows PLHIV, doctors and allied health professionals access to a simple and informative guide to cardiovascular wellness. Available in hard copy and on the Heart Foundation's website, it is readily accessible.

CEO Dr Lyn Roberts spoke passionately about the need for this resource and the reference group as being a crucial support.

Dr Howard Wright, Gilead's Director emphasised the partnership approach to the resource and how Gilead had identified a need for this to be done and offered funding to the Heart Foundation.

Professor Anthony Dart from the Alfred chaired the CVD and HIV working group. He spoke of the increasing number of PLHIV patients attending the CDV clinics and the importance of working with co-morbidities in a coordinated response with an emphasis on improving health outcomes for PLHIV patients.

The PLWHA Victoria Positive Speakers Bureau had been requested to provide a keynote speaker for the launch.

Sandra Porter was going to do



the keynote speech but withdrew because of an urgent personal commitment. Eric Glare stepped in with three days' notice. His keynote speech articulated the complexities of living with HIV and the personal challenges he has faced. Of note was that Eric worked on HIV Brain research prior to contacting HIV 10 years ago resulting in his research career being cut short. However Eric did manage to complete his PhD in asthma genetics after his diagnosis.

In his speech Eric commended the new resource and said "My story says loud and clear - knowing about safer sex is not enough. We can't just give young people a pamphlet and expect them to suddenly be practicing safe sex experts. Knowing is not enough - we have to know and understand. We have to understand how it applies to us as individuals. Cardiovascular wellness is the same - we have to understand how cardiovascular wellness applies to our own situation.

For me reading the new resource, there are no surprises and I think anyone who has informed themselves of cardiovascular wellness will say the same thing. Until now we have had to rely on existing resources and brief conversations with our doctors to get the angle on HIV. Now we have this new resource that helps those of us who live with HIV to know and understand how cardiovascular wellness applies to ourselves and how living with HIV increases our risk of heart disease.

I think this is an important achievement that will help many of

us."

In summing up Eric said "... as we say in science - learn from the extremes and they will tell you something important about the cases in between. To help PLHIV with cardiovascular wellness, knowing is not enough - we have to understand the situation that people are in, we need to understand their mental health. Sometimes they will be carrying a burden we cannot see, a burden we do not understand. When we help people and they fail we have to be careful that we don't stigmatise them and make their task worse.

Against the advice of this resource we are going to see a lot of failure - that is life. But don't give up on us. When we fail to achieve cardiovascular wellness, try something different. Don't give up on us because we need your support to trying again.

We must have room for stories of failure because the best success stories come from a triumph over failure. It is real stories of failure and success that inspire us."

PLWHA Victoria thanks Eric for his commitment and for delivering an outstanding keynote speech that drew sustained applause.

**If you would like a copy of his speech or the resource please contact PLWHA Victoria. To access the resource online: please visit [www.heartfoundation.org.au](http://www.heartfoundation.org.au)**

## Introducing the new recruit

Andrew McLean

My name's Andrew McLean and I am the newest member of the team at PLWHA Victoria. I have a background in sex and gender research and currently completing a PhD in Sociology at RMIT University. I've been teaching and undertaking research with the university for the past few years, alongside working as a volunteer for local GLBTIQ community organisations.

Due to the increasing number of speakers and speaking engagements for the PLWHA Victoria Positive Speakers Bureau, my role as Administrative Assistant was created to provide administrative support to the Coordinator.

There is a lot of work that goes on behind the scene of the Positive Speakers Bureau and during my first three months I have been learning about the day to day running of the Bureau, observing talks, meeting speakers and attending speakers training workshops.

It has been a highly rewarding and enjoyable experience working with the PLWHA Victoria team and I'm fortunate to be part of a team of highly dedicated, professional, knowledgeable and compassionate people.

Currently we are working on rolling out the HIV and Sexual Health Program to 40 schools in the Loddon Mallee region. Our aim is to provide

schools with the opportunity to hear our speakers talk about their experience living with HIV and the challenges of stigma and discrimination.

I have enjoyed great personal and professional development through PLWHA Victoria despite only being in the role for a short while. I am here one to two days per week amidst my teaching and research-based commitments. I am very excited to be a part of the Positive Speakers Bureau and look forward to building the capacity of the Bureau into the future and assisting in the education of young Victorians.

**Andrew is available to be contacted on 03 9863 8733 or [amclean@plwhavictoria.org.au](mailto:amclean@plwhavictoria.org.au)**

## GIVE it up for Sircuit

Suzy Malhotra

Sircuit once again held their annual fundraiser for PLWHA Victoria's Christmas Hamper Appeal on Sunday 15 July and raised over \$4000 towards this important program. Now in its third year, the GIVE party is the centrepiece in the bar's Xmas in July celebrations and provides punters with the opportunity to be part of a great gesture of goodwill by raising money to buy gifts that are delivered on Christmas Day to people living with HIV.

Sircuit have been keen supporters of PLWHA Victoria for over 10 ten years and have raised much needed funds for the Emergency and Distress Fund and the Christmas hampers through a number of fun and unique events including the

GIVE party, Bootclub and the very popular Adopt-A-Bear Auction.

Sircuit's Marketing Manager, Chris Driscoll said, 'The Christmas hampers have always had a special place in our heart. We want people who come to our bar to know that it's important to give generously and take time out to think about that person who may be doing it rough and not having such an easy ride.'

Volunteers and staff sold hundreds of raffle tickets on the night and customers bidded enthusiastically on various prizes ranging from IT packs and spa vouchers, to a signed Melbourne Chargers jersey and framed artwork filled with cash!

'It was a vibrant and lively evening with punters coming to the table,

bidding on fabulous prizes all in the name of supporting people living with HIV. We're really grateful to everyone who made this happen', Executive Officer Brent Allan said.

Our heartfelt thanks go out to the businesses and individuals who donated their time and products for the auction and the raffle:

**Sircuit, Bumpa Drag, Michael O'Donoghue, Lucrezia de Sade, Sam Minter, Malcolm Whitting, People to People IT Services, MOR Cosmetics, Dr Frank Barbagallo Adrenalin Healthcare and Emmanuel Ammo.**

# My Treatment Story: five PLHIV share their treatment experience

David Menadue

You may have seen posters on station billboards or in magazines and newspapers asking HIV positive people to “Start a Conversation with your Doctor”.

How curious you might think: I always talk with my doctor!

*If you were to read the smaller print, of course, you would realise this is about talking about the latest in HIV treatments. Recent research has suggested that it better for positive people’s long-term health if they are to treat earlier rather than later, to avoid long-term damage to their immune system. For some time doctors would only recommend treatment when a person’s CD4 count reached 350. Now the guidelines for prescribing antiretrovirals suggest it should be between 350 and 500, and some doctors will suggest starting above 500, particularly if a viral load count is high.*

*Following are stories by positive people from Victoria who have started treating relatively recently. While some of their stories leading up to deciding to take treatments are a little scary, once they have started treatments all have been pleasantly surprised that things have generally gone along smoothly.*

*Before you make a treatment decision though, it is always essential to have a good conversation with your doctor. You have to be ready to make a commitment to the process of taking pills every day (without fail!) and for some, it takes time to adjust to the idea of treatment after a new diagnosis. It is not usually essential to start treating straight away but your doctor is best to give you advice about that.*

## Cath’s Story

**“Nothing to stop me reaching my full potential in life”**

Cath had been living with seven years of depression when she was diagnosed with HIV. It was a double shock, having to deal with two very difficult diagnoses, but instead of giving up, she regrouped, talked to a number of positive women peers and has turned her life around in an inspiring way.

When I was diagnosed in August 2007, I didn’t receive any pre-test counselling and thought for a while that I was going to die. Even though I later received extensive post-test counselling, telling me that I could live well with the virus, I was overwhelmed by the news.

I told myself I could go it alone. I thought I could get better by getting physically healthy and after all, I had a high CD4 count –initially in the mid 600s and even climbing to over 1000 at one stage, with a low viral load. I hoped I would be one of those people who would never have to go on treatment.

I’d had many of the old fears about HIV treatment going around in my head. Would the medications ravage my body with facial wasting and lipodystrophy? Even though I was told that the new treatments didn’t cause these side-effects, I wasn’t so sure.

I was also worried about whether the HIV drugs would interact with a new antidepressant I’d starting taking.

Something started going wrong with my eyes and I developed the beginnings of CMV retinitis, an AIDS-defining condition. My optometrist

referred me to an ophthalmologist who kept saying that HIV was causing the problem. I didn’t want to acknowledge this as I thought that my high CD4 count didn’t support the idea that I could be developing an AIDS-defining illness.

I talked to members of Positive Women and was able to ask questions of them without getting dumb looks in return. I was told by all that everyone was different and that I should take time to listen to my body. So I did. It took about three months to tune in and I realised that it was time to discuss with my specialist, what the right HIV medications might be for me. My greatest concern was that they couldn’t interact with my anti-depressant. I was given a list of medication options, I did some research on possible side-effects and interactions and based my decision on what I felt was best for me.

Within four weeks on treatments, the CMV virus was no longer active in my eyes and that the scarring that had occurred was starting to heal. My viral load dropped from 14 000 to 33 copies! What an amazing result after only a few weeks on treatment!

It was certainly never an easy decision to commence starting meds. The reality of having to take pills every day for the rest of my life hit home and I did hit a bit of a funk around my 40th birthday as I reflected on it.

Overall though, I now feel years younger, happier and more energised. I know now there is nothing to stop me reaching my full potential in life.

Cath’s advice to people currently considering treatment is to think about the potential damage the virus might be doing to their immune system. She thinks people need to talk to their doctor about their treatment options and be assured that they will get support, including around adherence to medications. From her perspective, after her experience, people have nothing to lose.

## Scott’s Story

**“Determined to be proactive”**

Scott was initially worried about the side-effects of treatments, particularly as he also has another chronic disease he is treating, but the regimen he chose only involves one pill a day and he has only experienced a small amount of nausea. For him, the benefits outweigh that because he has much more energy – and an undetectable viral load!

I started treatment only three months after being diagnosed as HIV positive. My viral load was high and my CD4 count consistently low, but pretty borderline when it came to the treatment recommendation of falling below 350. So my doctor said it was up to me whether I wanted to start treatment or continue to monitor my count, and I decided just wanted to get started on it for the relative comfort of knowing I was fighting the virus.

Part of me was worried about side-effects and adhering to the daily regimen, but I was determined to be proactive. I suffer from another chronic auto-immune disease that requires ongoing treatment, and treating it is actually more complicated than treating my HIV, which on Atripla is only one pill a day! In addition, my adherence to my other medication has actually improved dramatically because I implemented a more consistent routine for myself in order to ensure I took my HIV treatment daily. To date I’ve only missed three doses of my HIV medication – so I’m about 98% compliant. The handy pillbox the drug company supplied helps a great deal too!

At first I did suffer from a few side effects, the most persistent and annoying was nausea in the morning. That subsided for the most part thankfully; occasionally it re-emerges just randomly but not so severely as to impact on my quality of life significantly.

Four months after starting treatment my viral load was already considered undetectable, and while my CD4 count has yet to rise significantly, I have found I’m feeling less tired all the time whereas I had been feeling chronically tired around the time of my diagnosis.

At this point I think establishing a better exercise routine, eating healthier, and improving my mental health, will actually do more for me than the treatment alone will do. Knowing that having an undetectable viral load reduces risk of transmission significantly has made me more confident about having safe sex with negative guys too. I’m not about to stop using condoms, but the stress of something accidentally happening has disappeared.

For me the decision about treatment is really quite personal. Obviously if your CD4 count is getting very low then it may be a necessity, but even people whose count is average may benefit from the knowledge that you are actively combating the virus and saving your immune system the trouble. Concerns about side effects are valid, but rest assured they

usually only last for an initial period and that if they continue, discussing your treatment with a good GP can result in modifying your treatment plan in ways that might lessen the side effects for you. In addition, more and more research is going into the effectiveness of treatment in preventing further transmission - which to me is worth the effort.

## Peter’s Story

**“Getting control of my health”**

When Peter was diagnosed, he did lots of research about HIV treatments and the virus: he researched online, spoke to positive friends and of course, his doctor. His main concern was getting his viral load down to undetectable.

It’s easy to forget what was on my mind before I started medication 11 months ago. Because I was in no physical pain, and because my CD4 count was still above 500, I may have been in a certain amount of denial about the seriousness of what had happened to me, despite that fact that my viral load was still over 300 000 copies. Although it was down from over 500 000 copies when I had been diagnosed 5 months prior to this date, I had no confidence that the viral load would continue to fall - and every reason to believe that I had found my “set point”. I felt that the only thing that would ever start to fall, over time, was my CD4 count. And that was a source of stress.

When I was diagnosed, I had been working overseas for many years, and received the news through a routine STD check while I was back in Australia on vacation. From that point onwards, all my big decisions revolved around “managing” my life and the virus. I knew enough about the typical outcome of a persistently high viral load to know that the best way to manage it was to take control while I was still healthy. In the months before I quit my job overseas, I did a lot of research online, and learnt about the effects of chronic inflammation in people who are untreated. At the same time, in the

months leading up to my decision to start medication, I started to notice small things, such as very slow healing of scratches, strange skin and mouth irritations that came and went, and swollen glands that stayed large for months on end - despite the great majority of my blood and biochemical parameters being normal. I knew my body was fighting a war, 24 hours a day, every day and night, and I wanted to give it every assistance.

As soon as I settled back in Australia, I discussed going on medication with my doctor, and gave myself a few months to get used to idea. I knew that once I went on it, I'd never be off it, so I had to think very carefully about what I was doing. I spoke to as many people I could who were already on medication, and their stories of adaptation gave me a lot of confidence. In the end, the decision came down to determining which side effects I could live with: 1) the possible side effects of the medication, which affect everyone slightly differently, or 2) the known side effects of chronic inflammation if I remained untreated, and the slow clonal deletion, over time, of the families of lymphocytes that fight infections and cancers every day. I also didn't want that virus getting into my brain and nervous system.

The choice of medication was another conversation I had with my doctor. We chose Atripla because of its proven record of excellent results in people with high viral loads, the convenience of one tablet a day, and the fact that my strain of virus was shown to be susceptible to it. It also had a pretty good record of minimal side effects. I chose a memorable date, and marked it with a great meal at a classy restaurant with a friend I'd met through Phoenix who was already on medication. I wanted to mark this day as significant - to always remember the way I made decisions to turn my health status around. I didn't want to drift into it and treat that day like any other. I had a nice 7-day pillbox, and at midnight, I took my first tablet and went to sleep.

In the first week, I felt nothing unusual except an increasing amount of fatigue, and I slept more than

usual. I occasionally experienced the vivid dreams associated with Atripla, but they weren't unpleasant. It was the "day 8 rash" that hit me the hardest. It quickly covered my entire body with hot red spots, and caused several sleepless nights. Although I took medication to help deal with it, it eventually burnt itself out after 8 days, and has never returned. My blood parameters showed some odd results in the middle of the rash, but I'll always be thankful for my decision to stay on that medication and not switch: within weeks, my viral load had plummeted to 150 copies. Magic!

Six weeks after I started medication, my viral load was undetectable and I felt like a million dollars. It was one of those "born again" periods of my life when I was filled with energy and optimism. My "post-medication high" eventually normalized out, of course, but my viral load remains undetectable 11 months later, and I have made sure I haven't missed a day of medication. I still have "memorable" dreams once every fortnight or so, but again, nothing unpleasant. My CD4 count has risen to 835, and my CD4:8 ratio is 1.2. All my blood test and biochemistry results are normal.

I always want to remain in control of my health and my life for as long as possible. Thankfully, I live in an age where medication will allow me to do that.

## Darren's Story

*"I did everything I could to avoid taking ARVs"*

Darren had seen people experience the side-effects of earlier HIV treatments, such as lipodystrophy (wasting and body shape changes) and did everything he could to avoid having to take them. He tried many alternative therapies, which worked for a while, but he soon realised the virus was having a major impact and he needed to take action.

For the first six years of my life with HIV I did everything I could to avoid having to take antiretroviral treatment (ARVs). At the time of my

diagnosis in 2000 such treatments had only been widely available for about four years and many people were still suffering extreme side-effects, the most horrific in my mind being the disfigurement caused by lipodystrophy. For this reason I carried a lot of fear around HIV drugs, to the point that I was about as scared of them as I was of the virus itself. When I first experienced a significant drop in my CD4 count, barely a year after being diagnosed, I panicked about the possibility of having to go on ARVs. Fortunately my immune health improved without intervention, but the shock empowered me to learn about and do all that I could to delay or avoid beginning treatment.

So began a journey of exploring natural therapies and adopting a more holistic, balanced lifestyle. This was positive in many respects, except that I was constantly motivated by a fear of ARVs. It led me to the point of refusing to have my blood monitored for more than four years, so I could avoid the anxiety of observing an unpredictable CD4 count and because I believed if I felt good I'd be OK. The truth was though that I didn't feel good. My energy levels were declining and I was dogged by chronic fatigue. I was in denial because I'd convinced myself that I'd be better off without ARVs and that I could find another way to remain healthy. I wanted to be part of that minority that can live with the virus and not be affected by it. But this wasn't the reality. When, in 2006, my skin was constantly breaking out in immune-related rashes, I finally surrendered. I had my blood tested, which revealed a CD4 count of 35. I immediately sought ARV treatment.

Taking the first pill was a frightening moment but also the mark of a turning point. I'd finally gotten real with myself about having HIV. The adjustment to being on ARVs wasn't easy. Many of the side-effects that I'd feared did and still do affect me. I've therefore been on six different drug combinations in six years. But faced with the choice between living with side-effects and not living at all, I choose to live. The improvement in my immune system was very gradual and hasn't yet reached an optimal

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point. However any improvement has been positive for me because it's reason to hope. Now when I take a pill I sometimes feel grateful, sometimes resentful but mostly I feel very little because it's such a staple in my routine. I find that it's very important to keep myself informed about ARVs and I'd encourage anyone living with HIV, whether on treatments or not, to educate themselves in this way. Although it's rarely easy or ideal, this can make the process of beginning and maintaining treatment an empowering one like it was for me.

## Markis' Story

*"Getting ill made me appreciate what HIV can do"*

Getting ill relatively early in his time of living with HIV taught Markis an important lesson about the value of getting the virus under control. While the illness was not likely to be caused by HIV, it was probably exacerbated by the damage done to his immune system.

"I was diagnosed in 2009 after an incident in which a condom broke. I experienced a seroconversion illness with flu-like symptoms and my doctor tested for HIV. My first results were a CD4 count of 700 and a viral load of 100 000 copies.

"I wasn't ready to start meds then. I wanted to keep the idea of having HIV in the back of my mind rather than something I thought about every day when taking a pill.

"Two years later, however, I developed a lump on the side of my neck. While I thought it might just be a transient infection, I'm glad my GP was wise enough to refer me to the Infectious Diseases specialists at the Alfred Hospital. They quickly diagnosed that I had Hodgkins Lymphoma. It was not

likely to be caused by having HIV, but my lowered immunity would not help my prognosis.

"I was told I would need 5 months of chemotherapy. I knew that chemo knocks your immune system around so I asked if I could get my HIV under control before I started it. I went on Truvada and Raltegravir and my viral load went down fairly quickly.

"The 5 months chemotherapy wasn't so bad. I didn't feel nauseous much of the time but I had to be confined to my apartment. I was told that other people could be more of a threat to me with their colds, flus and other germs. I am now in remission from the lymphoma and am pretty well back to normal.

"Getting cancer changed my attitude to having HIV. I now know that you have to look after your body if you are to avoid big illnesses that can really threaten your health. I am now more health-conscious, I get enough sleep and eat well. I monitor my HIV and now have a CD4 count above 500 and a viral load of 70 copies.

"My advice to newly-diagnosed people is to speak openly with your doctor. Tell them everything you do, including details of your lifestyle, your partying, recreational drugs if you do them. If you are not ready to take tablets, tell them so. It's no use starting something like HIV treatments and not doing it properly: you have to be ready to do it.

"If you do start treatments, write down any changes to your body that you notice and mention them to your doctor. They may or may not be related but there will be other options if you develop side effects. Also put tablets in places where you will remind yourself to take them. Maybe in the bathroom or with your breakfast cereals. It's very important to remember to take them every day."

Markis joined a Phoenix group for newly diagnosed people, run by PLWHA Victoria. "I found it very useful to share my fears and experiences with other pos guys. We have become very close as a group and a number of us still meet regularly after the group finished.

"Not everyone will be ready for a group, though. Some people will take time to adjust to the idea of talking openly to other people about having HIV. Maybe they should start by talking with a counsellor first to help them feel more comfortable about living with HIV."

***If you would like to share your treatment story, please send it to [smyers@plwhavictoria.org.au](mailto:smyers@plwhavictoria.org.au)***

***The article length should not exceed 400 words.***




 03 9863 8733  
 info@plwhavictoria.org.au

napwa.org.au  

 national association of  
 people living with HIV/AIDS

If you're living with HIV then talk to your doctor. Early treatment can have important health benefits and can protect your partners. Don't put off treatment any longer and learn about the latest developments.

**START THE CONVERSATION TODAY**

# Poslink Survey Results

## Shannen Myers

Poslink is the newsletter of People Living with HIV/AIDS Victoria. Six issues are produced a year and it is distributed to members, associate members, partner organisations and specific HIV services such as hospitals and medical clinics. Poslink is also distributed at events and workshops/support groups facilitated by the organisation, including Midsumma, ChillOut, community forums, Planet Positive and Phoenix.

Poslink was last surveyed amongst members in December 2007, receiving 20 responses. Feedback confirmed that readers wanted to see more content on personal stories of living with HIV and information regarding HIV treatments. Since 2007 the editor of Poslink has changed a number of times, as has the HIV epidemic and the way individuals access information.

The 2012 Poslink Readers' Survey was created on April 1, 2012 and closed 29 June 2012. It was available to be completed online, via email and in both the April (No. 62) and June (No.63) editions. The survey received 57 responses in total, which included 22 hardcopies and 35 online versions.

### Results

Overall 34% rated the quality of Poslink as 'Excellent' and 52% rated it as 'Good'.

47% have been reading Poslink for more than five years and just over 60% prefer the paper edition. With 14% not aware that Poslink is available online. Although only 6% identified that they didn't have a computer to access Poslink online, 63% preferred to receive the paper edition in the post rather than 'picking it up'

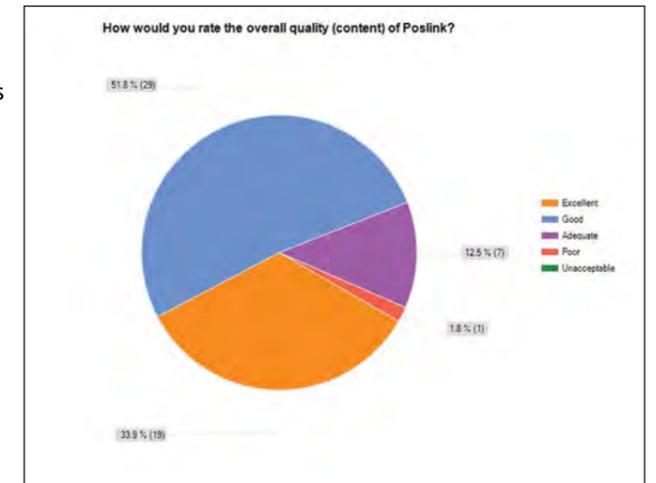
within a clinical or community setting.

80% of respondents identified that they read Poslink because they are HIV positive, 12% work in the HIV sector and 7% were a partner/relative/friend of someone living with HIV. Out of all the sources of HIV information available, 37% rated Poslink as 'Very Important' and 47% 'Reasonably Important'; as a result of reading Poslink 54% stated 'I have learnt something that is useful for me' and 28% stated 'I have learnt something that's vitally important to me'.

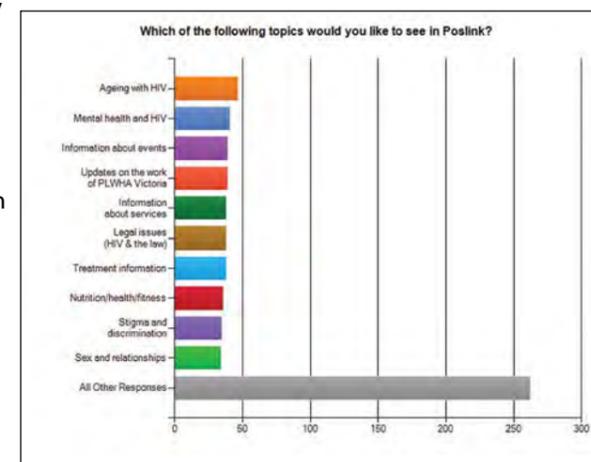
Respondents selected the following topics that they would like to see in Poslink: ageing with HIV, mental health, information about events, updates on the work of PLWHA Victoria, information about services, legal issues, treatment information, nutrition/health/fitness, stigma and discrimination, sex and relationships.

### Conclusion

The 2012 Poslink Readers' Survey confirmed that the newsletter



remains an important HIV resource among those surveyed. There is certainly a need to increase Poslink's online presence, not only to reduce environmental impact and cost of printing/distribution, but to enable a wider audience. There is a clear need to increase the quality of content and a wider variety of topics have been identified by readers as key topics they would like to see, with HIV and Ageing being the highest priority selected by readers. Although the survey identified that Poslink was easy to read, accessible and rated high on quality, over 75% selected that they had not made changes to their treatment, care, or made decisions based on something they had read.



The results from this survey will drive the direction of the newsletter for the next two years and ensure People Living with HIV/AIDS Victoria continues to produce a newsletter that is a valuable health promotion tool for members and the wider community.

**If you would like a full copy of the report please contact Shannen Myers, Senior Health Promotion Officer on 03 9863 8733.**

# A unique model of care

James May

James May speaks with Liz Crock and Campbell Smith about a thriving partnership between VAC/GMHC and RDNS (Royal District Nursing Service).

The Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC) HIV Services program and the Royal District Nursing Service (RDNS) HIV program, have an established collaborative working relationship which provides integrated home and community-based care for people living with HIV (PLHIV). For the past 21 years RDNS and VAC/GMHC have worked in partnership to provide nursing care and support in the community for over 1500 people living with HIV.

According to Liz Crock, one of three Clinical Nurse Consultants (CNCs) on the RDNS HIV team, RDNS provided hands-on education that enabled VAC/GMHC Community Support volunteers to work in 24-hour care teams, caring for clients who wished to die at home.' Today, with many clients in more stable health due to treatments, but others facing mental health and other co-morbidities, Liz says the focus is on providing nursing, allied health and volunteer support that preserves their clients' independence.

The RDNS HIV team now co-ordinates care for over 130 clients across Melbourne and the Mornington Peninsula at any one time. The Clinical Nurse Consultants (CNCs) provide specialist HIV nursing assessments and care planning and advocate for clients as they navigate the health care system. According to Liz, they educate RDNS nurses to monitor clients' health, assist with medication adherence and provide health promotion together with the HIV resource nurses at three busy centres.

They connect clients to the whole range of VAC/GMHC services; counseling, medical clinic and peer support agencies such as Positive Women, PLWHA Victoria and Straight Arrows, and many other community services. 'The result is fewer clients needing hospital admissions or nursing home care and a better quality of life for those living in the community.'

RDNS and VAC/GMHC Community Support staff do joint visits to assess clients and develop an integrated plan of care for them. They assure rapid, targeted responses from both services to their changing needs. 'We work together on a daily basis,' Campbell says. 'VAC/GMHC have about 80 volunteers all around Melbourne. Without RDNS it would be hard for us to follow up with clients quickly and effectively. RDNS are a medical arm to our volunteer program. They also link us in with people from the CALD community.'

VAC/GMHC and RDNS hold monthly care planning meetings to update each other on issues and client needs and for systemic advocacy, writing joint submissions, papers and conference presentations. They participate in each other's training courses, staff recruitment and working parties to ensure the community voice is heard at all levels.

According to Liz, one of the most important roles is advocacy within the health care system, both for individuals and on the broader level as PLHIV continue to experience



VAC Community Support and RDNS HIV Program staff with the Health Minister David Davis at the Partnership Celebration.

stigma and discrimination by health care professionals.

'Many PLHIV still have trouble finding suitable GPs and dentists in outer areas,' she says. 'People may not want to use local medical services for fear of disclosure within their communities. Some clients have never told anyone about their status except for us.'

Liz says the VAC/RDNS partnership provides a safety net for vulnerable clients. 'VAC volunteers are our eyes and ears,' she says. 'They pick up things we might not be aware of about our clients' conditions. The partnership is successful because it works from the grassroots. The two organisations share a philosophy of client empowerment. Both are client-centred and passionate about human rights and social justice for PLHIV.' As one client recently put it, 'RDNS and VAC have together kept me in my home for many years living with HIV, and that I prize very much because my individuality is preserved.' According to this client,

the upholding of a person's dignity and personality is the hallmark of the system – that's what it's all about.

An important recent initiative of VAC/RDNS is the nutritional project called 'Tuckerbag' – aimed at isolated and/or CALD clients. Tuckerbag delivers recipes and ingredients to encourage clients to cook healthy meals. The project has been undertaken with money raised by community groups such as GLOBE (Gay & Lesbian Organisation of Business and Enterprise), Vic Bears and the Ian Potter Foundation. NAB volunteers have also chipped in, helping to package items. 'The idea for Tuckerbag stemmed from us finding PLHIV with barely any food in the house,' Liz tells me. 'Some were very malnourished.' She says that many PLHIV are unable to cook nutritious meals, often as a result of poor physical and/or mental health or

a lack of cooking skills.

A recent evaluation report by students of Monash University found that the project has been embraced extremely well. For example, one Tuckerbag client said, 'I'm now more confident about cooking. I've started to use the kitchen as it's meant to be.' While another said, 'last year there were times when I virtually didn't eat but now I make it a priority.' According to Campbell, Tuckerbag has also been a great way to introduce people to other HIV services. 'It's encouraged PLHIV who are isolated to meet with volunteers and engage with the community,' he says.

Liz and Campbell say there will be a changing needs analysis of the VAC/RDNS partnership soon as they're getting more referrals, especially from clients in the outer north and western

suburbs of Melbourne. With the combination of refugee issues and CALD as well as an aging population of long-term PLHIV, there will be a growing need for support, they say. 'There needs to be more targeted, time limited support services in future,' Campbell says. 'With higher demand and limited resources we will need to be more targeted with support services in future,' Campbell says.

Liz and Campbell hope that the partnership between the VAC/GMHC's HIV Services program and the RDNS HIV program will continue to strengthen and grow. The partnership has been recognised as a unique model of HIV care internationally and they look forward to its continuing until everyone can finally say that the HIV epidemic is over.

## Positive Women Victoria

Supporting women living with HIV/AIDS in Victoria

Women living with HIV are hidden in society and hidden within the HIV community. Living with a secret has far reaching effects on the lives of women living with HIV.

Positive Women Victoria is creating a "My Journey" Kit that will be filled with the knowledge, experience and tips of women living with HIV from diagnosis to the end of our lives and all the challenges that it brings.

The kit will be a collective voice of the lived experiences of HIV positive women that will help support, nurture and be a part of the healing process for other women.

These experiences will be gathered together in a beautifully presented kit that will be used as a resource for other positive women along their journey in life and as an educational tool for the services we access.

We are looking for women who want to share their personal experiences of

what it's like being a woman living with HIV.

Share what you've been through with others by filling in our questionnaire.

No names will be taken. Names won't be used in the kit, just YOUR WORDS.

By participating in this questionnaire you are giving permission for Positive Women Victoria to:

- use the information from the questionnaire in the kit.
- to edit your information for the purpose of the kit while keeping its original intent.
- to store and use your information as resource materials in the future



If you want to be a part of the "My Journey" Kit, go online and have your say at: [www.surveymonkey/s/MyJourney](http://www.surveymonkey/s/MyJourney)

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## Anal Health (take two)

*Guy Hussey*

This is the second part of the feature on anal health that was published in the last edition of Poslink.

A range of practices involving the insertion of items or body parts into the 'bum' may affect and/or compromise the immediate environment within the anal region. This article focusses in on practices involving anal penetration and provides information on how to ensure good anal health.

The only physical barriers to anal penetration are the external (the anus) and internal sphincters; both are positioned close to each other. The external sphincter is the visible opening and is the one you are able to wash during daily hygiene and touch easily. The internal sphincter is not visible and leads into the rectum.

A person has voluntary control over the external sphincter. Movement of it can commonly be described as the 'clench factor'; when you clench your butt cheeks together you will normally be clenching the external sphincter at the same time. The nerve enriched external sphincter can also feel the additional sensations of hot and cold, wet and dry. The internal sphincter is controlled by the same neurological processes which ensure we keep on breathing; a person does not derive overt sensations (a dull sense of distension; pleasure and pain) from the internal sphincter and beyond into the rectum (last point of the gastro intestine). Both sphincters are used to facilitate passing faeces out from the body which is the body's natural cleansing process. However, some consideration needs to be given to penetrating this region.

Many people who participate in anal penetrative practices

plan to avoid messy accidents in the bedroom whilst engaging in pleasurable activities and some people just like to feel naturally clean. Unlike, the 'natural process' of cleansing (bowel motion and daily hygiene practices), some people choose to 'douche' (wash out the rectum) prior to anal penetration to ensure minimal mess or to simply maintain cleanliness.

Anal douching is the practice of cleansing and cleaning out the rectum, or to put it simply, to clean a lot of crap out of a very small space! You can pick up douching equipment from your local chemist and/or adult book store – a handheld douching bulb is possibly a good one to start out with; for people wanting further information see below. Anal douching can and does effectively work to clean out human waste and residue from inside but these practices are more about anal cleanliness than about anal health and to avoid accidents during sex. In this instance, cleanliness is not actually the benchmark to aim for even when it is a desired outcome of douching.

Whilst douching may be a good process to clean out residue from the rectum (e.g. in preparation for anal fisting or use of large toys) it also cleans away the natural mucosa lining (good bacteria) of the membrane lining of the rectum and does not serve to ensure the ongoing health and integrity of the rectum. Douching disrupts the natural balance of bacteria in the rectum and whilst this balance does return (and can be aided by the use of a probiotic and good healthy diet), it is no longer present during penetrative practices; research shows that there can be very little mucosa left on the membrane lining after frequent and regular douching.

All sexually transmissible infections can be found around the anal and genital region). They differ in impact to the individual anal region and some are strongly associated with being able to facilitate passing HIV along others whilst others (Human Papilloma Virus – HPV) are associated with an increase of anal cancer amongst PLHIV (see [http://www.plwhavictoria.org.au/downloads/PLW013\\_HIV-Cancer\\_FS\\_FA2.pdf](http://www.plwhavictoria.org.au/downloads/PLW013_HIV-Cancer_FS_FA2.pdf)) and may be related to other ongoing anal health issues.

Anal Health is still a 'new concept' and there is not a huge amount of awareness on this topic. Continually monitor the area for any changes both pre and post penetration and during daily hygiene practices similar to those cited in part one of this article.

Some basis tips to understand and or strategies to use:

- Understand what is going on with your arse and how this may affect its function?
- Find the best lube for your individual practice. For information on how safe your lube of choice is for your anal health and to make an informed choice see "Are Lubes Safe for Rectal Use? Next Steps for Researchers and Advocates," presented by Marc-André LeBlanc.
- Continue to develop your knowledge and practice about penetrative practices; a great resource which may be used is Anal Pleasure & Health: a guide for men and women by Jack Morin.

Yours in good [ANAL] Health!

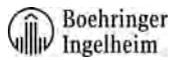
**References for this article are available by emailing [gussey@plwhavictoria.org.au](mailto:gussey@plwhavictoria.org.au)**





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# WorkingOUT



If you are living with HIV and looking for work, we can assist you through our Government funded employment service.

Contact SensWide Employment for a confidential chat or for more information about receiving support.

### SensWide Employment

Phone: (03) 8620 5177

TTY: (03) 9614 3062

Email: [info@senswide.com.au](mailto:info@senswide.com.au)

Web: [www.senswide.com.au](http://www.senswide.com.au)



# Save the Environment!

If you wish to do your bit for the environment and receive Poslink via email, please send your name and email address to:

[poslink@plwhavictoria.org.au](mailto:poslink@plwhavictoria.org.au)

Poslink is also available online to download at:

[www.plwhavictoria.org.au](http://www.plwhavictoria.org.au)



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