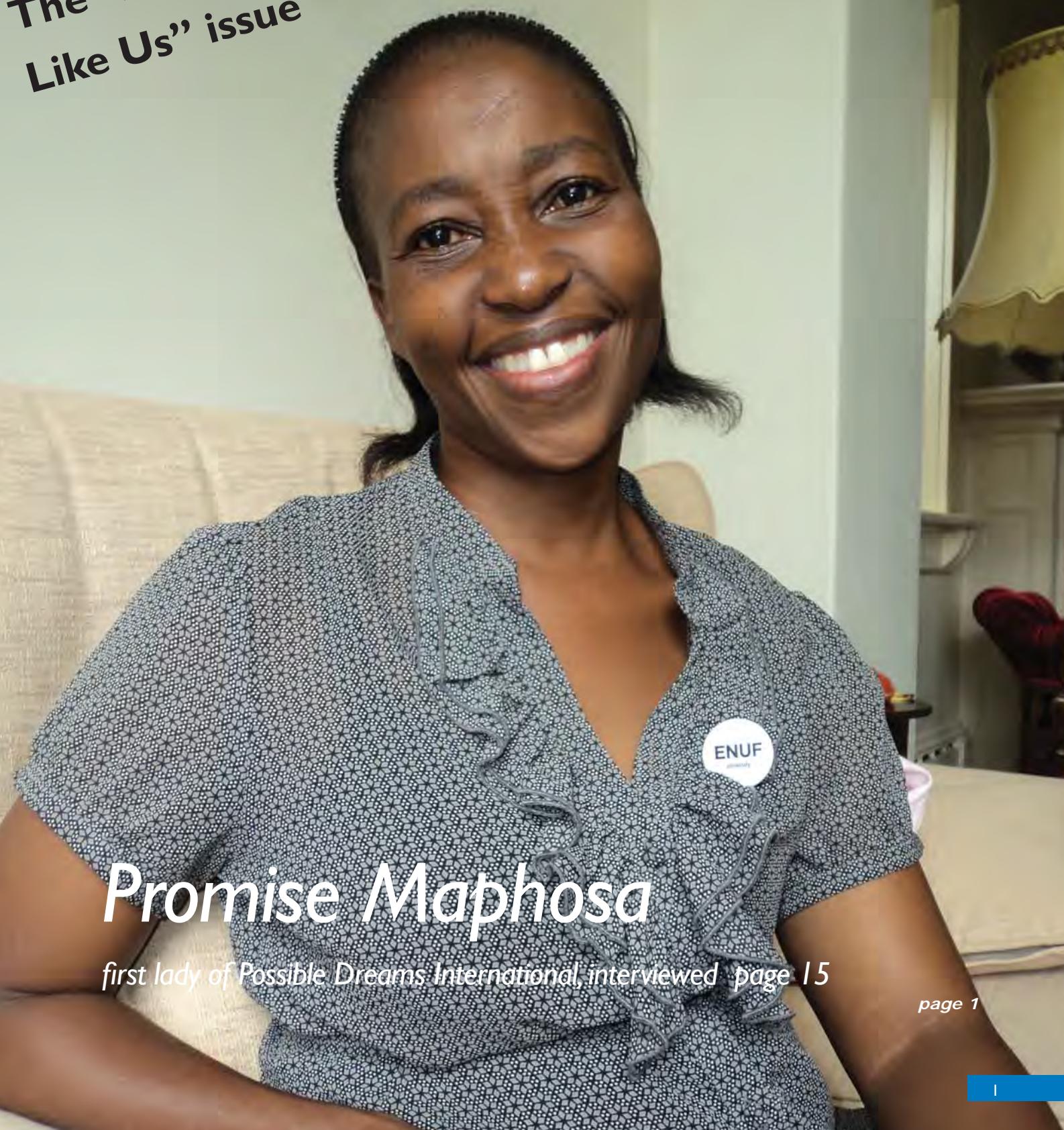


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poslink

The Newsletter of Living Positive Victoria

The “People
Like Us” issue



Promise Maphosa

first lady of Possible Dreams International interviewed page 15

page 1



Welcome to Poslink!

My name is Daniel Brace, and I'm thrilled to welcome you to my very first Poslink as editor. I am also HIV positive, a statement that pops up quite a bit in-between these pages. One of the joys of working at an organisation such as Living Positive Victoria is how lucky I

am to feel so supported and confident in making that statement.

Firstly, a huge congratulations to Shannen and hubbie Scott on the birth of their son, Oscar. Shannen is the usual editor of Poslink and I'm keeping the seat warm until she returns later this year.

This edition of Poslink is all about People Like Us: People with HIV; people who love and support people with HIV; people who work to fight the spread of HIV; people who work to eradicate the virus and stop it doing its damage; people who want to reach out, read and connect with the experiences of people with HIV. I felt that between these pages there was a such a wealth of community, so many wonderful real stories, both from here in Victoria and far beyond these shores, and all of them about PLU.

We're always on the lookout for contributors to Poslink. It's your magazine. If you're not already connected, Living Positive Victoria is on Facebook and Twitter, a great way to keep in touch in-between editions of Poslink. Special thanks to all our volunteer contributors, there was so much material to choose from, that I've kept some for the next edition, which looks back at 25 years of Living Positive Victoria and the incredible stories of those who have come along for the ride, coming soon!

You can contact me at dbrace@livingpositivevictoria.org.au and 03 9863 8733. Feel free to get in touch.

Daniel XX

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COVER PHOTOGRAPH: Pictured: Promise Maphosa, Photo: Paul Woodward

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Note

from the

President

Sam Venning



Pictured: Sam Venning Photo: Andrew Henshaw

Many of the concerns I had when I started HIV treatment turned out to be quite minor. Routine bloodwork results showed my HIV viral load plummet and immune system health return to normal. The results were very satisfying and I felt I'd made the right decision to start early to maintain my health and reduce the risk of passing on HIV. Peers reflecting on commencing treatment generally report the same feeling. New findings from studies showing real benefits to commencing treatment earlier and prompted Living Positive Victoria to produce a position statement to help those yet to commence treatment with up-to-date and compelling reasons to consider starting earlier.

The few treatment side effects can be easily avoided or managed and starting treatment a few months or years earlier is relatively insignificant considering I will be taking the treatment for many years and likely live to a ripe old age. One drug, Efavirenz, in my one-pill-a-day Atripla treatment, caused vivid dreams and interrupted sleep but these side-effects cleared after a few weeks – just as I worked out how to enjoy them! All up I found it fairly easy to accommodate.

Commencing treatment slows HIV and lets people living with HIV live longer, healthier lives. Living Positive Victoria is encouraging individuals living with HIV to start treatment early for their HIV infection. The advice and supporting information is presented in a position statement on Early HIV Treatment for Individual Benefit and for Prevention* recently issued by Living Positive Victoria. The statement draws on the increasing volume of research and expert opinion that early treatment has an important protective benefit for the individual's health and can also dramatically reduce the risk of transmitting HIV to others when used alongside other proven prevention measures like condoms.

There are indicators that a significant number of people living with HIV are not familiar with current HIV treatment advances. This comes from analysis of reports such as the Australian Research Centre in Sex, Health and Society (ARCSHS) HIV Future Six survey, Australian HIV Observation report and Tracking Changes Study. Past negative experiences or observations in terms of side effects and toxicities are still influencing many personal attitudes and beliefs behind a decision not to be currently treating. The decision to go on treatment has always been something that any person with HIV eventually has to face and we want to support people to consider starting treatment early – firstly and most importantly for their own health.

In a recent brief issued by the the Centre for Disease Control in the United States, states that "providing treatment to people living with HIV infection to improve their health must always be the first priority." It goes on to state "early anti-retroviral therapy helps people with HIV live longer, healthier lives and also lowers their chances of transmitting HIV to others." Similar statements have been issued recently by leading HIV agencies in the UK and in the prestigious New England Journal of Medicine.

It is important that anyone living with HIV and ready to take treatment is able to access treatment, regardless of their CD4 count (a measure of the damage being done by HIV in the body). Current regulations in Australia prevent people with higher CD4 counts (i.e. above 500 CD4 cells) from being prescribed treatment under the pharmaceutical benefits scheme. We are calling for the removal of this arbitrary restriction.

We will support anyone living with HIV who is willing to start treatment early to understand the importance of adherence to treatment, potential side-effects but also the health and preventative benefits of early HIV treatment. We also believe that an important group to educate and inform are couples where one person is HIV positive and the other HIV negative. Studies have shown that being on treatment dramatically reduces the risk of the negative partner being HIV infected.

We encourage discussion between people living with HIV to talk about commencing treatment. If you are yet to start treatment, consider talking with someone who has to learn about their experience. Those who have started treatment can offer valuable advice and experience about the positive aspects to starting treatment.

*The position statement can be found at online at livingpositivevictoria.org.au/living-with-HIV/resources.

Board Intros

*Introducing the
Board of Directors
of Living Positive Victoria*

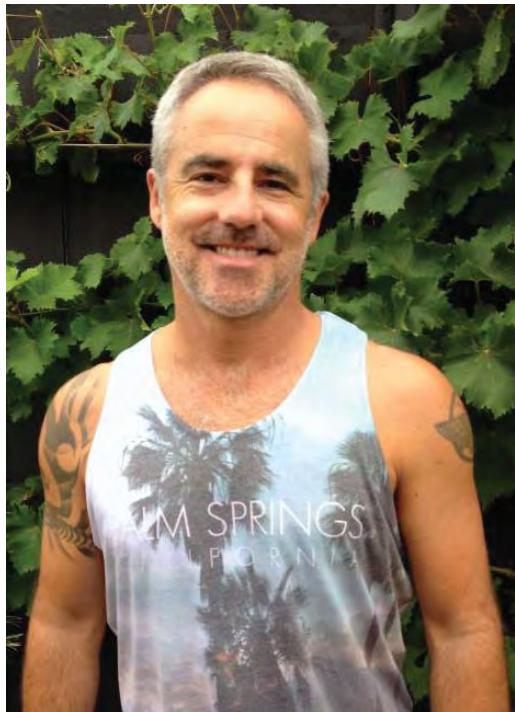


Greg Mutter-Director

I have been living with HIV for ten years. Initially, my university training was in accounting and business, but for the last 23 years I have worked in the education sector. Policies and governance are two of my favourite focuses. Recently I have been working with the Office of Prosecutions to review their guidelines to ensure there are not unnecessary prosecutions of PLHIV. I'm also an avid reader, especially science fiction. I've always appreciated giving back to the community and I make time to volunteer at a hospice, providing company, meditation and reiki treatments to people who are dying. I keep fit, try to meditate daily and live according to Mahayana Buddhist philosophy. I am confident that there will be a cure to HIV, or a treatment that halts the effects of the virus and its ability to be transmitted. Until then, our work is cut out for us to stop the continued stigma and discrimination that exists even within the gay community.



Pictured: Greg Mutter



Pictured: John Donnon

John Donnon-Director

What am I passionate about? Well, I want to see all PLHIV involved with and accessing services of Living PositiveVictoria. I am leading a Membership Working Group to better understand what the barriers to membership are and how we can break through them and get everyone involved. I work in professional recruitment in the Disability Employment Services sector and recently moved to the suburbs, where I'm renovating and landscaping. I believe that physical wellbeing is really important for people with HIV, and I love to swim and grow my own vegetables. It might sound corny, but I'm pretty happy about where we're at as PLHIV. Medical advances provide optimism, support networks are now widening into the broader community, and campaigns like ENUF are finally challenging the pain of stigma that we have all experienced. 2013 and beyond is our time to celebrate life all over again.

ENUF

campaign update

The ENUF campaign with its clear message to resist HIV stigma and promote resilience, has gone from strength to strength since being launched in December last year. Led by a growing team of Ambassadors, who are charged with actively promoting the message in the broader community, ENUF has been the focus of Living Positive Victoria's activities during the 'festival period'. Using all channels to get the ENUF message out into the community, the campaign has a strong social media and website presence on Facebook and Twitter, and calls on everyone in the community to challenge HIV stigma and discrimination.

If you haven't done so already, you can sign up to the ENUF pledge today online at enuf.org.au.

The ENUF pledge:

- I will not sit by and allow anyone living with HIV to fear disclosure
- I will take action when I see others gossiping about, rejecting and/or promoting negative stereotypes about people living with HIV
- I commit to being part of the solution, not part of the problem

The ENUF campaign is run by Living Positive Victoria and receives no direct funding. If you'd like further information on how you might be able to support the work of ENUF please call us on 03 9863 8733.



Pride March 2013, Living Positive Victoria/ENUF,

Ambassadors



Ji Wallace

ENUF's first ambassador, Ji Wallace, won Olympic silver in the 2000 Olympics in trampolining. He is one of only a few openly HIV positive elite athletes in the world. Since then, Ji has graced the covers of numerous local, national and international news articles and publications spreading the ENUF message and raising awareness about HIV.

Pictured: Ji Wallace, Photo: Jason Nicols



Photo: Melbourne Chargers

Melbourne Chargers

The Melbourne Chargers came onboard without hesitation, the team embody the spirit of ENUF. They are an inclusive rugby team and welcome everybody, regardless of age, playing experience, sexuality or HIV status.

Natasha Stott Despoja and Ian Smith

Natasha and her husband, Ian Smith, joined ENUF in February 2013 and their focus is about breaking down HIV stigma faced by women with HIV and to increase awareness and testing in straight men. Both are sophisticated, articulate communicators who command attention in the realms of politics and business.

Deanna Blegg

Deanna is known and respected in the HIV sector for her work with Straight Arrows. Deanna is also the 3rd World's Toughest Mudder, and openly HIV positive mother of two.

Deanna joined ENUF in February 2013 as well, and adds another powerful HIV positive voice to the campaign.



From left to right: Deanne Blegg, Natasha Stott Despoja, Ian Smith

Photo: Andrew Henshaw

Dean Beck

Superstar broadcaster Dean Beck joined the ENUF team of ambassadors in November 2012 and has since been tireless in promoting the ENUF message through radio and social media, especially through his work at JOY 94.9.



Photo: Dean Beck



Pictured: Ben Ruthmuller

Ben Ruthmuller

Mr Laird Leatherman, Ben Riethmuller, is openly HIV positive spokesperson and will be taking ENUF to the International Mr Leather Competition to be held in Chicago in May. Ben is an active member of the Melbourne Bear and Leather communities and is public about the joys and challenges of being in a long-term serodiscordant relationship.

Rachel Berger

Comedian, broadcaster, novelist, columnist, agitator, television entertainer, 'queen of stand-up satire and dominatrix extraordinaire of audiences', Rachel Berger has been fighting for people with HIV since the start of the HIV epidemic. Rachel continues this work by challenging HIV stigma and discrimination using comedy as a way to prompt people to think about HIV-related issues.



Pictured: Rachel Berger Photo: Luzio Grossi

Partners



Pictured: Sircuit crew supporting ENUF

Sircuit Bar Melbourne

Sircuit Bar Melbourne, located at 103 Smith Street, Fitzroy, is a proud partner of the ENUF campaign. Steven, Keller, Chris and the Sircuit Crew have been onboard in a big way, especially during the month of March, where they hosted the ENUF Dance Party and staff looked hot in our ENUF t-shirts. If you're dropping by, you can still buy ENUF-branded bottles of water with proceeds donated to continue funding the campaign. Check out what's coming up at sircuit.com.au.



What's up Doc?

Getting the best from your doctor with David Menadue

Anyone who has lived with HIV for a long time will tell you that one of the essential reasons they have managed to maintain their health has been their relationship with their doctor.

Everything from helping them to deal with their diagnosis, discussing when to start antiretrovirals (ARVs) and when to change them, monitoring side-effects to looking after general physical and emotional health, has been done in concert with their doctor.

So it is important to get the right one for you. Some people who have had HIV for a long time or who have a range of health problems related to that, may find a hospital specialist (in infectious diseases) might make for the best choice of treating doctor, at least for HIV care. Most people however will work with a GP for both their HIV and general health care.

GP who can prescribe HIV treatments

If you live in the city (and some regional cities), you should try to select a GP who is trained in HIV care, preferably one who is a S100 prescriber. This means they have done extra training in the use of ARVs (called S100 under the PBS scheme) and their interactions with other drugs.

In many rural areas (and outer suburban areas) however, there may be no trained S100 prescribers available and if you select someone who is to be your GP in those areas, it is a good idea to find a doctor who is prepared to "share your HIV care" with a S100 prescriber. (They are prepared to talk on the phone with an HIV-experienced doctor about things like your blood tests or whether symptoms are possibly HIV-related).

If you live in these areas, you will still have to travel to another doctor to get your scripts prescribed (such as a hospital or sexual health centre who provide ARVs) but these days many of the pharmacies associated with these centres will provide up to four months' supply of ARVs at a time to reduce this inconvenience.

Pick someone you like and trust

As with any selection of a partner in anything in life, you should look for a GP who you think you can establish a good relationship with, who you feel you can trust and respect. Like it or not, people with HIV will need to see a GP on a more regular basis than most other people to monitor their health and, until we find the "magic bullet" or cure for the virus, this is going to be possibly a life-long thing you will have to do.

If you want some advice on who to see in Victoria, it

is probably best to ask other HIV-positive people you know for recommendations or research local HIV-experienced GP practices at www.ashm.org.au/prescriber/ashmprescribers.pdf. (You can also ring the HIV and Sexual Health Connect Line on 1800 038 125).

I would argue that even people with HIV who are not on treatments should follow this advice as well because one of the biggest mistakes people make with their health can be to stop getting basic blood tests done, like CD4 counts or viral load, and to not see their doctor regularly. No one, in 2013, should end up in an Emergency Department of a hospital with an AIDS-defining illness because they haven't been seeing a doctor who is watching what HIV is doing to their immune system. (Unfortunately, it still happens all too frequently).

"Doctor shopping"

The other mistake many people make is to "doctor shop", changing doctors frequently. While this is probably a reasonable thing to do when you are first diagnosed to find the right GP for you, if you chop and change too much, no doctor is ever going to get a complete picture of what is going on with your health. Having the same doctor who can look up your medical history and see what your particular health issues are at a glance, is commonsense but it is surprising how many PLHIV ignore this advice.

One of the reasons they may "doctor shop" is that they are uncomfortable talking about some aspects of their lifestyle because they fear a negative response from their GP. Issues like recreational drug use or sexually transmitted infections (STIs) may be too embarrassing to talk about with one doctor so people go elsewhere.

If you have found a GP who you like and have confidence in, it is probably a good idea to build the courage to talk about these things and see their response. Some GPs are understandably conservative about such issues, others may take a "risk reduction" approach where they can provide advice about how to not let matters of sexual health or recreational drug use impact on your overall health, including your HIV care.

Take an active role

Many people are a little intimidated by doctors. They will go into an appointment and forget half the reasons they actually came to see their doctor because they want to get out as fast as they can. (Or sometimes their GP will push them through too quickly—something you shouldn't put up with, either!) You will get the best results from your visits to the doctor though if you are well

prepared beforehand and are an active participant in the conversation with your GP.

A good idea is to take a list of the things you want to raise with you when you go to the appointment. Raise possible side-effects to treatments or questions about HIV that you are not sure about. Ask your doctor if there are options to the treatments they suggest, any potential side-effects or what the risks might be if you don't follow their advice. Ultimately your health has to be in your control—if you don't like or understand your treatment, you may be less likely to follow it.

Many people will accept the words of the GP as gospel and don't want to challenge anything for fear of creating offence. This may work most of the time for some, but there will be times when things are not working for you and you need to speak up about it. A doctor can't read your mind. If you are experiencing bad diarrhoea for instance, it's important to mention such things in case they are related to your treatments or another health issue. A doctor will want to know if there is something that is causing you discomfort and they will also want to know if a side-effect is making it difficult to take your HIV treatments.

You are ultimately responsible for your own health—not your doctor. If you like to use complementary therapies (like herbal remedies, naturopathy or acupuncture), you should do what works for you—but tell your doctor that you are doing it. Occasionally there are alternative remedies that interact with HIV medicines.

When to treat

This advice also extends to when you should start taking HIV treatments. This is a complex area and there is some recent research that suggests that people with HIV should treat earlier rather than later, due to the long-term benefits to people's health. At the moment though the Australian Guidelines for doctors on when to treat

suggest that people with HIV may not need to start taking HIV treatments until their CD4 counts are down to 350. (There are variations to this advice, including if someone has a high viral load, where treating sooner might be recommended).

I have strong views about the value of HIV treatments because I have no doubt they have helped me survive thus far and kept me well for the best part of twenty years, after a horrible time of illness beforehand. But it is inappropriate of me to share these in an article on this topic. It has to be your choice, your decision about when to treat. All I would ask is that you make informed decisions about such an important part of your health care.

How can you become informed about the latest developments in HIV treatments? Read Poslink, look up the Living Positive Victoria website (www.livingpositivevictoria.org.au) and check out links to other sites or most importantly, ask your doctor.

David Menadue, OAM, is a regular contributor to Poslink. David was a founding member of People Living with HIV/AIDS Victoria, and held positions as President, Vice President and other executive roles with the organisation between 1989 and 2008, and is currently on the Board of the Victorian AIDS Council/Gay Men's Health Centre. He was awarded an Order of Australia in 1995 for services to community health. David is Chair of the Community Advisory Committee and a member of the Quality Committee.

Cardiovascular wellness for people living with HIV

People living with HIV are living longer due to more effective medicines.

As conditions relating to ageing, including heart disease, are emerging as health concerns, the Heart Foundation has produced *Cardiovascular wellness for people living with HIV*.

Available online and in print, find information on lifestyle factors such as nutrition, physical activity and healthy weight.

The Heart Foundation saves lives and improves heart health through funding world-class cardiovascular research, guidance for health professionals, informing the public and assisting people with cardiovascular disease.



Visit www.heartfoundation.org.au/hiv or call our Health Information Service on 1300 36 27 87

Looking Forward

The needs of women living with HIV will not be overlooked when the International AIDS Conference opens in Melbourne in July 2014, reports Heather Ellis.

Even though women account for nearly half of 34 million people living with HIV globally, their gender-specific needs are often overlooked in the fight against HIV. But these needs will be given a loud and clear voice at the 20th International AIDS Conference (IAC) in Melbourne from 20 to 25 July 2014. These voices will radiate out from the Women's Network Zone (WNZ) to reach governments, policy makers, researchers and the wider public globally. Running parallel to the conference, the WNZ is a community-based forum where women can network and share ideas in the response against HIV.

Run by women for women, it is a space where workshops, discussions and strategy sessions are held. It provides a valuable networking opportunity for women involved in HIV advocacy both globally and at the community level. At the WNZ, women can exchange information on the latest research and plan strategies to ensure the goal of access to antiretroviral treatments and health care becomes a reality for all women living with HIV. At the same time it is a vibrant colourful space of performance art as well as a nurturing and supportive space at an international conference that attracts over 20,000 delegates.

The key aim of the WNZ is to raise awareness at both the public and government levels about keys issues affecting women living with HIV such as greater access to HIV treatments and health services, reproductive health and rights, preventing violence against women, the rights of sex workers, issues affecting indigenous women, older and young women, migrant women, the criminalisation of HIV, and the ongoing key issues of stigma and discrimination. But it has not always been this way. Back in 2000 at the International AIDS Conference in Durban, South Africa,

a group of women banded together when they realised the gender-specific issues affecting women living with HIV were being ignored. The Women's Network Zone was formed and since 2000 it has run parallel to every International AIDS Conference, which is held every two years.

For Melbourne, the countdown has already begun. Women in Australia and the Asia/Pacific, in collaboration with global partners, have already mobilised to begin work to establish the WNZ at the Melbourne conference. With just over one year to go, a group of more than 30 women have already held three meetings. A steering committee has been formed and team leaders appointed to key roles such as advocacy, logistics, media, communications, volunteers and fundraising. Their dedication over the next year will ensure that the WNZ continues to build upon the momentum of Washington 2012.

Through the WNZ, women will forge many new networks with other women living with HIV around the world. It is a time when activist networks can be re-energised with new ideas and new passion from other women living with HIV.

If you would like to be involved in the Women's Network Zone at the International AIDS Conference in Melbourne from 20 to 25 July 2014, please contact:

**Tania Phillips on 9863 8747
executiveofficer@positivewomen.org.au, or,
Rebecca Matheson on 9863 9415
executiveofficer@straightarrows.org.au**



Tough Mudder

Obstacle Racing Champion, and openly HIV positive mother of two, Deanna Blegg was approached by Michael Chalmers of Chalmers Wealth about a sponsorship, Daniel Brace interviewed them both about the partnership

If physical challenges are your thing, Tough Mudder might be the perfect combination of exhaustion and exhilaration. Tough Mudder is a series of hard-core 10-12 mile obstacle courses designed by British Special Forces to test all round strength, stamina and mental grit.

It is wonderful then to be in the presence of Deanna Blegg, an openly HIV positive women who not only came 3rd in the World's Toughest Mudder competition in 2013, but has also ranked as the top Female Adventure Racer in Australia and one of the best Obstacle Racers in the world.

Deanna was recently approached by Michael Chalmers of Chalmers Private Wealth, who recognised her global achievement with a sponsorship proposal. Both Deanna and Michael spoke about the partnership:

Deanna, you're known to many due to your work with Straight Arrows, but it's your sporting achievements that brought you to the attention of Chalmers Private Wealth.

I am 43 years old, female, a mother of two children and HIV Positive. So to be mixing at Tough Mudder with the best in the world and placing was surreal and to place 3rd outright, well the feeling of elation is hard to describe. The respect amongst the Obstacle Racing Community has been humbling. Ultimately we are all big kids running around in mud, climbing over, under, in and through things for fun. I'm now being invited to events in my capacity as the World's 3rd Toughest Mudder. I feel very proud and honoured that Michael from Chalmers Private Wealth approached me about sponsorship.



Pictured: Deanne Blegg, Photo:Andrew Henshaw

How was the World's Toughest Mudder race?

The World's Toughest Mudder 2013 was held in Englishtown, New Jersey, USA. It was a 24hr event in temperatures of -3 to 7oC. The lap was 16 km and had 30 obstacles, and I was competing with 1,300 men and women from around the world. The aim was to complete as many laps as possible in a 24hr time period.

I had the goal to win. I naturally feel the cold and we were submerged in icy cold water at least 10 times per lap. I put a lot of thought and preparation into that aspect, including wearing a wetsuit for the duration of the event.

The first two laps really hurt and I thought 'how am I going to do this for 24 hours?' After lap number 3, the pace settled down and I got into a rhythm and just ran and ran and ran, lap after lap after lap. The night was lonely as the competitors dropped off one by one but I just didn't stop. I had my dear mother, who walked around the course all night to cheer me along. By early morning I was told I was 3rd outright in the world and only 10min behind the lead woman and closing the gap. That really inspired me. My final result was 3rd outright, 2nd female, and super super, super happy. I ran 130km and did over 250 obstacles in a wetsuit.

My body was sore but I felt incredible. Mum was there still right at the end, tired and exhausted from cheering me on. Five minutes after I finished I was already planning to race next year.

Michael, why were you so impressed with Deanna?

Well, I heard that Deanna had come 3rd in World's Toughest Mudder and was impressed - it's a mixed gender event, and renowned as one of the world's toughest obstacle course races. I then found out that apart from beating every male apart from one, Deanna was HIV positive and had been living with HIV for close to 20 years. This blew me away. I found a clip on YouTube of Deanna being interviewed and thought, what an amazing story of overcoming challenges.

Has finding out about Deanna's story with HIV challenged your perceptions about HIV positive people?

Absolutely! I had no idea that physically people could achieve so much living with HIV. My only experience with HIV prior to this was someone quite removed and HIV had a very detrimental impact on his life. He was a good bloke, but HIV hit him hard physically and emotionally. Meeting Deanna made me reassess what I knew about HIV and how people can overcome the negativity that surrounds it.

It's really great that a private business is publicly supporting an openly HIV athlete, but given the stigma and discrimination we know surrounds HIV it's also quite a brave decision – one which we obviously applaud. What was it that motivated you to support Deanna in this way?

Obstacle racing isn't just about being the fastest or strongest, it's about meeting whatever challenge or obstacle that is put in front of you. At Chalmers Private Wealth we help people through the challenges they face in their financial life, we work with you, educate you and help you better understand your financial position, whatever circumstance you find yourself in. We're also the first FPA Professional Practice in the Golburn

Valley, the highest possible designation of accountancy and we're proud of our achievement.

The decision to sponsor Deanna was an easy one; her attitude to life's challenges was similar to mine and her philosophy, 'don't let problems get in the way of achieving your goals', is exactly the attitude we have here at Chalmers Private Wealth. I look forward to introducing Deanna to my client base and I know they share the inspiration and admiration that we have for Deanna.

Congratulations on your sponsorship and partnership and on behalf of our readers, I wish you both the very best success.

Chalmers Private Wealth is located at 136 Welsford Street in Shepparton, (03) 5831 9000.

Join ENUF Ambassadors, Deanna Blegg and Ji Wallace in the ultimate physical challenge and be part of the the ENUF Tough Mudder team in September 2013. For more information please call Living Positive Victoria on 03 9863 8733.

In solidarity

Join communities around the world in the largest grassroots movement against HIV and AIDS

Photo credit: © Photo 20-20, Inc. / Getty Images. Photo: Candlelight Memorial of Cebu, Philippines. Photo: Candlelight Memorial of Cebu, Philippines.

30th INTERNATIONAL AIDS CANDLELIGHT MEMORIAL

Reduce Stigma, Ensure Access,
Increase Resources, Promote Involvement
www.candlelightmemorial.org

20 May 2013

living positive victoria
livingpositivevictoria.org.au

ENUF
enuf.org.au

5-6pm, Forecourt, ACCA, 111 Sturt Street, Southbank. RSVP essential to 03 9863 8733 or info@livingpositivevictoria.org.au

Living Well with HIV:

Making Choices with James May

Living well with HIV takes time and effort. There's a big difference between surviving and thriving with the virus. While medication has made life easier, HIV is still a huge challenge for many reasons. For me, the stigma and emotional burden of being HIV-positive is what I struggle with most. It's taken a great deal of soul-searching to come to terms with the diagnosis and make the most of life with HIV. After almost 13 years, I'm managing better than ever, but it still holds me back in some respects.

HIV changed my life completely. When I contracted the virus in my mid-20's I was the kind of person who always had an ashtray and a pack of fags by the bed. Regular exercise meant clubbing on pills and speed and a nutritious meal was a burger or kebab when I was hung over. I took pride in thrashing my body as hard as possible and seeing how many days I could go without sleep or a decent feed. I scoffed at people who did the gym, yoga or anything health conscious. I didn't know anyone 'naff' like that.

When HIV came along I was shattered. I knew things had to change but I had no idea what to do or if I had the willpower to do it. Giving up the fags and weaning off drugs and booze when you're down in the dumps isn't easy – especially when everyone you know is still living it up. I guess I resisted for a while but within a few years I'd pretty much stopped everything. I had a few beers and a drag of a friend's ciggie now and then. Most of the time I hung out at juice bars and drank carrots and celery. It took some getting used to but embracing a healthy lifestyle grew on me. I liked having energy, I liked having a clear head. I was bored with getting wasted – health and fitness was a novelty. Hanging out at a gym was never my thing but I got hooked pretty quick. If I had trouble getting there, I thought of the eye candy in the locker rooms. Working out went from being a chore to something I really enjoyed. It was great for my mind and body and my self-esteem too.

While life on the outside looked a bit dull, I felt way better in myself. I'd spent more than a decade riding the emotional slippery slide of drugs and alcohol. My peers were trashbags who staggered out of clubs at six a.m and slept the days away. Now I found myself drawn to people who did things differently. It was a tough transition, but worth the effort. Taking care of my mind and body made living with HIV much easier. I was more physically resilient, more emotionally sturdy.

While I felt ripped off to cop about the HIV diagnosis in my 20's, I now appreciate the personal development it gave me down the track. Contracting HIV made more sense – after I had a few years to shake off the trauma of the diagnosis. I felt more inspired and content. I was enjoying life on a new level – travel, nature, good food, interacting



Pictured: James May

with people in more meaningful ways. Taking up creative writing was a constant source of inspiration. I was dealing with my 'stuff' – that made me feel a whole lot better about myself. Finding peace was more important than looking for stimulation outside. Seeking long-term gains was more valuable than a quick-fix.

Living well with HIV demands constant reflection on my thoughts and behaviour. Otherwise it comes back to haunt me physically and emotionally. While my overall health is usually strong and my blood counts are stable, I still have plenty of tough days when nausea, fatigue and stomach upsets get in the way. For me, keeping the liver and digestive system in good shape is essential otherwise I get bloated, lethargic and run down. It basically feels like I've got a bad hangover, even though I haven't touched a drink. While HIV medication keeps my immune system in check, complementary therapies and good nutrition have proved highly effective in treating symptoms that still get in the way.

Living with HIV has made me more vigilant about my health. I've become more aware of how different foods, substances and emotions affect me. I can tell when something I put in my body doesn't agree with me. I know when I can get away with a bit of booze and junk food and when my body needs a good clean out. Having a compromised immune system means it can be easy to

get run down. Being more conscious of the way I think and feel and what I put in my body is essential if I want to live well with HIV.

While I value the personal development, sometimes being HIV-positive feels like a long hard slog. After almost 13 years I wish I could say it doesn't get me down but that's not true. It undermines my self esteem at times. I get frustrated with fear, resentment, negativity. HIV still holds me back socially and sexually – though not as much as it used to. I'd like to think that HIV has just made me wiser though. I look for more substance in life rather than fleeting highs. I don't waste as much time and energy on situations and relationships that are no good for me. I try to appreciate life and make the most of what I've got. Living well with HIV means making better choices. It means doing things that serve my growth and improve my quality of life.

James May is a freelance writer, based in Northern NSW who regularly contributes work to the HIV sector in Victoria. He has written for various magazines including MCV, Positive Living and HIV Australia

SEX DRUGS AND ROCK'N'ROLL: DO PEOPLE WHO LIKE

CERTAIN TYPES OF MUSIC USE MORE DRUGS?

Megan Lim is the Head of Sexual Health Research Program

Centre for Population Health at the Burnet Institute.

Every year since 2005, the Burnet Institute has surveyed young people at the Big Day Out (BDO) festival about their sexual behaviour, drug use, and other health issues. We have found that 34% of people attending the BDO had used drugs recently. They are more than twice as likely to report using drugs as other people their age.

Stating a preference for certain types of music was found to be associated with drug use. Those who favoured dance, house, metal, or rap music were more likely to have used illicit drugs recently, while those who favoured pop or alternative music were less likely to have used drugs in the past month. Ecstasy and cocaine use were particularly associated with liking dance music. People who liked dance or house music were also more likely to report sexual risk behaviours (for example not using condoms).

These findings do not imply that music in any way causes people to use drugs or have sex, or that everyone who likes dance music takes drugs. It is more likely that dance music, drugs, and sex are all common factors in being involved with a certain lifestyle or subculture.

You can read more about the report at burnet.edu.au/projects/17_big_day_out_studies_sex_drugs_and_rock_n_roll

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HEPATITIS VICTORIA

Promise Maphosa

an interview with Paul Woodward

Promise Maphosa, whose image graces the cover of this issue, is the first member of Possible Dreams International (PDI) Choir of Swaziland, a choir who sing songs of hope to those living in extreme poverty with HIV and AIDS in a country with the highest prevalence of AIDS in the world. The choir is composed of young people from the most remote rural areas of the country, some of whom are HIV positive. The choir sings songs of hope and quiet joy in the face of adversity.

My name is Promise Maphosa. I am 38 years old. And I sing Soprano in the choir. I was also the very first member of the PDI choir.

Brilliant: Promise, you are the First Lady of PDI! How did that come about?

Dr Maithri [the founder of PDI, originally from Melbourne] went to work for the HIV relief HomeBase Care and he had a conversation with my mother who was a volunteer. Dr Maithri came to my home and at that time I was so sick and he helped me get better. The next time he came he told me he had a dream about building a choir that would help raise the spirits of the very poor and the very weak and the very ill, and he asked me if I would help him. I said 'oh my god I would like to do that' even though I was sick and I couldn't walk at that point I just knew I had to be a part of it. To have that chance to help other people – I just had that zeal. Even though I couldn't stand up and walk I knew full well there are people in Swaziland that could not do a single thing for themselves as they are so ill – so my legs not working shouldn't stop me from helping them

So despite all this you still wanted to help others!

I just told myself that what the choir could do was so wonderful. Even if I were suffering, I know that there are people experiencing more pain than I. So those people are lying on the bed and whereas I can just about crawl on the floor to get to and from my bed there are those who can't even crawl or do a single thing. So I just wanted to show them that nothing is impossible. As long as you believe, you can do anything.

How hard is it for you to get to rehearsals for the choir? What does it take?

Well there is no transport for me of course. So I have to walk for a long time with my walking stick. I will have to stop and rest. All the way from home, I walk and walk. Then I rest and walk again. Sometimes I have to sit down until the pain has passed. I have to wait until the strength has come back again. But I just leave my home earlier so I can have this rest and not make myself late for rehearsals. And it's not a good road either!

In the current show you talk very movingly about your daughter and the strength she gives you. What was it like delivering that story to audiences each night?

It was hard each night thinking about her face because I miss her. But she is always close to me. Late last year I asked her 'what would you do if you found out I was HIV+' and she said 'Oh mum, I love you and that wouldn't change, you are so alive', so I told her there and then. I thought it was the right thing to do as they are taught about HIV in school. And she really has the spirit of nursing in her. She is such a good girl. She was the one who would come and remind me to take my medications, every day. Every day she would place them by my side and say 'mummy mummy, don't forget to take these it's 7 o' clock'. She is 11 years old now. Her name is Samogalisewe – it means 'given by god'.

You are brilliantly open about your status and experiences as a positive woman with your audiences and with the choir in general. How have they reacted to your disclosures?

Well not everyone loves what I do – they sometimes say 'so what' and 'why are you going on talking about this,' but the only thing is that I have to be honest about myself and my status. I just know that it's so important to do this, to make people be aware of what it's like out there so they can be prepared as best they can. It's their choice. I should be an example to the younger ones in the audience and in the choir itself. It's important that they get to ask the questions they need to in order to grow. They need to ask 'how do I survive?' They might not be negative forever. So this is why I share my HIV status. So they can come and ask me. I just want to see more and more young people living healthy lives. That's my intention.

Have there been any positive benefits to being as open as you are about your status?

Yes, some. I had a brother, who comes after me. When he got sick one time, he got fungi on his armpits which kept on complicating. I said 'how would you feel about getting a HIV test?' and he said (adopts voice and wags her finger) 'no, no, no that's the last thing I'm going to do'. And I said 'ok that's fine, I'm not forcing you'. He had a child, a little boy who I now look after when his mother deserted him, people often think he is my child we are so close. One time the sickness was so heavy he turned to me and said 'sissy, I think I need to do a HIV test; you have been such an example to me. And I now know I need to be responsible for my own child and be strong for him. I thought being HIV was the worst thing but you have shown me that you

can live and be healthy'. He's not the only person. In my community many people come to visit me at my home and want to have my friendship and I couldn't understand it at first as I don't go out and I live a very simple life. I'm not a special person. But then one time a person came and said 'oh sissy, I am not well and I have tested and they have told me I am HIV positive and I decided to come to you.' I said 'what do you want me to do?' and they said 'tell me how to live, you always look so healthy and happy and smiling all the time and always enjoying life, please tell me how you do it?' and I said to them 'the only thing you need to do is accept your situation. There is nothing else you need to do. Forget about the rest. Forgive anyone you need to. Forgive your partners. Forgive yourself. And then you will lead a happy life'. And then they get it!

I gotta say Promise – I love you! I always feel I learn so much about my own status when I hear you speak from the heart. You seem to have a lot more confidence in yourself too since we last met which is great to see.

Aww no I haven't. Have I? I wasn't aware! Well if I have maybe it's because I have told myself. I am free. I am still a human being and I'm alive. And I say to myself 'what's next'? I'm allowed to live my life, as I want it.

What have you noticed about the differences between Swaziland audiences and Victorian ones?

They give you the love. So much love. HIV people need to be loved. And Melbourne audiences have given me that. In Swaziland it's difficult being HIV positive even amongst family. They will sometimes leave you alone to be by yourself, in bed situations and locked in dark rooms, sometimes with no food at all whilst they go outside and enjoy their lives. But here everyone, once they hear about you, they want to come closer, and they want to know more about you, with the enthusiasm of love and I see that they have big hearts and love. Back home I like going to church and there was a time when I couldn't walk there because my legs were so bad. So I had to be taken to church and when they carried me to sit me down on the benches the congregation would look at me, and the people next to me would move away from me, one by one. And it made me so hurt. I thought 'my god, why have I come here?' Then I thought 'I have come here for the spiritual healing but it's here like I feel I am killing myself. They are Christians, why are they doing this? So I learnt that when times are dark, friends are few, but when everything is ok more friends come to you'.

Statistics suggest that Swaziland has the highest incidence of HIV than any other country in the world and yet few people choose to disclose their status – do you think that it's because of behaviour like you've just suggested that stops them from doing so?

I think it's because once you disclose your status it is very, very hard. For one, it's not easy for you to be employed. Like myself, I have so many qualifications and certificates but I'm not getting employed because they say 'we don't want to hire someone who will get ill easily and die on us'. And I just ask myself 'who are they to judge, no one knows my destiny, only God may know that, I may live much, much longer than these men who tell me this. Of course, some of them have now died.'

What do you think might be needed to help people to disclose more?

I think people need to accept their situation. Take HIV as you would any other disease. You can still do everything. You are fit enough to do anything you want. You can get married, you can have children, you can have anything you want. You are still a human being. Nothing has changed. You have been given a challenge. And as part of this challenge you have to know what to do and not to do. Life still goes on.

Finally, what message would you personally like to give readers of Poslink?

Just stay strong in being positive and keep up the good work in spreading the word. Keep talking and continue to teach, to help everyone live long. The more you talk the more people hear and learn. I think this is wonderful. We want to see a healthy world of course. But in the meantime we have to make a world that sees that having HIV is normal.

It's been amazing to have you here Promise!

Paul Woodward has worked with Possible Dreams International in Swaziland leading storytelling empowerment workshops and performance with AIDS orphans and HIV positive children. Paul was a senior lecturer in Drama & Physical Theatre at St.Mary's University College for 16 years specialising in performance theatre, multi-media performance, physical theatre and storytelling, he is currently working full time on a practice as research PhD investigating the performativity of HIV (dis)closure at Monash University in Melbourne, Australia, after winning a double international scholarship there.



Positive Women Victoria

In November of 2012, Positive Women Victoria (P'WV) held one of our famous "Health and Well-being Weekends", at the beautiful Hummingbird Eco Retreat, in the bushy surrounds of Red Hill. We had a full house with 17 of our members attending. P'WV Peer Support Coordinator, **Michelle Wesley**, shares some of the highlights.

Friday night's dinner was a great time with women catching up with other women who they haven't seen for a long time. New members to the weekend were welcomed with open hearts and arms.

After dinner, we formally welcomed everyone and discussed what it was that we each hoped to get out of the weekend. The day ended with a relaxation session led by Jasmin (PWV Health Promotion), as did Saturday, but many of us were just "too tired to relax"! So we went straight to bed. It's not just the physical activities that wear you out, but also the level of emotions that we experience over the weekend that can leave us feeling quite exhausted. Throughout the weekend the lovely Trish (counsellor) was available for individual counselling sessions, which were very popular. Trish also facilitated an extraordinary "Healing and Growth" workshop on Saturday.

On Saturday afternoon we participated in a Movement and Music workshop, which was energetic and fun, although most of us were slow dancing towards the end of the session! For those who could still stand, there was a hilarious Laughter workshop just prior to dinner.

Diedrie (Support worker at PLC) led a powerful Mandala Drawing session on Sunday morning. We have saved all the Mandalas we created, as a representation of our weekend. We asked participants what the highlight of the weekend was for them, you can see their responses in the opposite page. The food was

delicious, healthy and plentiful, with the majority of it being grown at Hummingbird. By the end of the weekend, Bruce, the chef, knew each of us by name. Each day Bruce made green smoothies for everyone and gave us each the recipe to take home.

There was ample free time across the weekend to allow for bush walks and chatting and sharing stories. Inbetween the workshops, the business of peer support took up all of our time. It is incredibly hard for women living with HIV in Melbourne to meet on any sort of regular basis. We are separated by the tyranny of distance and often through family, work or study commitments. Many of us live in a suburb where we don't know anyone else living with HIV and are unable, for various reasons, to disclose our status in these environments. This leaves many women socially isolated. So when we do get the opportunity to chat with women in the same boat, we make the most of it.

By far, the best part of the weekend was the constant peer support, the give and take. No stigma, no discrimination. It is absolutely vital for women living with HIV to connect with other women living with HIV to enable us to have information, health and well-being strategies, and above all, peer support. We gain strength through sharing our stories, by knowing we are not alone. We left the weekend with renewed vigour and we look forward to when we will meet again.



Mandalas from the weekend have been photographed and are shown here and on the following page along with some of the highlights as expressed by weekend participants.



“Reconnecting with friends and meeting new ones.”

“Connecting with my peers, not feeling isolated”

“Being together with other PWV members”

“Healing and nurturing”

“Inspiring weekend”

“For many PWV members, this weekend is the only time we get together to support each other. Without this opportunity, many of us would feel very isolated. Over the years we have all formed close and lifelong friendships.”

“I hope the positive energy helped us all”





Pictured: Jostein and Dean

GenY Guys

"Generation Y Guys" (GenYG) is a peer support and social networking group for guys in their 30s and under who are living with HIV. It is a safe and confidential social space moderated by Living Positive Victoria's peer educator, Vic Perri, where topics such as sex, disclosure and relationships will be explored. Dean and Jostein, two of the founding members of GenYG, spoke about their inner-superhero and why they are getting excited about the group.

"When you are first diagnosed, there are definitely feelings of shame and a process of grief, but following that, things settle down into a bit of a routine," says Dean, who is 31 and been positive for a few years. "You start regular doctors' visits, asking the questions like should I go on treatment, should I not, you get back on Scruff or maybe even discover Bareback Realtime. Then the real impacts of HIV start to hit you, the stigma, the constant monitoring of your health, role playing disclosure situations in your mind, awkwardness about sex, rejection because of HIV."

Vic Perri, the group's facilitator, reflected on some of the statistics around HIV infections in Victoria. "We believe there is a need for a group catering specifically for guys in this age group. 30% of all new HIV diagnoses are in the 24-32 year old age group. Because of stigma and discrimination surrounding HIV, it's hard for guys to come out publicly about HIV and so meeting other guys in a social setting who are also positive is a challenge. It's highly unlikely you're going to put your HIV status up on Facebook," Vic says. "We are being responsive to an articulated need from generation Y guys to create a safe space away from the sex/drug party and sex-on-premise venue scene."

"It's easier to find other pos guys these days online or on your phone, you can pick up at home, go to their place or out, but some of those hookups we know involve drugs and sex, and that's ok, there is no judgment in this group", says Dean. "But we wanted a space outside of that where everyone is on the same level and people can really connect, have conversations and share our reality," adds Jostein.

The reality of being diagnosed with HIV since the first treatments appeared in 1996 has been continuously improving. HIV positive people can now expect a normal life expectancy with less and less toxicity in drugs impacting their bodies. According to Dean and Jostein, this differentiates the needs of this group from others who may have been living with the virus for longer.

"There are less physical signs of having HIV now with better treatments and less side-effects" says Jostein. "Stigma is a big issue still though, and just talking through this with other guys in the same situation is really important. We still respect and honour those people who have had HIV for longer than us, but we are a new generation who need our own ways of coping and sharing experiences."

The Superman logo of the group was universally agreed upon by the group. "Who doesn't love a superhero?" says Dean. "I reckon it's a good fit because the act of coming out as positive, even to a group of other HIV positive guys, takes a certain amount of tapping into your inner-Superman."

Dating as an issue seems to rank highly with the guys, but the group will also talk about health issues and anything else that's on the minds of GenYG. Both Dean and Jostein are single (at the time of the interview) and both have experienced difficulties dating because of HIV. "Sometimes guys try and work through it, but it's something that's always there in the back of their mind and yours", says Dean. "It's rare to find a guy who is totally cool with HIV in his partner."

Do they think the group will be a good place to pick up? "Yes"/"No" simultaneously is the answer, followed by laughter. "We really hope that the connections made at GenYG are deep and lasting, and if that means there are connections, friendships, or even hook-ups made because of the group, well, that's even better," says Dean.

Gen Y G meets once a month. If you are a guy in your 30s or under who is living with HIV, call Vic on 9863 8733 or email genyguys@gmail.com for information .





Pictured: Jack Macenroth, Photo: James Franklin

talkin' bout GenY

Jack Mackenroth is famous in the US as an openly HIV positive spokesperson, model, fashion designer, entrepreneur, and the first openly positive contestant of the American reality show, Project Runway. Jack is also the founder of Volttage, a dating app for HIV positive guys. Jack spoke with us from Miami about being public, poz and picking up.

Was Volttage created as a result of your personal experience being HIV+ and in the dating scene?

I've had my fair share of unpleasant dating experiences with guys because of my status and I thought it would be amazing to have a dating/networking site where HIV status was not an issue. It's not just a pickup

site by the way. We want to build a massive global community of poz guys with tens of thousands of guys as a way to share news, health information and personal stories.

Do you think it's more or less easy nowadays to find guys to hook up if you're poz?

Because HIV treatments are so good, many guys don't disclose their status. That's great for them but it silences the conversation about HIV and contributes to the stigma. So I run into a lot of guys that don't understand risk factors or what "undetectable" even means.

Were your family and friends supportive of your going public with HIV?

Oh yeah. You have to remember I got HIV in 1990. Back then we were more concerned with survival than we were with opinions. I wanted to be public on Project Runway because I knew there were guys in the HIV community who would respond to seeing a healthy, successful, unashamed role model (pun intended). We still desperately need more of them.

Combating HIV stigma is a really hard thing to do. We have our own campaign called enuf.org.au, but it takes brave people to become public leaders. Any words of advice to the GenYG group who may be considering going public about their HIV status?

Yes. You will save people's lives with your bravery. It sounds cliched but every voice makes a difference. I also preach that letting go of secrets will set you free. When you let go of shame and blame no one can hurt you. If you don't feel bad about your status no one else can make you feel that way either. We all need to do our part to chip away at the stigma.

On behalf of some of our readers, are you single?

Single but looking to settle down. Send applications to @jackmackenroth on Twitter.

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Rebecca Matheson, Executive Officer of Straight Arrows, has recently joined the Global Coalition on Women and AIDS and now sits on the ICWGlobal international steering committee representing the Asia Pacific region. Here is her statement about the appointment:

First and foremost I am a mother, wife, daughter, sister, aunty, granddaughter, mentor, employee, advocate and a woman who has been living with HIV for 19 years.

I am a long time member of the women @NAPWHA network, advising on women and HIV in Australia for the National Association of People Living with HIV (NAPWHA). I have participated in policy development and implementation at state and national levels, consulting with women's networks and key stakeholders to ensure the lived experience of HIV is included.

I am a current member of the Core Advisory Group for WAP+, the regional network of women living with HIV in the Asia Pacific Region. Our role is to share information on a range of issues related to HIV positive women in the region, including sexual and reproductive health rights; to increase the capacity of HIV positive women to take on leadership roles; and to strengthen national networks of women living with HIV.

I am one of three women elected to represent Asia and the Pacific on the ICW Global International Steering Committee. This role includes advocating for policy and program makers to analyse their way of working and significantly and respectfully involve HIV positive women when developing, implementing and evaluating policies and programs. Through ICW Global I continue to facilitate spaces so that our members can discuss, analyse, prioritise, and exchange political ideas on the challenges faced by HIV positive women.

For the past seven years I have been the Executive Officer at Straight Arrows Inc, a not-for-profit organisation governed by and for heterosexual people living with HIV, and the lead agency for heterosexuality and HIV in Australia. I have a proven ability to liaise and develop positive working relationships with relevant stakeholders. With an approachable and professional personality, I enjoy interacting and working

with the diversity that working in the community sector brings. I have enjoyed working with colleagues to increase partner organisations ability to collaborate, network and influence policy at local, national and regional levels.

A key component of these roles is to ensure communication pathways reach individual women living with HIV, organisations and networks supporting them to manage their HIV. I continue to provide regular feedback on a range of relevant and up to date issues via various list-serves and websites. This information sharing is not limited to current issues but also includes personal dialogues, sharing of resources, reports and forum participation.

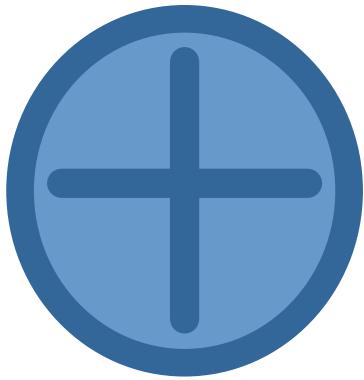
I continue to keep abreast of the priorities issues facing women living with HIV and those at risk in the Asia-Pacific region and I am able to connect the regional issues to the global context, and ensure women have access to information to manage their HIV and advocate for their rights.

I will continue dialogue with key stakeholders in the region and globally to ensure that service providers and other stakeholders are listening to the lived experiences of women and HIV. I am committed to consulting with women's networks and individual women living with HIV to bring their voices to the table and ensure that the global response is genuinely inclusive and respectful of women's meaningful involvement at all levels of the response. At a time when women's voices seem to have dropped off the agenda, I believe the coalition is well placed to lead, promote and inspire a reenergized level of activism and give voice to the global issues affecting women and girls at risk of and living with HIV.

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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 or can be requested by contacting 03 9863 8733.

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