

poslink



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Education, Information
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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
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Note from the President

Sam Venning

Pictured: Sam Venning Photo: Andrew Henshaw



When I was diagnosed HIV positive I was very interested to hear from my HIV-positive friends about their experience of commencing and adhering to treatments. I wanted to know how treatment would affect my physical and mental health and talking to my friends helped me make the decision to go on treatments.

Starting treatment gave me a feeling that I could take significant steps to fend off illness. Knowing that treatment improved my health and reduced the risk of passing on HIV helped reduce my anxiety about putting others at risk and challenged my fears that living with HIV would forever profoundly and negatively impact on my sex life and future relationships.

I was in Sydney early May to attend the National Association of People Living with HIV/AIDS (NAPWA) Special General Meeting and the launch of NAPWA's new national "Start the Conversation" campaign. Robert Mitchell (President, NAPWA) introduced three speakers: Simon O'Connor (Executive Officer,

Queensland Positive People), Dr Edwina Wright, (Infectious Diseases Physician, Alfred Hospital) and media personality and long-time HIV health advocate Ita Butrose. Simon's speech touches on the objectives and background thinking around the design of the campaign. The speech is reproduced in this issue of Poslink on page 10. The campaign targets PLHIV who have not yet started treatment and aims to encourage conversation about the benefits of modern treatments.

The primary benefit of starting treatment is to reduce viral load and maintain a strong immune system. The health and wellbeing of the individual with HIV should be the primary factor when selecting a treatment regime and when to start. For many, treatments are far less difficult to take, have fewer serious side effects/toxicities and are highly effective. Starting a conversation early with an HIV specialist will support an accurate understanding of treatment benefits and dispel concerns about side effects more commonly associated with older treatments.

As we understand more about the disease, we are increasingly aware that CD4 count or CD4 percentage are not the only factors that determine when to start treatment. Assumptions are sometimes made by HIV doctors about a patient's readiness to commence HIV treatment and clinicians are sometimes rightly concerned about risk factors for non-adherence. Starting a conversation early will help your doctor understand your readiness to commence and adhere to a treatment routine.

PLWHA Victoria supports NAPWA's "Start the Conversation" campaign which communicates to a broad population that PLHIV themselves play an important and active part to reduce and eliminate the spread of HIV.

The success of our national, regional and global programmes to effectively confront HIV requires the greater involvement of PLHIV. Publicly acknowledged involvement helps reduce stigma and discrimination and can be a powerful tool in breaking down the barriers of fear and prejudice. PLHIV have a great deal to contribute to a better understanding of living with HIV. Messages about the benefits of treatment are supported by others that have commenced treatment and can share a positive real-life experience.

There has been some criticism that the diversity of positive people do not feature in the initial phase of the campaign material. In Australia, men are overwhelmingly represented in HIV infections and it is therefore appropriate that men are targeted in the first phase of the campaign. Nonetheless, it is important that any future campaign imagery features the diversity of people living with HIV including women, people from culturally and linguistically diverse backgrounds, families and people with disabilities.

The release of the campaign is linked to NAPWA's recent work advocating for the adoption of national HIV treatment and prevention targets and a goal to mobilise the community to reach higher treatment maintenance targets, resulting in better health outcomes for PLHIV. This is a tremendously exciting campaign that has the potential to significantly impact and improve the health and wellbeing of HIV-positive people.

The campaign will feature heavily in magazines and billboards in several Australian cities; you may have already seen them on trams and major train stations in Melbourne. If you would like further information or support regarding starting treatment, please contact our office on 03 9863 8733.

Fancy a new logo?



PLWHA Victoria needs you to jump online and complete a quick ten question survey.

<https://www.surveymonkey.com/s/PLWHA>

You gotta have a (healthy) heart

David Menadue

Currently around 10% of PLHIV report that they are living with cardiovascular disease (CVD). Many more of us however, are at greater risk of developing it as 42% of people report raised cholesterol and triglyceride levels. HIV-positive people with diabetes (often partly caused by HIV treatments in the past) are at three times greater risk of developing it.

These figures come from a new resource especially created for PLHIV by the Heart Foundation in collaboration with a range of doctors and health personnel with experience in treating HIV and related conditions. It is called "Cardiovascular wellness for people living with HIV" and will be available at HIV sector agencies (like PLWHA Victoria) and on the Heart Foundation's website from July 2012.

Such a high percentage of positive people with CVD has been attributed to a range of factors. We know that a high percentage of PLHIV smoke (around 42%). We also know that protease inhibitors and nucleoside reverse transcriptase inhibitors (NNRTIs) can contribute to raised cholesterol and triglycerides. We are living longer with better treatments and people are developing age-related conditions – although the research is showing that the virus (in particular) is contributing to earlier ageing for some of us.

So what to do about it?

To try to prevent it and, if we are living with the condition already, what can we do to strengthen the most vital organ in our body?

Rebecca Lee from the Heart Foundation says they were grateful for the participation of a range of specialists in preparing the resource. "People in Victoria may be familiar with Professor Tony Dart from the Alfred Hospital and dietician Jenny McDonald who both have a lot of experience in managing HIV-related conditions.

They were joined by Dr Mark Baker, a GP from Sydney, sexual health nurse Glen Curran and Dr Kathy Petoumenos from the Kirby Institute to advise us on the content."

The best things that anyone can do to improve their heart health are:

Healthy Eating

- Include fruit, vegetables, wholegrain breads and cereals and beans and lentils every day
- Choose health fats, lean meat and poultry, low or fat-free dairy foods, nuts, seeds and oily fish
- Avoid or limit sugary, fatty and salty take-away meals and snacks
- Drink mainly water
- Minimise salt intake by choosing 'no added salt' or 'reduced salt' foods

Be physically active

- Moderate intensity exercise for 30 minutes on most days of the week
(The Heart Foundation guide for 'moderate intensity' is: You should be able to talk while doing it but not be able to sing!)

Strive for a healthy weight

- This is a waist measurement of less than 94cm for men and less than 80 cm for women
- Reach a healthy BMI which is calculated by combining your weight and height. A healthy BMI is between 18.5 and 25

Get regular checkups from your doctor

- Ensure that your blood pressure and cholesterol is checked regularly
- Seek advice from a dietician to ensure that you are eating foods that build up your good cholesterol and limit intake of bad cholesterol

Limit alcohol intake

- Two standard drinks per day is the recommended amount of alcohol intake to avoid damage to the heart and liver

Avoid recreational drugs

- Drugs like marijuana, amphetamines and cocaine put a lot of pressure on the heart and can cause serious heart problems

Look after your psychological wellbeing

- Getting support for depression or anxiety can help you to manage your health better, including your management of CVD risk factors

Quit smoking

- Smoking is a major cause of heart attack, stroke and peripheral arterial disease. A smoker's risk of heart attack reduces rapidly after only one year of not smoking.

Along with the resource, the Heart Foundation is providing more specific information for people with HIV on heart health on their website. There are links on the site to managing conditions like diabetes and information on how to measure waistlines or do a BMI calculation

The website address is www.heartfoundation.org.au. The HIV component of the website and resource will not be available until July. A launch is planned at the Positive Living Centre. You can request a copy of the resource from PLWHA Victoria once it is launched.

Opposites Attract Study

Does HIV treatment reduce the risk of HIV transmission in gay serodiscordant relationships?

Over the last few years, emerging evidence in heterosexual serodiscordant couples (where one partner is HIV-negative and the other is HIV-positive) has suggested that when the HIV-positive partner is on effective HIV treatments (antiretroviral therapy) and has undetectable viral load, the risk of passing on HIV to the HIV-negative partner is reduced. This evidence led to the publication of the "Swiss Statement" in 2008, in which doctors from the Swiss Federal Commission for HIV/AIDS stated that under certain conditions, HIV could not be transmitted if the HIV-positive partner had undetectable viral load.

Last year, this suspicion was confirmed in a large, multi-country randomised clinical trial. The trial, known as HPTN052, found that the risk of HIV transmission was reduced by 96% in the couples when the HIV-positive partner was on treatment. This extraordinary finding has led to a strong international push for "treatment as prevention" as a new HIV prevention strategy.

However, whether these large reductions in risk apply in gay male serodiscordant relationships is uncertain. Most studies have been based entirely on heterosexuals, and there was a total of only 37 gay male couples in HPTN052, or about 2% of the couples in the study. Answering this question is particularly important for countries like Australia, where HIV infection predominantly occurs in gay men. Additionally, in Australia it has been estimated that approximately 20-30% of infections each year occur in the context of ongoing gay male serodiscordant relationships.

There are a few reasons why the dramatic reduction in risk found in HPTN052 may not apply to gay men to the same degree as in heterosexuals. First, it is well-known that anal sex is about 10-15 times riskier for HIV transmission than vaginal sex. Second, research has shown that although more gay men are on treatments than ever before, the incidence of HIV among gay men has been increasing over the past decade in many countries, including Australia.

Research has also shown that the risk of acquiring HIV per act of anal sex has not decreased in the past decade. Third, viral load in semen is not always the same as viral load in blood. This is especially important in gay men as it has been found that urethral STIs can lead to increases in semen viral load even when blood viral load remains undetectable. More evidence for "treatment as prevention" in gay men is required.

Currently, there are two observational studies in the world that are designed to look at whether HIV treatment prevents HIV transmission in gay men. The PARTNER Study in Europe is currently enrolling both heterosexual and gay serodiscordant couples, and at present, one-third of the couples in the study is gay. In Australia, a brand new study has just started enrolling gay men in ongoing serodiscordant sexual relationships – the Opposites Attract Study.

The Opposites Attract Study is being coordinated by the Kirby Institute for Infection and Immunity in Society (formerly known as the National Centre in HIV Epidemiology and Clinical Research) at the University of New South Wales, and is recruiting men in sexual health and GP clinics in Melbourne, Sydney, Adelaide and Brisbane.

Along with the main question of whether HIV treatments and undetectable viral load will prevent HIV transmission, Opposites Attract will also explore important questions relating to HIV risk within serodiscordant sexual relationships. For example: Is the HIV viral load in semen the same as in blood? Do gay men in serodiscordant relationships talk about viral load with each other, and do they use viral load results to make decisions about their sexual behaviour? And what impact do sexually transmissible infections (such as gonorrhoea, chlamydia and syphilis) have on viral load and HIV risk?

This study will recruit pairs of men who are currently in a serodiscordant sexual relationship. The men in the pair can be boyfriends, life partners, or "husbands"; or they could just be "friends with benefits". The sexual relationship may have been going on for years, or possibly only a few weeks. The important things are that they have the opposite HIV status to each other and are in a sexual relationship with each other where they have anal sex (at least once a month on average). The pair can enroll in the study if they believe they will still be having sex with each other in the next 3 to 6 months.

After enrolment in the study, the men will have regular sexual health and HIV testing at a clinic, and will complete a short online questionnaire immediately after each visit to their clinic. They will also give some extra blood samples that will be put into storage. For HIV-positive men in Sydney, there will be the opportunity to participate in a sub-study looking at viral load in semen.

Understandably, some HIV-positive men may have some concerns about the legal implications of participating in a study like Opposites Attract.

A lot of effort has gone into ensuring that the legal risks are minimised, and there are important safeguards in place. For example: it will be documented that both partners have a very good knowledge of how HIV is transmitted in the specific context of serodiscordant anal sex; the HIV-negative partner will sign a declaration that he knows his partner is HIV-positive; and details about sexual behaviours such as unprotected anal sex will only be asked of the HIV-negative partner and never the HIV-positive partner. The study team has received detailed legal advice on these issues.

The Opposites Attract Study is now recruiting serodiscordant couples and pairs of gay men in serodiscordant sexual relationships.

For more information about the Opposites Attract Study:

Phone: 1800 129 073 (freecall)

Email: OppositesAttract@unsw.edu.au

Web: www.OppositesAttract.net.au

Participating Clinics in Melbourne:

- Alfred Hospital
- Centre Clinic
- Melbourne Sexual Health Centre

- Northside Clinic
- Prahran Market Clinic

Article by:

Ben Bavinton (Project Leader, Opposites Attract Study) and Prof. Andrew Grulich (Head, HIV Epidemiology & Prevention Program) Kirby Institute, University of New South Wales

Winter blues be gone

Judith Gorst

Practise Nurse from Prahran Market Clinic and Counsellor with Positive Health (Victorian AIDS Council) Judith Gorst, shares her ideas for fighting those undesirable winter blues.

Is it my imagination or has winter arrived earlier this year?

I grew up in England and vividly remember my mother digging out the winter vests sometime in October. These were aptly named "Chilprufe", and were woollen, warm and extremely itchy. We wore them until the days started getting longer sometime in April.

Keeping warm in the winter months is important. There are good reasons to put on an **extra layer of clothing** or another blanket on the bed. Not only do we feel better if we are warm we also can save on gas and electricity bills.

Many people feel that winter is a time to hibernate, to stay at home rugged up with the heater on and a DVD playing. This is understandable if it is wet and grey outside. However, for some this may lead to an increased sense of isolation and loneliness, not to mention an inflated utility bill three months down the track.

SAD (seasonally adjusted depression) is a recognised phenomenon. Shorter, darker days can negatively affect our mood in a subtle way. Finding things to do during the day, especially if you are not working, can be a challenge for some and this can be exaggerated during winter.

You may already have noticed that you are experiencing some of the symptoms of depression, for instance, lack of motivation and a sense of hopelessness or sadness. If this were the case I would strongly recommend that you **talk to your doctor**. Some people feel that they have to be ill or need a blood test before making an appointment with their GP. Your doctor is interested in your emotional well being as well as whether you are sticking to your medications.

He or she may suggest accessing some **counselling support** through Positive Health at the Victorian AIDS Council or through the Better Access Medicare scheme.



Apart from counselling, what else might be worth considering as a way to combat the winter blues? Getting out at least once a day is important. **Catching up with friends**, going to a film, museum or exhibition, taking a walk are all things that can break the monotony of a day.

Public libraries are warm places where no one suggests you move along. There are collections of newspapers and magazines, not to mention the obvious shelves of books.

I find librarians the most useful of community workers; they often have

a huge knowledge of local events and courses that may be of interest.

Winter can be an ideal time to **study something new**.

Libraries also have an enormous number of cookery books. This brings me on to food.

We all know that **eating well** is an important part of good health. In winter many people will opt for takeaway food as it is easier and means a trip to the supermarket is avoided. Healthy, nutritious soup is one of the good things about winter and a big pot can provide numerous, economical meals. Borrowing cookery books from the library, or from friends and trying out new recipes may help in increasing the variety and quality of food consumed. It may also prove stimulating. If you can read you can cook.

Winter is the time that flu tends to strike. Most doctors will recommend a **flu vaccination** for anyone living with HIV. Anyone with an impaired immune system is at greater risk of acquiring the flu. The vaccine is free.

If you have a low CD4 count it is still worth talking to your doctor about being vaccinated. You may

have a diminished ability to develop antibodies to the flu virus but the vaccine will provide some degree of protection. After being vaccinated your viral load may dip; this tends to be transient. Your CD4 count should not be affected.

Some of the patients I see will decline the flu vaccine stating that they have had some form of adverse reaction in the past. It is true that a proportion of people will experience some side effects similar to actually having the flu following vaccination. It is worth noting that, just because you have reacted one year, it does not mean that you will the next. Each year the flu vaccine is made up of different strains of the virus and, unless you are allergic to eggs, there is no reason for you to react on an annual basis.

So staying warm, eating well, maintaining connection with others and paying attention to your body are all goals during the winter months. Keeping a **positive attitude** can be a challenge but, in my opinion, wearing a few extra layers of clothing, even an itchy vest, is vastly preferable to those sticky, sleepless, humid nights of summer.

Support & Information

Positive Health

Tel: 03 9865 6700

Freecall: 1800 134 840

Beyondblue info line

Tel: 1300 22 4636

Lifeline - 13 11 14

Suicide Helpline Victoria

Tel: 1300 651 251

Mensline - 1300 789 978

HIV & Sexual Health Connect Line

Tel: 1800 038 125

Web: connectline.com.au

PLWHA Victoria

Tel: 03 9863 8733

Email: info@plwhavictoria.org.au

Positive Living Centre

Tel: 03 9863 0444

Email: enquiries@vic aids.asn.au

This article is intended to be used as information and to create awareness around mental health. If concerned by any issues covered seek medical advice.

Positive Women Victoria

Supporting women living with HIV/AIDS in Victoria

Positive Women Victoria are located at Coventry House with PLWHA Victoria and Straight Arrows. We offer peer-support, information, advocacy, newsletters, and social events for women living with HIV in Victoria.

Peer Support

Our Peer Support Coordinator, Michelle Wesley is available to catch up with women at our office on Tuesday, Thursday & Friday between 10am and 3pm, or at the PLC on the following dates:

Thursday 14th June

Thursday 28th June

Thursday 12th July

Thursday 25th July

Women in the House

Positive Women Victoria hold 'Women in the House' sessions between 1pm – 3pm on the following dates:

Friday 29th June

Friday 31st August

Friday 26th October

The 'Women in the House' afternoons are a great chance for women to meet other members, have a relaxing massage, and enjoy afternoon tea. Please ring Michelle on 03 9863 8747 for more information, or to book in for a massage.

Member Dinners

Our dinners are open to all positive women and are held in private rooms (at restaurants) so that women can talk openly. If you are interested in attending one of our member dinners, please contact Michelle on 03 9863 8747 for more information. The dates of our upcoming dinners are listed below:

Tuesday 24th July

Thursday 27th September

Tuesday 27th November

For more information about Positive Women Victoria's programs and services please contact 03 9863 8747.

Start the conversation

Simon O'Connor

Simon O'Connor, General Manager of Queensland Positive People, launched NAPWA's new campaign, Start the Conversation in May 2012. This is his speech.

I would firstly like to highlight that there is now overwhelming new evidence about the long term benefits of antiretroviral treatment. It is clear that untreated HIV is bad. It is equally clear that treatment can not only stop progression of HIV infection, but also help to minimise the long term health problems that can result from living with HIV, such as cardiovascular disease, cancers, neurocognitive impacts, and bone disease of which people with HIV are at higher risk of developing than the general community.

However, because these developments are new, it is likely that many, many people with HIV and the communities they come from are not yet aware of them. A lot of people are operating under an old view of HIV and its treatment – that there is a latent period after becoming infected with HIV which lasts for years, so treatment can be delayed without adverse health impacts. Many people may also regard HIV treatments as difficult to take, demanding, and having serious side effects and toxicities.

Today the picture is actually quite different – many people with HIV need only take one pill a day; treatments are effective long-term; and side effects and toxicities are minimal for many.

NAPWA believes that the recent, profound advances in HIV treatment and care can benefit many people living with HIV in Australia; and that people are entitled to be made aware of these advances; and that they should be available regardless of where

people live, their financial means or their CD4 counts.

To this end, NAPWA embarked on the development of the **Start the Conversation** campaign to try and ensure that every person living with HIV is encouraged to explore the latest information about personal health benefits – but in a way that was speaking to them in their own space and in their own role in their personal health management.

In this endeavour, I think that one of the obstacles to be overcome is the attitude promoted in various postings I have read recently on the net – some of which particularly caught my attention by seeming to imply that encouraging PLHIV to have conversations with each other and with their support people – and especially with their clinicians – about new approaches to when to treat, is challenging the concept of self-empowerment by being dictatorial.

I've read other postings suggesting that to consider treating HIV earlier than we have done to date – that is, treating HIV when you have over 500 CD4 cells – is irresponsible in the absence of formal research that would provide the "reliable" information that HIV-positive people with higher CD4 counts and their clinicians need before decisions can be made about when it is best to start treatment.

One posting went even further suggesting that the notion of recommending antiretroviral medications for healthier HIV positive people should be challenged because the benefits of treatment have not

yet been shown to outweigh the risks, and the best time to start treatment for healthier HIV positive people is not yet known. It suggested that to consider earlier treatment in the absence of research is somehow a violation of the HIV-positive person's rights to an informed choice. Apparently, we ought to wait passively for "some years", the writer said, until the research results become available.

Now don't get me wrong here – I'm all for conducting formal studies, trials and research that would definitively provide the information that assists HIV-positive people with higher CD4 counts and their clinicians to make the best treatment commencement decisions.

So, by all means, let's do the research. But let's not forget what we already do know and what we do have clear evidence for. We do know that HIV does damage to people's immune system from the time of seroconversion. I do remember those times when we used to think that HIV lay dormant for – oh, about 10 years – and then something that we didn't understand jump-started it into life – resulting in people becoming ill and – in far too many cases – usually dying. We do know now that HIV is never latent – it's not even lethargic. It's wrong to think that HIV is not doing constant damage to PLHIV who have CD4 cell counts of over 500.

So is it really responsible in 2012 for some to be suggesting that we still aren't sure whether the benefits of treatment outweigh the risks and therefore we should just wait? I wonder what the people who hold



If you're living
with HIV,
start a treatment
conversation
with your doctor

napwa.org.au
napwa national association of
people living with hiv/aids

this position make of the dramatic decline in HIV death rates since the advent of combination therapy – and I wonder if they personally knew people who are no longer with us because they chose to wait, in some cases based on advice from others.

The latest US Department of Health and Human Services HIV treatment guidelines, which are the main guideline reference used in Australia, have just recently shifted significantly to advocate that all PLHIV should consider treatment, whether newly infected or living long term with HIV. This is because of the important health benefits for the individual with HIV infection, but also the secondary benefit that being on treatment has in reducing the risk of transmitting HIV to others.

Of course treatments – of any description – for any disease or health condition – are never perfect and we always need to lobby for better treatments with fewer side effects that are better tolerated by everyone. We should heed the calls from those who want to assert the right that PLHIV have to a full explanation of the risks of medical interventions – but we must also insist on our right to have a full explanation of the risks of deferring medical interventions. All medications have side effects – but from my perspective, unless you are lucky enough to be one of the long term non-progressing minority, the side effect of not treating HIV is, in most cases, death.

Whenever I say this, some people have commented that they think it is

a harsh thing to say – but I have my reasons and my reasons are not trials or statistics. My reasons are actual people.

I would like to share with you Kim's story – a part of which I was privileged enough to personally share with her and also bear witness too.

Kim was a long-time member of QPP and she became a friend of mine – and she was always very anti-antiretrovirals because of their side effects. Instead, she chose her own path of exploring and utilising alternative therapies and excluding antiretroviral medications.

Initially, she was very happy with her decision and she made it in the full knowledge of the potential consequences – and I did support her in her choice. Even though she was aware of the potential consequences, I don't think she really believed that they would ever actually visit her – until she was admitted to the Royal Brisbane Women's Hospital and was diagnosed with aggressive, extensive and untreatable cancer. She immediately commenced antiretrovirals, but it was too late.

One of the last things she expressed to me was how remorseful she was about not having commenced antiretroviral treatment much earlier, and that she had made a serious error of judgement in waiting too long. Kim died a week later, and what she said had a profound effect on me. I have never forgotten it, because at the time I shared her view of delaying antiretroviral treatment for as long as possible. Since Kim's premature

death, I no longer held that view and I like to think of my significant change of opinion as Kim's legacy to me.

However, the Tracking Changes report was released last December by ARCHS, and it is the latest in Australian reports showing that a large number of people still believe – as Kim and I once did – that the HIV drugs remain a greater risk than the benefits they hold.

Tracking Changes also reported that the attitudes and beliefs of some doctors as to who should be on treatment are often based on assumptions of who will be able to be adherent and maintain treating long term. Promoting discussions between patients and doctors will surely provide greater insight into the context of treatments in a person's life today and how that can best be managed by them.

This is important because – as I said before – we do know that left untreated, HIV is busy doing damage. It's important because we do know that left untreated, HIV can kill. It's important because we have already lost too many wonderful people – and personally, I don't want to lose anymore because they are unaware of the latest treatment developments.

So again, by all means, let's do more research. But in the meantime, let's also encourage HIV-positive people to have new conversations about treatments.

This should not be perceived as dictating to PLHIV or telling them what to do.

This is not suggesting that a decision to start treatment – or a decision to defer treatment – should not be an informed one which, ultimately, must be made voluntarily by the person considering treatment in consultation with their clinician.

What NAPWA's campaign is doing is encouraging PLHIV to have vigorous conversations so that we can decide for ourselves what is best for us to do and when it is best for us to do it without being stigmatised for our decisions – whatever they are.

We know that for many people, their doctor is the trusted information source, and that the relationship with a doctor can be a major factor for people being able to discuss their issues and concerns. However, NAPWA urges all people with HIV to be proactive in their health decision-making – and that health decision-making at its best involves a strong partnership between doctor and patient.

Furthermore, research shows that in situations where people are dealing with a long-term illness, the outcomes are better for them when they are informed and able to take an active role in their treatment plan and work collaboratively with their doctors.

Is this not PLHIV fighting HIV and actively participating with our clinicians in making informed decisions about the care we receive?

Is this not reinforcing the inclusion and empowerment of PLHIV at all levels of the response to the disease – from calling for ongoing and new research and the regular review and revision of treatment guidelines – to the provision of services that directly affect us?

How can encouraging us to participate in conversations be regarded as a violation of our rights which are enshrined in the Denver Principles, as some people's postings on the net would have you believe? We know that every one of us has to make our own call on how to manage living with HIV, and NAPWA and its member organisations have this as a fundamental principle.

The Start the Conversation Campaign is critical to get the message out to people living with HIV about transformational changes in HIV treatment and prevention.

But that's not where it ends and there is still much work to be done. Apart from, and more important than negative attitudes posted on the net, there are regulatory and other systemic barriers to treatment access which must be overcome if doctors and patients are to take full advantage of these new advances. Data is also confirming that around the country there are people struggling with how to manage the costs, or access restrictions about seeing the right doctor and getting the best drugs for their individual needs.

We need to make sure we continue the advocacy work for improvements and more ways to support people – not just to be on treatment, but also to be able to stay on treatment. That means continuing the work to see more access than just the hospital pharmacies, and more drugs on one script, regardless of how many HIV drugs are needed.

NAPWA and its members will continue the work to empower HIV+ people to take a more proactive role in directing our treatment options. The Start the Conversation Campaign is also linked to other information and resources such as the NAPWA website, that NAPWA hopes will benefit every person negotiating their way through the process of getting appropriate treatment.

People must ultimately make judgements for themselves about how to incorporate new information into their lives, to improve their quality of life, and to get their optimal outcomes. But to do this they need the facts – and the NAPWA Start the Conversation Campaign aims to alert HIV-positive Australians and get them talking.

After all, having vigorous and challenging conversations is how we have arrived at where we are today in this country – so ongoing conversations must be encouraged and maintained.

Kim is just one of a number of people whose stories have contributed to my passion and my dramatic about-face on this subject. They all have names and I remember them all. The honoured phrase from last week, "lest we forget", applies to us too. So, if it's not already obvious, I probably need to disclose here that I do have a personal agenda.

I have a score to settle with HIV. I want revenge.

Am I biased? You bet.

Ultimately, instead of talking proudly about people living with HIV, I want to still be here to talk proudly about the people who conquered HIV. I want us to be the people that triumph over HIV and wipe its callous and unwelcome existence from the face of the planet once and for all. So I hope that challenging complacency and constantly upping the ante in the fight against HIV will always be included in our conversations too.

But for now, it is with great enthusiasm that I wholeheartedly endorse NAPWA's Start the Conversation Campaign – and I encourage all of you to get behind it, promote it and Start the Conversation for yourself.



03 9863 8733
info@plwhavictoria.org.au

napwa.org.au

napwa 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

Peninsula Health GLBTI Forum

Max Nigg

Peninsula Health co-ordinate's many community advisory groups to support different patient groups to ensure respect and equality. Peninsula Proud is the GLBTIQ community advisory group. Peninsula Health states that Peninsula Proud is the most proactive and engaged advisory group.

Peninsula Health decided to hold a GLBTIQ forum with the intention of building greater trust with the GLBTIQ community that reflects their inclusive commitment to diversity, respect and social justice.

Simon Ruth (Director of Complex Care) from Peninsula Health, and Leanne Bruce (Health Promotion Practitioner) from Hastings Community Health were responsible for coordinating the forum and sourcing the speakers.

They approached PLWHA Victoria's Positive Speakers Bureau on the recommendation of Marcus Younger and Michael Casley who are members of Peninsula Proud. They requested Shane Boyd as a speaker after reading Shane's 2011 World AIDS Day speech. The focus was to be the personal narrative of coming out, HIV diagnosis and accessing health services with a strong social justice component.

Other speakers included Karen Toohey - Acting Commissioner of the Victoria Equal Opportunity and Human Rights Commission - and Beth Wilson, the Victorian Health Services Commissioner. Nellie Thomas the well-known comedian, was MC for the day. Nellie is also a sexual health and ethics educator in schools.

The forum was held at Higginbotham Winery in Dromana – a wonderful location looking out over the vineyards to Port Phillip Bay.



Pictured: Shane Boyd, Karen Toohey, Beth Wilson and Nellie Thomas. Photo: Peninsula Health



Pictured: Leanne Bruce, Nellie Thomas, Beth Wilson, Simon Ruth, Karen Toohey and Shane Boyd. Photo: Peninsula Health

Many community based agencies such as the Royal District Nursing Service, the VAC/GMHC, local GLBTIQ groups and Victoria Police's Gay and Lesbian Liaison Officers set up information stalls on the day. The forum was very well attended with about 80 people, reflecting the diversity of the GLBTIQ community.

Shane Boyd spoke passionately about his coming out as a gay man and as HIV-positive. He spoke of the importance in accessing counselling and support and how that made an enormous difference in coming to terms with his diagnosis, mental health and wellbeing.

His story impacted significantly on one participant who cited similarities with Shane's story, but that he had not been able to achieve the same positive outcome. He is now motivated to make changes to his life and seek additional support for his mental health, drug and alcohol issues.

Shane's story led into Karen and Beth who outline the legislation and human rights we all should expect from a health service and the ways we can either self-advocate as patients or with the support of the Commissions' staff. A very interactive question and answer session outlined some of the problems occurring in the community.

One participant spoke of their friend who worked as a teacher and how year seven students would walk past her room at lunchtimes yelling out "leso, leso." Karen and Beth were able to outline the ways this could be addressed in a proactive way that was supportive of the teacher.

Karen also advised the participants of the redeveloping their website which includes a user friendly section where you can post anonymous stories about discrimination. This will allow the Commission to gather anecdotal evidence of any systemic

discrimination and observe what is happening in the broader community without people having to make a formal complaint.

The afternoon was highly informative and the participants all seemed to enjoy the day – especially the informal way the information was delivered by Shane, Karen, Beth and Nellie.

For further information please visit the following websites:

1. humanrightscommission.vic.gov.au/
2. health.vic.gov.au/hsc/

The Winter BBQ

A social afternoon for Positive people, their friends and family.

Enjoy great food, beverages and door prizes in a safe and friendly environment.



Date: Saturday 16 June 2012
 Time: 1pm-5pm
 Venue: DTs Hotel
 164 Church Street Richmond
 (cnr Church Street & Highett Street)
 RSVP: Monday 11 June
 Contact 03 9863 8733 or
info@plwhavictoria.org.au

No cover charge and complimentary food provided.

Planet Positive is a joint initiative of PLWHA Victoria, Straight Arrows, Positive Women Victoria & VAC/GMHC.

Anal Health (part one)

Guy Hussey

'Anal health' is a term, notion or phrase that is being increasingly banded around in relation to sexual practices and sexual health (PLHIV STI transmission – including HIV; anal cancer) but what is it actually referring to?

Is it simply making reference to a part of the body that is (generally) contained within our undergarments along with other bits and bobs and by nature out of sight out of mind!

Prior to talking about anal health from a sexual practice and sexual health perspective, it is important to understand it in generalist terms around general wellbeing, nutrition and digestion.

Within this (two part) article the term 'anal health' is being explored and defined holistically as the point of reference to 'ano-rectal' health. Physiologically, this includes the descending colon; colon (both specialised regions of the gastrointestinal tract and digestive system); rectum; and anal sphincters (internal and external).

In generalist terms anal health can also be used to describe the final restorative process with which the colon serves in the gastrointestinal and digestive process by way of removing remaining nutrients and excess fluid to provide a solid motion. The anal colon does this through both a delicate membrane and mucosal lining which adheres to it and absorbs remaining nutritional properties.

Some of the most general issues which can affect this region are diet related; a diet with good nutritional

value will generally ensure good bowel motions and a firm stool.

Overly hard stools are sometimes the result of prescription drugs or a diet too high in fibre which can result in constipation and result in fissures (small tears) to the anus.

If you detect the presence of blood either on toilet paper or within the bowl of the toilet, the brighter the red the fresher the blood meaning a localised bleed. (Bleeding higher in the gastrointestinal tract will result in a stool very dark in colour, almost black. If you are concerned about this seek out medical advice).

Some good simple tips to ensure general anal health are the following:

- Remember what goes in orally must come out. Try and ensure a good nutritional diet which is fibrous (a balanced diet not just high in fibre);
- In the first instance, when carrying out daily hygiene practices don't be

afraid to allow the fingers to linger to fully understand what the existing texture to the opening of the anus feels like.

- Be observant to any changes in texture from this point in time on; no one can understand your body like you (if unsure of what 'normal' is, have a conversation with you S100 prescriber or general practitioner)
- Don't be afraid to take a look back after a bowel motion to observe changes in colour of the stool; take note of the presence of any blood (bright red in presence) after a particularly hard motion, which can easily occur and as a one-off.
- For PLHIV, ensure samples (swabs) are taken from the anal region when screening for an STI regardless of the absence of any penetrative practices;
- Ensure the anal region is also examined during a prostate or gynaecological exam.

Part two of this article will look specifically at anal related trauma which may occur during anal penetrative practices and contextualise it within a broader sexual health focus, including the role of the mucosal lining.

This article is intended to be used as information and to create awareness around anal health. If concerned by any issues covered seek clinical advice.

References:

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Digestive_system?open (accessed on Friday, 18 May 2012 at 4pm)

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/anal_fissure?open (accessed on Friday 18 May 2012 at 4pm)



Treatment news

US regulators votes for approval of PrEP by large majority

The US Food and Drug Administration (FDA) took a decisive step yesterday towards approving the use of the combination pill Truvada (tenofovir/FTC) as a prevention method for HIV-negative people.

The FDA's Antiviral Drugs Advisory Committee (ADAC) voted by a majority of 19 to 3 in favour of recommending Truvada as PrEP (pre-exposure prophylaxis) for men who have sex with men, and by 19 to 2 with one abstention for an approval for use by the HIV-negative partner in serodiscordant couples.

There was a closer vote, however, when it came to recommending its use generally in individuals: 12 to 8, with two abstentions, voted for a general recommendation for any person at risk of HIV. The ADAC decision was taken after an all-day meeting on 10 May. This meeting discussed the findings of a written report and also heard submissions from a large number of community prevention and treatment advocates. Interest was such that the FDA extended the time for submissions from advocates and community members from one hour to two and had to organise a ballot for access to the hearings.

The written report had concluded that concerns about safety and HIV drug resistance were not sufficient to delay the introduction of PrEP. It also decided that concerns about poor adherence levels seen in some randomised controlled trials, and about whether PrEP would negatively influence behaviour to such a degree that people ended up at greater risk of HIV, were beyond the remit of the FDA.

"I don't think it's our charge to judge whether people will take the medicine," panellist Dr Tom Giordano told the Los Angeles

Times. "Our charge is to judge whether it works when taken."

Considerations of cost are also explicitly ruled out of the FDA's remit when it comes to approving a new drug or indication. The FDA is not bound to follow the recommendations of its advisory committees and will make a final decision by 15 June. However it is very rare for it not to do so and the large majority in favour of its approval for gay men and in serodiscordant couples makes this unlikely.

PrEP has always excited controversy amongst HIV prevention advocates and people affected by HIV. Some organisations have opposed its introduction and the AIDS Healthcare Foundation, in particular, has mounted a provocative campaign against its approval. "If you love Vioxx you'll love PrEP," read one poster displayed on bus shelters near the White House, referring to the painkilling drug that was withdrawn in 2004 when it was linked with heart attacks.

The majority of HIV prevention advocates, however, have supported PrEP. Mitchell Warren of the AIDS Vaccine Advocacy Coalition (AVAC) commented: "Some funders and policymakers have been awaiting a signal from the FDA before launching demonstration projects or developing implementation plans. "The time for waiting is over. We need to get on with the work of setting priorities and rolling out PrEP to people who can benefit the most."

The controversy was, if anything, reinforced when the randomised controlled trials (RCTs) of PrEP that have reported in the last 18 months – iPrEX, FEM-PrEP, Partners PrEP and TDF2 – produced strikingly different results, with headline efficacy levels ranging from zero (in FEM-PrEP) to 83% (for men in Partners PrEP).

Studies of drug levels found that these results could be explained by different levels of adherence in trial participants. PrEP was 92% efficacious in participants in iPrEX who had detectable levels of drug in their blood, and it is clear that adherence levels will crucially determine whether it protects the people who take it. At present, RCTs have only tested daily dosing of PrEP, though a study in France, IPERGAY, is currently testing its efficacy in gay men when taken on a before-and-after-sex basis.

In contrast, concerns about negative behaviour change and participants putting themselves at greater risk of HIV have not been supported by RCT findings, but it is recognised that these will only be answered by an open-label study in which people know for sure that they are taking the drug and not placebo.

Such a study, called PROUD, has been suggested for the UK and is awaiting a decision on approval. In this study, gay men attending genitourinary medicine (GUM) clinics in the UK who are at significant risk of HIV will be offered Truvada PrEP plus a package of behavioural support and counselling, but will be randomised to receive the PrEP component either immediately or a year later.

Principal investigator of the proposed study, Dr Sheena McCormack of the UK Medical Research Council (MRC), told aidsmap: "It is unusual for the MRC to talk publicly about a trial before it receives approval, but in the case of PrEP it is so important that the trial involves and is supported by its target community."

Gus Cairns

aidsmap.com.au/page/2350808/

Published: 11 May 2012

PHOENIX

WORKSHOPS FOR PEOPLE WHO HAVE RECENTLY BEEN DIAGNOSED HIV-POSITIVE

Take the first step to living well with HIV.
To find out more email info@plwhavictoria.org.au
or call 03 9863 8733.

People with Living HIV/AIDS
plwhavictoria.org.au

Poslink 2012 readers' survey

Tell us what you think - there is still time



Poslink newsletter has been a publication of PLWHA Victoria since 1997 and we want to know what you think about Poslink today.

Your feedback will help us direct the future of Poslink and enable PLWHA Victoria to respond to the needs of our readers.

If you would like to complete the survey online, you can access it until Friday 29 June from survey monkey:

<https://www.surveymonkey.com/s/Poslink2012>

If you would like a hard copy of the survey posted to you, please call 03 9863 8733 or email info@plwhavictoria.org.au. Please note survey's received later than 29 June 2012, cannot be considered in the evaluation.

Membership and subscription form



PLWHA Victoria Membership

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

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

For more information, visit plwhavictoria.org.au/members

Full member (I am a VIC/TAS resident living with HIV) As a person living with HIV, you are entitled to full voting rights. You must tick the Privacy Information Statement at the bottom of this page.

Associate member (I am not living with HIV eg; a partner, family member, carer, healthcare worker).

Note: Applications for membership must be approved by the PLWHA Victoria Board of Directors. Full members may be asked to provide verification of HIV status. The Rules of the Organisation are available online at plwhavictoria.org.au or can be requested by contacting 03 9863 8733.

Privacy Information Statement

PLWHA Victoria collects your personal information in accordance with our Privacy Policy (plwhavictoria.org.au/about/privacy).

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

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

You can access and correct your personal/health information by contacting us on 03 9863 8733 or info@plwhavictoria.org.au

I have read the Privacy Information Statement and consent to my information being collected and stored by PLWHA Victoria.

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Signature

Date

Poslink Newsletter

Members can receive Poslink, we produce six copies of Poslink each calendar year. Please complete the following:

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Quantity

I/We **do not** wish to receive any correspondence from PLWHA Victoria.

Make a Donation

PLWHA Victoria is a not for profit organisation dedicated to supporting people living with HIV. All donations over \$2 are fully tax deductible. For further information on making a donation please contact 03 9863 8733 or info@plwhavictoria.org.au

Please return the completed form to:

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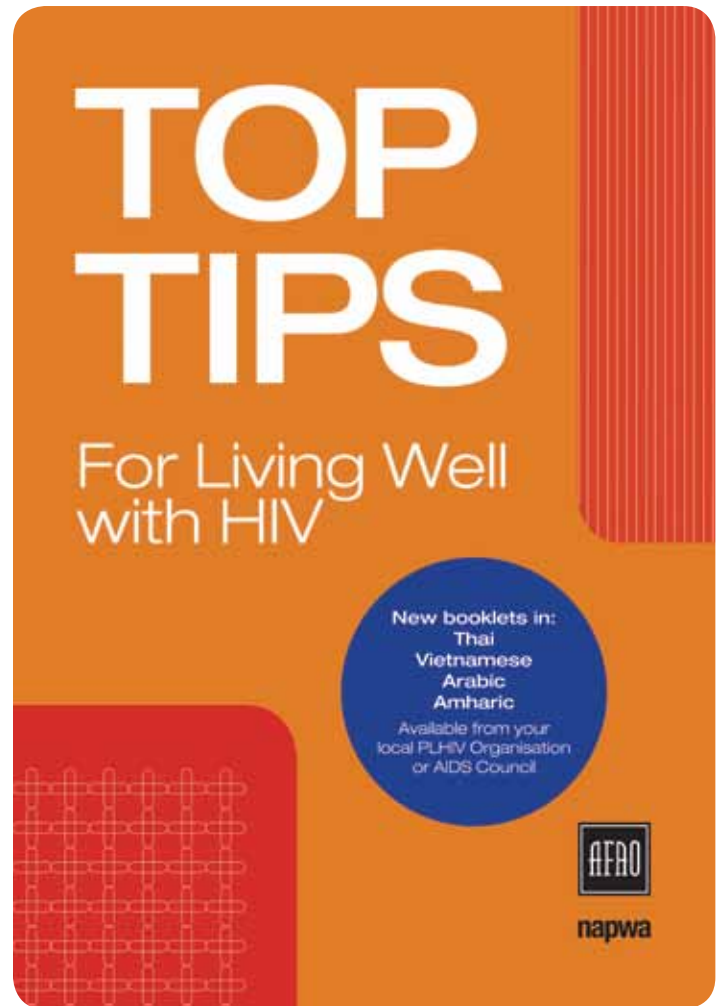
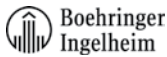
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