

# POSLINK

The Newsletter of People Living With HIV/AIDS Victoria



Suzy and Stephen staffing the PLWHA Victoria stall for ChillOut in Daylesford

## Issue 22 April / May 2005

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## The Other Side of AIDS – Melbourne Queer Film Festival *By David Menadue*

*The Other Side of AIDS*, a film made by Robin Scovill from Los Angeles, was shown to an audience of about eighty people at the Melbourne Queer Film Festival on Sunday March 20. It is difficult to say how well the film was received, with about half a dozen claps at the end of its showing but the response to the panel presentation held afterwards suggested – to me, anyway – that few people really agreed with a lot of the film's controversial premises.

The film began with a statement from Albert Einstein that

we should never stop questioning – and this effort is all about attempting to question some of the basic tenets of what we know about HIV/AIDS today (without really offering much in the way of concrete alternative answers, in my opinion). There are interviews with scientists who state that an HIV test is not actually a test for HIV itself but a test for antibody response to the virus. An activist called Christine Maggiore, director of the Alive and Well Foundation in LA (also we discover at the end of the film, the partner of the film

producer) is shown on the film getting considerable airtime on US radio talking about her theories that because of the test being for antibodies, that therefore HIV may not be the cause of AIDS and people may not be HIV-positive. Not being a scientist myself, I had to wait till the panel presentation at the end (of which I was a member myself) to hear Dr Darren Russell explain that that is the way medical science tests for many illnesses: hepatitis, polio and many everyday conditions. It is all about antibodies to the virus and the virus itself can

*(Continued on page 5)*



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## Note from the President Greg Iverson

### Advocacy

As a community group, advocacy is a large part for the focus of our work. We certainly believe it is not our sole function at PLWHA Victoria, but it is at our core.

Whether it is for a particular issue, for an individual positive person, action for a distinct sector of the HIV community, the positive community as a whole in Victoria, or nationally through our participation in bodies such as NAPWA and AFAO, advocacy work takes up the majority of our time at PLWHA Victoria.

And this work will only increase this year. The proposed changes to the welfare system, the shortage of adequate housing for the HIV sector, the still existing discrimination for many members of our community and other issues that are ongoing, mean that this year will see our advocacy work only increase and a need for our efforts to be maintained.

We have begun working on strategies and advocating for these issues already. We are currently actively involved on multiple levels in working with various state and national groups.

The board members of PLWHA Victoria serve on many other boards, national bodies, advisory groups, reference committees and on federal and state Ministerial advisory sub-committees such as the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH).

Recently, the board of PLWHA Victoria decided that we would like to explore mechanisms to allow more

participation by our members in the work of our organisation. One way that we can do this is by inviting members to nominate themselves as representatives of PLWHA Victoria to serve on some of these advisory committees. Most of these positions have been filled for this year by members of the board, but it is not unusual for us to receive requests for representation throughout the year and there are always areas and issues that crop up unexpectedly, where we are invited to give our response as representatives of the positive community.

If any of our members reading this would like to have the opportunity to participate in getting more involved in PLWHA Victoria, then please contact our office and let us know. There is always work that can be done in community organisations like ours. As is always the case, volunteers are always welcome - and not just in this area of advocacy that I am discussing here, but in all of the other facets of our work.

And along the same theme of advocacy and our work, it is important to remember that as a community organisation, we can only advocate for the community with the support of its members.

Our representation can only be as effective as the communications that we receive from those members. And we are only as strong as the make-up of our membership. The more members we have, the stronger and broader our voice can be in the upcoming representations that we make

# Advocacy

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on behalf of the positive community. And this year, strength in numbers is going to be more vital than ever before.

What this means is that if we can encourage more positive people to become members of organisations like PLWHA Victoria, Positive Women and Straight Arrows, then the more effective our voices and input can be in changes that will affect our lives and support structures.

If you know of any positive people that are not members and yet have said things like they always intended to join, actively encourage them to do so. Why not hand them one of our membership forms (which is located on the back page of this publication and also available through a phone call to our office)! There is no obligation on that person other than to register their name as a member of the positive community. All records are kept in the strictest confidence and if there is a concern about revealing your HIV status, there is always the option of joining as an Associate Member of PLWHA Victoria, which is a membership designed for HIV negative supporters of our organisation.

I am not saying with all of the above that it is time to go to the barricades just yet, but it is no time for letting our hard fought battles for rights slide.

There can be no denying that major changes are about to take place to the DSP and the welfare sector generally. This could have very negative effects on many HIV positive peoples' lives. It could also have a

beneficial effect, if handled in a socially just and proper way and if the affected communities are allowed input into this process of change. We will only be allowed this input if we make it so.

We could of course just sit back and see how these proposed changes affect us before we do anything, but then it would be too late to do anything about those changes. Or we could, as we are already doing in the HIV sector, ensure our voices are heard by actively engaging in the discussion to ensure that we maintain the rights that we have fought for and already won.

While the HIV community sector is involved in this process in lots of ways, there are also ways for individual members to have a say in the process.

One way this can be done that will greatly assist groups like the VAC/GMHC and the PLWHA Victoria bodies, is to make an appointment with your local member. Go see them and discuss the issues that concern you as a positive person. With the control of the Senate shifting to one party in July, it is time for a change in the emphasis of our advocacy. Previously, our efforts as a sector have been concentrated on those that held the balance of power in the Upper House or Senate. As one party will hold all the legislative power after July, we need to focus our efforts on getting our messages across to that controlling party. The best avenue to do this is through local representations to the members of that party. If you would like, we can arrange

a member from PLWHA to accompany you to the meeting with your local member to get our issues as a community across as well.

As I have often said, it is up to all of us to ensure that our voices are heard. Positive people have a right to have input into the issues that surround our lived experiences and a right to at least have a say in how our community is best served.

Finally, I would like to add a quick note of thank you to our staff at the PLWHA Victoria office. As our members would be aware, we are currently in the process of employing a new Executive Officer. I hope to inform the members in the next issue of Poslink the results of this recruitment. The interim process has meant that the staff in our office have had to take up the slack and everyone has performed beyond their normal duties. I want to thank all of them for their additional efforts. The office and organisation has been run effectively and smoothly through this time. In particular, I would like to thank Alan Strum who has taken on the demanding dual role of Acting EO as well as continuing his Treatment Information Officer work. He has performed beyond our expectations and has managed to juggle these roles with his hard work and enthusiastic approach. The board would like to extend a special thank you to Alan in recognition of those efforts.



## Note from the Acting Executive Officer Alan Strum

These last few months have been incredibly busy. There have been a number of issues raised by clients requiring advocacy around access to drug therapies, treatment inquiries have increased, meetings have been held with the Department of Human Services and with Minister Andrews for the DSP, events have been planned, and the Speaker's Bureau is about to be relaunched.

Our Positive Education Project Officer, Suzy Malhotra, has been busy liaising with the Country AIDS Network to organise an interactive event called 'Let's Talk About Sex Baby'. This event, for men and women, will be held in Bendigo at the RMH Club at 1pm on Sunday May 1. Suzy has also been liaising with Positive Women to organise an event specifically for their members that will cover self-esteem and body image. The event has been tentatively booked for 22 May. Women who are interested in finding out more about this event should contact either Positive Women or Suzy Malhotra at PLWHA Victoria.

Another program associated with the Positive Education Project that will be starting on May 10 is the Positive Talking workshop. This workshop will run for six weeks and is targeted at gay and other homosexually active men living with HIV for the purpose of strengthening their health literacy. It will cover topics such as caring for yourself and others, self esteem, general health, and maintaining peer support networks. If you are interested in participating in this workshop please contact Suzy on 9865 6756.

Suzy also organised our attendance at ChillOut in Daylesford where information was handed out to attendees on attitudes around sexual negotiations between HIV positive and HIV negative people. Suzy received support from a number of our board members at this event for which we are thankful.

On the Community Development front, Suzy worked

closely with Daniel Donnelly for the recent Planet Positive evening that was held at the Builder's Arm's Hotel. While I was not able to be present, I have been informed that around 50 people turned up to socialise and catch up with their HIV positive peers. Feedback from members was a bit mixed. Some loved the warmth and comfort of the outdoor space, the pool table and the cheap drinks while others were a bit weary of the night club / pub atmosphere. In general the evening was a success with the next Planet Positive planned for Wednesday evening 18 May at Vibe Café and Bar. Suzy will be on the prowl looking for other venues suitable for this event.

Suzy has also been working with Guy Kharn on the Positive Plots project. This project has been successfully running for a while now, providing a safe space for participants to do some gardening and enjoy the fresh air near the beach in St Kilda. Guy has informed us that he has a number of external commitments that require his attention and has handed the reigns of this project over to Suzy who will be following up with the participants to provide them with support for this project. Guy has put his heart and soul into this project to make it the success that it has become. I'd like to thank Guy

for his dedication and wish him well with his future endeavours.

Meanwhile, Max is now spending all his time at work on the Speakers Bureau. He has put together an exciting training program for the volunteers of the Speakers Bureau that will take place in late April. Around the same time we will put out some media releases to increase the profile of the project that will inform the broader community of the excellent work done by the Bureau. In 2004 the Bureau provided HIV positive speakers for 110 presentations on their lived experiences of HIV, stigma and discrimination to 2651 people. Max and all the volunteers should be congratulated for their efforts in raising the profile of positive people and their lived experiences in Victoria.

As you can see it has been a very busy and productive period for the organisation. On another note, this will be my last report as the Acting Executive Officer. I have decided my job as Treatments Information Officer is too much fun to give up so I did not apply for the EO position. I'd like to thank those who have provided me with support during this period and I have to say I have felt very loved and cherished and perhaps...even a little spoiled. Thank you!

## Free Wills

PLWHA Victoria offers members a limited\* free will-making service via De Ayers.

For further information, please contact Mark Thompson on 9865 6772 and he will arrange for De to get in touch with you.

\*Service covers up to six beneficiaries and no provision for setting up trusts, fund management or the like.

# What's Up, News and Information

## The Other Side of AIDS – Melbourne Queer Film Festival

*(Continued from page 1)*

be tested for with antigen testing. A lot of hullabaloo about nothing, it would seem.

There were numerous interviews with positive gay men, a number of whom had been positive for up to twenty years, some of whom had never taken antiretrovirals and had remained well. Some of these individuals postulated that the reasons for their survival had been their refusal to take the "fast lane" lifestyle of their gay peers, doing recreational drugs, sniffing amyl nitrate and "burning the candle at both ends with a blowtorch in the middle", to quote one individual (HIV negative in that case, I think). They felt that their gay friends had died because of lifestyle factors – with the assumption being made by some that these factors by themselves were enough to contribute to people's deaths.

I have no doubt that staying healthy whilst you are positive (avoiding the fast lane and so on) is an excellent way to slow progression to AIDS – and we have always thought there would be some lucky individuals who would live a long time without the need for drug treatments – but the suggestion from some of these people that a virus had nothing to do with the huge number of deaths from AIDS is an insult to the fight that so many of my friends went through in their last months trying to cope with the ravages of a virus that has killed the strongest and healthiest people I have known. I am upset that a film like this can dismiss the experience so many of us have been through with this epidemic to date – and suggest that people die from AIDS because of an overload of stress (pointing the bone, one psychiatrist in the film called it) and lifestyle factors. Without the virus, I contend, they would most likely still be here.

The experience of a number of positive mothers who were forced to give their babies AZT when they had already tested HIV-negative was an important issue to raise but as with the rest of the film, the actual scientific reasons for these decisions by various US

state authorities were not discussed with any rigour or detail. This issue has been hotly debated here in Australia too – and fortunately the rates of maternal transmission are low if precautions (including a short course of antiretroviral therapy during pregnancy) are taken – but there was never any attempt to show two sides of this debate or any historical background to the issue.

The panel at the end of the film was unfortunately seated in a way that had some people calling Mike Kennedy seated at one end a representative of the "right" (hardly so for anyone who knows him) and James M, who runs an alternative pozhealth website in Melbourne from the "left" – with a positive woman called Jane P and myself in the centre. James started with his expression of relief that a film like this had finally come out questioning some of the premises around AIDS. He expressed his concern about the effect of the stress of his diagnosis on his health and the constant pressure from doctors to get him to take HIV treatments (despite his 600 T-cells). There was a lot of propaganda put out by drug companies to sell drugs and we need an open debate on our understandings about the causes of and treatments we use for HIV, James said.

Lisa McPherson, a well-known Chinese medicine practitioner who has treated HIV positive people for many years, spoke of the need to treat "the whole person" rather than concentrate on T-cells or viral load results. Jane P spoke about avoiding the need to take HIV treatments for nineteen years until she became sick whilst travelling in Africa recently and how it is important to know that effective therapies were there when you need them. I was next, putting my belief that this film did not have a consistent line of argument about anything really – shifting from a number of people's views about HIV not being the cause of AIDS to a story about how HIV treatments wreck people's lives. We all know that HIV treatments are not

perfect, I said, but without them I wouldn't be here and many of my friends who have died would have given anything to have had the chance to take them – as would millions of people in Africa and Asia right now (interestingly the situation in these countries was not discussed in any detail in the film).

Dr Darren Russell provided cogent arguments about the scientific flaws in the film's arguments – they were "laughable" for most of the film with much of their scientific arguments being discredited in recent times in information freely available on the Internet today. Mike Kennedy suggested some dishonesty in the filmmaker's approach, not revealing openly that he was the partner of the main activist featured in the film, lying about not being a "dissident" to a scientist he was interviewing and possibly using out-of-date material throughout the film (such as the footage of a scientist talking about 2 classes of antivirals being available today—hardly the case with 6 different classes available in 2005!).

If anything good came out of this film being shown at the Queer Film Festival it was the chance for most members of the panel to at least refute the mad claim that HIV doesn't cause AIDS. As Mike Kennedy said, if that is the case, are we now suggesting that people don't use condoms? I hope that positive people will look into alternative therapies for their HIV – particularly those people who have not been infected for long and have a good chance of keeping their immune systems healthy by alternative means. No one should go on HIV treatments too soon and when you do, modalities like Chinese medicine can keep significantly with side-effect management. But let's not deny the realities of the past nine years where combination antiretrovirals have kept so many of us alive and restored our health. To do so is a form of AIDS denial that I think will bite its followers on the bum very badly one day.

# What's Up, News and Information

## CCR5 clinical trial in Melbourne

CCR5 inhibitors are a totally new type of drug that prevents HIV entering into cells. In order for HIV to infect a cell it first needs to attach to the CD4 receptor. The virus can then enter the cells via the attaching to the CCR5 receptor molecule or the CXCR4 receptor molecule. Most HIV uses the CCR5 (R5 virus) pathway for efficient replication. The CXCR4 (R4 virus) pathway is usually used in later stages of HIV infection and is associated with more advanced HIV disease or possibly faster disease progression. To date the CCR5 inhibitor being investigated has shown excellent results with very few side-effects. Pfizer's CCR5 inhibitor UK-427,857 is now available in Melbourne for 3 groups of people;

antiviral naïve people, antiviral experienced and people who have both the C5 and R4 virus present in their blood. *[Editor's note: If this drug proves to be safe it will revolutionise the way HIV is treated. There is one small concern that using a CCR5 inhibitor might force the virus from C5 to R4 (tropic) virus that could speed up disease progression. The key point is that we don't know if this will happen and what the outcome will be if it does happen. The study has been set up in part to answer this question. If you are planning on entering this study please feel free to call me if you need to discuss C5 and R4 (tropic) virus issues before going into the study. Alan]*

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## Herpes treatment confusion

PLWHA Victoria recently had a request for information about access to suppressive therapy for Herpes. We were surprised to find out that some doctors in Melbourne have been taking people with HIV off suppressive therapy for Herpes based on incorrect information published in the PBS drug access book.

Unfortunately the Federal Government made a decision in 2004 that no-one should be on Herpes suppressive therapy unless there is serological or microbiologic evidence of Herpes infection. This decision was made without consideration for people with HIV and the effect removing suppressive therapy might have on increasing the risk for transmission of HIV during a Herpes outbreak. To clear this up the National Association of People with HIV/AIDS contacted the Pharmaceutical Benefits Advisory Committee in 2004 that resulted in the

ruling being changed once they understood the error that had been made. The ruling was changed to allow people to remain on suppressive therapy provided they had been on suppressive therapy prior to May 2004. This information has now been published in the April edition of the PBS book. *[Editor's note: This is a very important issue around a person's right for access to an important treatment. Removing suppressive therapy for Herpes can be detrimental for people with HIV both psychologically and physically. You can stay on suppressive therapy so long as you have been taking the treatment prior to May 2004 or if you have pathology confirming the infection. If you are having difficulty getting this message across to your doctor we will advocate for you on your behalf to ensure you continue to have access to this treatment.]*

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## Threat to generic drugs for international programs

As antiviral access programs begin to roll out in resource limited countries where HIV is endemic, a new threat has arisen that could reduce access to generic drugs and increase costs. Most generic drugs for these programs come from India that provides the drugs 98% cheaper than patent protected HIV drugs. India provides more than half of the drugs being supplied to HIV drug access programs. In 1970 India removed itself from its obligations to follow international patent laws which resulted in a local booming generic pharmaceutical industry. In March this year India passed legislation to once again abide by international patent laws to allow the country to be a member of the World Trade Organisation. Drugs patented before 1995 will not be affected. Western pharmaceutical companies can now register all other

drugs that were patented after 1995. It will take two years for the patents to be processed during which time the generic companies can still manufacture the drugs. Once the new patents are approved the generic companies will have to pay the owners of the patents a 'reasonable' royalty. Any new drugs patented after January 1 2005 will remain the sole property of the patenting pharmaceutical company for 20 years.

Ambiguous wording within the Bill also leaves the generic pharmaceutical companies open to litigation that may act as a disincentive to produce new products.

This not only has major implications for access to cheap generic HIV drugs for the rest of the world but also has implications for access to cheap drugs for people with HIV living in India.

# What's Up, News and Information

## Planet Positive

After a brief break, Planet Positive returned to form on Sunday 11 March. In a departure from previous events, we took over the much loved Builders Arms Hotel in Fitzroy for a warm sunny afternoon of good company, fabulous food and great entertainment.

Now in its second year, Planet Positive provides a safe, informal and fun space for positive people to meet old friends, make new friendships and form support networks. Last month's event at the Builders Arms Hotel provided a great

space for over 50 HIV positive people and their friends to relax and enjoy all of this. Mel and the staff generously provided free welcome and soft drinks all night and the kitchen rustled up some delicious finger food.

The change of venue is just one of several changes we intend to try out for future Planet Positive Events. We'd love to hear your opinion on what you think makes a successful Planet Positive. Do you have a favourite venue that you think would work well? Any ideas on what you think would

make good entertainment? How can we improve on the food on offer at these events or do you like everything just the way it is?! All suggestions greatly received! Call Suzy on 03 9865 6756 or email at [suzy.malhotra@plwhavictoria.org.au](mailto:suzy.malhotra@plwhavictoria.org.au).

The next Planet Positive is on Wednesday 18 May at Vibe Café and Bar, 123 Smith Street, Fitzroy. The fun begins at 7.30pm. All positive people and their friends are welcome. No cover charge. First drink free and light catering provided. For more information call Suzy on 9865 6756.

## Public speaking for Positive people

The Speakers Bureau program of PLWHA Victoria recruits and trains HIV-positive people in public speaking to enable the wider community to have an understanding of the issues people living with HIV/AIDS face on a day to day basis whilst imparting the educational message of safer sex and helping to reduce stigma and discrimination against PLWHA's.

The Bureau is seeking committed individuals who are prepared to undergo training. We have also had numerous expressions of interest for younger speakers and would be happy to discuss the program with all those interested. The speakers are mentored via a "buddy" system and can attend talks as an observer until they are comfortable in participating. All speakers are required to attend a one day course in public speaking and there is a specific training manual that has been developed for this purpose. The Bureau also provides regular skills development training to enhance the speaker's skills. We offer total support to all speakers.

The program helps to reduce social isolation, enhances skills and fully-fledged speakers are paid for their speaking engagements.

The Bureau has memorandums of understanding with Positive Women Victoria and Straight Arrows thereby enabling the Bureau to have a very diverse range of speakers.

If you would like to become a member of the Bureau, meet some great people and develop new skills contact Max Niggli, the Speakers Bureau Co-ordinator, on 9865 6771.

## HIV & COMPLEMENTARY THERAPIES

Three seminars on research into & the effective use of Complementary Therapies for people with HIV

**VITAMIN SUPPLEMENTS & HIV - SAT. 9<sup>th</sup> April**  
**The latest research on nutrition, antioxidants, selenium, preventing drug side-effects and lots more.**

**BEYOND T4 COUNT & VIRAL LOAD - SAT. 7<sup>th</sup> May**  
**Many co-factors influence the outcome of infection with HIV, not just T4 count and viral load. Find out what they are and what to do about them. Especially important for people who want to postpone taking anti-HIV drugs as long as possible and people whose anti-HIV drugs are not working well**

**CO-INFECTION WITH HEPATITIS C & HIV - SAT. 28 May**  
**Complementary Therapies to assist in lowering elevated liver enzymes, reducing the risks of liver cancer, improving digestion and much more.**

WHEN: All seminars from 1:45pm to 3:30pm

WHERE: Positive Living Centre,  
51 Commercial Rd.  
Pahran

REGISTER: Please register at the PLC on 9863 0444

# What's Up, News and Information

## No Progress on Housing Review

People concerned about the current shortage of public housing for people with HIV/AIDS – and those positive people who were interviewed for the Review of Housing Needs of HIV positive people conducted in the latter half of 2004 – will be disappointed to find out that the Review's recommendations are not likely to be released by the two government departments who ran the process: Housing and Health (both part of the Department of Human Services).

When the Review report and recommendations – and the Government's response – were released late last year to the Reference Group set up to advise on the process, members were informed that, as the government was not happy with the Review document it would not be released to the public. Representatives from PLWHA Vic, Positive Women, Straight Arrows, AHAG and VAC/GMHC, who were at the meeting expressed dismay that those people who were interviewed for this Review and those desperately waiting for news on government action in this area, will not get to see the results of their input. Further dismay was expressed at the lack of a constructive response from these two government departments to the majority of the Review's recommendations. Whilst a further stakeholder meeting is to be held in June, at this stage PLWHA Victoria is concerned that, unless there is considerable pressure brought to bear, little will be seen for all the major efforts the organisation went through to get the issue recognised by government in the first place.

The central issue which PLWHA Victoria raised to get the Review happening all those

months ago is the acute housing shortages being experienced by plwha in the last few years. People can now wait up to seven years to be moved into long-term public housing in some areas with the Inner Metro South (which is close to the Alfred, the PLC and other HIV service providers) now an indefinite wait. The Western suburbs now involve a wait of up to 5 years for long-term properties. Transitional properties (units provided until you can be found a long-term public housing property) can be easier to find as AHAG (for instance) has rights to a number of these properties but the lack of long-term places means that some people are staying in these for periods up to 5 years, blocking further new people from entry to the pool.

### Change in 2-Bedroom Policy

One of the major reasons that new long-term properties are not coming on line is a change of policy towards HIV positive people by the various Office of Housing regional offices. Whilst officially PLWHA Victoria has been told that positive people only need to present a doctor's certificate stating that they are likely to need a carer in the future – and should then be provided with a two-bedroom property – the reality is that the various regional offices have changed their policy. It now seems as if positive people are unlikely to be put on the list for two-bedroom properties – which make up by far the majority of properties available in the metropolitan area – unless they have a carer who is going to move in or prove that they are receiving support from a range of carers. Single positive people

– by far the majority of those presenting for housing – are generally only being allocated one-bedroom properties and the waiting list for these given their low availability is the cause of the current logjam.

PLWHA Victoria and AHAG made a plea before the Housing Review took place for the two-bedroom policy to be clarified and an agreement made that positive people would continue to be eligible for two-bedroom properties as they had been since the epidemic began. The arguments presented by Housing Department representatives at the time were that positive people were much better now and less were likely to need carers and could not expect to automatically get a two bedroom place. We argued that positive people who become unwell will need family support and eventually carer support in many cases and this eventuality should still be catered for. It is understood that recommendations were made about this policy in the Housing Review—but of course, we are not allowed to discuss them!

### Rental Subsidy Scheme

Another suggestion which PLWHA Victoria and AHAG raised at the time of the Review was the need for some form of rental subsidy to positive people who were experiencing sudden hardship—such as a sudden illness or relationship breakdown – whilst in private rental and were having difficulty paying rent. Whilst it was thought unlikely that we would be able to achieve the implementation of the very successful Sydney system of Special Accommodation Subsidies in Melbourne (although we did ask for them),

# What's Up, News and Information

the idea of a special purpose subsidy for people experiencing this particular hardship whilst waiting to access public housing or until their circumstances stabilised, is still something which our organisations believe would have great value. We will continue to fight for the implementation of some system like this to try to help positive people avoid the slide in health and well-being that often happens in these crisis housing situations.

We all know the value of safe and secure housing in assuring that people's health is stable and over the years of the AIDS epidemic this has been very clearly demonstrated. I am on the In-Home Support Program committee and it is astonishing to see how people with serious HIV illnesses are able to improve their health if they are given access to quiet, pleasant environments – in that case, with appropriate attendant care to help them to get better as well. With some people with HIV climbing up into their fifties and sixties now, issues of supported accommodation and in-home support will become higher on our agendas. If we were looking for direction on issues like this from the Housing Review (which we were!), unless we make some noise about it, we don't look likely to get much action on that housing issue either. Stay tuned – we shouldn't give up the fight just yet!!

## **POS**<sub>itive</sub> **TALK**<sub>ing</sub>

### **The workshop for HIV + gay men**

**POSitiveTALKing** is a new initiative by People Living With HIV/AIDS Victoria. It is a workshop for gay and other homosexually active men living with HIV with the purpose of strengthening their health literacy.

#### **What are the objectives of the workshop?**

- To help build the capacity of the participants in order to enable them to maintain good physical health and well being;
- To enable the participants to increase their self-confidence and self-esteem in order to achieve well being;
- To encourage and support participants to view their status in perspective. To take control of their lives and be in firm control of HIV as only one aspect of their lives and not the only one;
- To encourage and support participants to play an active role in the prevention of the transmission of HIV in terms of respect for themselves and the men they have sex with;
- To breakdown the isolation of the participants by providing support from peers. This is done in the form of sharing and validating experiences with living with HIV;
- To provide the participants with a comprehensive range of resources.

#### **The workshop is about living with HIV**

It's not a therapeutic group but more about providing the right information about the health and social context of HIV. This can be given by the facilitators or it can come from the other participants in the group.

#### **So what's the difference between POSitiveTALKing and Peer Support Groups?**

The essential difference between this workshop and the successful and valuable ongoing Peer Support groups offered by the Victorian AIDS Council/Gay Men's Health Centre is that it has a structure. The workshop contains a variety of activities set by the facilitators that prompt discussion on the various issues that HIV+ people

**Vanessa Wagner presents...**

SUNDAY 1ST MAY  
1PM-5PM  
RMH CLUB  
264 HARGREAVES ST  
BENDIGO

A FREE EVENT ALL WELCOME  
FOR FURTHER INFO CALL  
CAN ON 5443 8355  
PLWHA VIC ON 9865 6772

## let's talk about sex baby...

**An interactive event about  
HIV, sex and looking after yourself**



Country AIDS Network (Victoria) Inc.



# What's Up, News and Information

deal with. This format aims to ensure a broad range of issues can be discussed.

## How's it going to work?

The workshop is designed to run over six to seven weeks as one session per week. The approximate time for each session is 2.5 hours. The activities in the first six weeks will be predetermined with the last session left free for further discussion of issues as they are nominated during the course of the workshop. The final session will see the closure of the group. It is also suggested to the group that they can organise a social dinner after the group ends. This includes the facilitators. The group is also encouraged to continue to meet after that. Not within the context of the workshop but in another more social and less structured form without the facilitators.

## What will we walk about?

### Diagnoses

- Initial thoughts and feelings when diagnosed.
- Self Esteem.
- Disclosure to family, friends, workplace, etc.
- Maintaining a sexuality.
- Where does positive identity fit in the community, Communal or individual?
- Non sexual relationships and support.

### Health

- Regular monitoring - white blood counts, viral load, and if on treatments other tests to determine impact of side effects such as blood sugars and lipids as well as liver/kidney function.
- Managing Co-infection with Hep C.
- General Nutrition and exercise.
- General hygiene and impact on one's health.

### Sexual Health

- Sexually Transmitted Infections (STIs) and the regular testing of.
- Impact on health of STIs including HIV progression.
- Re-infection/Superinfection.
- HIV transmission including assumptions, strategic positioning, etc. Hygiene practices that can influence risk in HIV transmission, eg. teeth brushing before oral sex, douching before receptive anal intercourse, etc.

### Treatments

- If or when to start, side effects, adherence, STIs, drug interactions, resistance, salvage therapy, etc.
- Complimentary Therapies

### Sex

- Disclosure, particularly in sexual negotiations, achieving satisfaction in sex.
- Sex (will I, won't I), sex in queer spaces (beats and s.o.p.v.'s), Internet chat rooms, etc.
- Confidence in safer sex including how to use a condom properly.
- Sexual dysfunction.

- Emotional health and self esteem and influence on sexual risk behaviours.
- Recreational drugs and alcohol and influence on sexual risk behaviours.

### Longer term relationships

- Sero Con/Dis-cordant relationships including the separation of what issues are to do with HIV and what's not.

### Social Aspects

- Poverty
- Going back to work.
- Rights and Discrimination.
- The Law and HIV.
- Travelling and Immigration
- Participation in clinical research such as vaccine trials or social research such as HIV Futures.

**POSitiveTALKing** commences Tuesday 10 May. For more information contact Suzy Malhotra, Community Education and Development Officer, on 9865 6756

## T-cell Variety Hour

The radio program on

**HIV - AIDS**

**Thursdays 8pm to 9pm**

**JOY Melbourne  
94.9 FM**



The Victorian AIDS Council/Gay Men's Health Centre

# What's Up, News and Information

## Let's Talk About Sex Baby... in Bendigo!

Vanessa Wagner hosts the first Country AIDS Network (CAN) Interactive Event **Let's Talk About Sex Baby (HIV, Sex and Looking After Yourself)** on Sunday 1 May at the Royal Mail Hotel in Bendigo. **Let's Talk About Sex Baby** takes a look at HIV and Sex and the different issues that help us make decisions on maintaining good physical and emotional health.

From managing side-effects of HIV treatments and concerns about body image, to issues of disclosing your status and negotiating safe sex, this forum aims to provide balanced and targeted information in an informal format with an emphasis on participation and fun. A panel of HIV specialist doctors, health educators and experts will discuss participants'

issues and invite feedback from the audience.

The event is being jointly organised between CAN and PLWHA Victoria and is funded through a Positive Education Grant from the Department Of Human Services to work with isolated HIV communities and people not connected to centralised HIV services.

**Let's Talk About Sex Baby** builds on a similar format to the Interactive Events run by PLWHA Victoria in Melbourne over the past 5 years. It has consistently attracted large audiences from the HIV community looking for up-to-date, extensive and expert information and guidance on maintaining good physical and emotional health. **Let's Talk About Sex Baby** will feature a local perspective on the issues

for people living with HIV/AIDS and will deal with many of the problems and concerns facing isolated and rural communities.

The afternoon begins at 1pm and entry is free. All city/country members and their friends are welcome! Sit back, relax and share your experiences and maybe win a fantastic prize from our generous sponsors and supporters. Food will be provided and the staff of RMH will be on hand to quench your thirst.

**Let's Talk About Sex Baby**, Sunday 1 May at the Royal Mail Hotel, 264 Hargreaves Street, Bendigo. 1pm to 5pm. For more information contact Adam at CAN on 5443 8355 or Suzy at PLWHA Victoria on 9865 6756.

### Volunteers! We Want You!

We've had a busy summer with a great presence at Midsumma, Chillout and PLWHA's Interactive Events and we're set to have an even busier few months with events that will need your help to make them a success.

We're looking for volunteers with a few spare hours a week to help us with various projects such as Planet Positive, Treatment Interactive Events and Positive Plots. You can choose how involved you want to get; from mailouts and administration to event co-ordination and publicity design, we've got a role for you!

For more information call Suzy on 9865 6756.

### ARE YOU HIV+ & HEP C+?

**Statistics show that it's common for people with HIV and HepC co-infection to feel isolated, confused and often very alone. But, that doesn't mean you have to deal with it on your own. Others face the same problems and issues each day. Confusion around their infection, sexuality, what to treat, how and when to start, doctors and also the problems with partners, family and friends.**

Why not get together with others in a similar situation? We are looking to conduct a specific support group just for people with this co-infection. We are also looking for people to train as facilitators to run these groups. So, if you are interested and would like more information please call Marcus at The Positive Living Centre on either (03) 9863 0444 (reception) or directly on (03) 9863 0424.

# Community Letters: The Scratching Post

**The Scratching Post is your connection to the community. You can write to us to share information or voice your opinion or concerns on issues that affect the HIV community.** Letters can be emailed to [poslink@plwhavictoria.org.au](mailto:poslink@plwhavictoria.org.au) or posted to 6 Clarement St, Sth Yarra 3141.

To the editors and writers of Poslink and to the Board of PLWHA,

Firstly a question, is it People Living with HIV/AIDS Victoria? **That is men and women Homosexual and heterosexual who are HIV positive?** Or is this organisation and Newsletter specific to Gay men who are HIV positive? Because if I didn't know better and I wasn't aware of what this organisation should stand for by community and government standards I would be erring on the view that it is an organisation and newsletter for gay men who are HIV positive.

As an HIV positive woman the last few Poslink, well no lets be honest here, most of the Poslink Newsletters are filled with articles for and about HIV positive Gay men. This upsets me because I hear people associated with PLWHA waxing lyrical in various speeches about being inclusive but I see **no demonstration of this**. Why is it that women who are positive have to kick and scream and make a lot of noise, even in their own positive community, to get any recognition?? Or even a bit more than a quarter of a page about pregnancy, which seems to be the only thing you think we are interested in?? And I'm sure it is difficult to find people who will write articles, but it's not difficult to find information on the www. about HIV positive women.

My last question is: Will you print this letter? And if you do will you belittle what I have said?

I will not put my name to this letter as I know that sometimes, voicing your opinion (especially

a possibly perceived negative one) can lead to nastiness.

For goodness sake, we appreciate and acknowledge everything that gay community has done in response to HIV/AIDS but we need to be valued and respected as human beings just as gay men who are HIV positive do!!

Thank you.  
A positive woman.

*Editor's reply: All feedback on Poslink and our advocacy work is welcomed at any time. So thank you for your feedback. Firstly I need to make sure that you are aware of the HIV organisation 'Positive Women' who provide services specifically for women with HIV including a newsletter. Their contact number is 03 9276 6918.*

*Your letter raises a number of issues for me. Yes we are PLWHA Victoria and yes we provide services and advocacy for all people in Victoria with HIV. Often our projects have a gay man's focus (but not always). And yes, you are right that not enough information is dedicated to women in Poslink. Consequently we would welcome any contributions you would like to make to the publication. If you are a member of PLWHA Victoria you are also able to be elected to the Board where you can have your say in how the organisation is run.*

*PLWHA Victoria will be running an event with Positive Women for positive women on 22 May. Our usual Treatment Interactive Events are for both men and women. We usually plan a female perspective. However we also have difficulty finding women who are prepared to volunteer as role players at the events (you are welcome to volunteer and work with us on this). The bulk of the information at these events is*

*mostly generic and generally applies to all PLWHAs. The same goes for much of the information that goes into Poslink. Unfortunately much of the clinical trial data is still mostly collected from men. However, when female specific information is provided in the data I always include this information in the articles. As you have referred specifically to the Women's Section not covering your needs I have decided to remove this section as most of the treatments section is for everyone, male or female.*

*We also provide a treatments information service. Please note that anyone can use this service who is HIV positive and yes, we do make sure that female-specific information is provided especially with regards to side-effects and reduced doses of some drugs (eg AZT).*

*When we go out to advocate to the government on housing and the disability support pension we make sure we cover all our members' needs. An example of this work is our advocacy for appropriate respite care where we always make sure the government is aware of the needs for women and children. At last year's National HIV Strategy consultation we were the only organisation to point out that children had not been included in the Strategy.*

*Many of our contributors are gay men and they will often write from their experience which may include mention of their sexuality. Regardless, you have made a good point. Thus I have arranged for Positive Women and Straight Arrows to contribute to Poslink. You will find their contributions in this issue.*

*I hope you see this as an appropriate response to your feedback and welcome your guidance in the future.*

# Shared Stories

Email your story to [poslink@plwhavictoria.org.au](mailto:poslink@plwhavictoria.org.au)

## The things I left behind

By Neville Braybrook

If one thing has become certain in my life it is that life is not broken up into parts. There are threads that connect one event to another and years down the track something comes up, a life event gets thought about (and felt) again and an insight is gained. The insight I am talking about particularly becomes useful in a broader sense – it can be shared and used in a way that may benefit others as well as me.

Recently I took part in a focus group that was aimed at researching the pre and post test counselling experiences of HIV positive people. I didn't realize until reflecting on the session just how significant an impact my diagnosis had on the destruction of the networks in my life and this also brought back memories of what it was like to feel alone in the strangest way possible immediately after leaving the clinic. Once the diagnosis was delivered, discussions had, information given and some counselling given I then found myself outside, alone and experiencing a profound loss of sense of future.

In reality what was immediately occurring was a destruction of my networks. By this I mean my connection with family, friends, work, interests, plans and ideas of my future. This is where I started to disconnect and "live in my mind rather than in my physical world", not that I was aware of this. Also significantly for me was the destruction of my view of the world and the society I lived in; everything was up for challenge and question, little retained its credibility.

The things I left behind during this phase of trying to understand my life in a whole new way are the very things I have been taking back these last few years.

- I dropped out of my studies - I am now studying again.
- I left my job - I am now working again.
- I lost my independence - I regained my independence
- I withdrew from my social world - I am becoming more social.
- I distanced myself from my family - I am reconnecting with my family.
- I stopped contributing to my community - I am reconnecting with my community.
- I stopped planning for the future - I now consider I have a future.

I have believed for some time that social isolation (disconnection from networks) is a major feature in the lives of

some positive people and my personal view of its onset for me is that very moment I walked out of the clinic and experienced that "strange and intense sense of aloneness in the world". An event that was more profound than I could have appreciated at the time.

The vital insight that has come from my reflection is that during any life changing event I should immediately look at what is valuable in my life and retain it, not leave it behind; being in shock was not a good place from which to make important decisions. The decisions I took all those years ago in isolation were my reaction and over-reaction. I hope my hindsight is useful to somebody else and I won't be arrogant and think that my experience is a complete template for others. We all have our individual circumstances but there are often common threads.

## ***POSitiveTALKing***

### **The workshop for HIV+ gay men**

**Tuesday 10 May 2005**

Do you want to share your experiences with other HIV positive guys in a confidential and safe environment? People Living with HIV/AIDS Victoria is running a new workshop called *POSitiveTALKing*. It will be a 2.5 hour session, once a week for 6-7 weeks. You'll have an opportunity to talk about feelings when diagnosed, self esteem, disclosure, sex and relationships. You'll also get heaps of info on general and sexual health, treatments, complimentary therapies and much more.

If you want to know more or if you wish to participate call Suzy Malhotra on (03) 9865 6756.

# Positive Women...

Positive Women (Vic.) Inc. have been invited to contribute to Poslink each issue, with articles focusing on HIV positive women. We will take this opportunity to highlight any issues that may arise for women living with HIV and update people on what we are doing and what events we are planning over at the Positive Women office. This first article will be short and sweet to start the ball rolling.

We have many events planned for 2005, my role as Support Worker at Positive Women is to not only offer Peer Support to our members but to create opportunities for women to meet in a social setting. Since the beginning of March we have been involved in a joint project with

Straight Arrows and an artist in residence at Fairfield House to create a fabulous mural on the fence of the driveway of Fairfield House. So far it has been a fantastic and fun experience for all. The first week of May will see us take our first brushstrokes to the fence, a daunting but exciting task. We welcome any Positive Women or Straight Arrows members to come along every Wednesday 11am – 4pm for the month of April. Come and join in and paint or just watch and have a cuppa. Once the mural is completed we will have a launch and **all** will be welcome. So watch out for the Launch date if you don't think you will be able to contribute to the painting.

Every Thursday at Positive Women we have a swimming support group that meets at St. Kilda Sea Baths to do laps and then relax and chat in the spa or hydrotherapy bath. A swift swim and a comfortable warm salt bath seem to be conducive to a great time to talk about things and catch up on the week's events. Once again if you are a positive woman you are most welcome to come along.

If there are any specific topics you wish to see discussed in Poslink pertaining to HIV positive women please contact me at the Positive Women office on 03 9276 6918 and we can plan an article for the following Poslink issue.

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## Straight Arrows...

In response to providing information to women with HIV, I have requested that Poslink reprint the section on Women Living with HIV from the AFAO publication *Treat Yourself Right*, published in 2000. As this women's section is quite large, it will be printed as a series of articles over the next few issues of Poslink.

Watch this space for updates.

Rebecca Matheson  
*Living positively for 10 Years*  
Executive Officer  
*Straight Arrows*

## Women Living with HIV

### Being an HIV positive woman

You may be reading this because you have recently learned that you are HIV positive or you may have known your diagnosis for some time, even many years. Either way, you probably feel you need to know more about HIV, how it can be managed and what treatments are available for women. If you have only recently been diagnosed, you may be feeling shocked, frightened, confused, angry or upset. These feelings are quite normal. Women diagnosed for many years can also have these feelings. It may help you to know that there are women from all over Australia and from all walks of life who are HIV positive. Positive women are from many different cultural and religious backgrounds, of all ages, sexualities, with and without children. Some women in Australia have been HIV positive for over twelve years yet remain well and

active. Nowadays, more and more women with HIV are living longer, enjoying healthy and fulfilling lives, working, studying, having relationships and children, and making their own choices about treatment.

### Getting information

Knowledge about HIV/AIDS and its management is increasing every year. New treatments are being trialed all the time, and there are now many drugs and therapies which have been shown to prevent, reduce or delay illness. This means that there has been a vast reduction in the number of people who are HIV positive who progress to AIDS. In fact, even without treatment, small numbers of people with HIV don't progress to AIDS-related disease. Now that relatively effective treatment is available, it's possible even after being diagnosed with an AIDS-defining illness, to

become completely symptom-free and even for the immune system to improve its functioning. Because there are so many benefits to be gained by managing your health, it is important that you start getting the right kind of information and support as soon as possible.

### **Support**

There are many people who can help you make decisions about the way that you manage living with HIV and AIDS. A list could include not only doctors and health professionals who have experience with HIV and AIDS, but also community organisations set up specifically to support HIV positive people. Other people living with HIV — especially other positive women — can be invaluable. It can help to hear how other women have dealt with issues such as relationships, sexuality, work, decisions about having children, telling people they are positive, treatment choices, and staying well. There are many free services, pamphlets and newsletters available from AIDS organisations and community health centres throughout Australia. Your state or territory AIDS council has a treatments officer who can give you information about treating and managing HIV. Most states also have support groups and organisations specifically for HIV positive women.

### **As a woman with HIV:**

- You have the right to take control over your own health and make your own decisions about how you live with HIV.
- You have the right to choose if and when you reveal your HIV status, or to keep your diagnosis confidential.
- You have the right to choose which treatments or therapies you use.
- You also have the right to refuse any treatments or therapies with

which you do not feel comfortable.

- You have the right to a full and active sex life.
- You have the right to have children.
- You have the right to work, or make changes to the way you work.
- You have the right to high quality health care, support and counselling in an environment which is supportive, sensitive and free from discrimination.

### **Does HIV affect women differently?**

There is very little scientific research specifically about women with HIV/AIDS, although this is changing. But there is no convincing evidence that HIV is clinically worse for women than men. There are large numbers of women living with HIV and AIDS throughout the world, and many share similar symptoms and experiences. The experiences of HIV positive women and their doctors provide a great deal of valuable information about the ways in which HIV affects women's bodies and women's lives. Some studies suggest that HIV may affect women differently, possibly causing greater damage to the immune system at an earlier stage. Although other studies have not reached the same conclusions, you may have concerns about this research, or wish to discuss it with your doctor. There is some evidence to show that HIV does affect women differently in some respects. This may be due to physical, social or psychological differences. HIV may affect:

- hormones;
- body weight and shape;
- your reproductive system;
- menstruation and menopause;

- your lifestyle and social circumstances.

### **Do women respond differently to HIV?**

In general, women's lives differ from those of men in a number of ways. Women are often the primary carers for others in their lives, often juggling these responsibilities with paid work. Therefore it is not surprising that while there are many issues facing both positive women and positive men, there are also some fundamental differences in their responses to HIV. A recent survey of some Australian HIV positive women suggested that women's experience of HIV may differ to that of men. The research found that:

- women are less likely than men to be taking antiviral or prophylactic (preventative) treatments for HIV (though two-thirds of the women surveyed were taking combination therapy);
- women are more likely to be in monogamous relationships than positive men;
- one in three HIV positive women is caring for an HIV positive partner or child, and half the women surveyed had dependent children.

Most of the women surveyed were heterosexual, although there were a small number of lesbians and bisexual women.

### **What you are entitled to as a positive woman**

While women remain a minority of people infected with HIV in Australia, as a positive woman, you are entitled to the same level of access to high quality information, clinical services and support as are positive men. AIDS councils and PLWHA groups are becoming increasingly sensitive to the needs of women. If you believe that you have received a lesser standard of service, you are entitled to make a complaint.



# Treatments Update: what's new, what's changed

## Report on the 12<sup>th</sup> Conference on Retroviruses and Opportunistic Infections

### Tenofovir works for Hepatitis B

52 people with HIV and hepatitis B (HBV) were randomised to receive either tenofovir or the anti-HBV drug adefovir. Results showed that tenofovir was at least as good at reducing HBV viral loads as adefovir. *[Editor's note: People with HBV who are taking tenofovir should not stop taking tenofovir without first consulting their doctor. Stopping tenofovir could result in dangerous liver inflammation due to a sudden increase in HBV replication.]*

### TMC 114: a pleasant surprise

In a dose ranging study of 397 people, the new protease inhibitor TMC 114 has shown some remarkable results in patients with drug resistance. At 24 weeks the highest dose of 600mg with 100mg ritonavir twice daily resulted in a drop of 1.85 log and a CD4 increase of 75 cells compared to a drop of only 0.27 log and an increase of 15 CD4 cells in the control arm which used other protease inhibitors. 47% of people on the high dose achieved an undetectable viral load (<50 copies/ml) and 72% had at least a 1 log drop. Phase III studies will now proceed with the higher dose. *[Editor's note: There is a lot of excitement about TMC 114. It has been specifically designed to attach to the HIV protease enzyme in a number of different places which is what makes this drug different to all the others.]*

### New drug specific to Hepatitis B

The drugs that are currently recognised for treating Hepatitis B (HBV) all have activity against HIV as well (3TC, tenofovir and adefovir). This often results in people with HIV having to go onto a full anti-HIV combination when they may only want to treat their HBV to prevent HIV developing resistance to the single HBV (and HIV) drug. Entecavir is a new anti-HBV drug that has now been tested in people with HIV and HBV coinfection. Results in 68 people taking either entecavir or placebo have shown that it effectively reduced the HBV viral load while not having any effect against HIV.

### Heart attack risk

The ongoing Data Collection on Adverse Events of Anti-HIV Drugs (D:A:D) study on 23,441 people were presented on the risk of heart attack. The latest results show an increased risk for a heart attack as 17% for each year a person is taking antiviral therapy. This has been reduced from 23% in the previous analysis of the data. In general the overall number of people who had a heart attack was 277. Other risk factors were also identified such as smoking, elevated blood fats (lipids) and lipodystrophy. *[Editor's note: Because of this study it is recommended that people with HIV not smoke. If you want to stop smoking you can call the Quit line on 131 848.]*

### New NNRTI: TMC 278

A dose ranging study of TMC 278 was presented. TMC 278 is a new non-nucleoside reverse transcriptase inhibitor (NNRTI) like nevirapine. Unlike other NNRTIs it is thought the virus will find it difficult to develop resistance to it and it may work in people who already have resistance to the current NNRTI drugs. The study was done in 47 people for 7 days with doses ranging from 25mg to 150mg. Results showed that the viral load was reduced by around 1 to 1.3 log in all groups. No serious side-effects were reported. *[Editor's note: Up until now resistance to an NNRTI has meant that this entire class of drug can no longer be used due to cross resistance between the agents. TMC 278 may very well change this paradigm and give people access to this type of drug again. Time will tell.]*

### Maturation inhibitor

There have been some previous reports about a new type of drug called a maturation inhibitor. Data was presented on how this drug inhibits HIV. HIV proteins are produced in one long strand inside infected cells but are cut up into small functional units by the protease enzyme. The maturation inhibitor, PA-457, provides a link between the different protein units so they can't be separated by the protease enzyme. Thus, the virus can't replicate if there are no functional small protein units being produced. A single dose ranging study where PA-457 was taken for one day only in 24 men has shown that the drug is highly potent. Viral load

# Treatments Update: what's new, what's changed

was reduced by around 0.5 log and the effect lasted for up to nine days. *[Editor's note: A 0.5 log reduction in virus is quite remarkable for a one-off dose. What is more remarkable is that this drug continues to be active for up to nine days which is a reflection of the long half life of the drug of around 2-3 days.]*

## **Atazanavir levels**

An Italian group investigated the levels of atazanavir in the blood to see whether a correlation could be found for efficacy and hyperbilirubinemia (yellowing of the skin). The investigators found that atazanavir worked well when the levels were above 150ng/ml but that (unconjugated) bilirubin significantly increased when these levels were above 850ng/ml. The investigators concluded that the ideal range for atazanavir was between 150 and 850ng/ml.

## **Fish oil reduces triglycerides**

A French study of 122 people on antiviral therapy has shown that taking Maxepa fish oil capsules (2 x 1g capsules 3 times a day) was able to reduce triglyceride levels by 26% compared to a 1% increase for those on placebo.

## **In The News**

### **Get ready to say goodbye to some older HIV drugs**

Roche Products have advised they will be withdrawing two HIV drugs from the pharmaceutical market in 2006. The two drugs to be removed from the market are ddC and Fortovase. There are many reasons why a drug needs to be withdrawn from a market but the primary reason is when it becomes no longer viable financially to produce the drug and when (better) alternatives are available.

ddC or Hivid was the 3<sup>rd</sup> approved agent for treating HIV in the early 90s. It has been an unpopular drug for quite a while due to its high association with peripheral neuropathy (pain, numbness or tingling in the limbs) and also because it has to be taken three times a day. Roche have advised that only 10 people are currently using this drug in Australia. The product is expected to be withdrawn from the market in late 2006. There are a number of new agents that people will be able to use instead of ddC when the time to change comes around e.g. 3TC, abacavir, tenofovir or ddI.

Fortovase (saquinavir-sgc) was introduced as a better absorbed version of Invirase (saquinavir-hgc) in the late 90s. Invirase was poorly absorbed into the body and needed to be taken 3 times a day with a large number of pills. Fortovase was developed before the introduction of ritonavir as a boosting agent for increasing protease inhibitor levels in the body. We now know that protease inhibitors work best when taken with ritonavir. Due to differences in side-effect

profiles between the two drugs, the best form of saquinavir to use with ritonavir is Invirase. Roche have developed a more convenient formulation of Invirase in the form of 500mg tablets which will be dosed as only 2 pills twice a day when taken with 1 capsule (100mg) of ritonavir twice a day. As the demand for Fortovase will become greatly reduced, Roche has decided to withdraw this product in mid-2006, but they will only withdraw the product once all patients have access to the new 500mg Invirase tablets.

In anticipation of any concerns regarding the withdrawal of these products, Roche have set up a special advisory board to provide guidance to the company. This will help Roche to identify support systems that may be required to help people through the transitional stages when the treatment change will take place. Roche have advised they remain committed to the area of HIV. They will continue to supply Invirase, T-20 and nelfinavir and remain committed to developing new HIV compounds through their ongoing research programs. *[Editor's note: The idea of changing a drug when someone has been on it for some time can be quite scary. Roche have a good track record of providing excellent support to the HIV community. I have every confidence that Roche will make this transition for people on these products as easy as possible given the circumstances. If you are taking either of these drugs, you have over a year to prepare for the change. If you have any concerns please call me on 9865 6718. Alan]*

# Treatments Update: what's new, what's changed

## **Tipranavir access**

Tipranavir is a new protease inhibitor that works well against resistant virus. This new agent is not yet approved in Australia but has been made available by Boehringer Ingelheim on compassionate grounds to people who have virus resistant to protease inhibitors with a CD4 count less than 150.

## **FTC now available**

FTC is a new (nucleoside analogue) HIV drug that is very similar to 3TC. One of the benefits of FTC over 3TC is that it hangs around inside cells where it inhibits the virus much longer than 3TC (half life = 39 hours). This means that FTC is 'more forgiving' when it comes to late or missed doses, making it more difficult for the virus to develop resistance to it. This drug is now available in HIV pharmacies. If you are the type of person who is late with doses or misses doses, you may want to talk with your doctor to see whether you would benefit from this drug.

## **Long term efavirenz side-effects**

A study conducted in Spain and the Netherlands has shown that central nervous system (CNS) side effects from efavirenz can persist for up to two years after commencing therapy. The study was conducted in 120 people who were taking either efavirenz or a protease inhibitor as part of a combination therapy. Results showed that 57% of people on efavirenz reported at least one CNS side effect such as dizziness, sadness, mood changes, irritability, lightheadedness, nervousness, poor concentration, disturbed dreams and sleepiness for up to two

years compared to 27% in people taking protease inhibitors. Investigators advised there were no significant differences in the amount of efavirenz in the blood between people with side-effects and those without side-effects who were taking efavirenz indicating that the side-effects are not related to increased exposure to efavirenz. It was concluded that, although persistent, the side-effects were considered to be mild and clinically tolerable.

## **Drug holiday update**

Results from a study in Sweden and Italy have shown that people who started treatment when their CD4 count was between 250 and 350 can stop HIV therapy for up to 61 weeks. All patients in the study had a CD4 count greater than 500 when they stopped treatment and commenced treatment again either by choice or when their CD4 count fell to 350. *[Editor's note: I am a great believer in people starting treatment in a way that allows them the option of taking structured treatment interruptions (drug holidays) in the future. This study clearly shows that starting treatment a little early allows for people to plan for drug holidays. Deciding when and how to take a drug holiday should always be done in consultation with your doctor or treatments officer to reduce the risk of resistance developing to the HIV drugs.]*

## **Kaletra maintenance therapy**

A pilot study of six people in Miami was conducted to see whether it is possible to use the potent protease inhibitor Kaletra as a monotherapy maintenance treatment following six months of triple combination therapy. All

patients took Combivir (ATZ+3TC) and Kaletra for six months and then switched to Kaletra alone for six months. Six months after switching to Kaletra monotherapy, four patients continued to have virus below 1000 copies/ml. The fifth and sixth patients were identified as not being adherent to medication and one of them reached an undetectable viral load upon commencement of taking the Kaletra according to the doctor's instructions. The sixth patient continued to have detectable virus. The investigators acknowledged that these results need to be confirmed in studies with more people. *[Editor's note: We moved away from monotherapy back in the mid 90s because it simply didn't work. But back then we didn't have potent drugs like Kaletra. Taking only one drug reduces side-effects and the cost of the drugs. In this study there were a considerable number of viral 'blips' above 50 copies/ml (undetectable). It will be interesting to see how well monotherapy with Kaletra works over a 2-3 year period in studies with 200-300 people.]*

## **Genetic testing to avoid side-effects**

Genetic testing on people in the HIV Swiss Cohort has indicated there may be a link between different genes and the increased production of triglycerides (fats in the blood) when people take the protease inhibitor boosting drug ritonavir. The genetic pattern associated with the increased rise in triglycerides was found in one out of every 6 patients.

# Treatments Update: what's new, what's changed

## **Alendronate can increase bone density**

People with HIV can experience loss of bone density known as osteopenia or osteoporosis. It is thought that the loss of bone density may be a complication of HIV infection. A study at the Washington University recruited 31 (13% women) HIV positive people who were randomised to receive or not receive 70mg alendronate each week for 48 weeks plus daily vitamin D (400 IU) and calcium (1000mg). Alendronate is a recognised treatment for osteoporosis or osteopenia but its use in people with HIV had not yet been investigated. After 48 weeks, the alendronate group had shown an increase of 5.2% in spinal bone density compared to 1.3% in people who did not take alendronate.

## **Depression and adherence**

A study in Colorado looked into antiviral adherence rates and the effect of treating depression in 1713 people with HIV at an urban clinic in Denver between 1997 and 2001. Of the 1713 people attending the clinic, 976 people were identified as depressed and were entered into the study. 450 people received antidepressant drugs, 507 were receiving antiviral therapy and 375 were receiving both antidepressant and antiviral therapy. Adherence was estimated by prescription refills at the pharmacy. The investigators found that adherence was higher in people taking antidepressants (65% vs 35% [for >72% adherence of pills]). Antiviral adherence was higher still in people who were adherent to their antidepressant (69% vs 31%). The investigators stressed the importance of regular

monitoring for depression, treating with antidepressants where required and checking adherence to medications.

## **ddI + tenofovir warning**

The European Agency for the Evaluation of Medicinal Products (EMA) has issued a statement to doctors in Europe warning against the use of combining ddI with tenofovir. The release follows poor results from a number of studies in antiviral naïve patients and drug interaction data. Please keep in mind that some people still need to use this combination where necessary. The following is a direct quote from the EMA press release:<sup>1</sup>

- "The co-administration of tenofovir disoproxil fumarate and didanosine [ddI] is not recommended within any antiretroviral combination therapy, and particularly in patients with high viral load and low CD4 cell count.
- Rare, sometimes fatal, cases of pancreatitis and lactic acidosis have been reported with the coadministration of tenofovir and didanosine.
- If this combination is considered to be strictly necessary, patients should be closely monitored for efficacy and didanosine-related adverse events."

In Australia both Bristol-Myers Squibb and Gilead who manufacture the drugs have provided doctors with an update on data available on the combination of ddI and tenofovir. Both companies have been in communication with the Australian Therapeutic Goods Administration that has resulted in a slightly different warning to doctors in Australia who may

need to prescribe the products together:<sup>2</sup>

"... clinicians should use caution when co-administering tenofovir DF and didanosine due to toxicity concerns. Additionally, due to the reported potential for virologic failure, caution should be used when co-administering tenofovir DF and didanosine in combination with either efavirenz or nevirapine in treatment-naïve HIV patients with high baseline viral loads."

*[Editor's note: The EMA release extrapolates data on ddI+tenofovir from treatment naïve groups on specific combinations to all PLWHA groups regardless of antiviral combinations. The Australian response is much more specific to the data that is available. There are some situations where using ddI with tenofovir may be appropriate, especially where there are limited options for using other drugs.]*

1 <http://www.emea.eu.int/pdfs/human/press/pus/6233105en.pdf>

2 Gilead Sciences (Australia)

## **Nevirapine toxicity increases with low BMI**

In a small study of 66 men and women taking nevirapine or efavirenz, people with a low body mass index (a calculation of height proportional to weight) were more likely to experience liver toxicity from nevirapine. No liver toxicity was reported in people taking efavirenz. Women with a BMI below 18.5 had a 50% chance of developing severe liver toxicity compared to 17% with a BMI more than 18.5. For men the probability of severe liver toxicity was 17% for a BMI < 18.5 or 7% if the BMI was greater than 18.5.



**Planet Positive**  
MELBOURNE

## An Evening for Positive People & their Friends

**Wednesday 18 May**  
**From 7.30pm till late**

**Vibe Cafe and Bar**  
**123 Smith Street**  
**Fitzroy**

NO COVER CHARGE

Light catering provided

First drink free

[planetpositive@optusnet.com.au](mailto:planetpositive@optusnet.com.au)

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### Acknowledgement

PLWHA Victoria would like to thank our sponsors for providing unrestricted educational grants to fund Poslink and Treatment Interactive Events in 2005.



### Membership application

*All details contained herein will be treated strictly confidentially.*

I wish to become a member of People Living With HIV/AIDS Victoria and to receive all privileges of said membership. I agree to abide by the Rules\* of the organisation at all times. I give permission to receive information from PLWHA Victoria.

Please tick  **Full Membership:** I am HIV positive and am able to provide verification of this if required.

**Associate Membership:** I do not wish to disclose my HIV status, I am HIV negative or I do not know my HIV status.

Signed \_\_\_\_\_ Name \_\_\_\_\_

Address \_\_\_\_\_ Postcode \_\_\_\_\_

Telephone (optional) \_\_\_\_\_ E-mail address (optional) \_\_\_\_\_

Please fax or post your membership application to: PLWHA Victoria

6 Claremont Street  
South Yarra VIC 3142  
Tel: 03 9865 6772  
Fax: 03 9804 7978

\*Copies of the Rules of the organisation are available from the PLWHA Victoria office.

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