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POSLINK

The Newsletter of People Living With HIV/AIDS Victoria

Issue 18 Aug / Sept + 2004

Inside this issue:

A Pirate Flagship from People Living With HIV/AIDS Victoria

By Guy Kharn

People Living With HIV/AIDS Victoria launched a ship with a difference on Thursday, 29 July. Deputy Premier John Thwaites, launched the vessel — a garden in the shape of a pirate ship—in the grounds of the Veg Out community garden in Shakespeare Grove, St Kilda.

The initiative, known as "Positive Plots", has been developed to enable five HIV positive people in the City of Port Phillip to garden with others in a safe, friendly, communal public space.

In keeping with the location and its affinity with the sea, the plot is designed as a mythical pirate ship, complete with masts and rigging. The design accommodates those with disabilities by offering three different garden bed levels and incorporates a handy work-bench and seat at the rear of the pirate ship.

Participation in the project will be free to the successful applicants and Veg Out has generously offered to provide complimentary seedlings to plant in the plot.

The President of PLWHA Victoria, Mr John Daye said, "Because of advances in treatment, general health and energy levels in many HIV positive people have improved considerably.

"As a result, many HIV positive people are now looking for new ways to get out of the

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Note from the Executive Officer

Mark Thompson

One of the less obvious services that People Living With HIV/AIDS Victoria provides its members is advocacy. In this column I would like to outline some of the ways in which People Living With HIV/AIDS Victoria advocates for its members and the wider HIV community and how we can help you with individual cases.

One major way that we perform this work is to act as a representative on committees and working groups when requested by organisations and governments; or sometimes, we ask to be a representative. As the peak organisation representing HIV positive people in the state, the government looks to PWLHA Vic to provide leadership and policy advice, so we are represented on committees such as the Ministerial Advisory Committee on HIV, Hepatitis C and Sexually Transmitted Infections, the Attorney General's Advisory Committee on Gay and Lesbian Issues and others. We are represented on advisory committees at major hospitals and health services and have members on the boards and committees of other sector organisations such as the Victorian AIDS Council, AIDS Housing Action Group and In Home Support.

PLWHA Victoria advocates nationally as well through its representation with the National Association of People Living with HIV/AIDS. We have two representatives on its board, plus David Menadue is Vice President and John Daye is the National Treatments Convenor. Through these roles PLWHA Victoria is able to contribute to policy on a national level and have input into national treatments and information campaigns.

We also advocate on behalf of members on personal issues. These may range from housing problems, discrimination, dealing with Centrelink and service issues at hospitals or other health and support services.

One of the important principles that we operate under is that of self-advocacy. When a person contacts us for assistance, we work with them to identify the issues and agree on a course of action. Usually, we can connect then with the services they want or need, or make a telephone call on their behalf seeking further information. For a more complex matter, we will advise them about different options they may take to resolve the issue. Often we will help the person write a letter or identify the department or agency who should be contacted.

However, if the problem has become intractable and we are requested to do so, then PLWHA Victoria will intercede on a client's behalf and actively advocate their issue.

At PLWHA Victoria, we always approach individual advocacy with the belief that the best result is the result achieved by the individual. It is only when all other avenues are closed that we will intervene actively in a case as an organisation.

It is important for us that members gain skills and experience in their own advocacy, and we work to help that process so that you are better equipped to advocate on your own behalf in the future.

Note from the President

John Daye

Since my last report, there have been a number of new developments in different areas. Our concerns about the Free Trade Agreement with the USA and its impact on the Pharmaceutical Benefits Scheme have been reflected in other parts of the community. I have provided an update below. The International AIDS Conference happens each two years and has just occurred in Bangkok. Comprehensive reports on this conference, and on my recent visit to Geneva which focused on treatment preparedness and treatments literacy, are also included in this issue. Our advocacy work around depression is beginning to achieve results and I have included some good news on this front. Finally, we are beginning to see some movement at last on the development of the 5th National HIV/AIDS Strategy with a first draft due to be released in the next couple of weeks.

Pharmaceutical Benefits Scheme and the Free Trade Agreement

PLWHA groups in Australia, including PLWHA Victoria, have been raising concerns about protecting the PBS since news of the FTA negotiations began to emerge more than twelve months ago. For people living with HIV/AIDS, as for many other Australians living with complex medical conditions, access to affordable medicines is a fundamental part of maintaining their health and wellbeing.

As John Howard revealed in an interview on Radio 3AW in July this year, the US believed that Australia was paying too little for American medicine. The Prime Minister revealed that when President George W Bush came to Australia in October last year, drug pricing was the one part of the FTA that George Bush discussed with him. John Howard said then, and has maintained since, that changes to the PBS were not negotiable.

At the core of Australia's PBS approval system is a process called 'reference pricing' which essentially means that the PBS will not subsidise higher prices unless the drug companies can provide hard evidence of a real improvement in outcomes. This system is very unpopular with the international pharmaceutical industry because it means that if a new drug does not offer more benefits, then it is priced at the same level as the cheapest drug in the same class. Many commentators believe that the US drug company lobbying around the FTA was designed to bring about changes to this system.

These issues were canvassed in a comprehensive way in the *4 Corners* program "A Bitter Pill?" which was broadcast on 2 August 2004. (A full transcript of the program is available online by going to http://www.abc.net.au/4corners/archive.htm and then choosing the 2 August 2004 link.)

In that program, Gerard Anderson, Professor of Health Policy at John Hopkins University in the US explained why this pressure was coming from the US FTA negotiators: "... because there's a lot of money coming in from the pharmaceutical industry into Congress and they are very interested in making sure that those contributions continue."

Interestingly, at least fifteen State governments in the US are considering introducing schemes similar to the PBS "reference pricing" model for buying publicly subsided drugs and this is causing some nervousness amongst the drug companies.

While some of the drug company supporters in Congress have claimed that there is no such thing as a free lunch and somebody has to pay for research and development for new drugs, Australia has made a major contribution to research on HIV drugs for example. Clinical research undertaken in Australia using HIV positive participants has provided some of the best research in the world about HIV medicines.

At the time of writing this report, the FTA amendment tabled by Mark Latham to prevent misguided patent applications being lodged to delay cheaper generic drugs was still being considered by the government.

However, it seems clear that the FTA will now be approved by the Parliament after some government/opposition haggling about some fine detail. PLWHA organisations remain concerned about other aspects of the FTA arrangements, in particular how the review mechanisms will work when a drug is denied listing on the PBS.

It is disappointing that on the eve of the FTA being approved, people living with HIV/AIDS are still concerned that aspects of the Agreement remain ambiguous and that there is still no clarity and certainty about the long-term

continuation of affordable medications for HIV positive people.

***Beyond Blue* depression study**
PLWHA Victoria has advocated for better research into depression amongst HIV positive people for several years now. We were delighted to learn recently that Victorian HIV Service and the Department of Psychiatry at The Alfred were successful in securing funding from *Beyond Blue* to fund research into depression in HIV positive people. This project will be conducted over three years with Associate Professor Anne Mijch as the principal investigator.

Australian Doctors Orchestra
On Sunday 12 September at 2.30pm, the Australian Doctors Orchestra will be playing a benefit concert for the David Williams Fund at Melbourne Town Hall. The orchestra is made up of 150 GPs. Dr Kate Cherry, who will be known to many of you, is the Treasurer of the Orchestra and suggested the David Williams Fund as this year's recipient. Tell people about this concert and encourage them to come along, the funds are solely needed through the David Williams Fund for HIV positive people who are experiencing poverty. Tickets are available from VAC/ GMHC at 6 Claremont Street, South Yarra 9865 6700 and from Readings Books and Music in Lygon Street at Carlton.

Planet Positive
The next Planet Positive is on Sunday 15 August at 1.00pm at Vibe Cafe Bar in Smith Street Collingwood. Come along and make some new friends, its great fun!

Meet the Board
Our AGM is coming up soon. If you are interested in standing for the People Living With HIV/ AIDS Victoria Board and would like more information about what being a board member entails and have the opportunity to meet existing board members, you are invited to our "Meet the Board" event on Friday 17 September 2004 at 6.30 pm at the Peter Knight Centre, 6 Claremont Street South Yarra. Please call 9865 6771 by Wednesday 15 September to let us know you are attending for catering purposes.

People with Living HIV/AIDS VIC

ADVANCE NOTICE

Annual General Meeting

Members of

People Living With HIV/AIDS Victoria

are invited to the

2004 Annual General Meeting

1.30 pm Sunday 17 October 2004

Vibe On Smith Cafe Bar, 123 Smith St
Fitzroy 3065

Business to be conducted includes election of board members, presentation of Annual Awards and acceptance of reports and financial statements.

What's Up, News and Information

PLWHA Victoria meets with MSHC over Deca

PLWHA Victoria met with Prof. Kit Fairley, Director of the Melbourne Sexual Health Clinic (MSHC), on July 21 to discuss issues around the new restrictive guidelines to Deca Durabolin that have been put in place at the clinic. During the discussions it was stressed to Prof. Fairley how Deca Durabolin greatly improves the quality of life for people affected by the virus and the HIV medications. Prof. Fairley was presented with PLWHA Victoria's policy paper on Deca Durabolin that contains a literature review of Deca along with suggestions for a set of guidelines the organisation considers would be more appropriate for Deca Durabolin use in the era of highly effective antiviral therapy. Prof. Fairley listened to all of the concerns put forward by the organisation and has committed to MSHC doing further research into the literature to re-assess the clinic's understanding on the uses of the steroid in the HIV population. PLWHA Victoria and the MSHC have agreed to work closely with each other in order to open up lines of communication. This will ensure that positive people receive representation at one of Melbourne's largest HIV clinics. Over the coming months, representatives from PLWHA Victoria will meet with MSHC doctors to discuss the benefit of the treatment and to address concerns doctors may have around prescribing of the drug.

While the restrictions remain in place for access to Deca Durabolin it is important to remember that the MSHC and attending doctors provide an excellent service to our community. Prof Fairley advised, "Melbourne Sexual Health Centre is committed to providing the very highest quality of care for the people living with HIV. The centre has made savings in other areas to increase the amount of nursing time available in the referral clinic and instituted a number of important programs. These programs have contributed to rising rates of adherence to antiretroviral treatment and seen a progressive rise in the proportion of individuals with undetectable viral load. We have also put resources aside to facilitate screening for STI's and are embarking on a number of projects to improve the quality of care at the centre, particularly related to the risk of cardiovascular disease."

Copies of the Deca Durabolin policy paper are available from PLWHA Victoria on 03 9865 6718.

Warrnambool set for HIV healthcare

In July PLWHA Victoria's Treatments Officer, Alan Strum, visited Warrnambool to present at the 2004 Blood Borne Viruses Forum organised by Jeffrey Robertson at Breaking The Chains. The forum was a major success for the region with presentations also provided from Straight Arrows, Positive Women, a local HIV doctor and the Hepatitis C Council.

Whilst in Warrnambool, Alan provided information about HIV drugs to pharmacists at the local hospital where they agreed to set up a streamlined, fully confidential system for HIV positive people in the region to access their HIV drugs. The local HIV GP, Dr David Richards, has attended the HIV Prescribers' Course and will soon be able to write HIV prescriptions for positive people living in the area. This will mean that people will be able to have their general health care needs taken care of locally by Dr Richards, which will reduce the costs and time involved for those who currently travel to Melbourne for their health care. Once Dr Richards receives his licence to prescribe the HIV drugs, he will be able to fax HIV prescriptions to the pharmacy at South West Healthcare. Patients can then call the Director of Pharmacy, Brian Dillon, on the next day to enquire when their drugs will arrive at the pharmacy and to make an appointment to see him in private. This will ensure that HIV positive people attending the pharmacy can do so in total privacy without fear of disclosure of their HIV status.

People who choose to access their antivirals in Warrnambool need to be aware that the HIV drugs will take up to five days to arrive at the pharmacy, and factor this into their adherence schedules.

Dr Richards is available for appointments at the Western Region Alcohol and Drug Centre Inc (The WRAD Centre), 26 Fairy Street, Warrnambool on 5560 3222 or at the Blood Borne Virus Clinic based at the Southwest Healthcare (Warrnambool Hospital) c/- The WRAD Centre at the above number.

What's Up, News and Information

Grant assistance scheme

The Dept of Human Services is offering a grant assistance scheme. The 'Utility Relief Grant Scheme" provides once-off assistance for domestic customers who are unable to pay their utility bills due to a temporary financial crisis. It is available for electricity, gas and water bills. People wishing to apply should contact their gas, electric or water company to obtain an application form. To qualify, the applicant will need to show that unexpected hardship [eg influx of medical bills] has left them seriously short of money. They will also need to hold a Pension Concession Card or a Health Care Card. For further info contact DHS on freecall 1800 658 521 or (03) 9616 7600.

Gene Therapy trial closed at the Alfred

The Gene Therapy trial using stem cell and ribozyme technology will no longer be recruiting at the Alfred Hospital. The study has recruited so well in Sydney, the company running the study, Johnson and Johnson, has been left with no choice but to pull back on clinical trial sites due to logistical issues associated with the high technical skills required for the study. This has resulted in access to the study closing at the Alfred. 'Interest from the local HIV community was so high that we will be pursuing access to future studies for this treatment,' A/Prof. Hoy said, 'I would like to thank everyone for their positive and enthusiastic support for this study.'

Bush administration muzzles US scientists

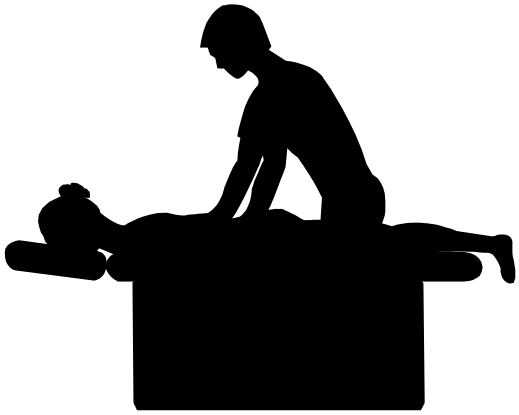
In the USA, Scientists working for the Health and Human Services Department (HHS) were recently outraged when most of them were refused travel funds to attend the International AIDS Society Conference held in Bangkok in July. This resulted in 40 presentations being withdrawn from the conference and the international community. Now it has been revealed that HHS has implemented a new policy disallowing the World Health Organisation from contacting any scientists in the US department without permission. Where permission is sought, a political appointee will only select specific scientists they deem appropriate to answer the WHO enquiry. This new policy gives the Bush administration political control over scientists and scientific information required by the multiple organisations on international health matters. The administration will now be able to refuse information to experts whenever it wants to stall international progress on controversial topics.

Free Massages donated to PLWHA Victoria

Stephen Fawcett, a doctor of Chinese Medicine who studied at RMIT and Nanjing in China has generously provided PLWHA Victoria with 25 free massage vouchers for our members. Stephen has been treating HIV/AIDS for sometime with Chinese herbal medicine. 8 of the vouchers were given away at our recent Treatment Interactive Event, *Extreme Makeover*. Another 8 will be given away at Planet Positive on 15 August. And the remaining 9 will be available to the first people who can contact PLWHA Victoria on 03 9865 6772.

Massages are valid only until 3/11/04 and can only be done on Wednesdays. Stephen practices at 195 Lennox street, Richmond: Tel: 03 9421 3303.

Stephen Fawcett: Melbourne Chinese Medicine Registration Board of Victoria registration number AH/0367.



International Treatment Preparedness(ITP): The Geneva Meeting

by John Daye
Health and Treatments Portfolio Convenor
National Association of People Living with HIV/AIDS

Background

A coalition of HIV positive people, supporters and treatment advocates united together at the 13th International AIDS Conference 4 years ago in Durban, South Africa calling for wide-scale access to anti-retrovirals. They protested about the lack of progress to access these life-saving drugs in the low-income nations of the world. It was a very defining moment in treatment activism because HIV positive advocates themselves decided that if they didn't take the lead and become central to drug access, millions more would die while the world continued to drag its feet.

Out of those protests, a movement was formed last year that brought together close to 125 treatment advocates from 67 nations for a meeting in Cape Town, South Africa called the International Treatment Preparedness Summit. The summit did not set up a formal organisation but established a coalition of activists to share ideas, plan and develop ways to scale up access to treatment and treatment literacy.

Geneva

Since that meeting, 29 treatment advocates met in San Francisco in February this year focused on international drug pricing. More recently ITP Treatment Activists met in Geneva in June. The Geneva meeting in June brought together 19 Treatment Activists, representatives and personnel from WHO, UNAIDS, The World Bank and the Collaborative Fund.

ITP Treatment Activists had 3 main objectives at this meeting.

1. Immediate assistance from UNAIDS, WHO, the World Bank and other UN agencies to develop specific country, sub-regional plans for comm-unity involvement in scale-up of AIDS treatment, which could be the templates for funding from the Global Fund to Fight AIDS, TB and Malaria or the World Bank and to identify major obstacles and needs to be addressed to support the community's work;
2. Support from the same agencies to work with us to sponsor a 2nd International Treatment Preparedness Summit where we can discuss the country and regional plans with partners and funders to plan implementation;
3. Financial support for treatment preparedness for communities through the Collaborative Fund for HIV Treatment Preparedness.

The meeting in Geneva was successful; it secured $1 million to begin regional and sub-regional treatment preparedness initiatives. Peter Piot, the head of the United Nations Joint Programme on HIV/AIDS attended a meeting with us to hear our concerns and planned strategies to mobilise treatment preparedness and the scale-up of AIDS treatment.

At this meeting it was made clear to the UN agencies that their strongest partner in the 3 X 5 Strategy (Treat 3 million by 2005) is the community—our lives are at stake—and they cannot succeed without our support and involvement in the scale-up of HIV/AIDS treatment.

The treatment advocates agreed to:

1. Providing an independent and critical voice as a scale-up of AIDS treatment rolls out—we will be the watchdogs to provide accountability and oversight of a scale-up on international, regional and country levels;
2. Identify and mobilise communities who are already working on or plan to work on treatment scale-up and treatment preparedness issues;
3. Properly document the community's expertise, experience, successes and needs for continuing and scaling up its work;
4. Sponsoring workshops to set regional priorities for treatment preparedness in Caribbean, South East Asia, South Asia and Africa;
5. Sponsoring the Second International Treatment Preparedness summit;
6. Training others and sharing our experiences, knowledge and successes in the provision of treatment, treatment literacy, mobilising communities and the other components of scale-up of treatment.

At our most recent meeting in Bangkok of ITP members Australians including John Rock (International Portfolio Convenor, NAPWA), Robert Baldwin (Regional Program Adviser, Asia Pacific HIV/AIDS Program) and myself it was decided that we needed to develop a clearer governance structure and guiding set of principles, that work is being undertaken now.

ACKNOWLEDGEMENTS
My attendance at the International Treatment Preparedness Meeting in Geneva was made possible through funding by the World Health Organisation

WHO'S GETTING ON, THEN?

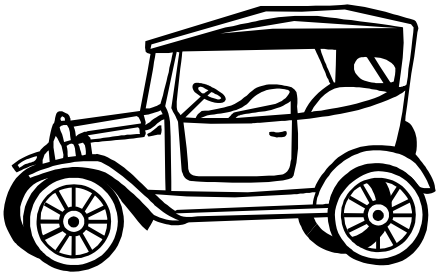
By David Menadue

Who would have thought that I would be here, in 2004, writing an article about getting old with HIV? To be told in the late eighties that I had two to three years to live after my first AIDS-defining illness and to be now contemplating the possibility of old age: it's all a bit weird, giving me a bitter-sweet feeling of having survived a difficult time but having lost so many good friends to the virus along the way. And to now be thinking about whether HIV may add its own complications to the process of getting older.

A sizeable percentage of people with HIV are in their fifties and sixties (HIV Futures 3 suggests it is at least 10%) and are probably encountering some of the usual effects of ageing. Heart disease, osteoporosis, arthritis and Type 2 diabetes are some of the illnesses which might start to affect people later in life, depending on their risk factors, but we also know that our HAART combinations can make these conditions more likely for us, anyway.

Less Sugar and Saturated Fat!

About 10% of people on HAART are developing Type 2 diabetes and many are discovering that the best way to keep their blood glucose levels down is to adopt a low saturated fat and low refined sugar diet. Several years ago I was diagnosed with the condition myself and was quickly bundled off to a dietitian to see if I could control my levels with diet alone. I was shown a chart of low glycaemix index foods which are digested more slowly in your body and don't cause rapid rises in blood sugars. Surprisingly, food like potatoes and rice were



high glycaemix index and, while I could still eat them, I was to reduce the amounts of these foods and try to cut out fried foods and limit those containing refined sugars.

Despite my best efforts, I still needed to take diabetes medication after a year on my improved diet: the HIV drugs are contributing to the problem causing a rise in my lipids and relatedly, blood sugars. With a bit of luck, good management, a good diet and some regular exercise, I'm hoping that I won't require insulin for my diabetes and that it won't become a significant issue in my life.

Coronary risk has become a reality for people on HAART too and we probably all know of one or two people who have experienced a stroke or a heart problem, which is very likely to be related to their antiviral combinations. Of course these effects are generally happening to people who have been on the tablets for a number of years – and as a number of people with HIV have moved into their forties and fifties, the co-factor of age is contributing to this risk factor for heart problems. It is likely that the drugs have sped up the occurrence of the problem – in the same way that smoking greatly increases the risk. Many of us are on medications to try to reduce our often very high triglyceride and cholesterol readings: some are on statins or fish oil tablets. Gemfibrozil reduces triglyceride levels. As with diabetes though, there are some basic things we can do to reduce the added risk that we experience from our HAART regimens. Some sort of daily aerobic exercise, brisk walking, swimming or cycling is obviously going to help, as is a healthy diet. And giving up smoking if we are still doing that all these years down the track! Or consulting with your doctor about changing from the classes of drugs most likely to cause high lipid levels, unless you're like me and are resistant to almost all but the major culprits of this problem: the proteases.

Boning Up

There is also osteoporosis or "thinning of bones" which has been reported in three to twenty percent of people with HIV, depending on the definition you use. Research is still being undertaken to work out the relationship between HAART and the condition but it does seem that the longer someone has HIV infection and their nutritional status may be important considerations. Other risk factors for this condition include a family history of bone disorders, low calcium intake, smoking and insufficient exercise. Having a good daily intake of calcium (at least three serves, such as from dairy foods) and maybe considering a calcium supplement are useful preventative measures against this problem, according to dietitians.

What's Up, News and Information

The most prominent indicator of ageing – your facial looks – is something those of us who have been on HAART for seven or eight years know can be associated with lipodystrophy, a common side-effect of the drugs. The loss of fat from the arms, legs and face which has been proven to be related to the drugs (and also to some degree, to HIV itself) and the weird redistribution of fat –

causing the lipo' belly and sometimes fat deposits in the breast area (in men and women) and on the back (sometimes called a 'buffalo hump') – are a source of considerable distress for a lot of us. The sunken cheek look, which many of us who have been on HAART since 1996 started to notice about three years later, was a particular ageing like phenomenon. It made us look older and more tired than we really were!

A Prick in Time

Some interventions arrived in 2001 to try to at least partially counter the facial fat loss (also called lipoatrophy). Injections of polylactic acid (brand name New-Fill) became available in Melbourne from plastic surgeon Dr Brett Archer as a treatment for the facial wasting. While the injections cost around $700 each and most patients require up to five or six injections, the Alfred Hospital has been able to find funds to run a free trial of the injections for eligible patients through the Infectious Disease outpatients area. I have been the recipient of six injections from Dr Archer and while I acknowledge that there was some pain involved with the procedure, the results have certainly been worthwhile and improved my feelings about my facial appearance. I certainly recommend it to those of you who are experiencing this very unpleasant side-effect of HAART.

Trying to get rid of the other aspects of lipodystrophy is not such an easy task. I have gone to gym to try to get rid of my lipo' belly with little success. A HIV-experienced personal trainer recently told me that all the sit-ups I was doing to try to trim my waistline were probably only contributing to my problem as getting rid of it is not as simple as tightening up my abdominals! Equally putting back on muscle after HIV wasting is not easy – steroids can help apparently but I'm not excited about their range of side-effects, either! Research is being conducted on a type of growth hormone in the US to see if it can work on removing the belly—one can only hope!

Regular Checkups

There are other aspects to getting older with HIV which probably warrant our attention: looking after your teeth becomes a critical factor as you age and people with HIV have added problems with gum problems (gingivitis) and loss of enamel. We need to see a dentist more regularly for checkups (regardless of our age) as our treatments can cause dryness in the mouth and subsequent higher rates of decay. Men should start getting checked out for prostate cancer more regularly after 50. There is some thinking amongst researchers that positive people are more prone to various cancers and should check out anything suspicious with their doctor. There have been reports of increased incidence of anal, penis, lip and lung cancers as well as the AIDS-defining cancers such as non-Hodgkins lymphoma. Even so, response to treatments for these cancers is considerably better in the age of HAART.

For all this though, your mental approach to the subject of ageing is probably the most important technique you have to handle it – if indeed, it raises any issues for you in the first place! The old adage "You're only as young as you feel" is as relevant for us as for anyone. We can worry about getting extra wrinkles, about not being as lithe and nimble as we once were, certainly not as easily able to pull a sexual partner – and we can chose to blame HIV as a major part of our woes – or we can just accept the passage of time, acknowledge with some satisfaction that we have survived living with a nasty, still sometimes lethal virus, despite a poor prognosis and to learn to age with some grace. Or should that be disgrace? I'll leave that up to you!

What's Up, News and Information

Continued from page 1

A Pirate Flagship from People Living With HIV/AIDS Victoria

From left to right: Steve, Guy, John Thwaites, David Menadue, John Daye, David Brand (Deputy Mayor, City of Port Phillip)

house and enjoy life more fully. We are aware that they are exploring opportunities to form new friendships and develop social networks.

"The intention of this gardening project is to meet those needs and reduce social isolation by forging closer links between HIV positive people themselves and the broader community.

"This is a pilot project and we hope it will result in PLWHA Victoria establishing more 'Positive Plots' in other locations around Melbourne."

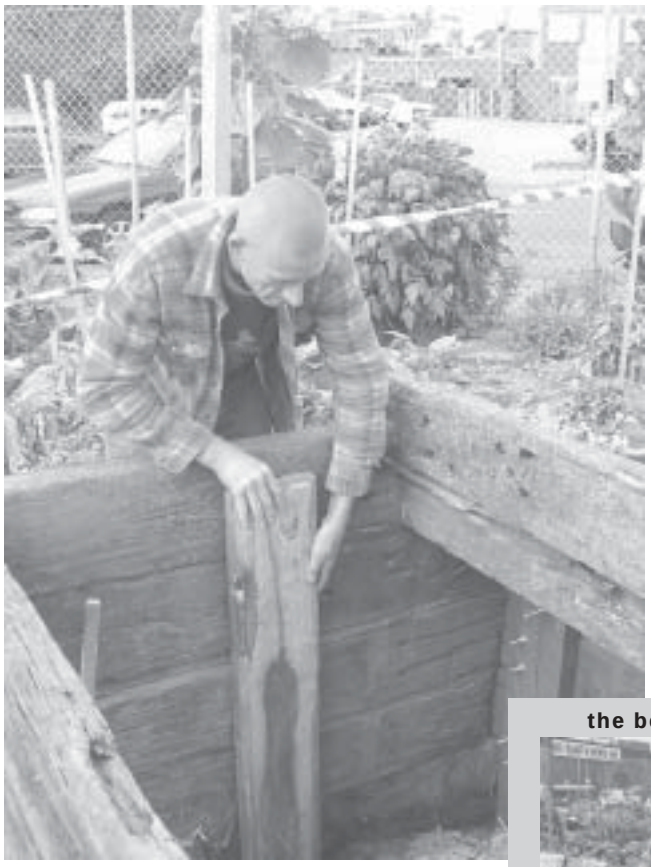
Positive Plots is a hands-on activity and there will be on-the-job coaching in gardening techniques. The participants have already been selected and will commence gardening shortly.

The pirate ship garden bed has become something of a landmark already at Veg Out. People Living With HIV/AIDS Victoria would like to thank the following individuals, organisations and businesses who provided assistance to Positive Plots:

A BIG THANK YOU TO

Robert Taylor	**Veg Out Community Garden**
Song- Cheh Teo	**Red Gum Supplies**
Sue Raymer	**Fulbry's Soil Supplies**
Fleur Kiley	
Shane Noyce	
Bruce Merrett	**Able Flagpoles**
Jo Jongebreur	
Matthew Legassick	**Earl's Hardware Store**
Tracy Routledge	
Steve Wiggins	

What's Up, News and Information



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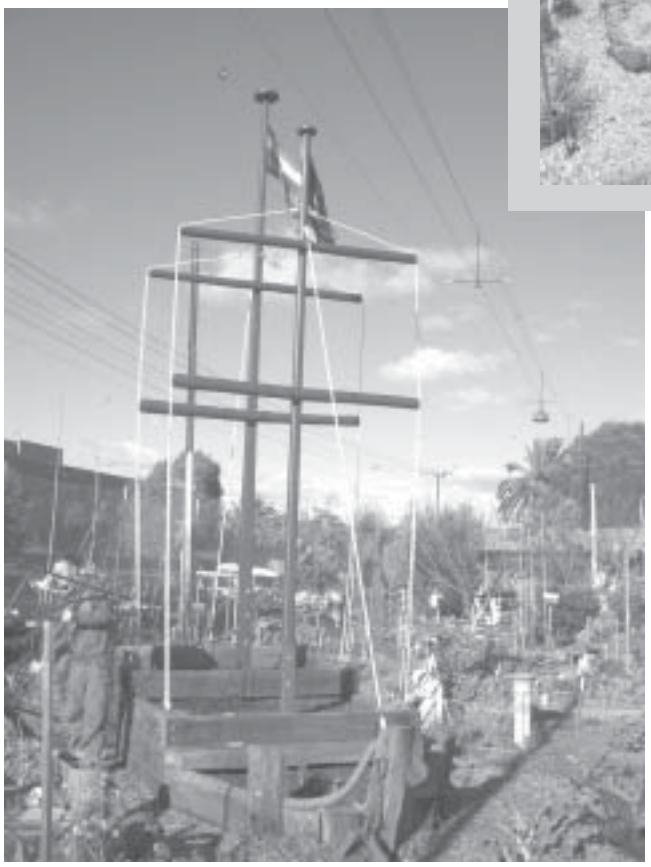

Maintaining the Master Narrative
– New Technologies, New Response –
A Report from HHARD Social Research & AFAO NAPWA Educators Conference,Sydney, May 2004. Report

by Daniel Donnelly

The biannual HHARD Social Research Conference and the AFAO/NAPWA Educators Conference were held jointly in Sydney from May 18-21. Both meetings were well attended by delegates from a variety of HIV/ AIDS Community Based Organisations, along with related sectors from across Australia and New Zealand. A wide range of papers related to all sectors and communities affected by HIV/AIDS and Hepatitis were presented during the 4 days. This report will focus on papers and discussions that are of particular interest to people living with HIV/AIDS.

Rises in New HIV Infections

In the last few years there have been notable increases in new HIV infections among gay men around Australia. A variety of trends have been associated with increases in infection rates. These include:

- Slowly increasing rates of unprotected anal intercourse with casual partners between 1996 and 2003
- Gay men having more anal sex (both protected and unprotected)
- Increasing numbers of positive men on treatment breaks or delaying treatments
- An increasing incidence of Sexually Transmitted Infections and their effects on HIV susceptibility and infectivity
- Falls in the frequency of HIV testing and an increase in numbers of recently infected men who are unaware of their HIV status
- A tendency for new infections to occur among gay-identified, community attached men in their 30's.[1]

Hull *et al* identified a reduction in risk behaviour in anal intercourse with casual partners for gay men on antiretroviral therapy which was very encouraging for HIV positive gay men. This study indicated that HIV positive men on treatment are more inclined to look after their health and the health of their casual partners. [2]

From a different perspective, a study by Jin *et al* looked at the behavioural risk factors for HIV seroconversion in homosexual men[3] showing that 61% of men interviewed believed that receptive anal intercourse was the most likely route of infection. Intoxication with alcohol (5 drinks or more) or mood altering recreational drug use at the event when transmission was most likely to have taken place was reported by 69% of the men studied. This was confirmed by statistics from a related study exploring associations with gay men's sexual risks[4] which also showed that sexual risk-taking was associated with not having a steady regular partner, less favourable condom attitudes, extensive participation in gay party scenes and in sex-on-premises venues, and larger amounts of alcohol intake.

There was a sense from conference participants that there were 'gaps' in the level of information present around feelings of inclusion and how people relate to the material presented in campaigns. Some felt that much of the material that has been developed lately around combating the rise in HIV infections has not been inclusive of people who may not identify with the groups the campaigns have targeted e.g. people who have casual sex with a regular partner or partners or are in relationships with one primary partner with occasional casual partners where disclosure of HIV status did not occur.

A common theme that was interwoven into many presentations throughout the conference reflected the need for educators to diversify their messages, taking into account the differences in the levels of understanding of HIV/AIDS, personal relationships and perceptions around HIV/AIDS, as well as the diversification within the target communities both in the cities and regional areas.

Positive In Prevention

HIV positive men and women have played a central role and will continue to participate in HIV prevention and education. It was recognised that as the 'body positive' continues to grow, maintaining HIV positive involvement in education and prevention strategies is vital in developing interventions that address the challenges of a shifting and ongoing epidemic, such as building 'cultures of care' between sex partners and recreational drug users.

The idea of 'positive in prevention' implies an engagement with the ethics of positive sexual practice that

examines both the rights and responsibilities of 'bearing the virus' when dealing with others. It also suggests that we attend to the ways that technology (such as testing, treatments and scientific expertise) both enables and constrains positive practices.[5]

For people living with HIV/AIDS who experience both the promise of treatments and the ongoing uncertainties of resistance, toxicity and unexpected side effects, the issues of the role of the positive person in prevention still seems to be very individualised and based on ones sense of self and personal values. What is clear, and was passionately expressed by a number of participants, was the apparent need for messages around prevention and education to be more inclusive of HIV positive people in the decision making and development processes. There was strong recognition that HIV positive people need to be actively involved in the development of campaigns targeting the HIV positive community as well as the wider community.

The complex issues around disclosure were discussed and considered in the context of the familiarity of HIV and the everyday aspect of life in relation to others and oneself. A paper presented on shared responsibility explored how "HIV can be simultaneously familiar and unspeakable (not just in the sense of disclosure, but in the sense of being unable to communicate one's embodiment of HIV). At times particularly when (the spectre of) disclosure frames an encounter or relationship as serodiscordant, shared responsibility can quickly dissolve into individual responsibility with positive men being positioned both as an infectious threat to be contained and as responsible for containment….'feeling infectious' figures as an interruption, which demands new modes of relating to others and ones self."[6]

The notion that new modes of relating to others and 'ones self' are evident of the amount of stigmatisation, discrimination and challenges faced by people living with HIV around disclosure and rejection of their HIV status when it comes to negotiating with sexual partners. The need for public and collective ethics around unsafe sex, individualism and responsibility was largely discounted with a demonstrated need for a combined community response and ownership of individual responsibility.

A World Online

The internet and chat rooms are a popular social space for gay men and are often interacted with as an alternative to other more traditional gay community spaces. There were a number of presentations throughout the conference that not only focussed on the use of internet chat rooms for the purposes of men seeking sexual partners and relationships, but also the use of chat rooms by young non-gay identifying men as an avenue to explore their sexuality in a safe non-confrontational manner. Men who use the Internet also report "experiencing stronger feelings of anonymity, safety and convenience than in other spaces"[7]. While many Gay men use the Internet primarily for meeting sexual partners, 60% of gay chat site users report they had found new friends and 24% of users report finding a boyfriend/partner. [8]

Research presented by the National Centre in HIV Social Research concluded that "50% of gay community attached men in Sydney and Melbourne use the internet to look for sex partners, indicating that the internet has become an important domain though which gay men meet each other…. Compared to Periodic survey samples, gay chat site users were more likely to be HIV positive, [and were] less likely to use dance parties and beats to find other men" [9]

For many educators, such high use of the internet by Gay Men, in particular HIV Positive men, for the purposes of meeting sexual partners, is an example of new technology that presents new challenges and complexities for the delivery of education messages around Sexually Transmitted Infections (STI's) and HIV/AIDS prevention. It was reported "While the communication that men have online with each other is generally quite specific, the base that communication evolves from is not. In reality men are not able to convey who they are by simply checking boxes or typing out a series of words to describe themselves, categories and words may be interpreted and understood differently by other men, leading to assumptions around the viewed sexual being. The effects of this in real time may be that men are not discussing the basics, the presumed of the assumed, but just getting on with sex" [10]

In light of the increasing number of Gay men presenting with STI's and the rising number of HIV infections, much work and study has gone into how educators reach this target group and how to use the technology of the internet to deliver their messages. One paper reported from a study from the Alfred where a sexual health nurse and health educator worked in a chat room inviting men to talk in 'private' reached the conclusion "that the men (who 'privated' them) wanted to talk about a complex array of sexual health issues and many exhibited low STI,

Continued page 14

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health and service support awareness". [11]

With an alarming number of men who use the internet for the purposes of meeting sexual partners reporting they are more likely to have unprotected anal intercourse with a casual partner in the last six months[12] "online outreach presents the opportunity for education to occur outside an interventionalist framework whilst embracing new technology to engage with users on many fronts, such as the promotion of PEP (post exposure prophylaxis), health alerts and outbreaks of dramatic increases in a particular STI to effective use of single-minded propositions to expose users to additional educational messages while not actually chatting with them". [13]

Policy Challenges for Community Based Responses to HIV[14]

There have been significant changes in the social and political context of HIV prevention amongst gay men. The first has to do with how gay men relate to HIV and the HIV epidemic. The second has to do with liberalism and health. The third involves questions of policy, governance and Commonwealth funding. The fourth has to do with the positioning of gay men and lesbians as socially inferior to heterosexuals.

Recent increases in HIV infections have strained understandings of how gay men relate to HIV socially. Some state-based AIDS organisations have repositioned themselves as gay and lesbian health organisations. The national HIV policy context changed with the Public Health Outcome Funding Agreements and the end of ring-fenced HIV/AIDS funding. It has been accompanied by a downgrading of the status of community participation in the partnership, and shifts in the governance of community-based education.

Some of the governance challenges may be relatively short-term, but the policy shifts are likely to continue. The challenges are simultaneously political, managerial and strategic. Scope to exercise flexibility of response is curtailed. The ongoing research challenge is to investigate what matters to gay men and where HIV fits in relation to that. Practical health promotion knowledge is currently subsumed by political priorities. Alternative sources of funding would seem to be a priority for professional integrity and independence for ongoing effective health education messages and campaigns.

The Changing Face of Activism[15]

Activism has made a significant contribution to Australia's response to HIV/AIDS. Vital to the success and even existence of many activist endeavours has been the public contribution of people living with HIV/AIDS.

Looking over the history of AIDS in Australia there appears to be three major phases: early mobilisation, inclusion and growth of community-based organisations and then the treatments periods. By mapping the styles of activist mobilisations and changes in the nature of the AIDS experience in Australia, it is possible to explore the motivations of people with HIV to contribute to AIDS activism and to identify some emerging challenges for the epidemic's third decade.

Initially fear, exclusion and the prospect of death mobilized people with HIV/AIDS in the Australian response. However, the treatments revolution has created a new situation that is less likely to stimulate activism of the style or extent previously experienced. The contribution of people with HIV to the Australian response to AIDS may be significantly different during the next phase of the Australian epidemic.

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5 Search Stream Two – Positive in Prevention. Butler, D.

6 Infectivity: the excess of 'shared responsibility'. Stephenson, N.

7 Your picture is your bait: use and meaning of cyberspace amongst gay men. Brown, G. & Maycock, B.

8 Cruising and connecting online: Findings and implications of the first survey of gay chat site users in Sydney and Melbourne. Holt, M., Murphy, D. & Rawstone, P.

10 Online Discussions. Hussey, G.

11 'Slipping through the NET': An online HIV and STI education strategy in gay men's chat rooms. Cummings, R., Price, B., & Hillier, L.

12 Cruising and connecting online: Findings and implications of the first survey of gay chat site users in Sydney and Melbourne. Holt, M., Murphy, D. & Rawstone, P.

13 Overview of online research. Hussey, G.

14 Policy challenges for community-based responses to HIV. Hurley, M.

15 Changing forms of HIV-Positive activism and the potential for new responses. Rankin, I.

Shared Stories

Email your stories to
stories@plwhavictoria.org.au

To Treat or Not to Treat

By Vic Perri

I've lived with HIV for so many years and have been able to avoid making the big decision. Well, no longer. After 20 or so years I finally had to bite the bullet. It was time. My counts weren't as good as they had been and my doctor advised that they weren't going to get any better. Mmm…how long could I wait? As it turned out not that long. A few more tests had shown that they were indeed getting to a point that I really had to consider starting. As a Health Education Officer I had kept up with the latest in treatments for HIV including all the problems such as the side effects associated with them. However things are getting better these days. There are less pills to take. There are less immediate side effects such as nausea and diarrhoea. While the older proteases seem to cause the long term effects of lipodystrophy, newer ones of that class and alternatives are less of a problem.

My doctor suggested that I start on 3TC (Nucleoside Reverse Transcriptase Inhibitor NRTI), Tenofovir (Nucleotide Reverse Transcriptase Inhibitor NtRTI) and Kaletra (Protease Inhibitor PI) which is a relatively new protease inhibitor. "What! A protease" I thought. I would really rather not do that I said. I just couldn't bear the thought of having to deal with body changes. Not that I'm a fit and taught muscled buffed Adonis. I do have a bit of a belly anyway and I'm a tad on the heavy side (brought up on way too much food) but my shape is at least proportionate. So I thought, "How about Efavirenz?" This Non-Nucleoside Reverse Transcriptase Inhibitor NNRTI) that seemed to have a pretty good profile in terms not increasing one's blood lipids as much as proteases and therefore hopefully less chance of lipo developing. He was ok with that. I also felt pretty good actually being able to have that negotiating power with my doctor. I felt empowered.

The combination was pretty simple. Three pills once a day at night. No food or liquid restrictions either. Pretty easy it seemed. Also there didn't seem to be any side effects from the 3TC and Tenofovir. However my first few days were still bad. I couldn't sleep for three straight nights in a row. I thought this is ridiculous. Was my body simply getting used to the Efavirenz? Apparently it affects the central nervous system. In one way it is an advantage because it is better than other classes at flushing out the HIV which can collect in pockets in the brain and elsewhere in the central nervous system. The disadvantage is that it can leave you with a funny feeling of being drunk and speeding at the same time. I asked my doctor if I could take the pills or more to the point the Efavirenz in the morning instead. He said that would be ok. Well that didn't help me. 2-3 hours after taking them in the morning my head would start to feel fuzzy and I found it difficult to focus on anything. This feeling would last for several hours. That was a real pain. It was a real disruption to my life. I just found it difficult to manage on a daily basis. After figuring that the initial problem of not being able to sleep when I was taking the Efavirenz at night was because my body was just getting used to it I thought that perhaps after a number of weeks it would be ok. So I thought maybe I could go back to taking it at night again. So I started (after asking my doctor of course) taking it again at night. I was so anxious for days thinking what if I can't sleep again. I couldn't bear the worry. However it was ok. I was able to sleep, thank God. Plus I felt ok in the mornings. Not only because whatever effect the Efavirenz was having was happening during my sleep but it was a psychological boost knowing that I was going to feel ok throughout the day.

Well in a matter of a few weeks my viral load dropped from around 70,000 which it had been for years to 480. The next count found my viral load down to undetectable. Wow, I just couldn't believe how quick it happened and I can't believe I had put up with the figure of 70,000 for so long. My Tcell count was only slightly up but my doctor said that while one's viral load can change dramatically T-cell counts take just a little longer.

There are many good combinations and of course everyone is at a different stage with HIV and may not have so many options. However it seems that for me, someone who had started treatments for the very first time, I could not have picked a better combination. In fact for anyone who is about to go on treatments for the very first time then 3TC, Tenofivir and Efavirenz is a pretty good first line combination. Good in terms of side effects, resistance and potency.

So am I glad I'm on treatments? Well I could say that there is no use in thinking about it that way since I didn't have much of a choice in the end. However I think I am. I have a lot more energy and psychologically I feel better knowing that my viral load is undetectable and my T-cell counts are slowly on the up. My doctor says that with the combination that I'm on it seems a pretty good chance of them working for many years to come. I feel pretty confident that they have indeed saved me.

Special Feature
2004 International AIDS Conference

Bangkok, 11 – 16 July 2004
By John Daye, Health and Treatments Portfolio Convenor
National Association of People Living with HIV/AIDS

The 15th International AIDS Conference held in Bangkok on July 11 – 16, 2004 brought together 19,843 delegates. It was the largest number of community advocates, scientists, researchers, educators, health care workers, decision makers and pharmaceutical industry ever to attend such a conference which is probably a measure of how deeply the impact of HIV/AIDS is being felt globally.

The theme of the Bangkok AIDS Conference was "Access for All", posing a direct challenge to wealthy nations to develop strategies to provide urgently needed treatment to nations who cannot afford it.

At this conference politics towered over science. The United Nations Secretary General Kofi Annan in the opening ceremony said that the international community is not doing enough to fight HIV/AIDS. He said "In Asia, HIV/AIDS is at a turning point – how you will address this challenge, will impact on the future of the region". The message heard repeatedly from people including Kofi Annan and Nelson Mandela was that the world was failing in its attempt to control HIV/AIDS. They pointed out that the world's response to HIV/AIDS remains woefully inadequate.

Although treatment has made having HIV surviveable in countries like Australia; scaling up access, particularly in the non-industrialised nations, has been too slow and since the International AIDS Conference in Barcelona 2 years ago an estimated 5-6 million people have died.

Demonstrations throughout the conference showed how frustrated people felt. The Prime Minister of Thailand Thaksin Shinawatra was heckled at the opening ceremony with chants and slogans of "No More Lies". Images of President George Bush either daubed in red paint or his effigy set on fire were not uncommon, so passionately did people feel that the leader of the wealthiest nation in the world was not taking HIV/AIDS seriously. Every day of the conference was marked with demonstrations from youth and children to protests demanding access to antiretrovirals.

Of note, the democratic presidential candidate Senator John Kerry announced that International AIDS Conferences will be welcomed back to the United States if he is successful in the November presidential election. He said, "I will work with Congress to lift the immigration ban on HIV-positive people that has prohibited the United States from hosting this lifesaving meeting".

In the closing address of the conference Peter Piot, the head of the United Nations Joint Programme on HIV/AIDS said that "world AIDS chaos within the next 10 years can be avoided if the right kind of action is taken" adding "of course we need condoms and clean needles, but we need to go way beyond that, way beyond *ABC*, a reference to the much criticised approaches of abstinence, fidelity and condom use that the United States is championing".

Despite the lack of any really big scientific break-throughs new material in several areas will make an important contribution to our understanding of some important issues.

I attended many presentations, meetings and saw many posters at the conference and have selected the following subjects to highlight in my report.

Maturation Inhibitors
The early development of an emerging and exciting new class of drugs, called "maturation-inhibitors", designed to stop harmless "juvenile viruses" produced inside infected host cells from maturing into harmful ones was presented at the conference as another mechanism for disrupting the HIV replicative cycle. The drug agent PA-457 uses another mechanism for disrupting the HIV replicative cycle. In testing it did not exhibit significant drug-drug interactions when used in combination with other HIV drugs. Results established that PA-457 is a potent inhibitor of HIV replication in the laboratory. The potent activity against HIV-1 observed in experiments with mice establish a proof-of-principle for this new class of compounds and strongly supports further development of PA-457 for the treatment of HIV-1 infection. PA-457 exhibits good oral bioavailability and a long half-life in trials with mammals [1, 2, and 3].

UK-427,857 (CCR5 Inhibitor)
Another new drug agent presented UK-427,857, a CCR5 Inhibitor blocks the interaction of HIV and cells. This agent was shown to have good bioavailability and short-term antiviral activity. In a study of 80 HIV positive subjects UK-427, 857 in doses up to 300mg twice a day was safe and well tolerated. Doses of greater than 100mg administered either twice a day or four times a day resulted in viral load reductions of greater than 1 log when given as short-term therapy These results indicate that further evaluation of UK-427,857 for the treatment of HIV infection is merited. Data reported at the conference suggests that the majority of individuals with CD4 cell counts above 50 will have virus treatment. Results from further studies are eagerly awaited [4, 5 & 6]. This agent is about to commence international trials in early 2005 and Australia will be one of the clinical trial sites.

TMC114
More data was presented about TMC114/ritonavir, a potent, next generation protease inhibitor showing that no dose adjustments are required when it is taken with tenofovir[7]. Additional interaction trials with TMC114/ritonavir and other antiretrovirals are currently underway. Earlier presentation of this agent at other conferences have shown that it is a potent drug for highly protease inhibitor experienced subjects and shows activity against HIV-1 strains resistant to all currently available protease inhibitors, suggesting an improved resistance profile [8]. Clinical trials for this drug are underway in Australia.

Reverset
Following data presented at 11th Retroviruses Conference in San Francisco earlier this year a further study of 30 treatment naïve HIV positive people were recruited for 10 days monotherapy of reverset—a nucleoside reverse transcriptase Inhibitor—and was found to exhibit high antiretroviral potency. The new nucleoside analogue D-D4Fc (Reverset) is well tolerated and effective in both treatment naïve and treatment experience people. It has been demonstrated to have a very long half-life which means that it would potentially be a once-a-day drug. This drug is known from test tube studies to be effective against HIV resistant to AZT, 3TC and other nucleoside analogues[9].

TORO Study
An update on 96 week results from the Toro study of fuzeon (T20) indicated this agent is effective with few systemic side effects. Of note, one important advantage of entry inhibitors is their potential for improved tolerability due to few interactions with cellular metabolic processes. This drug is of particular significance for HIV positive people whose medication is no longer effective in controlling the virus. HIV drug resistance is a growing problem and another potent agent in the arsenal to fight HIV is important especially a new agent that blocks HIV replication in different ways to existing drugs. Of the 661 subjects randomised to receive T20 at the start of the study, 368 (56%) have continued to week 96. Unfortunately for all its benefits it is not an easy drug to take. It is administered by injection twice a day and frequently causes transient skin reactions or small lumps beneath the skin. Reasons for subjects leaving the trial included safety issues (134 subjects, 20%), injection site reactions (47 subjects, 7%), adverse events or laboratory test abnormalities (81 subjects, 12%) and death (6 subjects, 1%) [10].

Tenofovir
Of significance and also reported by *aidsmap.com* were five different cohort studies that found that the risk of kidney toxicity on tenofovir (nucleotide analogue), is rare in people who commence the drug with normal kidney function. A further study using more sensitive measurements did find mild kidney abnormalities. Some of the studies alerted clinicians to the problem of administering tenofovir with other known potentially kidney toxic drugs such as indinavir [11, 12, 13, 14 & 15]

Tipranavir
Boehringer Ingelheim held a symposium where they discussed tipranavir and reviewed data presented showing the new protease inhibitor to be effective for many people with protease inhibitor resistance. Of significance though is people who have 3 or more mutations may not respond as well to this drug.

IMANI Study
A very interesting new strategic approach to initial therapy in treatment-naïve individuals was a pilot study of Kaletra monotherapy. The purpose of the study was to see if single agent therapy could be effective for virologic control and preserve future treatment options and reduce toxicity issues. Kaletra as a single agent therapy exhibited virologic efficacy comparable to combination PI therapy. The study in 30 patients showed that the response to kaletra monotherapy was not compromised by the high percentage of advanced disease in these subjects. Significant toxicity was not seen. This novel approach to initial treatment warrants further investigation [16].

Superinfection
Material presented about superinfection left more questions than answers. On the one hand a study of 33 HIV positive subjects by Grant and colleagues found no evidence of HIV superinfection among highly exposed couples [17]. On the other, Smith and others, the investigators who presented material on the incidence of superinfection at the Retroviruses Conference earlier this year presented further material about this subject in 3 individuals showing that superinfection was associated with a change in antiretroviral susceptibility. This data about superinfection showed that it had a negative effect on each of the 3 subjects' clinical course by increasing viral loads and decreasing CD4 counts[18].
We are no closer to a better understanding superinfection given contradicting data but the

potential for more widespread superinfection and the impact this could have on prospective treatment is sobering and good cause for caution.

Atherosclerosis
Patients on protease inhibitors are more likely to have atherosclerosis as evidenced by greater coronary artery calcification and an increase in carotid artery thickness. This study demonstrated the link between protease inhibitors and atherosclerosis but did not explain how this occurs (pathogenesis)[19].

Lipoatrophy
It is well understood that facial lipoatrophy is a huge challenge in the treatment of HIV/AIDS because of its stigmatising and negative effects on self-esteem. A study presented at the conference showed that facial atrophy treatment with PMMA treatment injections could to be efficient, long-lasting and safe. The study reported that treatment had a positive influence on patients, improving their quality of life and helping recover self-esteem[20]. Discussions with Australia's leading expert in this particular field Mr Brett Archer, Plastic Surgeon, make it clear that there are a number of critical concerns about this product. It is a permanent filling agent, so it cannot be altered once the patient has had the treatment. If infection occurs at the time of the treatment then the patient will have to deal with a life-long infection which cannot be treated by antibiotics. The incidence of infection, skin lumps and "spitting of the substance" through the skin is much higher.

Structured Treatment Interruptions
With the numerous presentations about structured treatment interruptions it was good to hear a HIV positive person's experience of taking a break. Rung Chiangpa, a young man from Bangkok currently taking part in the STACCATO trial said that there are a number of ethical issues related to structured treatment interruptions, and these require individual, personalised decision making. He described how he has been strongly supported both prior and during the trial and admits that he probably wouldn't have joined the study without it[21]. He highlighted just how important ongoing support and monitoring are when taking a structured treatment break.

The final results of a small Thai study have shown that using CD4 cell counts to guide treatment interruptions is a safe way to reduce the time on therapy and its cost while maintaining good virologic and immunologic responses[22 & 23].

In a study by Burman and others examining HIV transmission risk among patients enrolled in a large clinical trial evaluating treatment interruption it was found that high-risk behaviour is relatively common amongst persons enrolling in the SMART study and the rates vary little by demographic or clinical criteria[24].

In a small pilot trial by Katzenstein and others[25], more than half of the subjects were able to discontinue treatment for up to 2 years, using a decline in CD4 counts to less than 350 as a threshold to initiate treatment. A number of studies have been done on structured treatment interruptions that use increased viral load as the indication to resume treatment. In this study CD4 count threshold was used to determine when to restart treatment. Of the randomised 47 subjects the investigators gave the 18 weeks of IL-2 in addition to their regular treatment. This novel approach was used to see whether IL-2 blunt the fall in CD4 cells and in this arm of the trial did better in preserving higher CD4 counts. Specifically, the median CD4 counts achieved were 1331 in the IL-2 group and 757 in the other group.

A number of studies were presented about structured treatment interruptions from different approaches. Each of these studies provided different results. The long-term consequences of structured treatment interruptions and repeated interruptions and the impact they can have on future treatment options remains unclear.

HCV / HIV Coinfection
A very interesting study by Tural and colleagues looked at the effect of structured treatment interruptions on patients who had Hepatitis C/HIV co-infection. This study showed that treatment interruption over time leads to marked increases in hepatitis C viral load. The increase in HCV viral load at 48 week follow-up raises serious concerns regarding the safety of prolonged periods off treatment in co-infected patients[26].

Papua New Guinea
Tracey Newbury from AUSAID presented work undertaken in Papua New Guinea in one of the late-breaker sessions. Her presentation outlined the strategic approach of the AUSAID program in Papua New Guinea in response to the burgeoning HIV epidemic there. She focused on a multidimensional approach necessary to effectively provide timely and agreed levels of financial and technical support. To achieve this AUSAID has focused on supporting and strengthening government systems, supporting local leadership while promoting best practice and ensuring that

decision making is informed by the local situation.
A number of lessons have been learnt by AUSAID over the course of their involvement which include;
True partnerships are hard work and require open and honest dialogue;
To assist we need to have the confidence that we understand PNG's systems, capabilities and constraints;
We need to build our skills to ensure that we do add value;
We need to be prepared to be involved for the long-haul.
It was good to see important information and strategies to deal with HIV/TB and Malaria being examined at the conference. An important question was raised after the presentation about the need to urgently to provide treatment — through international bilateral support — and within the constraints of resources to strengthen health systems so local responses could be sustainable over the long-term[27].

Satellite Meetings

3 X 5 Strategy Meeting
On the previous day before the conference the World Health Organisation arranged a 3 X 5 Strategy (treating 3 million people by 2005) satellite meeting to review its progress. Despite grave and pessimistic concerns by many about access to antiretrovirals WHO announced that it is only 60,000 short of its July 2004 target for getting people onto treatment. Dr Jim Koong Kim of the World Health Organisation at the meeting to review the progress on the 3 X5 Strategy and target announced that the initiative has so far reached 440,000. He said that obtaining financial support for the 3 X 5 Strategy has been a huge obstacle in moving forward, but Canada's recent generosity had enabled the program to move forward. I think one of his most important statements was "3 X 5 is the only morally defensive target", referring to the urgent need for access to antiretrovirals to stem the tide of preventative deaths.

International Treatment Preparedness Coalition Meeting
ITPC met in Bangkok to follow-up a request for funding for treatment preparedness from WHO. WHO has announced a call for submissions of up to $1,000,000 to support community based treatment preparedness initiatives. This meeting spent time examining how that process will work. Key features of successful initiatives included that it is community driven and involve multiple organisations/stakeholders in its implementation. The structure of ITPC was discussed at some length at the meeting and since the meeting John Rock (International Portfolio Team-Leader) and I have had input into the design of the governance structure and its principles. Discussion also occurred about how to use excess Cape Town funds (US $40,000); this still has not been resolved.

Turning Back the Tide Meeting
This meeting was organised by AFAO and Gay Men's Health Crisis Centre New York. I

attended this pre-conference satellite meeting focused on addressing the rises in HIV infections in major gay communities. Material was presented about Sydney, Australia, New York & Los Angeles, North America, Thailand and London. An interesting series of presentations were made in the morning which showed some similarities around the world but also showed the different challenges they face as well. One of the things that emerged was that the different factors that drive the infections vary greatly between cities for example London – Brighton, New York – San Francisco, Sydney – Melbourne. One of the areas that all cities had in common was a desire by funding bodies and in some cases community to identify a single cause for the increases which would suggest a single solution however the educators from each of those cities indicated that there were multiple causes which require multifaceted solutions.

Meeting with Tibotec

I met with the Paul Stoffels, President, Karen Manson and Lew Sibet of Tibotec (Belgium) who are working with Johnson & Johnson designing a new gene therapy agent for the treatment of HIV. This new approach to treating HIV is in small scale clinical trials here in Sydney. It uses CD4 stem cells with ribozyme genetic material inserted into cells. The genetically modified cells are propagated and then place back in the subject. This study will test whether the ribozyme will protect the new genetically modified CD4 cells from infection. Tibotec are pharmaceutical company that produce TMC114.

Paul spoke very favourably about the progress being made in Australia with this work. Although only at a discussion level we talked about the design of a clinical trial involving this new gene therapy with other new antiretroviral agents including TMC114. Other leading treatment activists were also in attendance at this meeting and it is clear there is a high level of interest in the development of this new approach to treating HIV.

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

In the news

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Partners at increased risk of drug resistance

A US study published in the Journal of Infectious Diseases has found a resistance rate of 8% in 1082 patients studied at centres across the USA between 1997 and 2001. Interestingly individuals whose partners were taking anti-HIV drugs had a 14% prevalence of resistance compared to only 6% of individuals who did not have a partner taking anti-HIV drugs.

Atazanavir boosts ritonavir and saquinavir

A study in 18 people (2 female/16 male) investigating drug interactions between atazanavir (300mg), ritonavir (100mg) and saquinavir-hgc (1600mg) has provided the following results:
ritonavir increased by 41% (AUC)
saquinavir was further boosted with atazanavir by 60% (AUC) beyond regular ritonavir boosting
atazanavir blood levels appeared to be unchanged by saquinavir beyond regular ritonavir boosting
The investigators advised that further research is required to ensure that combining saquinavir and atazanavir with ritonavir leads to effective viral control.

New dementia risk identified

Data presented at the *9th International Conference on Alzheimer's disease* in Philadelphia showed that an HIV protein may increase the risk of dementia in the aging HIV population. In normal aging, the brain produces a protein called 'amyloid beta' that is thought to be required for Alzheimer's disease to develop. Usually amyloid beta is broken down in the brain by an enzyme (protein) called neprilysin (NEP) which protects brain cells from damage. Test tube studies have shown that an HIV protein called TAT can inhibit NEP resulting in an increase in the amount of amyloid beta. These results have been confirmed in an autopsy study looking at the levels of amyloid beta in HIV and non HIV infected brains. If HIV replication is not controlled in the brain, the researchers are concerned that accumulation of amyloid beta may increase the risk of dementia similar to Alzheimer's disease in the aging HIV population. However, amyloid beta alone does not cause Alzheimer's disease.
ref: hivandhepatitis.com

Prostate cancer higher with HIV

A study published in the July edition of *Cancer* has shown a significantly higher incidence of prostate cancer in HIV positive men than the general population. The study consisted of a cohort of 269 men who underwent digital rectal examinations and/or prostate specific antigen (PSA) testing which is an indicator of prostate cancer. Over a third of men in the cohort aged greater than 60 years had prostate cancer (4/11 patients > 60 yrs). The investigators concluded that prostate cancer was common in older men with HIV and was associated with duration of HIV infection. The investigators also cautioned that the study was a preliminary investigation only with small numbers and advised that more research is required to confirm their findings.

3 year tenofovir data

3 year data on tenofovir versus d4T (26% women) has been released in the *Journal of the American Medical Association* showing people on tenofovir had a more favourable lipid profile than those on d4T i.e. lower cholesterol and triglycerides. Only 3% of people taking tenofovir developed lipodystrophy compared with 19% on d4T. Importantly kidney function was the same between the two groups (good news for tenofovir).

Integrase inhibitor in development

Integrase is an HIV enzyme that allows HIV to merge with human DNA. Merck have developed a compound called L-870812 that has recently had preliminary testing results published in *Science*. Investigators tested the new drug in monkeys against a genetically altered type of HIV that mimics HIV disease. The drug appeared to work against the virus and was considered to be well tolerated with no evidence of clinical toxicities.

FDA releases a warning against tenofovir for Hepatitis B

Since its release, tenofovir has proven to be an important and safe treatment for people with HIV. However, there are quite a few people with HIV who are also chronically infected with Hepatitis B (HBV). Tenofovir appears to be able to inhibit HBV as well as HIV which makes it an excellent candidate for co-infected people. When treatment for HBV is withdrawn, the liver can become dangerously

inflamed as the HBV begins to replicate again. The FDA is recommending that all patients be tested for HBV infection before commencing tenofovir.

Saquinavir, ritonavir and amprenavir study

A 24 week study of 11 heavily pre-treated people (9 men and 2 women) taking other antivirals with twice daily1000mg saquinavir + 100mg ritonavir + 600mg amprenavir was published in the *Journal of Acquired Immune Deficiency Syndrome*. Blood levels of the drugs showed that amprenavir significantly decreased the levels of saquinavir and ritonavir. As such the saquinavir doses were increased to 1400mg and ritonavir to 200mg twice daily. At these doses the blood level of saquinavir was 62% (AUC) of that obtained prior to the addition of amprenavir while amprenavir was increased by 149% (AUC). At 24 weeks the viral load was reduced by 1.55 log (mean) in six people who remained on therapy.

Resistance to NNRTI has no benefit

When people become resistant to HIV drugs sometimes staying on the failed therapy can still be beneficial as the resistant virus tends to only replicate slowly in the presence of the failed drugs. This helps to slow disease progression in people with few effective drug options.

In Paris patients were recruited into a study to look at the benefits of ritonavir boosted atazanavir. 19 patients who were resistant to their current NNRTI therapy (nevirapine or efavirenz) withdrew the NNRTI two weeks before commencing atazanavir to avoid any potential drug interactions. After two weeks the NNRTI blood levels were low enough to show the drugs were no longer working against HIV. Removal of the NNRTIs did not result in an increase in viral load, showing that NNRTI resistance does not slow down HIV replication. Thus remaining on either nevirapine or efavirenz once resistance has been confirmed is of no benefit for people with few treatment options.

FDA approves new HIV combination tablets

Two new combination tablets have just been approved in the USA by the Food and Drugs Administration. One called Truvada from Gilead, is a combination of tenofovir and FTC (FTC is not approved in Australia yet). The second is called Epzicom from GlaxoSmithKline which is a combination of abacavir and 3TC.

WOMEN'S SECTION

Drug toxicity study in pregnant women

The Paediatric AIDS Clinical Trials Group Protocol 1022 published in June looked at the differences in toxicity for 2 different drug regimens in 38 pregnant women. The drug regimens chosen were either nevirapine or nelfinavir with AZT and 3TC. Drug therapy commenced between 10-30 weeks of pregnancy. There were no CD4 restrictions. However, enrolment into the study stopped after the manufacturer of nevirapine put out a caution for women commencing therapy on nevirapine with CD4 counts greater than 250. 21 women started their combination therapy with nelfinavir. 17 women started with nevirapine. 82% of the participants taking nevirapine had CD4 counts greater than 250 at the beginning of the study.

Total Group

Toxicity Leading to Treatment Discontinuation

Nelfinavir	N=21	(1)	5%
Nevirapine	N=17	(5)	29%

CD4 > 250

Toxicity Leading to Treatment Discontinuation

Nelfinavir	N=14	(0)	0%
Nevirapine	N=14	(5)	36%

All of the nevirapine toxicities occurred over 2-26 weeks of therapy in women who commenced treatment with a CD4 count greater than 250. One woman on nevirapine died from liver toxicity (CD4 > 250). The authors of the study warn that these results should not be mixed up with the benefit of single dose intrapartum nevirapine (given at birth) that can reduce mother to child transmission in resource poor settings. They also advised that the small numbers of people in the study may have lead to an over-estimation of liver toxicity in this group that might not be the same in a larger study sample.

[*Editor's note: Liver failure in women on nevirapine is rare and tends to occur within the first 6 weeks of treatment. Most*

serious side effects from nevirapine occur in the first 18 weeks of commencing treatment. See Poslink issue 15 for the manufacturers warning on the use of nevirapine in women. Single dose nevirapine has become a contentious issue given the possibility of resistance and the advent of treatments becoming more readily available in developing countries.]

Kaletra and pregnancy

Preliminary results were released from the PACTG 1026 study looking at blood levels of anti-HIV drugs in women, including those taking twice daily Kaletra (lopinavir/ritonavir). 12 women who became pregnant were closely studied both during and shortly after pregnancy. Investigators found that 10 of the 12 pregnant and 1 of 4 post-partum women did not meet the target levels of Kaletra. Only small amounts of Kaletra were found in the umbilical cord. The investigators concluded, 'Low levels of Kaletra during pregnancy could lead to inadequate viral suppression'.

Multivitamin study in African women

A study looking at the benefit of multivitamins in pregnant women in Tanzania was recently published in the *New England Journal of Medicine.* 1078 women were recruited into the study during 1995 and 1997 which had 4 arms:

- Vitamin A supplementation
- Multivitamins
- Vitamin A and multivitamins
- Placebo

The women were followed until August 2003. Results clearly showed a reduced rate of death or disease progression in the women who took the multivitamins who also had an average of 48 CD4 cells more than the placebo group along with reduced symptoms of fatigue, rash, upper respiratory tract infections and oral/ gastrointestinal problems. Vitamin A supplementation showed no benefit when used alone and reduced the benefits obtained from the multivitamins.

Antiviral treatments can affect pregnancy

A study from Spain that was reported at the International AIDS Conference has found that duration of antiviral therapy increases the risk of pre-eclampsia and foetal death. Pre-eclampsia is known as pregnancy induced high blood pressure with the presence of protein in the urine. The investigators found that between 2001 and 2003 there was an incidence of 11% pre-eclampsia in HIV positive women vs 2.8% in HIV negative women. Foetal death occurred at a rate of 6.1% in infants from HIV positive women vs 0.5% from HIV negative women. As most of the complications occurred between 2002 and 2003 the investigators decided to review patient records from 1985 to 2003 and found the single most common factor associated with the complication was the use of any kind of antiviral therapy before pregnancy. The risk increases by 1.09 fold for each month of treatment which the investigators believe may be due to long term toxicities associated with the HIV drugs.

People with Living HIV/AIDS VIC

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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.