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The Speakers Bureau is sponsored by unrestricted educational grants from:

Abbott Virology
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Note from the Executive Officer Sonny Williams

The last few months have been busy for everyone at PLWHA Victoria. Alan and Suzy arranged a launch of an HIV Travel resource entitled *Up, Up and Away: tips for the HIV positive traveller*. We were successful in having the event sponsored by Roche Products and as a result were able to launch the resource at the State Library. So if you are thinking of travelling overseas we can send you a copy of the resource. In the near future we will have this resource available on our website.

All staff and most of the board attended the NAPWA conference in Adelaide. This conference provided us with the opportunity to network, attend workshops, provide feedback and of course showcase some of our project work. PLWHA Victoria were indeed fortunate to have abstracts from Alan, Suzy and Max accepted along with Guy Kharn who presented on Positive Plots and one of our Speakers Bureau members Eric Glare who presented a poster. As a result, with five members of PLWHA Victoria having abstracts accepted, we were well represented at the conference.

In November we held our AGM at the PLC this year which was well attended and provided an opportunity for the organisation to present to the membership an overview of the work carried out for the past twelve months. Reflecting back

on the past year, the achievements by the organisation highlights the importance of collaboration between services to achieve common goals. For example since May, PLWHA Victoria has been working closer with the Positive Living Centre with the establishment of outreach services within the centre every Thursday. This has only been made possible through the generous donation of office space for our organisation by the Victorian Aids Council. Copies of the annual report are available from the offices of PLWHA Victoria and will also be available from our website soon.

In December PLWHA Victoria launched World Aids Awareness week at Parliament House with the Youth Affairs Minister the Honourable Jacinta Allen MP. Eric Glare and Meg Warner spoke at the launch to 55 people. Media representatives from MCV, Bnews and Positive Living were present. The Speakers Bureau provided HIV positive speakers to JOY Radio every hour for December 1st as well as speakers talking across Melbourne.

Vanessa's Christmas Nosh was held at The Vibe Café in Smith St, a combination of a Treatment Interactive Event – treatments update and an opportunity for people to relax and socialise with a chance to

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Note from the President Greg Iverson

I would like to apologise for my absence at this year's AGM. The reason for my non-attendance was a personal one; I was on my way to the meeting when I received a call to tell me that a very close friend of mine, who I was assisting in caring for, had just passed away. I immediately went to his house to spend the day with his wife and two young children that have been left behind.

It is a sad time for me personally, as I was very close to this friend and his family and I hope that the membership understands that in situations like this, we have little choice but to go where we are needed most.

I have been told that this year's AGM went very well, which is always good to hear. A big thank you to Tony White for his excellent provision of food for the day.

I would also like to thank the outgoing members who left the board and welcome the three new members who have joined us for this coming year. We had no need to hold an election process due to the fact

that the amount of nominations this year matched the vacancies that were left by the outgoing members.

In particular, I would like to make mention of one longstanding member who has left Pat Garner. Pat has served on the PLWHA Victoria board for 8 or so years now – a huge commitment that has to be acknowledged. He has always been one of the driving forces of the organisation and has been tireless (despite having a very busy professional life) in his work for plwhas in Victoria.

The Positive community owes Pat (and other long-term members and volunteers like him) a lot. All too often the work that is quietly being done in the background by these people can be left unheralded. But one thing is certain: if this work was not being done, then plwhas in this country would be in a far worse position than we now find ourselves.

So Pat – THANKS!!!!!! You will be sorely missed from our ranks.

My report this month is my World AIDS Day speech which was broadcast on JOY Melbourne on 1st December. World AIDS Day this year had the theme 'Let's Talk About It'.

HIV/AIDS has slipped off the agenda for many areas of society today, and this timely theme is there to remind people that the issue has not gone away – nor have we. It is time to renew and re-invigorate our messages to the wider community whenever and wherever we can.

Also on World AIDS Day, we inaugurated Michael Rogerson into our Legends series. The Legends series is our way of celebrating and remembering some of the people who have fought so hard for the rights of positive people within ours and the broader community. Michael passed away in 2004. He was the founder of Straight Arrows which provides support services and information for heterosexuals with HIV. Michael is sorely missed to this day by all of us within the positive community❖

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win great door prizes donated to PLWHA Victoria by various sponsors, without the support of whom we would be unable to provide these gifts.

The New Year sees the organisation gearing up for the

Pride March on Sunday February 5, so if you would like to participate not only in Pride but also in the Midsumma Carnival in anyway contact the office on 03 9865 6772❖

What's Up: News and Information

The Alfred Review

The Department of Human Services has held a number of community consultation meetings to discuss proposed changes to the Alfred HIV services. Proposed changes in the review have been put forward to ensure the Alfred is able to continue to provide services that will meet the changing needs for the HIV population in Victoria. Also, part of the changes are to ensure that HIV funding will be used specifically for HIV services and won't be able to be

used elsewhere within the hospital system. Such changes include the closure of some acute care beds in 7 West, which are no longer needed, and shifting the funding to develop or initiate other services. PLWHA Victoria and the VAC/GMHC have been actively involved in these consultation processes to ensure that any changes will be what the HIV community want and that services are delivered in a manner appropriate for the community❖

New combination tablets available

GlaxoSmithKline have launched their new tablet Kivexa which is now available by prescription from HIV pharmacies. Kivexa is one tablet taken once a day that is a combination of 3TC and abacavir. Running hot on the heels of Kivexa is the new Gilead combination tablet called Truvada which is a combination of tenofovir and FTC, and will be

available on the PBS from February 1. [*Editors note: A new study will be commencing in 2006 called the STEAL study. This study is designed to see whether there are any differences between Kivexa and Truvada. People accessing either Truvada or Kivexa prior to enrolling in the STEAL study will not qualify for entry into this study*]❖

Bird Flu warning for Africa

As Bird Flu slowly migrates around the world, health authorities have been doing their best to reduce the impact that Bird Flu can have on humans by implementing strict public health policies and controls. It is thought that the final destination of the Bird Flu will be East Africa where many people have compromised immune systems due to HIV infection. One theory is that HIV will provide an

environment where the Bird Flu can replicate and mutate easily making it a greater public health threat than previously experienced. Officials believe that HIV may provide a trigger for a Bird Flu epidemic as previous observations of Bird Flu have shown that the virus is able to replicate in large quantities in immune-compromised people with cancer❖

Spare a thought for people in Zimbabwe

With the Zimbabwean economy in tatters, people living with HIV/AIDS are finding it more and more difficult to cover the private cost for fixed dose antivirals. Since July the cost for monthly fixed dose antivirals has increased from ZIM \$200,000 (US \$7.70) to ZIM \$1.2 million (US \$46). As it is becoming more difficult to afford the basic necessities in life in Zimbabwe, people not on

treatment programs are tending to sacrifice their antivirals to buy food or pay for their children to attend school. Even generic pharmaceutical companies manufacturing HIV medications are finding it difficult to purchase the raw materials required to produce the antivirals as they don't have enough foreign currency to do so❖

Vanessa's Guide to Staying Young

In October 2005 PLWHA Victoria held a Treatment Interactive Event on HIV and Aging. Normally these events run smoothly without any hitches but this time around our hostess with the mostest, Vanessa Wagner, was not able to attend at the last minute due to an injury from running around on the beach up at Byron Bay. Luckily Brett Hayhoe and Alan Strum were able to take her place at the last minute. The talented Amanda Monroe also came to our rescue and provided entertainment to open the afternoon's session. Joe McLean from Heavenly

Solutions pulled a volunteer out from the audience to show how to do facials for that natural youthful glow. Dr Richard Moore from the Carlton Clinic, the Alfred dietician Katherine Lin, Pat Garner and Bill O'Laughlin chatted with the audience about topical issues related to aging and HIV and pointed out how we are venturing into unknown territory with our bodies as the long term effects of HIV and drug therapies are unknown in the population that is living longer as a result of effective treatments❖

What's Up: News and Information



Vanessa's Guide To Staying Young

Left: Joe McLean from Heavenly Solutions showing how to do a facial
Above: (left to right) Dr Richard Moor, Bill O'Laughlin, Pat Garner and
Katherine Lin

Right: Amanda Monroe and Colin Krycer



Vanessa's Christmas Nosh – treatment update

On Sunday December 11, PLWHA Victoria held it's annual Christmas Nosh and update on HIV treatments. Alan Strum, Treatments Officer, presented information on the current state of affairs with HIV drug therapies. Alan indicated that there are a number of drugs which are no longer commonly used for the treatment of HIV which will result in the withdrawal of at least 2 if not 3 HIV drugs in 2006. Drugs that will be withdrawn will be ddC and Fortovase. However, Alan was quick to add that anyone currently taking Fortovase will be provided with Roche's new formulation of saquinavir which will be available in 500mg tablets through a product familiarisation program (PFP). A new formulation of Kaletra will become available in 2006 to some people through a PFP. The new formulation of Kaletra has already been approved in the USA and is only 2 tablets twice a day that don't require refrigeration and it is thought will have less diarrhoea than the current formulation. Other new drugs that should be available in 2006 through clinical trials or compassionate access programs and that should be active against resistant virus are:

Protease inhibitors (PIs)

- tipranavir
- duranavir (TMC 114)
- brecanavir (GSK)

Nucleoside analogues (NRTIs)

- AVEXA 754 (replaces 3TC)
- reveset

Non Nucleosides (NNRTIs)

- etravirine (TMC 125)
- TMC 278 (maybe)

Integrase Inhibitors

- MSD's integrase inhibitor



It is possible that Pfizer's CCR5 inhibitor, maraviroc, might become available late in 2006 but the community will be waiting for full safety data before pressing Pfizer for access to this drug.

Other changes that are taking place in 2006 are the introduction of new combination tablets from GlaxoSmithKline called Kivexa (abacavir + 3TC) and from Gilead called Truvada (tenofovir + FTC).

Alan also indicated that there are currently 86 drugs in development that have not yet been tested in humans and another 23 drugs that are in clinical trial.

Following Alan's presentation, Vanessa Wagner chatted with Dr Jonathan Anderson to place HIV treatments into perspective. Dr Anderson indicated that treatment for HIV in 5 years could look very different to current treatments with the possibility for the introduction of some once weekly treatments (time will tell).

PLWHA Victoria would like to thank all our participants, volunteers and sponsors for making this treatment interactive event such a great success❖

What's Up: News and Information

Change to Fuzeon (T-20) water vials

Roche have advised that the vial of sterile water supplied with Fuzeon (T-20) has changed from 1.1mL to 2mL. This has been done for registration purposes. The amount of sterile water to be used from the vial is still only 1.1 mL when mixing the T-20 suspension i.e. don't try to use the full 2mL and only draw up 1.1mL of the water. After the suspension has been mixed then only use 1.0mL of the solution for injecting.

A new vial of water should be used to mix each vial of T-20 i.e. don't try use one vial of water to dilute 2 vials of T-20 as there won't be enough water for the final mixture which may result in a worse injection site reaction if the mixture is too strong.

Anyone who has any questions about this change should chat with their nurse, doctor or treatments office❖

New Vic Health Act

Victoria will be changing the Health Act in 2006. The Health Act covers many areas that are relevant to people with HIV such as contact tracing and pre and post test counselling (and many other areas of interest). A number of the proposed changes to the Act would provide the Government with broader powers to manage health emergencies such as dealing with a bird flu epidemic. In some ways these broader powers come across as being a threat to civil rights but may be necessary just like the changes required and made to legislation for the Federal Government to protect the community from the perceived threat of terrorist attacks. The VAC/

GMHC and the Australian Federation of AIDS Organisations are holding a meeting in January to provide guidance to community based organisations who wish to submit comments on the proposed changes to the Act. PLWHA Victoria will be submitting a formal response to the Government by the end of January. The VAC/GAMC is also planning to hold a community forum on the New Health Act for individuals who may want to make a submission. This will be held at the PLC, 51 Commercial Road, Prahran at 1.30pm on Saturday 21 January❖

Up, Up and Away – tips for the positive traveller

In November PLWHA Victoria hosted the 'HIV Travel Launch' at the State Library which was attended by over 60 people. Dr Andrew Gowers and Dr Nick Medland presented on a number of medical and practical issues that people with HIV need to be aware of when deciding to travel overseas. John Rock also presented on his personal experiences of travel as an HIV positive person. The information booklet is available from PLWHA Victoria or can be downloaded from www.plwha.org.au (PLWHA NSW). For further information on travel you can also talk with Alan on 9865 6718. The launch and the booklet were sponsored by Roche. *[Editor's note: This booklet covers pretty much everything you need to know about travel and HIV. However, the booklet recommends sending medications to other countries*

through the mail which I think is not very practical since the introduction of identification required for parcels, is not legal, and can lead to drugs being stored in incorrect conditions]❖



(Left to right) John Rock, Nick Medland, Andrew Gowers

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STI RoadShow

In November PLWHA Victoria hosted the Australian Federation of AIDS Organisation's STI Roadshow. Dr Darren Russell presented and discussed information on sexually transmitted infections and their impact on the health of people with HIV. Of

particular importance is the change that has occurred in the frequency of STIs resulting in gay men needing to be screened for STIs more frequently. Poslink will provide further information on STIs and HIV in an upcoming issue❖

PLWHA Victoria Christmas Hampers

PLWHA Victoria volunteers were busy giving out over 30 Hampers to people with HIV who were in hospital on Christmas day. This is an important activity for our organisation where we are able to help our colleagues feel a less lonely and isolated on a day where society tells us that we should be surrounded by family and friends. The visit from our volunteers and the Hampers help those of us who are unfortunate enough to be in hospital to feel that

they have not been over-looked by the spirit and good will of the season. Thanks go to our volunteers and our sponsors for making this day possible: Frank, Alex, Tony, Pat, Neville, Albi and John, Anna Georgiou, David McCarthy, Levi Strauss, SHE Australia, Peter Alexander, Dee Bees, Simon & Schuster, Holden, Mitsubishi, Audi, BMW, Melbourne Queer Film Festival, Bill Gianoulis and JOY Radio❖

'Living Positively' - A personal health coach pilot

My name is Ian Coutts and I am working as the Project Officer for a new 12-month pilot project that is being undertaken between the VAC/GMHC and PLWHA-Victoria. The project is titled '**Living Positively**' and is aimed at HIV positive people who are looking to make changes to their life in terms of developing healthier living strategies and skills.

Sometimes many of us may feel in a rut and want to make changes or improvements to our lives, but lack the motivation or confidence to follow through with these desires. The project is intended to provide individual one-on-one assistance to help you meet your health and life goals by using a goal-centred approach. There will be regular meetings with your health coach, who will help you define your goals and priorities, provide encouragement and support, and will also be able to arrange for group and/or individual skill development programs to take place. Some issues you may want to address could include (but are not limited to) things like: better diet and nutrition, an exercise/fitness plan, smoking cessation or better budgeting strategies etc.

Particularly for issues around smoking cessation, nutrition and exercise, you will be able to tap into workshops offered by PLWHA Victoria at PLC.

The ultimate aim of the project is to provide you with the confidence to make positive changes to your life, to learn new skills and to also develop the ability to sustain these changes in the long term.

As the project is a pilot project, on-going evaluation will be taking place to monitor the effectiveness of the project and therefore it is requested that you commit to participating in the project for a minimum of 6 months. It is planned to run 2 six-month programs as part of the pilot (the 2nd program will commence in June/July). It is hoped to recruit a maximum of 15 people to the program by late January for the first round.

If you think this project might be for you, or you are just interested in finding out more information, I can be contacted at the Positive Living Centre Monday to Friday on (03) 9863 0444, mobile: 0409 829 463 or email: ian_coutts@vic aids.asn.au❖

Access Information centre launch their new name and logo!!! The Education + Resource Centre



•hiv•hepatitis•sti•
education+resourcecentre
www.accessinfo.org.au

2005 has been a very exciting year for what is now the 'Education + Resource Centre' at The Alfred.

The Education + Resource Centre has and continues to be a very valuable service for many people living with or affected by HIV, Hepatitis and Sexually Transmissible Infections (STIs).

The launch of their exciting new image reflects the expanded nature of the service whilst also clearly identifying what the service is about.

In addition to the drop-in centre and comprehensive website, the Education + Resource Centre now incorporates health education. Many people in the wider community unfortunately continue to be unaware of the correct facts relating to Hepatitis & HIV. This lack of knowledge in turn feeds the stigma and discrimination that exists within the community.

Through the provision of health education, the service can assist in informing people and correcting many of the myths and misunderstandings relating to blood borne viruses. Importantly, health education plays an important role in empowering people to minimise harm to their own health through the promotion of safe sex awareness and safe injecting practices.

For those of you unfamiliar with the service, here is a snap shot:

All you need to know

The Education + Resource Centre offers a free and confidential service for people seeking information about HIV/AIDS, Hepatitis and Sexually Transmissible Infections (STIs).

Who is the service for?

General Public
People Living with or affected by HIV
Hepatitis or an STI
General Practitioners
Health Professionals
Community Agencies
Schools & Tertiary Institutions
Students



What does the service include?

- Information & resources
- Specialist library
- Supply of brochures & posters
- Website

Health Education sessions
Drop-in Centre

Referral to testing, treatment & support services
Plain language Fact Sheets
Quarterly Newsletter❖



SMART Study Stopped

A study called Strategies for Management of Anti-Retroviral Therapy, otherwise known as the SMART study, has been closed due to advice from the Data Safety and Monitoring Board (DSMB).

The SMART study is a large randomised international study investigating differences between continuous antiviral therapy compared with structured treatment interruptions (drug breaks) guided by CD4 counts. It is one of the largest HIV studies ever conducted with 5472 people recruited since January 2002 from 318 clinical sites and 33 countries including Australia.

At the time of the review by the DSMB, the average time people had been in the study was 15 months. Preliminary results showed that people in the structured treatment interruption arm were at more than twice the risk for disease progression than those who were taking antivirals continuously. There was also an increase in cardiovascular, kidney and liver disease complications in the interruption arm which goes against what researchers thought might happen.

Investigators have now been notified of the close of the study and have been requested to encourage people on treatment breaks to recommence treatment. Participants will still be provided with follow up from clinics. The researchers

will be deciding what type of long-term follow up may be required in order to be able to gather and assess further research information. [*Editor's note: While more than a 2 fold increased risk of disease progression sounds bad, it is actually only based on a very small number of events. People who are in this study should be aware that for the most part people in both groups have done very well. If you are currently on a treatment break and you are approached to recommence treatment be sure that going back onto therapy is what you really want to do. Taking HIV drugs requires commitment to ensure that you don't miss doses. At this point in time I don't really know what these results mean. We will need to wait a few months for the full data to be examined and released before anyone can really comment on the outcomes of this study.*]

Personal Advertisement

Guy in Ocean Grove looking for people in the area for friendship. Please contact PLWHA Victoria with your details on poslink@plwhavictoria.org.au or 9865 6718.

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Awards at the Annual General Meeting of PLWHA Victoria

This year's annual general meeting was held at the PLC on November 27. No elections were required as there were as many nominations as there were vacancies. 3 people left the organisation in 2005 and 3 members successfully stood for the board. The new board consists of Greg Iverson, David Menadue, Brett Hayhoe, Stephen Eustace, Suzanne Lou-Gooey, Jeffrey Robertson, John Willis, Andrew Fuller, Tony White, Daniel Donnelly, Neville Braybrook and a Straight Arrows position candidate to be advised.

PLWHA Victoria would like to thank Allan Clark, Rebecca Matheson and Pat Garner for their contributions to the organisation as board members in 2005.

The Annual Report was distributed at the meeting and will be available on line shortly. Otherwise, anyone wanting a copy of the report can request one from our office on 03 9865 6772.

At each AGM, PLWHA Victoria acknowledges the work of people who have contributed to HIV/AIDS. This year's list of recipients is listed below.

1. President's Award

This is presented at the discretion of the President to an individual, group or organisation that has demonstrated visionary leadership in improving the quality of life for HIV-positive people. Often the recipient will have served over a long period and contributed to high level improvements in services for positive people and to an increased awareness of HIV issues.

Tobin Saunders (aka Vanessa Wagner)

Tobin has been a great worker for PLWHA Victoria for a long time now. He has assisted in making our events not just educational and informative, but entertaining and enjoyable as well. His alter ego of Vanessa is largely responsible for the popularity of our Treatment Interactive Events and Forums, for which we have always been very grateful.

2. Clinical Excellence Award

This award is presented to an individual, group or organisation that has made a prominent and exceptionally distinguished contribution to the treatment and care of positive people.

Dr David Richards

In acknowledgement of David's ongoing commitment to helping break down the stigma and discrimination in the medical sector in the Barwon

South West Region. David has played a very significant role in supporting people either at risk of or living with a blood borne virus and establishing links with local service providers to offer the best quality of care for people living within the Barwon South West Region

3. HIV Media Awareness Award

This award is presented to an individual, group or organisation that has made a remarkable and striking contribution to significantly improve awareness in the community through the means of the media.

The Advertiser (Bendigo)

This year's award goes to the Bendigo Advertiser who earlier this year reported on one of our Treatment Interactive Events held in Bendigo in partnership with the Country AIDS Network. The staff of the Advertiser had a prominent and significant presence at the event and went to great lengths to interview participants, guests and report accurately on the content of the day. The end result was a full page spread in the paper that comprehensively and responsibly reported on the facts about HIV and the issues facing plwha living in country Victoria. We salute the Bendigo Advertiser's concern to keep issues related to HIV in the public arena and we hope they will provide a

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positive example to other journalists in the gay and lesbian as well as the mainstream media.

Research Progress Award

This award is presented to an individual, group or organisation that has made an outstanding contribution to the positive community through the research they have undertaken. General features of this award are for innovative, quality research that leads to a significantly enhanced understanding of the positive community that feeds the development of quality care initiatives or services.

The Research Nurses at the Alfred Hospital ID Unit

There have been teams of HIV research nurses working under the supervision of Associate Professor Jenny Hoy since the Fairfield Hospital days – over a period of fifteen years. Their work continues to be at the cutting edge of HIV research, with some 25 projects currently managed through the Alfred. We would like to acknowledge the very patient-centred approach which the current team take, with meticulous attention shown to addressing all patient concerns, thorough attention to follow-up and most importantly, the friendly and caring service which they provide. We thank Janine Roney, Sally Algar, Melissa Bryant, Karen Hutchinson, Craig Scholten and Teresa Girke for their work with the Alfred Hospital ID Research Nurses.

5. Volunteer Commitment Award

This award is presented to an individual, group or organisation that has made an outstanding

contribution and commitment to positive people through their volunteer work for PLWHA Vic.

Shane O'Toole and Jason Holland

Shane and Jason are long standing volunteers generously donating their time to PLWHA Victoria assisting with Treatment Interactive Events and Midsumma, they are both willing to pitch in and effortlessly carry out any activities given to them. Both Shane and Jason are open, friendly people and are regarded as valuable and important members of our team and community

6. Community Endeavour Award

This award is presented to an individual, group or organisation in the community who through their endeavours has made a substantial and important contribution to the recognition of the issues and needs of positive people.

Guy Kharn

Guy Kharn for his ongoing commitment to the Positive Plots Community Garden Project. Guy Kharn has been affiliated to PLWHA Victoria for a number of years and in a variety of roles. He has been a Director on the PLWHA Victoria Board and more recently as the co-founder and designer of our Community Garden Project Positive Plots. Guy's commitment and dedication to this project has been overwhelming. His passion and drive to help members of the positive community who are socially isolated and facing financial hardship resulted in the development of a pilot project that in its first year has been deemed a great success and looks

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set to grow even further. We value Guy for his passion, energy and friendship and his continued support of the positive community.

Julia Freeborne

Julia Freeborne has the role as an HIV Services Co-ordinator at the Positive Living Centre. Julia has an open, friendly and welcoming manner along with an infectious sense of humour; Julia is also an advocate for all positive people rights. From an organisational point of view, Julia has gone out of her way to facilitate introductions since PLWHA Vic has opened an Outreach Office. Julia has made sure all our staff feel welcome and part of the PLC team and been a main driving force in introducing PLWHA Vic to the membership at the PLC. We are grateful for her professionalism, warmth and friendship.

7. Speakers Bureau Award

This award is presented to an organisation, sponsor or individual that has made an outstanding contribution to the further development of the Speakers Bureau. The recipient will have strengthened the capacity of the Bureau to deliver it's vitally important work of reducing HIV/AIDS stigma and discrimination in the wider community and raising awareness of the issues of living with HIV/AIDS.

Murray Altham

For his ongoing promotion of the importance of HIV Positive speakers being in front of audiences providing education and prevention messages to the wider community.

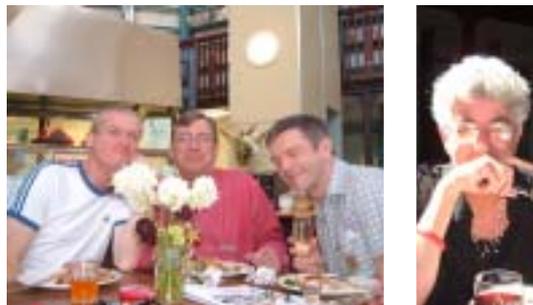
Murray is a constant mentor of the Speakers Bureau and has conceptualised ideas that resulted in significant benefits to the speakers and their audiences. Murray is also commended for his initiative and facilitation skills assisting TasCAHRD and PLWHA Victoria with sponsorship that allowed participation of our speakers in the launch of Tasmania's World AIDS Awareness Week (WAAW) 2003. Murray's enduring support of the organisation and especially the work of the Speakers Bureau has been a constant and for this we recognise him with the 2005 Speakers Bureau Award.

8. Special Acknowledgement Award

This award is presented to an individual or organisation that has given extraordinary support to PLWHA Victoria

Marg Hayes

Marg Hayes is the Co-ordinator for the Catholic Aids Ministry. This award is in acknowledgement of your commitment and contribution to the physical and emotional wellbeing of PLWHA's, and the warm and



open hospitality you provide at Catholic Aids Ministry.

Cameron Mole

Cameron Mole is the Male Sexuality Officer at Monash University Caulfield Campus. During this year's Annual Sexual Awareness week at Monash University Caulfield Campus, a fundraising event was organised by Cameron, this was the first time that proceeds from the Sexual Awareness week were donated to a charitable organisation.

9. Exemplary Service Award

This award is presented to an individual or organisation that has given extraordinary support to PLWHA Victoria over the years.

Kevin Guiney

Kevin left the PLWHA Victoria Board last year to become the President of VAC/GMHC – after more than twelve years involvement with the organisation in one capacity or another. He was the PLWHA Vic representative to the VAC/GMHC Board way back in 1993 and served in the roles of Secretary and Treasurer of the newly incorporated PLWHA Victoria after 1999. Kevin has shown the organisation incredible dedication and loyalty and was regarded by previous Boards as a bastion of common sense and sage advice. We miss his input and hope he will return to our Board one day in the future.

Pat Garner

Pat has worn the tag of the "wise elder" on the Board with dignity and we hope pride. He has been an extraordinary source of support and counsel for many people on the Board over his long period of service over the past seven years. He has a nose for detecting "bullshit" when he sees it and pulling the Board into line when he knows that we are being distracted from the reasons we are meant to be here for. Pat's work with the Catholic AIDS Ministry has been a particular highlight of his work with the Board but he has been a passionate advocate for all positive people who will be sorely missed. Thank you Pat for your enormous contribution❖

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 or posted to 6 Clarement St, Sth Yarra 3141.

THANK YOU

I wish to take this opportunity to say thank you to PLWHA (VIC.) for the opportunity of serving as a Board Member for the last 8 years. It has been a pleasure and privilege to have been able to work beside so many fine and committed people, but due to work I do not now have the time available to continue at a Board level.

In particular, I wish to say a special "thank you" to David Menadue and John Daye; both David and John have been invaluable guides and advisors to me in so many ways.

I was particularly honoured to receive an "Excellent Service Award" at the Annual Meeting; I have been fortunate to have received other awards for various reasons but, to me, this award was the ultimate and is one that I shall cherish very, very much.

I wish also to extend my very best wishes to the Board and Staff for future and further success as the peak body for PLWHA's, and I urge ALL members to support them in their efforts. The tasks they have to handle are sometimes very delicate and not always easy, but with the support of us all, we shall maintain PLWHA (VIC.) in its rightful place as top of the tree for PLWHA's here in Australia.

Pat Garner ❖



Dear Poslink

I guess I'm writing to see if there are others like me, and I wonder what they are doing to keep themselves focused and well. My story in short is that I am a 39 year old gay man and have been positive for nearly 18 years. During the 18 years, I have been on treatments and off treatments, not really knowing what the best solutions have been. I have been extremely well over the 18 years, not having any major illnesses or hiccups. I guess I'm lucky, as I have seen some friends who have not been so lucky and have gone in a flash. I guess for the first 10 years I did nothing but try and cope with having this disease, and during this time there was no support offered to me, so I was a little self-destructive and very lost. At no point in time did I think I would still be here 18 years later. I guess the hardest thing to cope with in the early years was not knowing what to do, nor could anyone at that time offer me advice that made sense. Not even my Doctor could offer me real solutions or support. I have found that to be the most frustrating thing to deal with, the unknown and no real answers to any of my questions or concerns.

In 1996 I went to a different clinic and met another great doctor who suggested I try treatment. I did this for about 5 years and had great success with the regimen I was on. During the time I was on treatment I had an undetectable viral load and my T-cells remained at good levels. I stopped treatment in about 2001 because I developed a buffalo hump which was quite pronounced. This I found was caused due to the meds I was on. Again no one told me that this could happen. I had the hump removed and stayed off treatment until 2004. During the time I was off treatment it took quite some time for my viral load to show signs that the virus was active again, and even then my viral load remained very low and I

remained healthy. In 2004 I decided to go into the SMART study, thinking this would be a good way of keeping up to date, and it was also a way of taking control of my health again.

I'm back having an undetectable viral load and extremely healthy. I guess the frustrating thing I still face even though I am part of a study, is that there is still no feed back as to what I should be doing, how things are going, or even if there has been and reported side effects to the new meds that I am on. My GP is a very caring man and is up to date with what's going on in the world of HIV & AIDS. But I still have that feeling of the unknown, not really being in control of things, as was as that horrible feeling of being in the dark. Again no real answers to my question and no real feed back even though I'm part of a study group.

I have now started to see a naturopath. She is helping with diet and alternative therapies to keep my body and mind strong. I'm actually getting more comfort and advice from her than I ever got from any doctor or expert in the field of HIV and AIDS. I'm a little surprised that 18 years down the track some things have not really changed. I don't know if I will ever get the answers I'm looking for. I still keep very much to myself and maybe that's the issue. It may be time for me to meet others like myself, and to be involved in groups such as Poslink. Looking forward to your feedback.

Kind regards
SA

Dear SA

Your letter raises a number of issues which are difficult to address in writing. The key theme of your concerns appear to be that you are feeling isolated and uninformed. Organisations such as ours and other HIV organisations are in

Community Letters: The Scratching Post

place to address your specific needs. And yes, there are other people out there like you who have had HIV for many years and who are doing well...you are not alone! Some are heavily involved in our organisation where they feel fully informed and empowered. I will attempt to address some of your issues below:

Isolation

Even though you have had HIV for 18 years, your letter indicates that you have never received any form of support. While you have done well health-wise, you have lived through some of the most difficult years of the HIV/AIDS epidemic where many of our friends did not survive. It is fantastic that you are a long term survivor. However, it is possible that you may (or may not) have unresolved emotional issues hiding deep down inside that might need to be addressed. I would suggest making an appointment to chat with one of the counsellors at the VAC/GMHC. Even if you are okay emotionally, touching base with a counselor can be a first step in setting up your support networks. To arrange to see a counsellor you can call 9865 6700 and ask to speak to the Duty Worker between 2pm and 4pm. You can also join an HIV positive support group at the Positive Living Centre (PLC) where you will have the opportunity to share experiences with other HIV positive people and maybe even make some new friends. The person in charge of support groups is Marcus Younger and you can call him on 9863 0444. The PLC is also a drop-in centre and provides dinners every Tuesday and Thursday evening for \$3 (members) and \$5 (non-members/guests). Around 40 to 50 people attend each dinner and the friendly staff at the PLC will introduce you to lots of people while you are there. I would suggest you call ahead and speak with Julia on 9863 0444 to let her know that it will be your first time

there and chat with her about becoming a member. PLWHA Victoria runs social evenings for positive people called Planet Positive. This event takes place every two months usually in the evening and gets around 60 people attending from diverse backgrounds. Planet Positive dates and locations are advertised in Poslink which you will get automatically if you are a member of PLWHA Victoria or you can call our office for details on 9865 6772.

Feeling uninformed and in the dark

Things have changed significantly since you were diagnosed and we now know lots about HIV, the drugs, living well, diet and exercise. Doctors often don't have the time to sit down and provide you with all of the information you may need. This is where you can chat with me directly and I will be able to tell you pretty much everything you want to know. I would suggest you make an appointment to see me (Alan) on 9865 6718. I often spend up to 2 hours at a time providing information to our members and clients. I usually like to give too much information rather than too little. And, if it is too much, you can come back and see me again for further clarification. The information I give to you, along with some counselling, should help alleviate your feelings of 'being out of control and in the dark' and will provide you with the skills to be able to talk further with your doctor about other things you may want to talk about. We also hold information sessions in the format of Treatment Interactive Events where you can not only learn about HIV issues but also meet other HIV positive people.

Your personal health and information on the drugs

You have had HIV for 18 years and your three year treatment break indicates that your body copes well with HIV but I would

need to see your viral load and CD4 cell count history to be able to give you further information. Unfortunately, while the drugs work well against HIV, they can have a number of side effects with buffalo hump not being very common. I have one client who has never taken HIV drugs. We didn't know much about side effects going back to 1996 when the drugs were first introduced but now we know lots more about the drugs and their associated toxicities. As such, we are now in a position for people to take the least toxic drugs first which have minimal side effects. And we also know that people should probably defer treatment until around 350 CD4 cells as opposed to starting early in order to avoid long term side effects. There are also lots of new drugs in development and we will see many new treatment options become available over the next 5 – 10 years. In general, things are looking really good and most people with HIV can look forward to long and relatively healthy lives.

This letter is just a first step in providing you with some information about HIV and support services. It's now up to you to take the next step and reach out to those of us who are here to help you. I have enclosed a referral sheet for your information that has contact details of many support and information services in Melbourne. Please call me if you have any further questions or to make an appointment on 9865 6718.

Regards
Alan Strum
**Treatments
Information Officer**❖

Body Composition

Co-Factors in HIV - No. 3

By Jim Arachne, Positive Living Centre

Welcome to a third article on Cofactors and HIV. Cofactors are very important to understand as they can strongly influence the course of HIV. Previously we've looked at two other well researched cofactors – antioxidants (glutathione specifically) and the hormone DHEA. This article focuses on a cofactor which, for most of the history of HIV, has been a better predictor of outcome than T4 count! And, unlike T4 count, its something you can directly influence and improve.

To get a clear idea about this cofactor we need to have a basic understanding of "Body Composition". Body composition refers to the amount or percentage of fat, muscle, bones etc. that your body is composed of.

Research now shows that some aspects of body composition make a big difference to how HIV affects you in the long run. There are two main measures of body composition that have been shown to affect outcome of HIV:

1) Body Mass Index

Body mass index (or BMI for short) is a simple measure of body composition – its just your weight (in kilos) divided by your height squared (in metres). BMI is an independent predictor of how you'll go in the long run with HIV. This means that BMI has an affect on the outcome of HIV infection that is independent of T4 count – that is, it has an effect that is quite separate from the effect of a high or low T4 count.

Someone who weighs 80kg and is 1.83 metres tall (6

feet) has a BMI of 23.9 whereas someone of the same height but who's a lot thinner – at 60kg – has a BMI of 17.9.

An African study shows how important BMI can be (1). From 1992 to 2001, researchers measured the BMI of 1,657 people newly diagnosed with HIV and followed them up to see how their BMI was related to how long they lived. They found that "BMI at diagnosis is a strong, independent predictor of survival....". Specifically, they found that people with a BMI of less than 16 lived, on average, only 9 to 10 months after diagnosis. However, people with a BMI of 22 or higher did much better. They lived an average eight to nine years longer. A BMI of less than 18 "remained a highly significant independent predictor of mortality" even after taking into account the effects of age, sex, if people were taking Bactrim, if they had TB or muscle wasting at diagnosis, and baseline T4 count.

A BMI of less than 18 was "comparable to that of a CD4 count of less than 200 in predicting mortality within 6 months of diagnosis."

However, this study was conducted in Africa where few people have access to modern anti-HIV drugs. Because of the beneficial effects of these drugs in Australia, BMI is not such a crucial predictor now as it was in the 1980's. However, another measure of body composition remains very important - it's called the "Phase Angle" and it's an even better predictor of outcome than is BMI.

2) Phase Angle

Phase Angle is not as easy to measure as BMI. A dexa-scan (sometimes used in hospitals to measure body composition in people with lipodystrophy) gives a very accurate measure of Phase Angle. However, much easier to use is a "bio-impedance analysis" machine. These are about the size of a transistor radio. A couple of electrodes are attached to your skin and a reading is taken - the test takes only a few minutes. Some naturopaths use these machines and various gyms and a few health food stores also have them on their premises. You could also check with a dietician if they have access to one. They are used to calculate measures of body composition such as body fat and lean muscle mass as well as Phase Angle.

Phase Angle is a measure of the "metabolically active tissue" in the body. This includes all the muscles of the body, (including muscle of organs like the heart), sinews and tendons plus the nervous system. Phase Angle is a key marker of health and ageing.

i) Just how important phase angle is was shown in a 1995 trial where people with HIV were followed up for over a 1000 days. (This was before triple combination therapy was available so many people were just using AZT).

Of 12 factors – such as T4 count, use of AZT or PCP preventative medication, Phase Angle, serum albumin, age etc. – Phase Angle was found to be

Body Composition

Co-Factors in HIV - No. 3

By Jim Arachne, Positive Living Centre

the best single predictor of who lived and who died and was a better predictor than T4 count ($p < \text{or} = 0.0001$).

ii) A second trial was reported from Germany in 2000 involving two hundred and sixty-seven people with HIV. They were all attending the outpatient clinic at a large university hospital in Cologne. This was a more relevant study than the previous one as 91% of them were using triple combination anti-HIV drugs or began using them during the study.

After taking into account the influence of T4 count and viral load, people with a Phase Angle equal to or higher than 5.3 had a 58% less risk of developing AIDS when compared to people with a phase angle less than 5.3. Higher Phase Angle was associated with a 49% lower risk of death.

Researchers concluded; "Despite the favorable effects of HAART on the status of HIV-infected persons, low phase angle remains an independent prognostic marker of clinical progression and survival."

The lead researcher, Dr Achim Schwenk, base at St Georges Hospital in London, said; "The results of this study show a strong ability of the phase angle to predict survival and clinical progression in people with HIV, independent of the degree of immunodeficiency and viremia."

Two other important findings from this study were:

- T4 counts and Phase Angle were both good, but

independent, predictors of outcome of infection with HIV.

- Phase Angle was a better predictor of outcome than was viral load.

So, given the importance of body composition, and Phase Angle in particular, what can you do to tip the balance in your favour?

Your aim is to increase your Phase Angle and avoid things that may reduce it. Increasing your Phase Angle means increasing your quantity of "metabolically active tissue". Three big influences on this are:

Factors That Help to Increase Phase Angle:

- Resistance exercise
- Sufficient high quality protein
- Adequate rest

Factors That Increase The Quality Or "Healthiness" Of Metabolically Active Tissue:

- Good nutrition, especially protein and essential fatty acids
- Good mitochondrial function
- Dehydration can cause a high, false-positive score.

Factors That Decrease Phase Angle:

These are things to avoid or reduce. The main cause of a decreasing Phase Angle score is loss of metabolically active tissue. So loss of muscle mass is a big issue here. Factors that contribute to this are:

- Ageing
- A low-protein/high carbohydrate diet
- Lack of exercise
- Inflammation
- Insulin resistance
- Stress
- Low thyroid

Increased body fat can also lower Phase Angle as the percentage of muscle in the whole body becomes less.

Additional Factors that Decrease the Quality or "Healthiness" of Metabolically Active Tissue are:

- Nutritional deficiencies and/or malabsorption
- Toxicity
- Free radical damage
- Mitochondrial toxicity or damage.

Some of these things are straight-forward to begin addressing. Others may need specialist advice from a relevant dietician, naturopath or personal trainer. Ask around for assistance if you need it❖

References:

1. "Body Mass Index at Time of HIV Diagnosis: A Strong and Independent Predictor of Survival". M A van der Sande and others. *Journal of Acquired Immune Deficiency Syndromes*. 37(2): 1288-1294, October 1, 2004.
2. "Bioelectrical impedance analysis as a predictor of survival in patients with human immunodeficiency virus infection". Ott M, et al., *J Acquir Immune Defic Syndr Hum Retrovirol* 1995 May 1; 9(1): 20-5.
3. "Phase angle from bioelectrical impedance analysis remains an independent predictive marker in HIV-infected patients in the era of highly active antiretroviral treatment." Schwenk A., et al., *American Journal of Clinical Nutrition*, Vol. 72, No. 2, 496-501, August 2000



PositiveWomen

Supporting Women Living with HIV/AIDS

And so we come to the end of another year. I hope for all it has not been too overwhelming and this year will pass gently into another.

I attended the 10th Biennial NAPWA conference in Adelaide this November and it was, as the organisers had surely hoped for, a good one. It was great to be amongst so many positive people and have that sense of community. On the Thursday before the conference started, positive women from around Australia were given the opportunity to meet and spend the whole day together in informal workshops. We were also treated to a wonderful meal that night. It was great to have the time before the conference to get to know our peers and then see them throughout as friendly faces. I think the best thing for me was seeing and hearing young positive people at the conference; what a breath of fresh air and such vibrancy and energy. I attended one of the Activism Workshops, as did many other positive women, and we were lucky enough to here a young woman, positive since birth, give an enchanting and overwhelming speech about her life and her need to speak out. I don't think there was a

dry eye in the room when she finished. I just want to say thank you – you inspired a lot of us that day!

It was also very humbling to have, once again, the HIV positive delegates from PNG. The women who attended the Women's Day showed us all that we are very lucky to live in developed countries being HIV positive; so many things that we take for granted they are fighting tooth and nail for. They are literally fighting for their lives!

On the 22nd of November at the Positive Living Centre (in a joint event with PLWHA, Straight Arrows and Positive Women) we had a young HIV positive woman from South Africa come and speak about her work in South Africa with Oxfam and her experience of living with HIV/AIDS (she also was at NAPWA). One of the most startling things for me to learn was that the Female Condom was for women in Africa – a life saver and a curse. In Africa if the woman can bring a condom, a FEMALE condom to the relationship she can protect herself against STIs and HIV/AIDS but the man in the relationship can also say to her, 'If you don't have a FEMALE

condom we can't use protection'. Not only are they very hard to get, but they are also generally more expensive than the male condom. It is just another shining example of the gender imbalance in beautiful Africa. Here in Australia the female condom is a novelty and a rather cumbersome one at that!

We are winding down for the year at Positive Women – well sort of. We have a number of events to end the year with for our members. There is a barbeque at Veg Out in St. Kilda with Straight Arrows and another at the St. Kilda Botanical Gardens with Positive Women members and families. Call the office for more details. To begin the New Year we will once again have the fantastic MAC Makeovers and Dinner for Valentines Day. Keep your eye out for the flyer!

I also wanted to extend my thanks to everyone for their lovely words and support throughout my pregnancy. I have felt buoyed by everyone's enthusiasm and genuine interest and care. Thank you! ❖

Karen

Women Living with HIV

(Final part 5, reprinted from *Women Living with HIV* from the AFAO publication *Treat Yourself Right*, published in 2000.)

Gynaecological conditions

Vaginal thrush (candidiasis)

Candida albicans is a naturally occurring yeast which generally lives in harmony with its human host in the gut, the folds of the skin, the anus, the mouth and the vagina. Thrush occurs when the balance of this yeast is disturbed and it multiplies out of control.

Are you at risk? There is always some *Candida albicans* living in the vagina, but it can 'multiply' to above normal levels when there is a change in the vaginal environment (for example, in sugar or pH levels). Generally, the yeast co-habits happily. But if the immune system is not working well, the *Candida* can start to behave like an infection. Vaginal thrush is a very common infection in all women, regardless of HIV status. However chronic, or very frequently recurring vaginal

thrush is the most common gynaecological disorder in women with HIV. Thrush can also occur in other parts of the body (the mouth and the oesophagus). This is more common when the immune system is weaker.

What are the symptoms? Symptoms include crotch-itch, tiredness, and a furry, white, usually odourless vaginal discharge. Women being treated for thrush may be re-infected by male partners during unprotected sex because thrush can be found under the man's foreskin. Your doctor can advise you on things you can do, such as wearing cotton underwear and avoiding perfumed soaps, which can help reduce the occurrence of symptoms.

How is it treated?

Topical antifungal agents Topical antifungal agents are treatments which are applied to the affected area. There is a range of topical treatments, some of them natural therapies, which may be helpful. These include:

- live yoghurt which contains the bacteria *Lactobacillus acidophilus*—some practitioners maintain that the bacteria in commercial *Lactobacillus acidophilus* yoghurt is not effective;
- broad-spectrum anti-fungal creams or powders such as Canesten. These are available from your chemist. You won't need a prescription, but you will have to pay for these products: topical antifungals were recently removed from the Schedule of Pharmaceutical Benefits.

STRAIGHT
GROWS



Services & support for
HIV+ heterosexuals
& their families.

Systemic treatment for recurrent thrush

For more serious thrush, antifungal drugs may be used. These include: fluconazole; itraconazole; amphotericin B.

Anti-candida diets You may have heard that *Candida* can be managed by special diets, which eliminate foods supposed to cause *Candida*. However, many doctors believe there is no evidence that these diets have any impact on candidiasis, and warn they can be dangerous in positive women because they can cause weight loss.

Cervical cancer

Cervical cancer is a preventable condition and if diagnosed at an early stage, can be cured. Cervical cancer and cervical cell abnormalities affect many women regardless of their HIV status. But evidence suggests that the kinds of cervical cell abnormalities that can lead to cancer are more common in HIV positive women. Not all cervical cell abnormalities (a condition called cervical dysplasia) mean you have cancer or are likely to get it. However, more severe kinds of dysplasia are associated with the development of cancer. These possibly pre-cancerous changes

**A PLWHA Victoria
Representative
will be at the PLC
every Thursday
from
12noon - 7pm**

Max Niggel
Speakers Bureau
Suzy Malhotra
Community Development
Alan Strum
Treatments Information

are graded into three tiers according to their severity: CIN 1, CIN 2, and CIN 3. (CIN stands for cervical intraepithelial neoplasia). *CIN 1* means there are some mild changes, with a small risk of developing cancer (about 7 percent); *CIN 2* changes have about a 50 percent chance of becoming cancerous; *CIN 3* changes are severe, and may mean cancer is already present and active. If you have a pap smear which shows such high-level dysplasia, your doctor should immediately refer you for further tests. An examination of the cervix called a colposcopy may be recommended. The cervix is closely examined under a microscope and cells may be taken for testing. Some people argue that this test should be routine in all HIV positive women, but others disagree, saying it is unnecessary unless pap smear results are abnormal, as some women can find colposcopy invasive and painful. Some researchers have suggested that progression to cervical cancer may be faster in HIV positive women. Invasive cervical cancer is an AIDS-defining illness.

Other risk factors Some kinds of the human papillomavirus, a sexually transmissible infection which causes genital warts, are strongly linked with cervical cancer. You may have been exposed to this virus even if you've never had warts. A blood test will tell you this. Smoking appears to be a risk factor. The risk of developing cervical cancer also increases with age: women may be at increasing risk from their mid-30s.

Effectiveness of treatment
The main reason it is important

to detect cervical cancer or pre-cancer early is that it appears current treatments may be more likely to fail in HIV positive women, especially women who have a low CD4 count. Abnormal cells which have been treated (eg. through laser surgery) may also be more likely to recur.

Importance of testing The main message for HIV positive women in terms of cervical cancer is that early detection is critical. This should include:

- regular six to twelve monthly pap smears (discuss the exact frequency of tests with your doctor);
- further referral if your pap smear shows abnormal cells;
- aggressive treatment in the case of severe dysplasia.

If you think you may have been exposed to HPV or genital warts you may want to consider undergoing a simple biopsy procedure that can determine which strain/s of the virus you have been exposed to.

Pelvic Inflammatory Disease (PID)

PID is an inflammation of the pelvic area usually caused by untreated sexually transmitted diseases like gonorrhoea or chlamydia. Some women have PID without knowing as the inflammation is not necessarily painful. Untreated PID can become increasingly painful and can cause infertility. PID seems to be more common and more severe amongst HIV positive women. The symptoms can be mild, moderate or severe:

- pain or cramps in the lower back and abdomen

- pain during intercourse
- deep pelvic pain
- pain going down to the top of the legs
- bleeding between periods
- vaginal discharge that is smelly but not usually itchy
- high temperature
- fatigue.

If you notice any of these symptoms or have any concerns about PID, talk with your doctor. PID must be treated by antibiotics. In severe cases women may need to be admitted to hospital.

Pap tests (pap smear)

Women living with HIV and AIDS are advised to have a pap test every six months. A pap test is a simple procedure in which a sample of cells is swabbed from the cervix (at the top of the vagina), to test for any unusual changes which may suggest the risk or presence of cancer. It is not uncommon for women to have a condition that is called 'cervical dysplasia', regardless of HIV serostatus. This means that your pap test result shows some abnormal cells. These abnormal cells can potentially lead to cervical cancer.

A pap test is a painless procedure which can easily be performed by your GP. In general, HIV negative women are advised to have pap smears every two years. While there are no guidelines in Australia on the regularity of pap smear tests for HIV positive women, it is generally recommended that tests be done every six to twelve months. This is because cervical dysplasia, or the presence of abnormal cells, is

more common in HIV positive women. The presence of abnormal cells does not mean you have, or will get cancer, however, they do indicate a potentially pre cancerous condition. Recent advances in treatments have meant that many positive women have pap tests at a twelve monthly interval rather than the previously recommended six monthly. It is best to chat with your doctor about how often you should have the test. Progression from cervical dysplasia to cancer may be more rapid in positive women.

If you have a pap smear and cervical dysplasia is found, your doctor should recommend a colposcopy. This is a slightly different test. The cervix is observed using magnifying equipment and cells may be taken from the cervix for further examination. (This is called a biopsy: a tiny piece of skin is snipped off under a local anaesthetic). Cervical cancer can be difficult to treat. However, it can be prevented if abnormal cells are found early enough by routine testing. Pap tests are available from any general practitioner or nurse practitioner and also through women's health centres, Family Planning clinics, and some STD and HIV clinics❖

Useful links

www.positivewomen.org.au
[www.whs.sa.gov.au/
project_hiv.php](http://www.whs.sa.gov.au/project_hiv.php)
www.pozhet.org.au
www.straightarrows.org.au
[http://
womenandaids.unaids.org](http://womenandaids.unaids.org)
<http://www.icw.org>

Urgent Call for Volunteers

PLWHA Victoria desperately needs volunteers to assist with the Midsumma festivities such as Pride and Carnival.

Please call Suzy on
9865 6756

Treatments Information Service

Do you have any questions about HIV and drug therapies?

Call Alan on
9865 6718

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

1 December 2005: WORLD AIDS DAY SPEECHES

World AIDS Day at the Positive Living Centre: Speech by Brent Allan, Manager HIV Services.

It is my pleasure to welcome all of you here on behalf of the VAC/GMHC board, staff and volunteers. This is a special event for us and all the more special this year due to the combined efforts of the Quilt Project, Straight Arrows, Positive Women and PLWHA Victoria.

World AIDS Day this year has an Australian theme "Lets talk about it" which encourages all sectors of civil society to open up and talk about HIV/AIDS in order to battle the silence which far too often leads to HIV/AIDS related stigma and discrimination.

However, I want to take a few moments and focus us upon the international theme " Stop AIDS - keep the promise" and remind everyone about some of the promises that have been made, some of the promises that have been kept and some of the promises that have been broken or not yet delivered upon.

Internationally

International statutory bodies such as the United Nations and the World Health Organisation as well as the international drug companies who produce the life-saving medications for people living with HIV/AIDS promised that no person living with HIV/AIDS should be denied these life saving medications. Still far too many people are denied these drugs for the simple fact that they are poor – in the world of HIV/AIDS, poverty kills.

Many people will remember the Act-Up slogan "Silence = Death". The HIV slogan for the new millennium is certainly "Poverty = Death". Even in our community nearly 70% of positive people indicate that they find it difficult to meet the daily costs of living such as paying for clothing, utilities and housing and over 50% of people living with HIV/AIDS find it difficult to pay for food and transport.

Australia

Early on in the response to HIV/AIDS in Australia, an explicit partnership was formed between government, research, the community and people living with HIV/AIDS. A promise was made to work together, to respect each others role and duly consult with each party before action was taken thus avoiding any unnecessary duplications in services

and maximising both the financial and human resource commitments that are necessary to response to HIV/AIDS. Often touted as the hallmark of the Australian response and the envy around the world, but in practice I wonder where the promise of partnership has gone?

Community

Many people affected by HIV/AIDS made promises in those dark days before effective antiretroviral treatments to care and support people living with HIV/AIDS. This included their partners, their friends, family members and often complete strangers. As we celebrate the clinical advances which have lengthened the lives of people living with HIV/AIDS – the promises of care and support have diminished; fewer people are putting up their hands to help out and the levels of financial donations which keep essential services operating for people living with HIV/AIDS have significantly reduced.

Yet the number of new infections are rising in Victoria, as they are around the world, and as people living with HIV/AIDS live longer they are living with increasing complexities which challenge their abilities to live well and expect well in the future.

People Living With HIV/AIDS

People living with HIV/AIDS have an important role in our world – our diagnosis often comes with plenty of burdens and plenty of responsibilities. I believe that all of us living with HIV/AIDS are educators (sharing our knowledge about HIV/AIDS with our families, friends and lovers); we are advocates (often challenging the HIV/AIDS bigotry, shame, stigma and discrimination); and we are role models to other positive people. Either explicitly or implicitly, those of us living with HIV/AIDS make promises to ourselves – to stay healthy for example; to our partners to do what we can to reduce the risk of transmission, and to our positive friends – to remain by their side no matter what.

This World AIDS Day I would like to ask all of you here tonight – what promises have you made?❖

1 December 2005: WORLD AIDS DAY SPEECHES

JOY Melbourne World AIDS Day Speech by PLWHA Victoria President Greg Iverson

The theme we have adopted in Australia for this year's World AIDS Day is 'AIDS - Let's talk about it'.

My first thought was, let's talk about what?

After living with this virus for over 20 years now, there are so many things that I could say in relation to HIV and AIDS.

Why am I still here?

Why have all my old friends died?

Why is it that I am one of the lucky ones who survived the horror period of the 80s and early 90s, when there were no medications and AIDS was a death sentence?

Why are rates of new infections increasing in Australia now? The Australian response and education around this epidemic is recognised as one of the best, yet people are still taking risks with their lives.

Why are there still so many complications with the medications that I have to take just to survive?

Why, why and why?

No-one can ever give the answers to these questions and largely, it is a waste of time and precious energy to pose them. So we stop asking the questions and try to get on with life.

And this lived experience of HIV is different for everyone. It is true that there are commonalities that all who are positive can say that they share, but the 'on the ground' reality of living with this virus is one that can only be truly understood on an individual basis.

For some, they live with the virus with no effects whatsoever. At the other end of

the scale, there are those who sero-convert and are gone within the space of a few months.

And then there is the large range in-between. Those of us who live with differing levels of complications, co-infections and debilitating side-effects, that emerge and re-emerge from periodic bouts of illnesses, trying to keep some sort of life going.

Don't think it's easy. I can tell you first hand it's not.

And the drastic changes currently underway in this country within the welfare and industrial relations systems, are only going to make life harder for all those that suffer from chronic illnesses.

There does seem to be a growing perception within Australia that the AIDS crisis is largely over. We now have new medications that help keep us going. So what's there to fear?

But virtually all of these medications have side effects and no-one truly knows what the effects of long term usage of these toxic regimes will be. The costs of these medications are ever increasing as well. The Americanisation of this country's infra-structure to the user pays' mentality is terrifying for those of us in our position.

And yet it has to be pointed out we are lucky in our western society.

Third world countries have not even begun to see any real improvements for their people, mainly due to corporate greed and a lack of will by global institutions.

We are not blameless on this issue either; here at home, amongst our Koori and Torres Straight Island populations, infection rates are proportionally far higher than in those in the wider community. We need to

do so much more to assist these people, on whose land we now live.

But AIDS is no longer the headline grabber it once was. Except for events like World AIDS Day, it is now largely ignored by the media in this country.

HIV/AIDS hasn't gone away. It is still killing and affecting millions, literally, throughout the world.

So what can we, the HIV infected and affected people in this country, do about this?

We can keep reminding you all that we are still here. We can keep reminding you all that there is a larger world out there that is suffering far worse than us. We can keep reminding you that millions are dying unnecessarily due to a lack of treatments that could be made available. We can keep reminding you that AIDS hasn't gone away.

And how do we do this?

Simple. Let's talk about it.... ❖

ALSOCare Call for Volunteers

ALSOCare & Benevolent Society Inc, the charitable arm of The ALSO Foundation, has opened the

**ALL SO FABULOUS
OPPORTUNITY SHOP**

We need volunteers to lend a hand at the shop in Collingwood!

For further details call ALSO on 9827 4999 or email members@also.org.au

2005 NAPWA Conference

NAPWA Conference 2005

NAPWA's national conference of people living with HIV/AIDS takes place every two years. The most recent conference was held in Adelaide, South Australia, from 18-20 November 2005.

A major event of particular interest to people living with HIV/AIDS, the Conference program included guest speakers drawn from across Australia and covering diverse fields, from the professional to the cultural (excerpt from *nawpa.com*).

NAPWA President Gabe McCarthy opened the conference and David Buccanan launched the Declaration of Rights for People Living with HIV/AIDS which can be found on pages 27 and 28.

More specific information on this conference can be found at www.napwa.org.au. The following information is from those people from PLWHA Vitoria who attended the conference.

Feedback: PLWHA Victoria Board Members

Greg Iverson

This was only my second NAPWA conference – the first being one I attended many years ago when it was last held in Melbourne.

To this day, I describe my feelings of attending that first conference as the same as those I had when I first went into a gay bar (many, many years ago as a young innocent(?) 17 year old!!!) – that is, one of a sudden realisation that I was not alone, but that there were many others with a shared life experience out there just waiting for me to link up with them. As Gabe McCarthy (current President of NAPWA) said in her closing speech, NAPWA Conferences were much like a family reunion. After this, my second NAPWA Conference, I couldn't agree with her more!

The two highlights for me from the various sessions on offer



at NAPWA this year (so many to chose from!), were the ones on the subject of Aging and HIV, a topic that is only now getting the attention that it deserves in this era of HAART, and another on the subject of disclosure – still a major issue for many PLWHAs.

Both of these sessions were well attended and while we may not have even got close to solving any of the issues in these two vital areas, it was a fascinating exercise to be involved in them; if only to see the amount of concern that exists in our community around these issues – one fairly new to our focus and the other that has been around since the beginning of the epidemic.

One positive step that came out in the Aging session was news of the establishment of a group in Western Australia specifically looking at HIV and

Aging issues. An outcome from this conference was that the wheels have been set in motion to establish a similar group on this side of the country with ties to the WA group.

As usual I had only one criticism of the conference - it was far too short. Apart from the chance to catch up with old friends within the HIV community, these conferences always serve to re-invigorate you, help you understand that you are not alone and to serve as a great exposure to fresh ideas and experiences of HIV positive people from all over our country. I would encourage any positive person to attend the next NAPWA Conference in 2007.

David Menadue

The NAPWA Conference was probably the most enjoyable of my many years of involvement

with the organisation. At a time when community interest in HIV is waning I find it fascinating that there is such a high level of engagement around the work of NAPWA and it's conference— there were about 300 attendees and some excellent presentations with evaluations suggesting it was a great success, enjoyed and appreciated by the vast majority.

My favourite parts of the Conference were the opening and closing ceremonies. Rodney Junga-Williams' emotional welcome and closing speeches, Ian Grubb's informative and humorous insight into working in the HIV sector globally and the two indigenous guys' song at the closing. Very moving experiences. The presence of so many women and children at the closing ceremony was a testament to the inclusiveness of the organisation these days and the value of the **Women@NAPWA** group and their work. I look forward to the next one and sharing that peer experience with other positive people which is such a highlight for me with these meetings.

Brett Hayhoe

This is my second NAPWA Conference - and both have been rewarding, informative, and educational. The social aspect of a NAPWA conference to me is as rewarding though as the content [which in Adelaide's case was of an extremely high standard].

I couldn't agree more with Gabe McCarthy's comments in the closing plenary that "NAPWA Conferences were like a family reunion....you may not know everyone, but you all have something in common and you want to meet everyone you can".

I look forward to the next and the next after that. As a Positive Guy, there can be no better forum than a NAPWA Conference.

Suzanne Lau-Gooley

Great conference for too many reasons to list them all here. Positive women are usually in such a minority at Australian HIV

meetings, so one highlight for me was the largest presence ever of positive women at a NAPWA conference, with about 50 women meeting at the pre-conference Women's Day , to discuss, celebrate and commemorate together. (Victorian women were especially there in force!) Our resolutions and a beautiful panel were then presented at the Closing Plenary. I was also very pleased to present our Positive Women Digital Storytelling Project at the Creative Exhibitions afternoon. Women comprised one of the most diverse groups there, including women from indigenous or migrant backgrounds, visitors from PNG, East Timor and Africa. There is also the next generation emerging. We heard a young positive woman, having grown up with HIV since birth, speak passionately of the continued need for her and other young positive people to share peer support through interstate events, such as Camp Goodtime.

Wearing my other hat as co-convenor of NAPWA's international portfolio, I was particularly interested in the sessions dealing with migrant and international issues. Ian Grubb, health policy advisor in the HIV/AIDS unit, at the World Health Organisation in Geneva, gave two presentations on the progress and challenges of scaling up HIV/AIDS programs worldwide, including the failure to reach the target of 3million people on ARVs by 2005. WHO is also failing to lead by example on GIPA, the Greater Involvement of People with HIV/AIDS, judging from Ian's wry comments on the lack of acknowledgement and participation of positive people, in the doctor-dominated WHO.

Neville Braybrook

Attending NAPWA this year was a first for me and some time back I submitted an abstract which was accepted. I presented a paper on being HIV positive and practicing in the sector, which of course is not a new subject but it is one that has been taken for

granted, and organisational policies around this have become out of date. While much of the effort to keep up with change is around care, support and prevention, little has been done to actively retain and support positive workers through clear and current policy. My interest is to develop this so that positive workers can be retained, and can inform on issues along with the positive community.

Also at NAPWA I focussed on attending presentations that had a care and support angle. This is the area that interests me the most and where I would like to develop my skill base. Making contact with my interstate counterparts and NAPWA representatives helped me better understand how Victoria sits in comparison to the other states. It also helped me understand how important the contribution of state orgs is to NAPWA. The VAC/GMHC and PLWHA Victoria jointly funded my attendance so thank you for the privilege.

Pat Garner

NAPWA was as usual a most enjoyable experience and full of highlights. It was great to catch up with friends from other states, meet new people, compare notes and ideas, discuss generalities and contribute to workshop discussions. To particularise, 2 items really took my attention and interest.

#1 The session on Ageing.

Before the advent of ARVs, this was a subject that did not enter into the equation - nobody was going to last long enough to age!!! Now, we find that it is a very relevant and important part of PLWHA's lives. They, like anyone else, have to make provision for this aspect. It is envisaged that by 2010, 50% of the positive community will be over the age of 50 (Pitt). This then begs the question - what and how can PLWHA organisations assist? The major areas to be considered and addressed are health, housing, aged care, service provision,

financial management. PLWHA members should be aware that these issues are on the future agenda and so should be encouraged to contribute their thoughts and ideas when the time is right. Make your opinions known and you are then assisting yourself for when you belong to this special "aged" category.

#2 The Declaration of Rights for People Living with HIV/Aids.

This Declaration was officially declared and promulgated at NAPWA, and was met with unanimous approval. It is a comprehensive declaration that covers 21 major points. I would encourage our members to obtain a copy and I am sure that this could be organised through the Office. I sincerely hope that it will be widely distributed and made known to all sectors of the general community.

Over the last couple of weeks, I spoke at St. Francis Xavier Church, Corio, and at St. Anthony's, Alphington, on account of World Aids Day and representing Catholic AIDS Ministry and PLWHA.

At the conclusion of each of these talks, I presented a copy of the Declaration to each Parish, and I was thrilled and encouraged to be told that they would be displayed prominently in each Church. This is surely a good forward sign of wider acceptance, which will hopefully allay the "myths" that still abound. Already, we have mooted the idea of wider distribution of the document.

So, thank you NAPWA, Gabe and Jo, and all the hard workers who put together this wonderful conference which, I am sure, enriched all those who attended, and my deepest wish is for that enrichment to flow on to all members.

Stephen Eustace

I attended the 10th annual conference of People Living with HIV/AIDS in Adelaide as a Board representative in my capacity as Treasurer of PLWHA Victoria. Although I was unable to contact any other Treasurers or Webmasters, I was to meet and greet many Board members of Victorian and Interstate HIV/AIDS organisations and attend some eight or nine workshops covering everything from new and emerging treatments to the care and

support needs of the combination of HIV and Aging, the latter of which I have a personal interest as I find it is often difficult to determine whether a particular illness is due to HIV/AIDS or the fact that I'm aged 64.

Overall I was pleased to learn of the many efforts of other organisations in this field.

Feedback: PLWHA Victoria Staff

Sonny Williams

Attending an event, function or meeting in a new role is always challenging; going to the NAPWA conference in a new role from a new state was a whole new ball game. You are in a sense the new kid on the block again, so it's natural that you wonder what people have heard about you, are you on the right track, what are you up against and the yard stick you are being measured against. Layered on top of this of course is the fact you have your staff and the vast majority of your board present at the conference so you feel in a sense as if all eyes are on you and you are in a do or die situation. PLWHA Victoria also had five abstracts accepted for presentation over the three days of the conference show casing aspects of our work over the past twelve months, so as you can see no pressure at all!

Well NAPWA gave me the opportunity to link up with people I have met at previous conferences, I was able to meet with my former boss as well as an opportunity to network across the three days of the conference. It is always great to check out programs other organisations have on offer, and talk about what has work, what hasn't, plus how we can work together better and talk up my new organisation! The other aspect of being at the conference is the chance to observe the people you are working with; how they interact with their peers and other delegates, picking up on their strengths and weakness, the styles they adopt and their ability to adapt to different situations and the feedback you receive.

NAPWA also provided me with the opportunity to introduce Sarah Bearup, the new Executive Director for Positive Women Victoria, to various members and organisations I have worked in partnership with over the years. It's

always good to have someone who can provide the introductions especially when you are new to the area. After all it can be intimidating when it is your first conference.

Attending conferences is a two way street, you get out what you put in. Conferences are hard work. You are working from the time you arrive until you leave; from over a cup of coffee, a meal break, attending presentations and participating in feedback sessions. Your time is taken up.

Alan Strum

I was most impressed with the solidarity of positive people attending this conference. What stood out for me the most was that there were many people attending the conference who still live in isolation with their illness. As such, this conference provided a safe place where many people were able to gather together, learn new information, and share stories about their experiences.

As a staff member I was asked to organise and run two workshops with presentations and attend one panel. The first workshop was on libido and HIV where I opened with a brief description of sexual function for both men and women and some of the reasons why people with HIV experience problems with sexual function. Dr Virginia Furner from Albion Street in Sydney then presented on the physical and emotional reasons that may cause problems with sexual function. We then broke out into separate groups where men and women could discuss their issues in private.

The second workshop was on the changing roles of Treatment Officers in Australia. This was a joint effort presentation developed by all Treatment Officers from around Australia, the Treatment Officer's Network. It was great to see how Tony Hand from NTAC provides services to clients in the remote area of Alice Springs. Jenny MacDonald presented on all the aspects of the different work that Treatment Officers do around Australia and I presented on the history of Treatment Officers. Together we were able to present to the community on the diverse roles and services we provide for our clients around the country. What really stood out is that as a Treatment



Officers, we really have to be a jack of all trades, not only providing information on HIV and drug therapies but also providing information on immigration, travel, diet, exercise, how to access services, advocacy, housing and the list continues.

My congratulations to NAPWA who really did a splendid job putting together this highly informative and engaging conference. I would strongly suggest people consider attending the next conference in 2 years time as this conference really does have something for everyone and I think anyone from the HIV community would benefit from attending.

Suzy Malhotra

The NAPWA conference was my first and like all novices, I was both daunted and intimidated by what I thought I could expect. The reality was far from that and I found the experience welcoming and informative, with the opportunity to converse with some of the most respected and experienced members of the sector.

I was overawed by Rodney Junga-Williams' emotional and welcoming speech and enjoyed the wryness and insight of Ian Grubb's presentation on the HIV sector globally. On behalf of PLWHA Victoria, I gave a presentation on the Health Promotion experience of Victoria and

discussed the efficacy and success of our programs such as the Treatment Interactive Events.

The conference was particularly significant for me because of the opportunity to hear Guy Kharn talk about the phenomenal success of Positive Plots, the gardening space for plwha to address the ever present issues of social isolation and poverty. Guy has invested skill, expertise and commitment in setting up the project and has now left the organisation with a legacy that we will continue to build upon.

I'd like to thank NAPWA for putting on a fantastic conference and for giving the opportunity to so many individuals from the HIV community to come together and share their skills, experience and friendship.

Max Niggli

This was my third NAPWA Conference that I have attended and was by far the most diverse in both the people attending and the presentations. I was particularly impressed with the opening and closing plenary and the poignant speeches by Rodney Junga-Williams.

Ian Grubb's presentations and international perspectives of working for the World Health Organisation provided valuable insights.

Michael Salter's presentation on "Developing a Charter for Community Engagement" emphasised the critical importance of engagement between the research and community sectors. The benefits of capitalising on community strengths provide legitimacy on both academic and community levels that collaboration brings to the research.

Peter Canavan's presentation on "Finding the place of wellness in Health Promotion" showed that there were gaps in PLWHA health promotion requiring additional focus with the proposal for a National audit of emerging issues. Peter stated that there needs to be a re-development of the Ottawa Charter in more culturally specific ways.

I presented a short workshop on "Positive Speaking for Positive People" to an enthusiastic group including delegates from Papua New Guinea.

NAPWA's Conferences are such a great opportunity to re-establish contacts with my peers from interstate and overseas, and creates an environment that is re-invigorating allowing me to have a host of new ideas for the coming year.

Declaration of rights for people living with HIV/AIDS

18 November, 2005 - 6:50pm

Life • Love • Participation

The National Association of People Living with HIV/AIDS (NAPWA) is Australia's peak non-government advocacy organisation representing PLWHA community based groups from each of Australia's States and Territories.

WORLDWIDE, approximately 40 million people live with the human immunodeficiency virus (HIV), which causes AIDS. Half of all adults living with HIV/AIDS are female and in sub-Saharan Africa, the most affected region, the figure is nearly 60 per cent¹. Twenty million people have died from AIDS since the first cases were identified in 1981. More than 14 million children have become AIDS orphans, and despite antiretroviral therapy that has significantly reduced AIDS-related deaths, the HIV population has expanded alarmingly, increasing by more than 50 per cent since 1991².

The need to find effective ways to deal with the transmission of HIV, in all nations, rich and poor, is now greater than it has ever been. And with more people living with HIV than at any time in our past, the need to protect their health and human rights is also greater than it has ever been.

Human rights are fundamental to the response to HIV, for three reasons: *ethical*, because all human beings have a right to health, to life and all other human rights; *legal*, to implement the International Declaration on Human Rights and the many other international and national laws and guidelines on human rights, and for *pragmatic* reasons, because it is beyond doubt that a human rights based response, which empowers our whole community to avoid infection, and which treats those with HIV with respect and inclusion and aims to properly manage their health, is significantly more effective in reducing the spread of HIV than a response of silence, discrimination or exclusion³.

The Rights we now declare uphold not only the rights of those with HIV and AIDS, but are made for the greater good of our community in their promotion of its ethical and physical health. These Rights implement the self-evident precepts, embraced in international law, ethics and basic common sense, that no one human is more human than another, that no one human being has more worth than another, and that all human beings have equal human rights.

These Rights are declared to improve the quality of our *Life* and the *Life* of the community at large. They are centred in *Love*, as this is the ultimate foundation of all human rights. They will be carried out through our *Participation* in all aspects of the consultative and decision making processes in relation to them.

These Rights are firmly anchored within existing human rights laws and guidelines, and adopt, in large measure, the *International Guidelines on HIV/AIDS and Human Rights* of the United Nations Commissioner for Human Rights (UNHCR) and the Joint United Nations Program on HIV/AIDS (UNAIDS), revised in 2002 after extensive worldwide consultations and chaired by eminent Australian jurist, Mr Justice Michael Kirby⁴.

We, the peoples in Australia living with, and affected by HIV/AIDS, through our National and State representative bodies, CONFIRM our Right to Life, Health and the other Rights enshrined in the *Universal Declaration of Human Rights*, and DECLARE, for ourselves and for the good of our Society in general, our RIGHTS as follows:

1 (Full Rights)

The full complement of human rights under international law, those most relevant to HIV/AIDS — including the Right to:

- life
- liberty and security of person
- participate fully in public and cultural life, including freedom to practice spiritual and cultural beliefs
- the highest standards of physical and mental health
- non-discrimination, equal protection and equality before the law
- share in scientific advancement and its benefits
- freedom of opinion and expression
- freedom of movement
- privacy and confidentiality
- freedom of association
- work
- marry, form relationships and have a family
- equal access to education
- social security, assistance and welfare
- a reasonable standard of living
- seek asylum
- be free from torture and cruel, inhuman or degrading treatment or punishment.

2 (Co-ordinated Response)

The Right to a coordinated and effective response from all levels of government in Australia to the HIV/AIDS pandemic.

3 (No Discrimination)

The Right to live free from harmful discrimination or stigma which in any way relates to our positive HIV status, and to be treated with respect and dignity.

4 (Sex)

The Right, as consenting adults, to a full and satisfying sex life. 5 (Participation) The Right to:

- participate at every level of consultation, decision making and implementation regarding HIV/AIDS advice, policy, laws, treatments, funding, research, education, resourcing and financing, and all other matters relevant to the HIV/AIDS response;
- be represented in the governance of all organisations that are involved with HIV/AIDS or which provide any service in that regard; and

- form autonomous, self-governing organisations of people living with HIV/AIDS and for those organisations to be consulted and listened to in all levels of HIV/AIDS decision making.

6 (Testing)

The Right to confidential and comprehensive pre- and post-test counselling and to give informed consent. The Right to HIV testing and monitoring without coercion. This includes an enabling environment for the upholding of privacy and the protection of confidentiality.

7 (Treatment)

The Right to the highest quality and standards of specialist medical treatments of our choice. The Right to refuse treatments if we so choose.

8 (Care)

The Right to any quality and specialist medical care, palliative care and support services suitable and acceptable to the individual including:

- the Right to life-saving and life-prolonging health care;
- the Right to have our psycho-social needs addressed as well as our biomedical needs, and in particular, the Right to quality and specialist psychological and mental health services;
- the Right to make fully informed and voluntary decisions about our participation in clinical trials, to access quality care regardless of our agreement or refusal to participate in HIV/AIDS research;
- and in each case we have these Rights without regard to our ability to pay or the absence or type of health insurance and coverage.

9 (Medications)

The Right to access HIV/AIDS medications and treatments as and when we need them, and regardless of our capacity to pay. This includes the Right, protected through legislation, to access and advocate for new and emerging medications, as clinically necessary and through emergency access measures.

10 (Family and Relationships)

The Right to marry, to form and maintain family and partnership arrangements, and care arrangements as we choose, including:

- the Right of HIV positive women and HIV positive men to have children and to make fully informed decisions in that regard;
- the Right to adopt children, and to maintain custody of our own children; and
- the Right to require that Australian Governments protect and promote these Rights in the legal system and create supportive and enabling environments for women, men, children and the family and the partnership arrangements we have described herein.

11 (Housing)

The Right to acceptable standards of housing, including the Right for people with life-threatening HIV/AIDS to have priority access to public housing.

12 (Education)

The Right to education, at all levels within the community, unrestricted on the basis of HIV status.

13 (Prisoners)

The Right to community standard health and treatments for those with HIV/AIDS in custodial settings. The Right to health for those in custody. This includes the Right to access, treatment

prevention technologies, condoms, clean needles and the like free of charge.

14 (Injecting Drug Users)

The same Right to health as any other Australian. Access to programmes which protect the health of people who inject drugs and reduce HIV transmission (such as needle syringe programmes, substitution and rehabilitation therapies) are a human right. Laws must be enacted by Australian Governments to protect that right and in so doing the public health of the community.

15 (Indigenous)

The same Right to health as any non-Indigenous Australian, and the same Right to the same standards of health as any non-Indigenous Australian, delivered in a culturally appropriate way, which reflect the differing and particular needs of Indigenous Australians.

16 (Multicultural)

The Right to receive all information and services, and to attain all of the Rights which we now declare, provided in a culturally acceptable manner and spoken and written in the language of their choice, and through an interpreter if necessary.

17 (International)

The Right to require that all governments, organisations, corporations and other bodies in Australia share their knowledge and experience regarding HIV/AIDS issues and promote and protect our Rights at the national and international level. This includes the fulfilment of Australian international commitments through specific HIV/AIDS programs and in the programs of all groups involved in the Australian international HIV/AIDS response.

18 (Freedom of Movement)

The Right of people living with HIV/AIDS to freedom of international movement and migration privilege, as accorded any other individuals. This also includes the Right to seek asylum and not be refused on the basis of their HIV status.

19 (Death)

The Right to die with dignity and in the manner the individual chooses.

20 (Implementation)

The Right to secure, through policy and legislation, protection in both the public and private sectors for those with HIV/AIDS. This should be achieved through enforceable codes of conduct and professional practice.

21 (Accountability and Enforcement)

The Right to require that Australian Governments enact and adopt monitoring and enforcement mechanisms to implement our Rights, with appropriate penalties where that is not done, together with affordable and effective administrative and civil remedies to enable and ensure our Rights are appropriately enforced. The Right to require Australian Governments to review, enact and reform legislation to protect and promote each of our Rights which we now declare.

*Declared by people in Australia living with HIV/AIDS, through their National, State and Territory representative bodies at the Tenth Biennial NAPWA Conference, Adelaide, South Australia on Friday November 18, 2005.

¹ United Nations Population Fund, International Conference on Population and Development, *Program of Action*, September 1994

² UNAIDS 2004 *Report on the Global AIDS Epidemic*, July 2004.

³ Dr Peter Piot, UNAIDS Executive Director, Speech to the 59th Session of the UNHCR, Geneva, 19 March 2003; see also Ralf Jürgens, *Human Rights for People Living with HIV/AIDS*, Partnership to fight HIV/AIDS in Europe and Central Asia, Dublin, 24 February 2004, with numerous references.

⁴ UNAIDS and UNHCHR, *HIV/AIDS International Guidelines on HIV/AIDS and Human Rights* 1998.



Treatments Update:

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what's new,

what's changed

Bioject2000 clinical trials for T-20

The fusion inhibitor known as T-20 or Fuzeon stops HIV from entering into cells and has been successful in reducing viral loads and increasing CD4 counts. T-20 is an injectable drug that has few side effects except for injection site reactions. In order to overcome difficulties that some people may have injecting T-20, Roche will be testing a gas powered injection gun called Bioject2000 in two clinical trials in Australia. The first study will be recruiting a small number of people who have never used T-20 previously. The second study will recruit larger numbers of people into three randomised arms; injecting with the current sized needle (27), injecting with a smaller needle (31), or injecting with Biojector2000. All participants will have the option to access the Biojector2000 after the first 12 weeks of the study. Access to the Biojector2000 will be limited and will only be available through clinical trials in Australia as the product is not registered for general use. Talk to your doctor if you are interested in participating in one of these studies when they commence.

Hepatitis C drug access changes

PLWHA Victoria has been informed that the Therapeutics Goods Administration has recently changed the rules around access to Hepatitis C (HCV) drug therapy. The requirement for a liver biopsy has been removed which will result in more people with earlier liver disease having access to the life saving treatment. This is particularly important for people who are coinfecting with HCV and

HIV, as it means access to HCV treatment will be available earlier when the immune system is more functional and can assist better in eradicating the Hepatitis virus from the liver. Poslink will update you with the official indications once they have been released.

HCV in semen

In recent years researchers have been advising that the rate of sexual transmission of Hepatitis C (HCV) has begun to rise. A study published in *AIDS* in November looking at HCV in the semen of HIV positive and HIV negative men has shown that people with HIV are more likely to have HCV present in the semen than their HIV negative counterparts (38% vs 18%) and that HCV in the semen was related to the HCV viral load in the blood. Investigators advised of the importance for people co-infected with HIV/HCV to practice safe sex to prevent transmission of HCV to sexual partners.

Bone problems

An Italian study of 179 HIV positive people published in *Journal of Acquired Immune Deficiency Syndromes* has shown that 54% of people have problems with their bones. 43% had osteopenia, a decrease in bone mineral density, while 11% had problems with osteoporosis, a decrease in bone mass. 37% of the study population was female. Researchers found a correlation with older age, low body mass index, a high viral load and duration of antiviral therapy. It was concluded that the correlations found indicate that HIV and antiviral therapy play a role in osteopenia and osteoporosis in people with HIV.

Death rate for HIV same as general population

A study in France of 2279 people with HIV has compared the rate of death for people with HIV to the general population for both gender and age. All study participants were taking protease inhibitors as part of their HIV therapy. The study found that people with a CD4 count greater than 500 had a death rate the same as the general (matched) population.

2 CCR5 inhibitors stopped

Schering Plough has announced they have stopped a treatment naive clinical trial for their CCR5 inhibitor 'vicriviroc' due to lack of efficacy. While a treatment experienced study is continuing it is looking like this product may not proceed for further development.

Meanwhile GlaxoSmithKline has announced the withdrawal of their CCR5 inhibitor 'aplaviroc' from further development due to liver toxicity problems occurring in patients enrolled in two studies.

Maraviroc (CCR5) toxicity reported

Recently two of the CCR5 inhibitor drugs were withdrawn from clinical trial due to liver toxicity issues. This has left Pfizer's maraviroc as the only continuing CCR5 inhibitor in clinical trial that is close to registration. Pfizer have reported that one case of severe liver toxicity has been reported in over 1300 people studied. The toxicity resulted in a liver transplant being required for the affected patient. However, the case identified was complex with other compounding factors that may have resulted in the toxicity occurring in this one patient. The

Data Safety and Monitoring Board made some recommendations for maraviroc protocol changes that have all been implemented by Pfizer to ensure the same complications do not occur with other patients in the study.

New Hep C treatments

Three new drugs were presented at a conference of the American Association for the Study of Liver Diseases for the treatment of Hepatitis C (HCV). Each drug is still in early development (phase I or phase II). The new drugs appear to work in people who were previously non-responders to standard treatment. One of the new drugs is a nucleoside analogue (like ribavirin) called Valopicitabine while the other two drugs are protease inhibitors called SCH503034 and VX-950.

New protein inhibits HIV

A test tube study published in *Gene Therapy* has shown that a protein extract from St John's Wort can inhibit HIV gene expression by inhibiting cellular and HIV proteins that switch on or enhance the HIV gene replication process. The protein has been called p27^{sl}. St John's Wort is a complementary therapy often used for the treatment of depression. The investigators warn people with HIV not to self-medicate with St John's Wort as it interferes with HIV protease inhibitors and can lead to the development of viral resistance to the protease inhibitors. Additionally, while the protein extract inhibits HIV in test tubes, the investigators have pointed out that they don't know how much of the protein is naturally occurring in the plant extract of St John's Wort, how much would be required to inhibit HIV and whether the protein actually makes it into the cells in the body where HIV resides. *[Editor's note: This is an interesting development. It's always nice to see that a naturally occurring substance can work against HIV. However, as is pointed out in the article it is important that we wait*

for more information before deciding whether this is a good option for people with HIV to use. I need to emphasize St John's Wort does interact with some HIV drugs and is not recommended for use for people on treatment.]

Efavirenz levels and toxicity

Approximately 50% of people still experience mild neuropsychiatric side effects from efavirenz a year after commencing treatment. A Spanish study of 17 people (3 women) has shown that people with efavirenz blood levels higher than 2.74 micrograms were 6 times more likely to experience central nervous system (CNS) problems with the drugs than those with lower levels. *[Editor's note: Information like this is interesting only. I find it frustrating when this type of information is released and the investigators haven't looked at whether reducing the amount of efavirenz to below 2.74 micrograms in the blood would have reduced or stopped the CNS side effects in the affected patients.]*

HIV-1 adapting to humans

A Belgian study has shown that HIV-1 appears to be adapting to humans over time. Researchers compared samples of HIV collected in the late 80s and compared their level of 'fitness' to HIV samples collected in 2002-2003. On average HIV samples collected in 2002/03 were only 55% as fit as samples collected earlier in the epidemic. The researchers advised this is probably due to the virus adapting to the human immune system and losing some efficiency via mutations in order to avoid being detected by the immune system. It is thought that the more the virus mutates and the more fitness it loses, the less harm it will ultimately cause in the long term.

10th European AIDS Conference

Early HCV treatment

2 studies were presented on Hepatitis C (HCV) and HIV co-infection in people treated shortly after infection with HCV showed that early HCV treatment was as good as treating people with later HCV disease regardless of HCV genotype.

OK study at 72 weeks

The OK study is a pilot study investigating the use of Kaletra only (monotherapy) vs three drug therapy including Kaletra in 42 people who had been virologically suppressed for more than 6 months before entering the study. At 72 weeks, 81% of those taking Kaletra only still had an undetectable viral load which was comparable to those in the triple therapy arm.

TMC 125 (NNRTI) results

TMC 125 (etravirine) is a new NNRTI which has been designed to work against virus that is resistant to nevirapine or efavirenz. In the studies mentioned below an old formulation of TMC125 was used. However, a newer version has now been developed that increases the activity or absorption of the drug that is now being tested in Phase III studies.

The TMC125-C203 was designed to look at toxicity of the new drug in 240 people at 400mg, 800mg and 1200mg twice daily versus placebo for up to 47 weeks depending on the dose taken. TMC125 displayed an 8% incidence of rash that was similar between men and women and did not display any neurological activity. In general the drug appeared to be safe and well tolerated.

The TMC125-C223 study was designed to investigate that efficacy of the new drug in 199 people with virological failure at 400mg or 800mg doses taken twice daily with optimal

background therapy versus placebo. After 24 weeks both groups had a viral load reduction of just more than 1 log (e.g. reduction from 100,000 copies to 10,000 copies etc). 75% of participants dropped out of the placebo group versus only 6 who dropped out of the active drug group.

[Editor's note: In a recent US press release, Tibotec advised of a study commencing shortly that will investigate the safety and efficacy of their new protease inhibitor TMC 114 in combination with TMC125. Both of these drugs are reported to work against drug resistant HIV. This will be the first time that two new drugs will be available in combination in a clinical trial and is good news for people with few options. It would appear that this clinical trial will be running in Australia and will most likely commence recruitment within the first three months of 2006.

NB. In a recent press release from Tibotec, a phase II TMC125 study has been cancelled due to poor virologic response to people taking the active drug. However, given previous good results, Tibotec will be continuing with the development of the product in Phase III studies which they say are better designed than the study that was cancelled. The company will do further investigations to see whether they can find an underlying cause for the poor performance of the drug in the phase II study.]

Seventh International Workshop on Adverse Drug Reactions and Lipodystrophy in HIV, Dublin.

'Poly' pill for heart disease

At this conference Professor David Cooper from Sydney advised of the intention to investigate the benefits of a new 'poly' pill for cardiovascular disease. The pill would be studied in 8000 people

with HIV if the consortium is successful in raising funds for the clinical trial. The 'poly' pill only cost around \$20 per person per year and aims at reducing blood pressure, reducing cholesterol and preventing blood clots. Some experts believe the 'poly' pill should be given to anyone over the age of 55 and that such a pill could potentially reduce the risk of heart disease by 50% and stroke by 60%. Others believe that a 'one size fits all' approach would not work in the HIV population.

Surprise fat gain

A 12-week Australian study in 33 people with HIV investigating the efficacy of pravastatin for reducing cholesterol has shown a surprising result in fat gain. The 16 people receiving pravastatin showed an increase in subcutaneous limb fat (fat under the skin) of 0.72kg compared to an increase of 0.19kg in the control group for those not taking the drug. The investigators advised that the increase in limb fat that was achieved in only 12 weeks was equivalent to or better than limb fat increases observed after 48 weeks in people who had switched from AZT/d4T to either abacavir or tenofovir in the RAVE sub-study. AZT or d4T are the key drugs associated with fat wasting. Only 2 people in this study were taking AZT or d4T.

Facial fat improves in RAVE sub-study

The UK RAVE sub-study study investigated the changes in body fat in people who changed from AZT/d4T to either tenofovir or abacavir. 47 people entered the study. 48 week results showed that 68% of participants either had improvements in cheek fat or no further decline. There were no improvement in fat stores around the temples. People taking tenofovir had a 0.39kg increase in limb fat while those taking abacavir increased by 0.3kg.

Supplement increases fat

A study from Finland presented data on fat gains achieved in people taking a supplement called Nucleomaxx (mitochmol). Nucleomaxx is a sugar cane extract rich in the DNA (RNA) building block uridine. Uridine is normally manufactured inside cells by healthy mitochondria and is used for DNA (genetic) and RNA (protein) synthesis and cell function. In this study 20 people taking AZT or d4T were randomised to receive Nucleomaxx or placebo. AZT or d4T are known to cause lipoatrophy or fat wasting. Nucleomaxx was taken three times daily for 10 days each month for three months only. Limb fat increased by 0.9kg in the Nucleomaxx group. Total body fat increased from 19% to 25% and visceral (tummy) fat also increased by 0.2kg. *[Editor's note: Nucleomaxx looks like a promising treatment for lipoatrophy, especially for people who need to take AZT or d4T. More research is required on how to use this product. There are some indications that it should not be taken with ddI. The data shown is the scheduled dose taken in people taking AZT or d4T and may not apply to people not on these drugs. I recently spoke with Dr Graeme Moyle from the UK who advised people who wish to take Nucleomaxx should only take it for a maximum of three months. Nucleomaxx costs approximately \$450AUD per month and can be purchased from*

www.tabsandmore.com. Other sources of uridine may be available elsewhere at cheaper prices. If deciding to take Nucleomaxx please consult with your doctor first. PLWHA Victoria has contacted NAPWA to discuss the possibility of a Nucleomaxx clinical trial in Australia and we will keep you informed if any studies are to commence here]❖

Further information:

www.nucleomaxx.com (information)
www.tabsandmore.com (purchase)
www.mitocmol.com (information and discussion groups)



Planet Positive
MELBOURNE

An Evening for Positive People & their Friends

Wednesday February 8
From 7.30 till late

Call 9865 6772 for location

NO COVER CHARGE

Light catering provided

First drink free

planetpositive@optusnet.com.au

Planet Positive is a project of
PLWHA Victoria



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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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Melbourne
Sexual
Health
Centre

Qualified sexual health nurses are now offering free and confidential sexual health testing and treatment at selected sex on site venues. Call 9347 0244 for details or visit our walk-in clinic in Carlton.

No appointment necessary. If you wish to be anonymous, you can - we don't ask for your Medicare Card.

Melbourne Sexual Health Centre
580 Swanston Street, Carlton
Telephone: (03) 9347 0244

Opening hours:
Monday - Thursday: 9.00am - 5.00pm
Friday: 1.10pm - 5.00pm

www.mshc.org.au

get wise get screened

If you are a sexually active man who has sex with other men, it is recommended that you be screened for sexually transmissible infections every 3 to 4 months.

Additional clinics specialising in sexual health:

(Medicare card and ID cards are required. Some clinics may charge for services).

The Centre Clinic
Rear 77 Fitzroy Street
St Kilda
Ph: (03) 9525 5866

Carlton Clinic
88 Rathdowne Street
Carlton
Ph: (03) 9347 9422

Prahran Market Clinic
131 Commercial Road
South Yarra
Ph: (03) 9826 4500

Middle Park Clinic
41 Armstrong Street
Middle Park
Ph: (03) 9699 4626