

talkabout

Where we speak for ourselves

#122

august - september 2002

The Magazine of People Living With HIV/AIDS NSW Inc.





HIV - INTEGRATIVE TREATMENTS FORUM

www.plwha.org.au

The Forum aims to raise general awareness of and provide information about how to integrate complementary therapies in the treatment of HIV.

Integrative treatments combine standard medical therapies with a broad range of natural and holistically orientated treatments, which are vital in the long-term management of HIV and toxicity.

SATURDAY, 26 OCTOBER 2002, 9.00am - 4.30pm

Target Theatre, Powerhouse Museum

Cnr Harris and Macarthur Streets, Ultimo NSW 2007

SPEAKERS*

- Jim Arachne (CTTO**, VAC)
- Elyane Brightlight (Acupuncturist)
- Ingrid Cullen (Fitness Trainer)
- Peter de Ruyter (Herbalist)
- Maree de Suza (Kinesiologist)
- Megan Mathews (Medical Practitioner)
- Greg Millan (Reflexologist)
- Richard Murphy (CTTO, ACON)
- Simon Sadler (Dietician)

There will be the opportunity to ask questions at the end of each session.

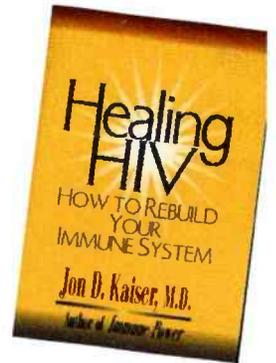
*Speakers may change without notice. **Complementary Therapies Treatments Officer.

COST \$22.00 and \$11.00 (Concessions)

Lunch, morning and afternoon tea are kindly supplied by **European Catering**. A copy of *Healing HIV, How to Rebuild Your Immune System*, by Jon D Kaiser MD (kindly donated by the author) and other materials will be provided to attendees.

There are limited places so book early to avoid disappointment. No refunds, although place is transferrable.

Please retain receipt for entry to Powerhouse Museum.



PLWH/A (NSW), INC HIV - INTEGRATIVE TREATMENTS FORUM

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It's lifestyle in this issue of *Talkabout*.

The documented effects of many prescription drugs used to treat hiv/aids have led people to investigate alternative or experimental treatments. The benefits and detrimental effects of cannabis, used by some to alleviate the symptoms of chronic disease, are a hot topic. Promoting the benefits of cannabis for medical purposes is controversial.

If you have hiv/aids and you don't currently use cannabis, the Publications Working Group isn't advocating that you go out there and look for it. Cannabis is not a legal drug and there are a lot of adverse effects.

In John Cumming's treatment update on page 10, some of these adverse effects are listed. Depression and anxiety are major concerns for many living with hiv/aids. If you are thinking about trying cannabis to see whether it improves your appetite or helps you sleep better, think about the source. It's the era of hydro – hydroponically grown cannabis – and the cocktail of pesticides and fertilisers often used might outweigh the benefits. Think carefully about what you might be consuming.

ACT UP (AIDS Coalition To Unleash Power) fought for access to effective and appropriate treatments that had been tested. Plwha need to know more about the pros and cons of canna-

bis and that relies on trialing a tincture of cannabis that contains no additives.

Friendship, support, and a healthy lifestyle are the main ingredients for living longer and having a better quality of life. Maintaining, or returning, to work is possible if you've got support, security and the opportunity to access training. Use the services provided to get healthy and stay healthy.

Housing isn't off the agenda. Supported accommodation services will return next issue and an update on the Department of Housing's changes to SASS.

Susan Hawkeswood

in this issue

TALKABOUT

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DISCLAIMER

Images of people included in Talkabout do not indicate hiv status either positive or negative.

Agony Aunt, Rob Hardy, gives plwha some advice on surviving a DSP medical review on **page 4**.

Treatment Briefs on page 5 looks at two recent studies – tenofovir and the effects of combination therapy during pregnancy. For more details on the combination therapy and pregnancy study, see Michael Carter's report on **page 13**.

Does cannabis help? ACON Treatment Officer John Cumming summarises some of the medical and legal issues on **page 10**.

From illness to fitness – Getting fit for the games, in this issue's **colour section**, is Shane Hurley's story about regaining strength.

HealthyLIFE+, coordinated by the Positive Men's Project at ACON, is



p os action

with **Antony Nicholas**, Executive Officer PLWH/A (NSW)

After being told that my last few pos actions were too contentious, I have decided to focus on something that I assume is not controversial at all but we in the office are quite excited about.

Recently, NSW Health called for expressions of interest for hiv health promotion demonstration projects across the state. PLWH/A (NSW) has been very fortunate (and rightly so, since a lot of blood, sweat and tears went into the applications) to receive funding for several new projects focusing on health promotion for hiv positive people. This allows PLWH/A (NSW) to develop its own health promotion messages specifically targeting information and education needs of hiv positive people in NSW. Through collaboration with other organisations, the information will be relevant to all hiv positive people across Australia.

Over the next several months, you may start to see adverts asking for participants to engage in workshops, focus test designs and information, and a range of other activities. We hope that hiv positive people will engage in these, as they will assist us to produce better resources with you, not just for you.

Kathy Triffit will be the Senior Project Officer responsible for these projects. Kathy is well known, in the sector, through the

retreats, and her academic and published work on 'self documentation and self imaging for people living with hiv and aids'. People may not also know that Kathy was one of the original founding committee members of the PLWH/A (NSW), as it was known back in 1989.

There are several key projects that will have some overlap and all will benefit from input and design from the community. The projects will produce workshops, forums and campaign material. In the near future, Talkabout's colour insert will grow to include health promotion and education information. If you have some ideas on these, please send them to healthpromotion@plwha.org.au.

Other projects will cover positive sexuality, sexual health, visibility, healthy lifestyles and building awareness of hiv and plwha in the general community. As part of our other health promotion work, our well respected Positive Speakers Bureau will develop a resource for schools about the lives of positive people and basic safe sex messages for teenagers. This will link the impact of having an hiv positive speaker in schools with important information and education for youth.

All these projects will increase the profile of PLWH/A (NSW) and hiv positive people

within our communities. These projects will assist PLWH/A (NSW) to become one of the most prolific plwha organisations in Australia, in regard to health promotion, and assist build stronger links with other organisations that produce resources, like ACON, AFAO and NAPWA.

projects will cover positive sexuality, sexual health, visibility, healthy lifestyles and building awareness of hiv and plwha

returning. Graham Norton gives the lowdown on **page 12**.

The Positive and Negative Conference, held this year in Sydney, explored serodiscordance. Four views about the conference begin on **page 14**.

A recent retrospective held in conjunction with the Changing

Communities Conference is reviewed by Kathy Triffit on **pages 16-17**.

Robert Baldwin, Clinical Nurse Consultant, took part in a session on hep C at the Rural HIV Forum held at Nelson Bay. See **page 18** for information about co-infection with hiv and hep C.

Volunteers who can help – and some of the organisations you can volunteer for – are featured on **pages 22-25**.

The Federal Privacy Act, introduced in December last year, aims to protect your personal information. PLWH/A (NSW) has finalised its Privacy Policy, published on **page 28**.

Q An hiv positive friend recently had a Disability Support Pension medical review and was told he was no longer eligible for the pension owing to health improvements. I've been hiv positive for 15 years and left work 8 years ago when I became unwell. Although my health has been good for the past two years, I feel anxious about the prospect of returning to work. With all the welfare changes being reported in the media I am now worried I could lose my pension too. What should I do?

A Don't wait until your pension is reviewed before you do anything. Planning ahead and setting achievable goals in the short-term is the key. Because many plwha are living longer and have improved health, it is likely that more people like your friend will have their pensions reviewed. However, an improvement in physical health is not the only factor to consider. There are other issues to address such as decreased confidence, loss of work skills, lifestyle changes and maintaining health while working. Returning to fulltime work after 8 years is overwhelming and not advisable. Focus on more achievable things you can do in the short-term to prepare yourself if you return to work in the future. Focus on engaging in activities that improve your self-esteem, develop skills, build work tolerance and help you adjust to a commitment or routine. Many plwha I work with have found that getting involved in volunteer work, courses or other personal projects is a good first step.

A huge range of volunteer opportunities are available. You can start with the number of hours you think you can cope with and gradually increase your workload as you adjust to the routine. The Positive Decisions Program administered by PLWH/A (NSW) offers a 3-month work experience and training program.

TAFE offers outreach courses for specific groups such as Information Technology for Mature Age Men. These courses can be a great way of breaking the ice to develop skills, confidence and engage with others. Community Colleges also offer a range of courses at reasonable prices for both work-related skills and leisure interests. Learning about a new interest or developing a personal project can provide a sense of achievement and build self-esteem. The Rattan Fund administered by The Bobby Goldsmith Foundation provides one-off grants for projects or activities that develop skills and improve wellbeing. TAFE also waives the enrolment fee for people on a pension.

For more information or to make an appointment, contact Rob Hardy from Positive Employment Support at the Bobby Goldsmith Foundation, ph 02 9283 8666, email rob.hardy@bgf.org.au

PLWH/A (NSW) Community Development Officer
Will Klaasen profiles what's happening in NSW

An apology

Apolgies to Les MacDonald of The Darlinghurst Bookshop for failing to acknowledge his generous support of PLWH/A (NSW) Inc in the last edition of Talkabout. The Darlinghurst Bookshop has long been a supporter.

The Bridge

Friends of the Bridge was formed by housemates, family, friends, carers and volunteers to raise money and increase the profile of the services provided to people living at The Bridge. All money raised helps create extra recreational and rehabilitation programs for residents. Thanks to this support, a garden program has been designed for Bridge residents with help from a 4th year horticultural student. For more information on how you can make a donation, volunteer or assist with supplies please contact Diana Jefferies on 02 9552 6428.

The Western Suburbs Haven

Living in the Western Suburbs and a little lonely for company, or thinking of picking up a new skill that is fun and helpful? If this is you, call Pat Kennedy on 02 9672 3600 and ask about Wednesday night sewing classes. I've heard excellent reports. The management committee is urging all members and anyone who lives in the west to continue offering their volunteer services. The Haven has been extremely busy and Pat really could use your help. Remember that on the nights of PASH, held every 2nd and 4th Saturday of the month, the raffles are held by The Haven. For more information on any of the support and rehabilitation programs The Haven runs, call or drop in have a coffee and chat.

Planet Positive - Positive Living Centre (PLC)

What can I say about the last Planet Positive night held 28 June at the PLC? Despite the chill, White Xmas and Plum Puddings was a huge success with one of the best crowds I have seen for a long time. Thank you to everyone who braved the night and came out. I would like to say thank you to all sponsors with our giveaway door prizes, Sharpes Chemist, BMG Records, Kens of Kensington, Signals, Bodyline, Café Comity, Aussie Boys, a big thank you to Kent Gryphon (our much loved Santa) and Shelly Legs Diamond who gave a great performance. The next Planet Positive is 6-10pm, Friday 13 September so let your imagination go.

Final thoughts

Recently, there have been letters to community newspapers about the advocacy role of a number of hiv/aids organisations. Over the last six months, I have asked all plwha, family and friends to give us case histories and documentation about your issues or it is very hard to compile information to use or employ useful strategies. For some, it is hard to write a letter, which is why we always advice people to ask someone you trust to do this for you.

We need times, dates, people involved and the facts of the situation. Keep a diary of all communication you have with service providers and others. Writing a letter outlining your issue can help you put aside your anger and frustration. In the last 6 months I have given out my email so you can provide us with the information we need. At the time of publication, no emails have come from plwha. If you have issues, my email is willk@plwha.org.au. All information you supply will be collected and used as directed by our Policy Guidelines.

treatment briefs

Tenofovir increases blood levels of Videx EC

A recent study has shown that the new nucleotide reverse transcriptase inhibitor Viread (tenofovir) can have a significant impact on the blood levels of VIDEX EC (didanosine)¹. The study, conducted in partnership with the manufacturers of both drugs, looked at how two different dosing approaches affected blood levels of Videx EC when taken in combination with tenofovir. Either Videx EC was administered without food two hours before taking tenofovir with food, or both drugs were taken together with food. When Videx EC was taken on an empty stomach, taking tenofovir 2 hours later caused a 46% increase in the blood levels of Videx EC. The increase in blood levels of Videx EC was even greater (60%) when Videx EC and tenofovir were taken together with a light meal. Similar increases were seen when Videx was given in the buffered tablet formulation in combination with tenofovir. Blood levels of tenofovir were unaffected by either Videx EC or Videx tablet formulations. These findings indicate that there may be an increased potential for Videx (didanosine) related side effects such as peripheral neuropathy and pancreatitis when is used in combination with tenofovir. At this stage the appropriate dosage for either Videx EC or Videx tablets when taken with tenofovir has not been established. It is therefore recommended that people taking tenofovir and either Videx EC or Videx tablets should be monitored closely for toxicities. A separate study has provided further evidence that tenofovir is effective against hiv that has become resistant to the nucleoside class of antiviral drugs².

Combination therapy and pregnancy

A study published in the New England Journal of Medicine has found that the use of antiretroviral medication by women during pregnancy does not lead to increased rates of premature birth¹. Researchers analysed data from several large studies that involved 2,123 hiv positive pregnant women. The women were divided into four groups based on whether they were taking combination therapy that included a protease inhibitor, combination therapy without a protease inhibitor, monotherapy or no therapy. It was found that the rates of premature delivery, low birth weight and other key criteria were the same for women receiving combination therapy without a protease inhibitor, monotherapy and no therapy. The study found that there was an association between protease-containing regimens and very low birth weight (less than 1,500 grams) but this finding was based on small numbers. Furthermore, it is likely that women who were taking regimes that contained a protease inhibitor had more advanced disease. Any small increase in the risk of low birth weight was therefore likely to be outweighed by the significant advantages of therapy for both mother and infant. These findings come at the same time the European Union has produced its 'first ever' guidelines for the prevention of vertical transmission of hiv from mother to baby².

1. New England Journal of Medicine (13th June 2002) Vol. 346; No. 24; Pages 1863-1870
2. Reuters Health, 20th June 2002

Treatment Briefs are written by ACON's Treatment Information Officers. Phone 02 9206 2036/2013, tollfree 1800 816 518, email treatinfo@acon.org.au

1. Bristol-Myers Squibb, Scientific Affairs Department
2. AIDS 2002; No. 16: Pages 1227-1235

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LawAccess NSW

LawAccess NSW was launched this morning by the Attorney General Bob Debus. The new service merges the Legal Aid Commission HelpLine and the Law Society of NSW Community Assistance Department. LawAccess NSW is a free service providing a single point of access to legal and related assistance services that are best able to assist with legal problems and questions. Law Access also provides free one-off telephone legal advice where the customers circumstances, type of matter or finances meet LawAccess criteria. Customers can contact LawAccess NSW for legal information and referrals on 1300 888 529, 1300 889 529 TTY or at LawAccess Online at www.lawaccess.nsw.gov.au

The Attorney also launched today LawAccess Online, a new web service of the Department, designed to provide easy access to quality plain language legal resources and legal assistance services from across the legal sector. The new service indexes resources from over 100 justice sector organisations and currently holds over 1,500 plain language factsheets. Customers can use a legal topic index to find resources on different areas of the law such as family law, drink driving and domestic violence or search for resources by language, keyword and various other methods. Almost one third of the resources on LawAccess Online are in languages other than English.

The service is an initiative of the NSW Attorney General's Department, NSW Legal Aid Commission, Law Society of NSW and

the NSW Bar Association in cooperation with the Combined Community Legal Centre Group and Public Interest Advocacy Centre.

LawAccess is a business centre of the NSW Attorney General's Department and is funded by the NSW Government and the Public Purpose Fund of NSW.

To find out more about LawAccess NSW, go to LawAccess Online at www.lawaccess.nsw.gov.au

AFAO and NAPWA launch updated hiv positive gay sex booklet

The updated *HIV Positive Gay Sex* booklet aimed at engaging hiv positive gay men and some hiv negative gay men in Australia on issues related to hiv serostatus, gay sexuality and sexual contact is now available. Published by the Australian Federation of AIDS Organisations (AFAO) and National Association of People Living with HIV/AIDS (NAPWA), NAPWA President Phillip Medcalf said the release of *HIV Positive Gay Sex* came at a crucial time:

'It is an important time for *HIV Positive Gay Sex* to be re-launched and simultaneously for a campaign for hiv + gay sex to be put into the

community to raise awareness,' Medcalf said. 'The recent research in the Futures III report, documenting the lives of positive Australians, reveals that dealing with disclosure and negotiating fulfilling sex lives for hiv positive gay men remain sensitive areas. This requires continued understanding and awareness on the part of all gay men. NAPWA is pleased at the timeliness of the release of the updated *HIV Positive Gay Sex*.'

AFAO National President Bill Whittaker said that the *HIV Positive Gay Sex* booklet was significant given that recent data from various surveys suggests an ongoing need to engage with hiv positive men around the issues of safe sex and sexual health.

'Hiv/aids in Australia faces a potentially dangerous period for a number of complex reasons,' Whittaker said. 'One of these is the continuing practice of unprotected anal intercourse with casual partners by both hiv negative and hiv positive gay men in Australia and the consequent risk of new hiv transmissions,' he said. '*HIV Positive Gay Sex* aims to reduce this.'

Recent research has highlighted that hiv positive gay men continue to face stigma and discrimination. Despite this, most hiv positive gay men continue to play a vital role in preventing hiv transmission. *HIV Positive Gay Sex* aims to provide support for the maintenance of safe practices by hiv positive gay men.

HIV Positive Gay Sex includes updated medical information and more specific safe sex guidelines. It also addresses in more detail issues such as anonymous sex situations, disclosure and negotiation in safe sex situations, those issues particular to seroconcordant and serodiscordant relationships and the use of recreational drugs in relation to sex.

Male rape victims offered help

The NSW Rape Crisis Centre has produced the fourth edition of *Surviving Rape*. It covers dealing with police and the legal system and tries to show victims they are not alone as they work towards recovery. It also includes information about the Child Protection Act and details to help those supporting rape victims are also included. The guide is now in its 20th year. Copies of the book are available through Redfern Legal Centre Publishing.

news.com.au

Users ignoring hep C risk

More than one-third of injecting drug users in Melbourne, Sydney and Perth are at risk of contracting hepatitis C by sharing materials, according to a study. The Australian Blood-borne Virus Risk and Injecting Drug Use Study (ABRIDUS) interviewed 150 injecting drug users in the three capital cities during the past month. People under 25 years of age were most likely to take risks.

Findings were:

- 18 percent of injecting drug users shared a syringe
- between 30 and 40 percent shared their injecting materials, such as spoons, filters, water and tourniquets.

The Turning Point Alcohol and Drug Centre in Melbourne said the study provided new evidence about the extent of high-risk practices by injecting drug users contributing to the spread of hepatitis C.

Study co-author, Craig Fry, said the study had major implications for service providers and policy makers. He said it showed the need for a review of funding priorities, education initiatives and prevention programs.

news.com.au, 24 June 2002

Paul Maudlin reports on Barcelona

Well, it's certainly been a conference which has had lots of controversy, complaints and at times totally overwhelming!

There was a mass protest walkout at the opening ceremony while the Spanish health Minister was speaking. Her speech was in Spanish, so we had no idea at the time what was going on. We'd been sitting in the Olympic stadium for over an hour. Our protest pamphlets, which we'd been handed outside, were confiscated on entering. It apparently was all about the visa problem for Third World delegates coming into Spain. It was amazing to see literally thousands of people stream up out of the stadium. The Spanish Ministry of Foreign Affairs clarified that participants must demonstrate sufficient economic means to obtain an entry visa, as detailed in Spanish law.

The Ministry indicated that instructions had been given to accelerate the process because of the great number of requests for entry visas. Nevertheless, according to a European Press release, the Ministry indicated that 'sometimes the visa applicants do not fulfill the requirements that Spanish law requests, such as the minimum economic means that an individual must have when entering the country, and that the process will ultimately depend on whether delegates are able to fulfill these legal conditions.'

For me, the video presentation was a blast. They didn't put it on the cultural program and I was reduced to writing the details of time, place and venue on my flyers and handing them out at various places. I also handed out flyers at the railway station as delegates waited for the train.

The 200 videos were distributed by myself, Kathy Triffitt, John Rule and Brent Beadle.

I attended two wonderful workshops, one about education for schools and the other about speaking out in public. The second was from my PSB training manual and recently written course notes for the hep C training I facilitated recently. John Rule was in the same workshop and it was good for him to see that PLWH/A (NSW) are doing something good and are taken seriously!

Permanent AIDS Memorial Survey

There's been a lot of discussion over the years about establishing a permanent AIDS memorial. The Grove at Sydney Park of course already provides an important opportunity for remembering but, according to a survey conducted late in 2001, many people want a permanent memorial in the Darlinghurst area.

PLWH/A NSW has followed these discussions and attempted to participate supportively in moving the issue along. Nevertheless, after a community survey, support from government and HIV organisations and lots of community discussion the community still doesn't seem very far advanced.

PLWH/A NSW continues to believe that a permanent memorial in the Darlinghurst area is an important initiative. We sense the importance of the issue for people living with and affected by HIV/AIDS and we want to continue to provide a positive voice supporting the construction of such a memorial. We want to let the community know that we're moving forward to do three things in particular:

1. To ascertain the potential funding opportunities which remain for the construction of a memorial.
2. To meet with the Mayor of South Sydney Council, John Fowler, as well as the Mayor of Sydney Council, Frank Sartor, to establish their commitment to the memorial.
3. Ascertain the support from people living with HIV/AIDS in particular for the construction of a memorial in Darlinghurst.

We would be happy to get your feedback on the issue if you'd like to provide that. We want to assure you that PLWH/A NSW has not dropped the issue and we'll keep fighting to establish a memorial in the Darlinghurst area.

John Robinson, President, PLWHA NSW

Housing coalition

SASSters is a coalition of SAS/S clients, their friends and families, who have been forced to form their own lobby in the face of the continued disregard of their wishes by the ACON/PLWHA/BGF associations. We are disappointed by the lobby in their presuming to know what is best for us, and by their lack of empathy concerning the impact of the proposed changes on their clients.

Declaration

For future reference we [SAS/S clients] would like it known that:

The SASSters coalition feels it has been underrepresented by those we believed were commissioned to advocate for us. There has been no consultative process by the lobby alliance to ascertain our wishes. As the ACON/PLWHA/BGF lobby alliance is not in accord with the wishes of members of SASSters, we do not accept or acknowledge their representation of us in any way and the ACON led alliance does not have permission to negotiate on our behalf. We will not be deliberating, negotiating or meeting with the alliance in any forum.

We would prefer to liaise with the relevant Department of Housing representatives on our own behalf, to speak for ourselves.

Here are SASSters only wishes:

SAS/S clients who were approved SASS before the proposed review retain their current choice of subsidised private rental. We suggest this be known as the 'pre-review clause' and SAS/S rights be continued without threat of either termination or compulsory relocation into public housing.

We believe our proposal maintains SAS/S as a cost-effective scheme for the government while avoiding a negative impact on pre-review clause clients. See the website www.angelfire.com/indie/sassters for further information.

Italian activists seize stand

A group of Italian hiv positive activists seized occupation of the Gilead stand, who are major sponsors of this conference. This group of activists condemned with total indignation the improper conduct that Gilead Italia has continued to maintain with them. After repeated attempts to open lines of communication to the company the policy they have adopted towards them has been to limit the relationship with the community to the medical profession. This group claims that the attitude of Gilead has been one of profound disrespect towards the hiv positive community in Italy. Those responsible at Gilead prefer to treat the hiv positive community merely as passive patients and trial subjects for their products, without offering them the possibility for honest and direct dialogue. They claim that the right to be informed about the development in the pharmaceutical industry is not a privilege of doctors but also of those who consume the products every day. They further claim that it is not only insulting but also demeaning that a pharmaceutical company should have to be reminded of a concern of this nature at a conference of this magnitude. Moreover, they claim that they have not been given answers as to why patients in South America, Asia and Africa have not been allowed access to the Gilead product tenofovir. They question the absence of this basic information being available to them and the consequence of this absence on patients who have neither information nor treatment available to them. For this reason, they demand that Gilead not only make its products and related information available to the developed world but that it recognizes an ongoing consultation with hiv positive people as a necessary part of research and product development.

New executive director at BGF

Simon Watts has been appointed BGF's Executive Director. Watts will commence at BGF on 21 August 2002. Watts has worked for ten years in the provision of services for people with a disability including people with hiv/aids. Most recently, he has managed Planning and Data Analysis for the NSW Department of Ageing, Disability and Home Care. He has also worked in the HACC Program and at the Guardianship Tribunal. Watts has served on the Boards of Australian Catholic Relief, PRIDE Sydney Lesbian and Gay Community Centre and ACON.

BGF President, Peter Brennan said, 'The selection panel unanimously recommended Simon as an outstanding choice for this important role.'

'We are excited to be able to appoint someone with Simon's leadership and management skills, his knowledge of and networks within government, and his obvious commitment to the community through his longterm involvement as a volunteer. His experience in strategic planning, policy development, government liaison and operational management will stand BGF in good stead to meet the challenges that lie ahead.'

Watts said, 'I am delighted to have the opportunity to lead BGF, and to work in partnership with plwha to help meet their needs.'

'I am passionate about community based organisations and I am excited about reengaging with community through BGF. The combination of members, supporters and staff are big strengths of BGF and that's a great combination to move forward with.'

Advanced HIV undiagnosed in one third of US patients

More than one-third of people diagnosed with HIV at four major clinics in large US cities already had CD4 cell counts below 200 cells/mm³, and were thus at immediate risk of aids-related illness, according to research published this week in the *Journal of Infectious Diseases*.

The study also found that more than half of patients were already candidates for antiretroviral therapy under US treatment guidelines, which recommend treatment for anyone with a CD4 cell count below 350 cells/mm³.

The study looked at medical records from 2,223 people diagnosed with hiv in Washington DC, Los Angeles, New Jersey and Baltimore in 1999. 59% of those diagnosed were black, 12% Latino and 29% white, corresponding closely to the proportions of newly

diagnosed individuals from various ethnic groups across the United States. No ethnic or sex differences in CD4 cell count at the time of hiv diagnosis were detected.

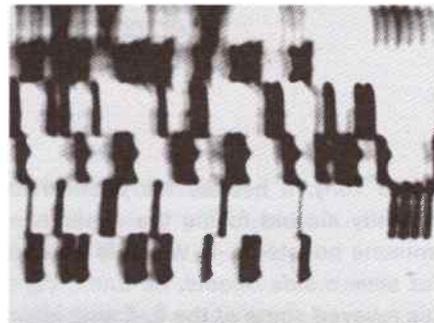
The authors recommend that efforts to promote hiv testing should be stepped up, both to improve an individual's chances of a good response to treatment and to reduce the risk of transmission within the community.

A recent audit of UK treatment centres found a similar proportion of patients had been diagnosed with hiv and begun treatment with CD4 cell counts below 200 cells/mm³.

Dybul M et al. Evaluation of initial CD4+ T cell counts in individuals with newly diagnosed human immunodeficiency virus infection, by sex and race, in urban settings. *Journal of Infectious Diseases* 185: 1818-21, 2002.
www.aidsmap.com

ATA campaign

The AIDS Trust of Australia commercial has been re-edited and modified. Apart from the elderly couple scenario, all scenarios are now represented with actual people living with hiv/aids. The AIDS Trust has announced that organisations like PLWHA and BGF will receive up to 10% of donated monies.



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m edical cannabis: does it help?

ACON Treatment Officer **John Cumming** summarises some of the medical and legal issues

When Tony, a healthy hiv positive man recently started taking the experimental immune booster IL-2, which is notorious for severe side effects, he found cannabis relieved some of the IL-2 side effects. 'On IL-2 you find it very hard to sleep. The trial nurse wanted me to take sleeping pills but the last thing I wanted was to wake up with a sleeping pill hangover on top of the IL-2 side effects. Hash cookies actually helped me to sleep and also minimised the nausea caused by IL-2.'

The medicinal properties of cannabis have been recognised for thousands of years. It was used in ancient China to relieve constipation, to improve appetite and for childbirth pain. Queen Victoria used tincture of cannabis (available over-the-counter in British chemists until the Misuse of Drugs Act was passed in the 60s) to relieve menstrual cramps. Cannabis is beneficial for people with hiv as a pain reliever and an appetite stimulant. It has been shown to help people who have hiv wasting gain weight. It is also widely used to relieve insomnia and the symptoms of stress and anxiety. Cannabis can be smoked, eaten, or drunk in a tea.

How does it work?

Although the mechanism by which cannabis produces its effects is unknown, more is becoming known about its physical effects. The drug's ability to reduce pain, stimulate appetite and induce euphoria derives from its effect on the central nervous system. Unlike other recreational drugs which act by disrupting brain processes, the active ingredient in cannabis, a chemical called THC, acts on receptors in the brain that are involved in thinking, memory, pain perception and motor coordination. Discovering this, scientists hypothesised that since the normal brain produces these receptors, there must also be a substance produced by the brain itself that acts on these receptors. In 1992, scien-

tists discovered a substance produced by the brain that activates the THC receptors and has many of the same physiological effects as THC. The scientists named the substance anandamide, from a Sanskrit word meaning bliss.¹ Scientists are now actively investigating anandamide's function in the brain.

Does cannabis interact with hiv medication? American researchers found that cannabis caused a decrease in peak levels of the protease inhibitor indinavir but concluded that this decrease did not impair the effectiveness of the protease inhibitor.²

Adverse effects of cannabis

- Cannabis impairs coordination and can cause nausea and vomiting, anxiety and paranoia.
- Cannabis smoke may be potentially carcinogenic.
- Cannabis has been shown to have adverse effects on the immune systems of some animals.³
- Some surveys of cannabis users have found an association between daily use of cannabis and depression and anxiety.
- Cannabis can interfere with people's ability to adhere to their hiv medication schedule.
- Eliminating adverse effects

For people wanting to use cannabis medically, some of these adverse effects could be eliminated if the therapeutic substances in cannabis could be isolated and formulated. Dronabinol, a synthetic form of THC that is used as an appetite stimulant, has been available in the US for some time. UK drug companies have produced two cannabis-derived pain-relieving formulations in the form of a pill and a spray applied under the tongue. Neither formulation gives a 'high'. The UK Department of Health announced in February this year that these cannabis-based pain relief drugs could be available on prescription from the National Health Service within two years.⁴

Police in NSW are trialling a cannabis cautioning scheme in which people caught with 15g or less of cannabis are cautioned rather than charged.

Some surveys of cannabis users have found an association between daily use of cannabis and depression and anxiety.

C



Cannabis is beneficial for people with hiv as a pain reliever and an appetite stimulant.

Cannabis use and the law

In NSW, you are breaking the law if you possess, use, grow or sell cannabis. Penalties relating to small quantities of cannabis can range up to a \$2000 fine and/or a 2-year jail term. However, in several recent NSW cases, people with hiv convicted of possessing cannabis successfully appealed against their convictions, using the defence that their use of cannabis was medical, not recreational. Police in NSW are trialling a cannabis cautioning scheme in which people caught with 15g or less of cannabis are cautioned rather than charged.

For some time the Medical Cannabis Information Service, based in Nimbin NSW, has been supplying cheap, quality-controlled hash cookies by mail to people who can provide a medical certificate justifying their need for it.

One of the organisers of the service, Andrew, says that the service was set up in response to the many people suffering from cancer, MS, arthritis, chronic pain, wasting, hiv/aids and cerebral palsy who coming to Nimbin from hundreds of miles away to get cannabis. The compassionate aspect of this service does not alter the fact that it is an illegal service. Although Andrew has been interviewed and questioned several times by police about his connection with the service, no client of the service has ever encountered similar problems.

In September 1999, the Australian Medical Association (NSW) and the Law Society of NSW joined with the Australian Committee for Medical Cannabis in calling for controlled provision of medical cannabis. In response, the NSW Government established an expert working party, which included ACON representatives, to investigate the use of cannabis for medical purposes. In 2000, the working party recommended to the NSW Premier that cannabis be provided on a compassionate basis to patients who may benefit from its use.⁵

Andrew believes the government wasn't completely sincere in the appointments to, and terms of reference of, the working party. 'I've spoken to several members of the working party, including the Chair, Professor Hall,' he said. 'It became apparent that, amongst other things, supply was not to be addressed. It has been pointed out to the government that the question of 'lawful source' has not been attended to at all. The Premier thinks it's OK to certify a patient to go out and buy cannabis of inconsistent quality, at \$400 an ounce on the blackmarket. We asked, will the police help if a patient is ripped off, or isn't happy with the deal? We asked, if a certified patient can grow 5 plants, how can it be expected that they possess no more than 30 grams of dried herb. We have made several proposals to government, including a supply regime whereby quality controlled, consistent supplies of cannabis could reach patients for about \$1 a gram.'

In April 2000, Andrew asked the Special Minister of State John Della Bosca about the medical cannabis issue and was told it would be dealt with by the end of the year. When he asked the same question of the NSW Premier the response was 'As a matter of fact it's on my desk now.'

On 24 June 2002, I wrote to the leaders of the NSW Liberal and Labor parties asking them what steps they would take to put the working party's recommendation into effect if they win the next state election. Liberal party leader John Brogden responded, 'At this stage, the Coalition position is that it is a matter for shadow cabinet to decide when and if the government introduces legislation.' Premier Bob Carr did not respond by June 28.

Andrew believes that all those concerned about access to medical cannabis should write or phone the Special Minister of State John Della Bosca.

Contact details

John Della Bosca NSW Special Minister of State, ph 9228 4777
Level 33, Governor Macquarie Tower,
1 Farrer Place Sydney 2000.

Medical Cannabis Information Service
PO Box 500 Nimbin, NSW 2480
<http://www.medical-cannabis-information-service.com/>
email mcis@gasgroup.com

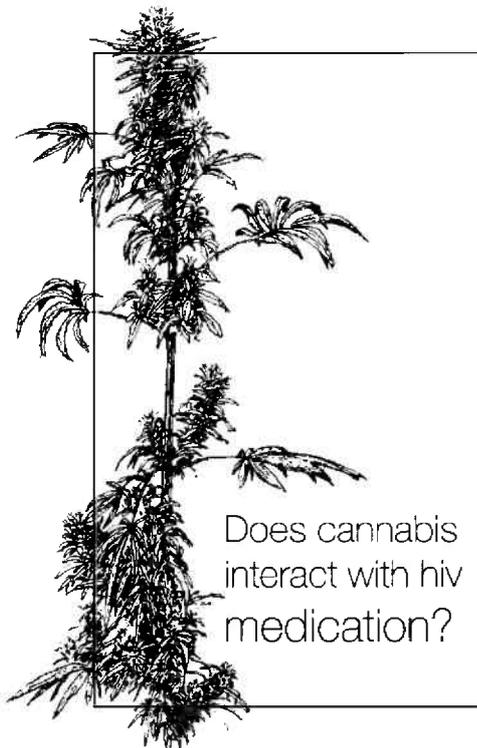
¹ Catherine A. Sasek. Marijuana: Mind Over Matter Teacher's Guide. The Office of Science Policy and Communications, National Institutes of Health. NIH Publication No. 00-3592 December 1997.

² Bradley W. Kosel et al. The effects of cannabinoids on the pharmacokinetics of indinavir and nelfinavir AIDS 2002;16:543-550

³ The health and psychological consequences of cannabis use National Drug Strategy, Australian Department of Health and Ageing, Monograph Series No. 25

⁴ BBC News, 18 February, 2002.

⁵ Report of the Working Party on the Use of Cannabis for Medical Purposes, NSW Government August 2000



Does cannabis interact with hiv medication?

Wanna get fit?

Graham Norton - Positive Men's Project Coordinator at ACON - gives the lowdown on HealthyLIFE+

Exercise, eating well and finding ways to manage stress can make a difference between doing well with hiv and actually feeling healthy. Last year, a group of 12 positive gay men participated in a trial program called HealthyLIFE+ that attempted to address those issues.

A year later, Neil still raves about HealthyLIFE+ 'It was very worthwhile ... of all the things I've participated in, HealthyLIFE+ has been the one program that motivated me to improve myself.' Wayne has similar praise: "HealthyLIFE+ has let me look for paid employment, before that I was thinking I might be able to manage a day or two somewhere. Now I have more energy, confidence and self esteem!"

Neil and Wayne are two of the participants who trialled HealthyLIFE+ as an exercise program that attempted to help positive people gain back some of the body shape they had lost through lipodystrophy and aids wasting.

Neil says that he had some wasting in his arms and did not know what to do about it. 'I was wanting a bit of exercise discipline and I needed someone to tell me what specific gym work would help me in my weak parts.' Neil said, 'I really liked the weekly seminars and the specific instructions that were tailored to my problems and needs ... I noticed changes but particularly liked the fact that Simon did measurements electronically and I could see that although my weight did not change, my body fat reduced noticeably and my muscle mass increased.'

Wayne goes further and says, 'I'm not embarrassed to take my shirt off in public now - before, you could have counted the ribs from one hundred paces. Wayne was looking to lose his excess stomach weight and improve his general health so he could go back to work.'

Neil and Wayne were really impressed with the broad structure of HealthyLIFE and

I'm

not embarrassed to take my shirt off in public now - before, you could have counted the ribs from one hundred paces.

would recommend this program to anyone wanting to make some body shape changes.

Simon is the Nutrition Manager at the Albion Street Centre. He was one of the fitness and health professionals that were an integral part of the program. Not only did participants get a free membership at Gold's gym but there were expert seminars on all aspects of healthy life, from body image to goal setting and dealing with stress. All participants also received before and after body measurements, nutrition advice and personalised programs and instruction during the program.

During the program people were given options and ideas for putting into practice what they had learned after the program finished. Neil is no longer attending a gym but the program got him doing some regular exercise and he bought some dumbbells to use at home. He said that he liked the hints, such as using tins of food for weights and other non-gym methods of exercising.

As Neil said, 'Twelve months on, I can't see as much change as I did but I am still trying. I now have a guilt complex cause I should have more discipline. I was impressed to see the enormous difference in some of the others in the group and would recom-

mend it as being very worthwhile to be exposed to things you can do and to help you feel good about yourself.'

Wayne is also still enthused about the program. He continues exercising regularly at the gym. He says the program was a watershed for him. He has changed his body shape, put on weight and actually kept it. Wayne says, 'If you haven't been to the gym before, stick with it. It might be a lot of hard work but it's worth sticking to it for the results.'

Another part of the program was the development of a HealthyLIFE+ booklet designed to provide some basic information and tips for gay men living with hiv who want to live a healthier life. It contains information about good eating, joining a gym and strategies people use to wind down as well as information about body image, treatments, drugs and complementary therapies. This booklet is due for release through ACON in August.

ACON is about to run healthyLIFE+ again in Darlington and applications are invited from positive people experiencing weight loss through lipodystrophy or aids wasting. For more information about healthyLIFE+, a registration pack or a copy of the booklet, please phone HIV Living on 9206 2000.

Hiv drugs and birth risk

Michael Carter

Treating hiv-positive pregnant women with a combination of anti-hiv drugs does not increase the chance of premature delivery or still birth, according to a study published in the 13 June edition of the New England Journal of Medicine. The findings contradict earlier studies which found that giving HAART to women with HIV-1 dramatically increased the risk of premature delivery.

Investigators conducted a retrospective analysis of the medical records of 2,123 pregnant women with HIV-1 who were enrolled in seven separate clinical trials, received antiretroviral treatment during pregnancy and went on to deliver infants between 1990 and 1998. Of these, 1,580 received monotherapy, 396 HAART without a protease inhibitor and 137 HAART with a protease inhibitor. Also included in the study were the records of 1,143 pregnant women with HIV-1 who were enrolled in the same studies, but who did not receive any kind of antiretroviral therapy.

Unadjusted rates of premature delivery (before week 37), low birth weight, very low birth weight and still birth did not differ significantly between the treated and untreated groups. However, unadjusted rates for premature delivery were significantly lower in the treatment arm, and were similar for women who received monotherapy or HAART. After adjustment for risk factors such as hiv disease progression, indicated by a low CD4 count, and tobacco, alcohol and illegal drug use, the rates for adverse pregnancy outcomes still remained similar in the treated and untreated groups.

Contrary to the findings of earlier studies, the administration of a protease inhibitor during pregnancy did not lead to increased rates of premature or very premature delivery. Nor were women who received HAART regimens without a protease inhibitor any more likely to have a premature baby.

The study also established that women

Contrary to the findings of earlier studies, the administration of a protease inhibitor during pregnancy did not lead to increased rates of premature or very premature delivery.

who were given HAART without a protease inhibitor delivered fewer babies of low or very low birth weight than women who received no therapy or monotherapy. However, women receiving combinations including a protease inhibitor were more likely to have a low or very low birth weight baby than those who either received no therapy at all or monotherapy.

Overall, the study authors found that 'the risk of an adverse outcome of pregnancy was not associated with the use of combination antiretroviral regimens.' In particular, 'the risk of premature delivery was not significantly higher with combination therapy than with monotherapy or no therapy.'

They suggest that their findings contradict earlier studies because the present study was able to adjust for risk factors of adverse outcome in pregnancy, including previous premature delivery, and tobacco, alcohol and illegal drug use. In addition, the investigators were also able to take into account the degree of damage hiv had caused to the mother's health, a control which was not included in earlier studies.

The authors suggest that women receiving a protease inhibitor may have been at greater risk of delivering a low or very low

birth weight baby because of the stage of maternal hiv disease, noting that it was likely that 'women who received combination therapy with [a] protease inhibitor had more advanced disease.' However, they argue that the slightly increased risk of having a baby of low birth weight is 'outweighed by the substantial benefits... [of] protease inhibitors for both mother and infant.'

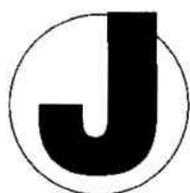
Limitations of the study include lack of information about the precise time when HAART was initiated, early pregnancy loss, congenital abnormalities, or long-term health of the infants. Nevertheless the study concludes that 'the risks of adverse outcomes of pregnancy that are attributable to antiretroviral therapy are low and are likely to be outweighed by the recognised benefits of such therapy during pregnancy.'

Tuomala RE et al. Antiretroviral therapy during pregnancy and the risk of an adverse outcome. *New England Journal of Medicine* 346, 24:1863-1870, 2002

'Protease inhibitors do not increase the chance of premature birth', www.aidsmap.com

Pozneg People: Dealing with serodiscordance

The Positive and Negative Conference 'Dealing with serodiscordance' was held in Sydney by Pozhet. Here are four views.



Jackie: A participant's view

What truly impressed me was the big turnout, nearly 60 people, on a cold wet winter Saturday! I had heaps of people to talk to from as far away as Mildura, Melbourne, the Southern Highlands, the Blue Mountains, the North Coast around Lismore, the Illawarra and the Hunter, as well as Western Sydney. Thanks to a special grant, some of us from the country were given a positive scholarship that paid our accommodation, so the talking went on late into the night.

Serodiscordance is my everyday life and it was great to hear there is genuine concern about improving services and support for people dealing with this, regardless of whether we're a negative partner, a positive person, or a family member affected by the virus.

We all know from hard-won experience that living in a pozneg world takes courage, stamina and a whole lot of humour. The key question for most of us is: What is it about pozneg relationships that makes them so hard to get started, and to keep going? Throughout the day we used different and interesting ways to explore this central theme, always taking care to look at it from both a positive and a negative perspective.

We built on our skills in relating with others in our pozneg world:

- protecting our status - in serodiscordance we all need to have our status protected
- communicating across the pozneg divide
- handling family problems
- preventing disclosure nightmares

One thing became obvious - regardless of your status, 'stepping over the line is necessary', as one bloke put it, if you want to start a pozneg relationship.

We also got down to the nitty gritty of how to and when to do safe sex, and how to become parents when hiv is in the picture. Wanting to be a dad for many positive men is a natural part of getting on with their lives. For positive women, antiretrovirals may reduce the risk of transmission during pregnancy but positive men have the added dilemma of not wanting to infect their negative partners.

By the end of the day it was clear that, positive or negative, we share many things despite the division of our different hiv statuses. We all deal with fear and prejudice, still haven't found the you-beaut, failsafe way to disclose, are shut away in the eerily invisible isolation of hiv, have lost relationships along the way, have had our life expectations irrevocably changed and think more carefully about the future.

If we are positive, we have the immediate health problems of hiv, and if on treatments are most affected by taking pills. If we are partners, we face the risk of seroconversion. We agreed that the positive person's status can dominate pozneg relationships and this has to be watched out for so that others aren't marginalised. And finally, although the longterm health histories will be different in all pozneg relationships, stress is common to all.



David: A hiv positive man and Pozhet Coordinator

Exploring issues around serodiscordance has always been high on the priority list for the Positive Heterosexuals project. Over the years, it's always been of great concern to me that negative heterosexual people living in serodiscordance generally receive

little consideration in hiv/aids policy statements or from services. Yet in the context of heterosexual hiv/aids, negative people have always formed the greater part of the equation. For every positive heterosexual person there are possibly five negative people (partner, child, parent, sibling, close friend) living in a serodiscordant relationship with that person. These negative people are the intimate world for nearly all of us and are often the only people, other than health professionals, who are aware of our hiv status. That's why the Pozneg People conference was a landmark event for me: it's the sort of work that's closest to what gives me personal happiness.

While serodiscordance is the posh term used nowadays to describe a mixed status couple, it's not a user-friendly word that the diversity of people in Pozhet can use to speak about their experiences. So for the workshop we developed the terms 'pozneg', 'pozneg people' and 'pozneg world' to bring the concepts around serodiscordance closer to our own reality.

The five workshop sessions focused on the key people who live in a pozneg world and what dealing with pozneg issues meant from their perspective. We increased our understanding of the differing needs of all those who live with us in this world.

During the day hiv positive men, women and their partners were asked to nominate from a list of topics the aspects of their relationships that most concerned them. Remarkably, both positive and negative partners gave equal weight to the following concerns:

- Anxieties around keeping sex safe
- Feeling lonely and isolated
- Feeling anxious about illness and what's going to happen
- Finding the right support for my partner
- Losing the intimacy between us
- Wanting to have a baby and worried about hiv transmission



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G getting fit for the Games

Plwha can join FitXGym, in Surry Hills, and visit the gym to train with other positive people. **Shane Hurley** is gearing up for the Games in October.

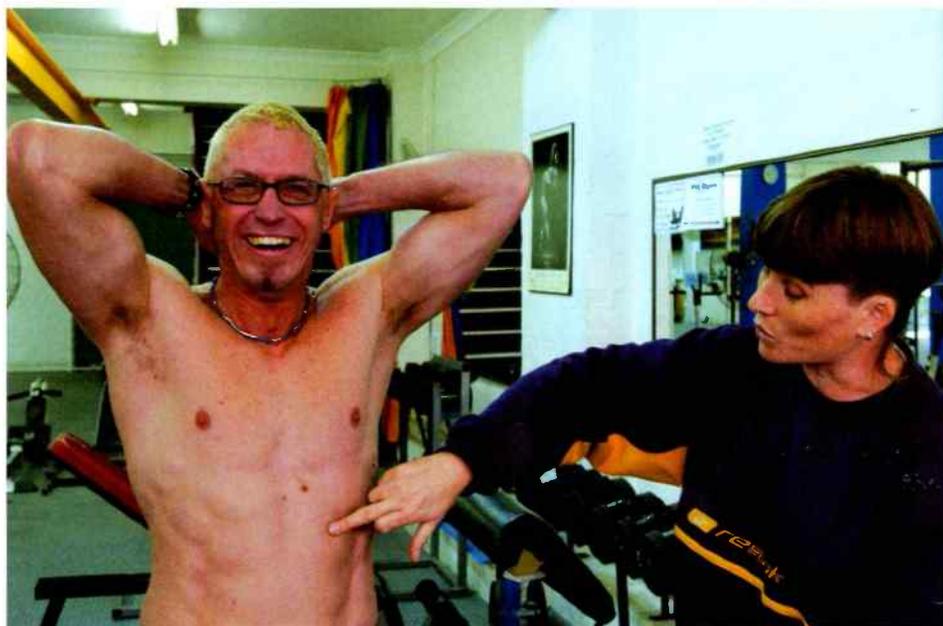
Hi there, my name is Shane. Now that you know me, let's get the particulars out of the way: Yes, I do competitive bodybuilding. Yes, I am hiv+.

Now I would like you to meet my personal trainer, Ingrid Cullen. Ingrid has been training me for approximately 18 months for the Gay Games 2002 VI in Sydney, which I am competing in. Ingrid is a personal trainer at FitXGym in Surry Hills. She teaches exercise for hiv+ men and women to maintain their health and learn to live with hiv in a state of wellness.

My story starts three years ago after having pcp (pneumocystis carinii pneumonia), which is an aids defining illness. The treatment for pcp made me lose half my body weight. By the time I recovered, I weighed between 30 and 40 kg. I went to the gym looking for social contact and to try and get my health back. I was also being treated for fatigue. I couldn't go back to swimming, which I used to do with Wett Ones – the gay swimming group. I needed to find something that would get my energy levels up and give me social contact, as well as having a physical benefit. So I got myself up off the sofa and went looking for a gym to join. That was four years ago.

The first gym I went to was at Broadway. A friend of mine used to own this gym but, unfortunately, he is now longer with us. The Broadway gym was known then as one of Sydney's leading gay gyms. It had a good knowledge base for training your body and was advertised as a good social contact for gay men, so I joined up. Not knowing much at the time meant I had to get a personal trainer, which was provided as part of my membership. However, the gym got sold and I had to move to another gym to continue my training.

I met Ingrid at Broadway when I used to train there. When Ingrid moved from Broadway, so did I because I was aware of her knowledge about hiv and physical education and knew she was a competitive body-



builder, which is what I wanted to do. I phoned Ingrid, made an appointment, joined and started. These days, I only use Newtown gym for my aerobic routine because they still have good cardio equipment. If we at FitXGym could find a good sponsor, or someone to donate the aerobic machines that we need, like treadmills, or help us out with funding to buy the equipment, this would be a big help. A lot of our hiv+ members have neuropathy or neurological deficits caused by hiv/aids.

I am lucky. I have set up a very good support network, which includes people who advise me on the supplements that, being positive, I need to take. The NSW bodybuilding suppliers have been very supportive as I get closer and closer to the games, especially Brain Pollard and his specialised team.

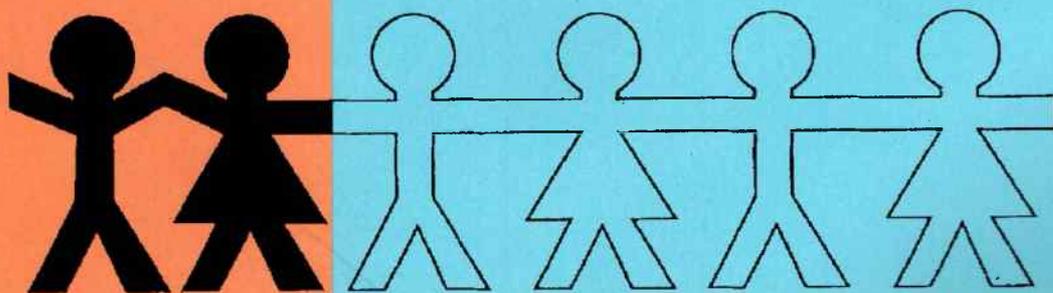
Ingrid has also been very supportive, helping me achieve my goals as an hiv+ bodybuilder who competes. Doing bodybuilding has made me achieve my goals and given me clear thoughts and aims, particularly with the Gay Games coming up. As time draws closer and closer, I must admit I am getting very excited. My direct health team at the Darlinghurst Medical Centre and my doctor have been a very good support. To these people I owe a lot. As the games have drawn closer and closer, they have helped with support - both physiological and physical. To me, bodybuilding is very competitive and I suppose the joy of showing your body off gives me a chance to show the world: 'Hey, look at me and my hard work!'

A photograph showing the back and right arm of a man with short, light-colored hair. He is wearing a thin chain necklace. His right arm is raised, and a woman with dark hair, wearing a dark blue long-sleeved shirt, is smiling and looking at him. She appears to be assisting or encouraging him. The background is a gym or fitness center with various exercise machines and a rainbow flag on the wall.

the treatment for pcp made me lose half my body weight. By the time I recovered, I weighed between 30 and 40 kg.



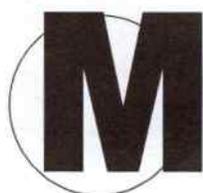
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heterochat or any
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1800 812 404**

While today we may talk about 'post-aids euphoria', these concerns also remind us of the ongoing struggles of men and women dealing with the everyday reality of serodiscordant life.



**Miranda Shaw:
Sexual Health
Promotion
CSAHS**

During my workshop session 'mentalk, womentalk - all about sex', two thirds (66.7%) of all participants, positive heterosexual men and women and their negative partners, indicated that they experienced anxiety about maintaining safe sex practices. My workshop session focused on a number of hard and fast safe sex messages that have been delivered to both the positive and negative community through health information and education.

Group participants were asked to share information about their own experience of translating these messages into 'real life' sexual encounters by commenting on frequency of condom use, use of water-based lubricant with condoms, use of condoms and/or dams for oral sex, withdrawal prior to ejaculation and frequency of hiv and sti testing.

Results indicated that most participants used a condom 'often' or 'always' during penetrative sex, with lubricant used only 'occasionally'. When a condom was not used during penetrative sex, most people practised withdrawal as a way of minimising the risk of hiv transmission 'often' or 'always'.

Condoms or dams were rarely used during oral sex. Most people had made a conscious decision based on their understanding of the

low level of hiv risk associated with oral sex. Quite a few in the group had never seen a dam before.

The majority of people in the group are having hiv and sti tests every 6 - 12 months. A number of people felt that hiv testing for negative partners served only as a reminder of the possibility of transmission. The anxiety experienced waiting for hiv test results was also a key factor for partners in their decision to be tested and how often.



**Lisa Ryan:
Policy Analyst,
AIDS and
Infectious
Diseases
Branch NSW
Health**

Lisa opened the workshop saying that it was a remarkable occasion as people had gathered from across NSW and Victoria to talk about their struggles and triumphs in living in serodiscordance.

'We know from social research such as the 'Futures Studies' that most positive women and men with regular partners are in relationships with people who are hiv negative. We also know that relationships are important for individuals' health and quality of life, but that they bring challenges for each partner, and they require attention and support. One of the clear messages that men and women like yourselves, men and women in hiv serodiscordant relationships, have given services is that you need information which helps you to make decisions in your daily lives. That includes information about hiv and heterosexual safe sex, as well as information about disclosing hiv status to a part-

ner, information about managing hiv and family life, dealing with how hiv affects your identity as a positive person or a negative person, and insight into what's going on for your partner - information about the range of issues for the person abseiling down the face of life with you.'

Lisa also brought the welcome news that an additional \$60,000 would be given to the Heterosexual HIV/AIDS Service to improve the services that support participants, regardless of whether they are a negative partner, a positive person, or a family member affected by hiv/aids. The money will be spent on resources, including an information kit and website, and to provide positive and negative women and men with information to make healthy decisions that support and strengthen relationships. As part of that work Pozhet will be training health workers to improve their understanding of heterosexual hiv/aids and serodiscordance.

Pozhet thanks the following people who made the Positive/Negative Conference possible:

Angela Taggart (FPA Health), Cassandra Romberg and Lucia Darvill (Sydney Children's Hospital), Denise Cummins (CNC RPA Hospital), Deidre Griffiths and Rewa Gemmell (Volunteer Services Sacred Heart), Irene Coonan and Peta Sirec (childcare), Jane Kirton (training consultant), Kirsty Machon (AFAO), Lisa Ryan (AIDU NSW Health), Margaret Mines (Coordinator Tree of Hope), Marie Lavis (Pastoral Care SVH), Michael Rogerson (Straight Arrows Melbourne), Miranda Shaw (Sexual Health Promotion CSAHS), Patricia Austin (Senior Clinical Psychologist SVH), Rosie and Wendy (panellists), Robert Ball (The Sanctuary), St. Patrick's Business College Darlinghurst.

Read my lips - + silence = death

Kathy Triffit* comments on a recent retrospective



Retrospectives HIV/AIDS in Australia: Historical Perspectives on an Epidemic was held on 27 May as a satellite event to the Changing Communities Conference, presented by the National Centre in HIV Social Research and the Australian Federation of AIDS Organisations. Panels were organised under the following themes:

- Presidents and Executive Directors
- Social Research
- Different Perspectives on the Epidemic
- Living With HIV Treatments and Gay Educators

More than 20 speakers talked from experience and gave a range of perspectives on the hiv/aids epidemic as well as the political, governmental, and community responses. Stories were recalled ranging from the official voices of the epidemic, including Dr Neal Blewett, Ita Buttrose, Phil Carswell, Bill Whittaker and Don Baxter to that of the community voices, such as Bev Greet, Kirsty Machon and myself.

In this article, my intention is not to offend speakers or organisers of the forum. I want to raise some issues and speak of the silences of the epidemic and the omissions of its history(ies), while at the same time

acknowledging that it is impossible to cover the diverse and different perspectives in one day. However, in this instance, what has been unwittingly imposed is the regulation of history to produce dominant and officially sanctioned histories. This was demonstrated by an overwhelming focus on government, epidemiology and research perspectives.

The lived experiences of plwha and that of 'grass-roots activism' were given a minor and marginal voice and relegated to the theme of different perspectives. If one of the aims of the forum was to 'develop a deeper appreciation of our current situation as well as provide new impetus and ideas for moving forward by sharing political, governmental and community experiences', what are the implications of this privileging of certain perspectives of history?

Aids treatment activism of the early 90s is worth more than a passing comment. It emerged as a response to government neglect with no specific medical agenda or priorities, and a lack of confidence in the capacity or willingness of medical and pharmaceutical industries to act in the interest of plwha. Aids activism resulted in the availability of experimental drugs as early as possible, through compassionate clinical trial designs

and expanded access schemes. It sought to provide options for people with hiv and aids, and assist individuals to make up their own minds about those options through access to information. Do any of you remember the first ACT-UP (AIDS Coalition To Unleash Power) demonstration outside the Australian Drug Evaluation Committee's office in Kent St, Sydney in April 1990? Its members wore the iconic black and pink silence = death and knowledge = power t-shirts. This early emphasis on collective political action provided the impetus to negotiate the cultural/political and representational regulations on hiv and aids including hysterical media images, discrimination, drug policies and community attitudes. Okay, the moment of classic aids activism has now long passed. Then we hoped for drugs that would work; now we hope for drugs which will keep working.

Looking back, we can all doubtless remember a series of different stages in the history of the epidemic, relating mainly to particular people we knew who have died, the availability of effective treatment drugs, and the changing political climate that Dr Blewett eloquently spoke of.

Acts of memory, remembering and his-



The lived experiences of plwha and that of 'grass-roots activism' were given a minor and marginal voice and relegated to the theme of different perspectives.



tory share similarities. Both are selective and protective. My memories are not your memories. Memory has its own history, both in the lives of individuals, remembering, and in whole collectivities of memory. Such collective memories will often be in sharp conflict with one another. Collective memory is also limited by institutions and the criteria they employ, which privilege certain angles of memory, some elements to the exclusion of others.

Memory and history are culturally organised in the preferred likeness of those who possess the power to define the past. For the individual, memory involves a degree of intersection between recollected experience, and the tug of institutionally sanctioned 'official' memories and histories.

These sanctioned memories or histories have refused, for example, women's voices both hiv positive and negative. Most of us remain the un-named women of the epidemic. In Robert Ariss's book *Against Death: The Practice of Living with AIDS* (1997), he briefly refers to two women involved in the formation of PLWH/A (NSW). However, he does not name them. I am one of those women. The other, Julie Bates, was sitting in the audience on the day of the forum.

Sanctioned memories or histories have also refused the voices of carers, supporters and friends. They have refused the experiences of loss and grief.

I wish to also acknowledge something of the neglected histories of the identities developed by plwha in relation to their own lived experience. We heard little about the ways in which the epidemic has really affected their inner lives, for example, how personal and social identities may be affected by questions of loss. Several people commented on the absence of plwha 'grass-roots' perspectives: the difficulties the day presented because of a strong feeling that one should not speak in public about questions of personal loss. Focusing on governmental, epidemiology and research perspectives has resulted in neglecting the most intimate, personal experience of the epidemic on the part of those in its midst, above all the experience of loss and grief.

The documentation of individual and community histories is paramount. That is to say, effective responses to hiv need to be made in relation to what has past, our history(ies) and in relation to changing needs. These are the ordinary, sometimes difficult, everyday narratives of plwha. These issues and

others raise practical and moral questions for both 'official' and 'non-official' responses to the epidemic. What does it mean to fashion community and alternative histories? A concern that considers the histories of plwha in relation to their own lived experiences – a domestic and private relation fragmented with feeling and day-to-day detail.

History must be a shared production in which several narrations can be heard side by side. It is important that we negotiate our relationship to our own history and therefore to the conditions under which our lived experiences are remembered. This history must consider the inventive means that people have employed in order to respond to and manage a positive diagnosis, to reclaim and celebrate experiences of death and dying, to renew the self and its sexualities, and to survive within a sometimes hostile social environment. We must define and own these histories or they will not survive us.

... And, perhaps, 'this is how communities communicate, how streets talk eloquently about those who passed along them.'¹

*This is a personal view.

¹ Simon Watney, *Imagine Hope. AIDS and gay identity*. London and New York, 2000. P.167. Although Watney is referring to memorials; this quote has relevance in this instance.

Double dose: HIV and hep C co-infection

Robert Baldwin is currently the Clinical Nurse Consultant for hepatitis C for the Northern Rivers Area Health Service and the acting Manager SHAIDS (Sexual Health & AIDS Service) based in Lismore.

At the Rural HIV Forum 2002, held in Nelson Bay in May, a diverse group of presenters held two sessions focused on issues related to hep C. These issues included treatment and care, models of community support, epidemiology and learning through games. The turnout of participants for our sessions was very pleasing. This ranged from approximately 20-30 people and was pretty interactive, considering some of the content for the sessions was fairly intense, such as information on the latest treatments and patterns of infection.

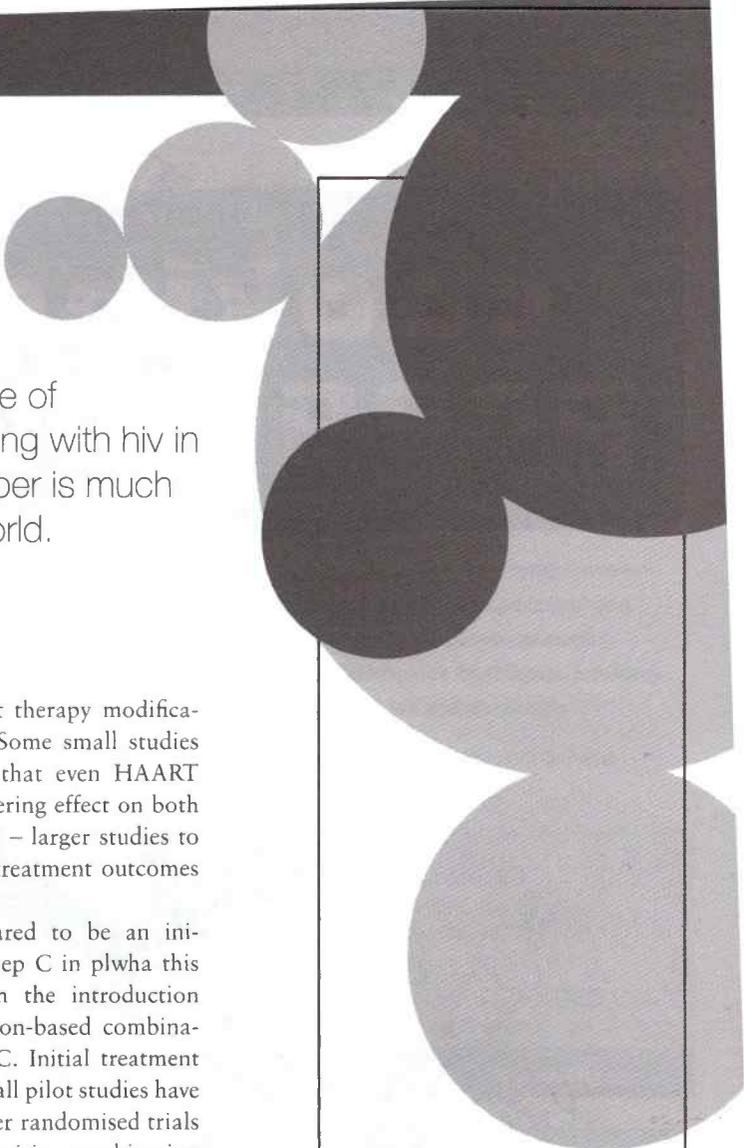
One of the sessions that we presented, which may be of particular interest to many readers of *Talkabout*, was on the topic of hiv and hep C co-infection. It was very satisfying to us that this session was quite interactive and many participants raised questions and issues from their personal perspective of being co-infected with both viruses.

As many of you will know, hep C is a virus that has been around for many decades. A blood test to identify the virus was only developed in 1990. It is believed that more than 200,000 people are infected with hep C in Australia, with up to 16,000 new infections yearly. Hep C is mainly transmitted through blood-to-blood contact and many people have caught the infection through sharing injecting drug use equipment. Some people have caught the infection another way, such as receiving blood products before testing commenced in 1990, tattooing that did not use sterile procedures, and being exposed to contaminated blood in their country of birth through medical procedures. It is important to note that a percentage of people infected with hep C cannot identify their route of transmission. Risk of sexual transmission is thought to be low, and is thought to occur when blood-to-blood exposure occurs, such as during rough or poorly lubricated sex, menstruation and when using sex toys.

Discrimination against people with hep C is a major issue, particularly within health care settings, as was shown in the 2001 *C-Change Report on the Enquiry into Hepatitis C Related Discrimination* by the NSW Anti-Discrimination Board. This discrimination is often related to actual, assumed or past drug use and the perception that hep C is intimately linked to drug use. For more information phone the NSW Anti-Discrimination Board on 1800 670 812 or www.lawlink.nsw.gov.au/adb.

About three quarters of people with hep C will remain infected with the virus for life unless effectively treated. The effects of hep C are generally quite longterm over many decades and can range from mild fatigue and nausea to liver disease, including cirrhosis and cancer in a small proportion of people with the infection. Treatments for hep C have been evolved over the past decade and currently consist of a combination of interferon injections and ribavirin tablets. Interferon is a naturally occurring human protein now being manufactured and is given by self-injection three times a week. The treatments are not perfect, they do not work all the time and can have many side effects, but they have been improving.

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hile only a relatively small percentage of approximately 10-14% of people living with hiv in Australia also have hep C, the number is much higher in many other parts of the world.

People with hep C often use alternative or complimentary therapies, such as Chinese herbal treatments. These have not been shown to clear the virus; rather they can provide relief from some of the symptoms of the disease, to varying degrees.

While only a relatively small percentage of approximately 10-14% of people living with hiv in Australia also have hep C, the number is much higher in many other parts of the world. In the USA it is believed that over a quarter of a million plwha (30%+) also have hep C. The number is even higher in some parts of southern Europe, where up to half of plwha also have hep C. Despite our low proportion, this still means more than 1,000 people in Australia are currently living with hiv and hep C. Making sure they are provided with good quality care is vital.

It is worthwhile noting that the usual screening test for hep C (antibodies) can become unreliable if people are co-infected with hiv, particularly if they have severe immunodeficiency. There is a more accurate test (PCR RNA) that can be done in these situations. It appears as though there is an increased risk and rate of liver disease in co-infected people and this increase may be related to decreases in immune function, that is decreases in CD4 counts. However, one of the key messages is still the same in regard to hep C and liver disease – alcohol can increase the rate and level of liver disease (fibrosis) and all people with hep C should aim for a low (or nil?) alcohol intake. It is not as clear as to what effect hep C has on hiv disease progression.

Highly active antiretroviral treatment (HAART) for hiv can be used for people with hiv and hep C but extra care and monitoring is usually required. An example of this need for extra monitoring can be seen with the possible flair in hep C viral load and liver enzymes (ALT) that can be seen in the initial first few months of HAART. These levels will usually return to pre-treatment levels over

the next 6-9 months but therapy modifications may be required. Some small studies have been giving hope that even HAART by itself may have a lowering effect on both hiv and hep C viral load – larger studies to examine these types of treatment outcomes are needed.

Although there appeared to be an initial reluctance to treat hep C in plwha this may have changed with the introduction of HAART and interferon-based combinations therapies for hep C. Initial treatment response results from small pilot studies have been promising and larger randomised trials of interferon and ribavirin combination therapy are underway. A new longer acting interferon, pegylated interferon, is available under trial or compassionate use conditions. This form of the drug has further improved response rates (clearing the hep C virus). The advantage of people taking this treatment is that pegylated interferon only requires an injection once a week. This treatment is not yet available for people with hep C who are also infected with hiv, though this situation may change. Research continues to develop other medications to treat hep C.

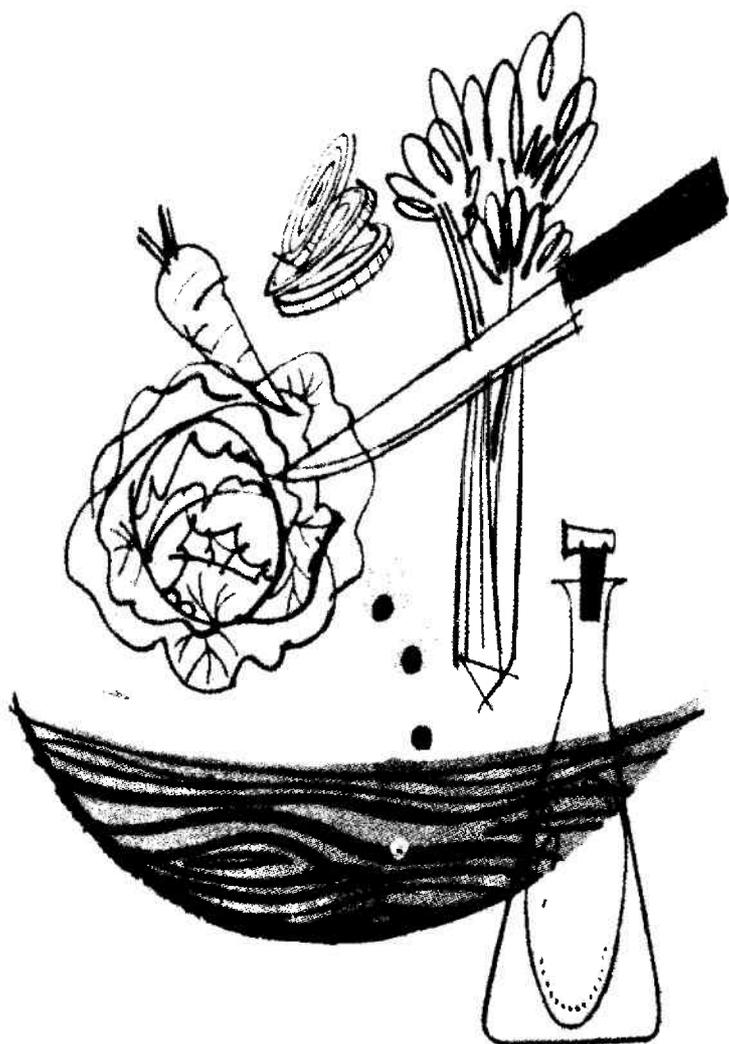
The long and the short of it is that there are people with hiv and hep C in Australia. The news is not all bad and both diseases need to be taken into account when health decisions are being made. There are treatment options for people with hiv and hep C and these need to be considered in light of such issues as individual's choices, quality of life, disease progression and past treatment experiences. A multi-disciplinary team approach is needed to provide care to people living with both hiv and hep C and that team must include health care workers experienced in treatment issues for both hiv/aids and hep C.

Robert can be contacted on (02) 6620 2980 or email robertba@nrhs.health.nsw.gov.au if you have any comments or questions about this article.

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reatments for hep C have evolved over the past decade and currently consist of a combination of interferon injections and ribavirin tablets.

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POSITIVE + DECISIONS

A PLWH/A (NSW) INC INITIATIVE



OPTIONS



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The Ankali Project

There's a level of confidentiality you can rely on with an ankali that can't rely on with your friends. **Vincent, Karl and Adam** all have an ankali, and spoke to **Susan Hawkeswood**

a**about the Ankali Project**

'Ankali' means friend and this is often how the volunteer is viewed: someone to have a chat and a coffee with. An ankali is someone who is available when you don't want to put partners, friends or family under stress to support you.

The Ankali Project provides volunteer emotional and social support for plwha, their partners, family or friends. The Project began in 1985, in response to the psychosocial issues that plwha were experiencing. Since then, 1,500 volunteers have provided support to more than 1,800 clients.

Living with hiv has changed a lot since the introduction of antiretroviral drugs. Ankali has adapted to this change in a number of ways. Living longterm with chronic illness, social isolation, mental health problems, poverty, uncertainty of treatments, and adapting to change have been addressed. This ensures that volunteers can support clients appropriately. With plwha living longer, there is an increased need for the community and home support Ankali offers. The range of Ankali relationships is broad. The volunteer is there to provide support even when a number of professional people and friends are involved.

If you think you might benefit from the services of an ankali, phone 02 9332 9742.

John Coady

Vincent approached Ankali about 18 months ago, after his psychologist suggested he get in touch with the organisation. The loss of his partner left him very isolated. He describes the changes having an ankali has made to his life. 'Very positive changes. Me and my ankali, I would consider very good friends now. He's helped me a lot. I rely on his advice. He's helped me mentally quite a lot.'

Practising safe sex is a big issue for Vincent. 'I lost my partner and all of a sudden I have to go out there, wanting sex. It frightened me and in a way it still does and it was good to have an ankali to talk with about this because I didn't know what to do. Do I tell them first? Or do I tell them after I meet them a second time, or what? I was getting different stories from different people. That was causing a lot of problems.'

Karl had an ankali for two and a half years. 'I literally hit the wall. Everything went wrong for me. I was evicted from my flat because of my cat, after 15 years in the one flat. I was staying with friends over here in Redfern. I was coming to see a psychologist at Albion St, who suggested I come round here.'

'I felt comfortable immediately. I had one ankali for a couple of months but it didn't work out. She was a very nice person but for some reason or other she had a lot more problems than I did.'

Karl was then introduced to Carol. 'It's been excellent every since. She's been very positive for me and I can talk to her about anything, which is very good at my age. It's hard to meet up with people again. When you've lost a lot of your very closest friends over a period of time, you do feel extremely isolated and alone.'

'I'm a very solitary person. I find that the influence of the Ankali Project is so good. I mean, Carol and I can go out and socialize and have a wonderful time but then I have

problems. Well I did. I can talk to her about it, you know, without any fear of being told 'back off'.'

'We're a close age and Carol's a gay woman so I can pretty well relate to her, discuss anything with her. She has a grandson that she likes to chat about, talk about, and see once a week. I talk about my family. We love reading. We love books. We go out, as Vince said, to a cheap eatery once a week, get a \$5 steak, couple of glasses of wine, put \$2 or \$3 through the poker machine, and that's our day out. It's very nice. I can talk to her about anything. We've become, over the last 2 and a half years, quite close, as close as I can every get to anybody. I find it very hard to go socializing anymore on my own. Most of the friends that I had are dead now. It's been excellent for me. I'm a bit slow at getting with friendships and relationships and this is on a professional level at one point, then it's an emotional, personal thing in another way. It works very well.'

For Vincent, the main benefit of the Ankali Project is socialising. 'I don't have a great group of friends just at the moment, a big group of friends. That is something he is helping me with, trying to get me to go out to more places. I go out with him every Saturday afternoon and he'll ring me every Thursday night to organize where we're going to go. We go to the beach, just for coffee, and walk along the beach. We go to restaurants, cheap eats, to a movie. I find my ankali and I have very similar taste. Or other times we just sit down and discuss a social problem I might have, which I thoroughly enjoy doing. These days, we've become so close, he will tell me if something is going wrong with his life and I find that quite a good compliment that he does that because it means that we have become quite close, and I will give him my suggestions, which is totally what you're not supposed to be doing.'

Vincent thinks it is easier to talk to his ankali than a lot of his friends who have hiv. 'A lot of them have got their own problems and you don't feel you should be burdening all yours onto them as well.'

When Adam arrived in Sydney, he knew only one person. He has had an ankali for four years, who he sees once a week.

Adam arrived in Sydney from New Zealand, with his partner, six years ago. His partner died four months after they arrived and Adam spent most of the next two years in hospital. When Adam arrived in Sydney, he knew only one person. He has had an ankali for four years, who he sees once a week. 'It's difficult. Everyone's really busy with their own lives. It's just nice having someone to talk to.'

Adam's current ankali is his third. The first left for personal reasons before he became too attached. He didn't get on with the second one. Adam and his ankali socialize together. 'After four years of friendship, I know some of his friends and he knows some of mine. If they have a problem, maybe you can help out. It's quite important that you do that, so you don't feel like you're taking all the time. We go for coffee and a chat, see a movie, maybe have a drink.'

When an ankali was first suggested to Vincent, he said no. 'I thought they only dealt with people who were very sick.'

'It was not a service that would take you out somewhere and be your friend and just be a companion to you for a while, help you out with some social issues. I never thought that. I never heard that's what they did.'

'I always did everything myself. I was used to doing it just with my partner, not with a stranger or anything. I thought I could solve all my own problems.'

Karl's experience was different. 'It was suggested to me through the psychologist that I should go and talk to my friends, longstanding friends. These were two straight people at the time, and I'd known them for a long, long time over the years and helped out in many ways. They just didn't want to know about it. When I told them I was hiv, had been at that stage for 15 years, they just said, well, that's your way of life. Keep it to yourself. We don't particularly want to know.'

After losing 'a whole swathe of friends' to aids, Karl found he was starting to lose friends he'd worked with. 'People I'd worked with and developed relationships with over the years, I was losing them as well.'

'The psychologist said to me, well, why don't you pop round to Ankali. I'll ring them now. If it hadn't happened immediately I would have backed right off.'

When Karl arrived at Ankali, he felt comfortable being able to speak about things he couldn't speak to very close friends about. 'And that eased a lot of tension for me at that particular time. I needed very much to talk to someone.'

Adam faced a negative reaction from some friends when he started seeing his ankali. 'Some people have said, isn't it like having a rent-a-friend kind of thing, and isn't it false. I didn't care; I just thought it would be nice to have someone. Because everyone else works and it's an awful long day, especially if you're awake all night as well.'

After he recovered from his acute illness, Adam faced similar criticism again. 'Someone did say, 'You don't need it anymore'. Just an acquaintance ... These people that say these things have their own problems and issues with different things.'

'It might just be that he was really ill or he might be feeling bitter at that stage and he thought that's what he needed to hear.'

Karl also faced pressure from gay positive friends, who said to him, 'What do you need an ankali for? You've got enough friends to support you.' But they didn't support me in the way I wanted them to. They brush you off.'

'I have a couple of close friends I've never told I'm hiv because I think they wouldn't be able to cope and it would create a bit of tension between a friendship that's been going on for a long time, so I just say nothing. With Carol, I can talk openly about things. I've

been to hospital a couple of times and she comes with me.'

Vincent thinks it is easier to talk to his ankali than a lot of his friends who have hiv. 'A lot of them have got their own problems and you don't feel you should be burdening all yours onto them as well. With you ankali, he's a healthy man. You can more or less just tell him anything. He's not going through a health issue. He's just there to listen and help you through it. But with your friends, they don't want to hear you complain again, so you feel you don't want to ruin the friendship. I know two people who have hiv and they swear by me as friends but I don't tell anybody I've got an ankali. Only a couple of people know I've got an ankali and even those people, they don't rush around and tell everybody I've got an ankali. It has been said to me recently, somehow it got mentioned, and somebody said, 'Oh, I'm over that period. I don't need that sort of person anymore in my life.'

Karl: 'I'm a very solitary person. I find that the influence of the Ankali Project is so good.'

Got time on your hands?

Positive+Decisions Program

Executive Director **Georgina Harman** and Fundraising Manager **Suzi Chinnery** describe what volunteers do for the Bobby Goldsmith Foundation and what plwha can get out of it

Positive+Decisions is a PLWH/A (NSW) initiative to assist hiv+people who are interested in updating their skills.

The Bobby Goldsmith Foundation (BGF) encourages plwha to volunteer. Plwha can make an ongoing commitment to volunteer for BGF or just be available for a couple of hours. 'It's really up to the individual to commit as much as time as they want to. We've got a huge number of opportunities,' said Executive Director Georgina Harman. 'It's street collections. There's also things like answering the phone, helping with mail-outs, stuffing envelopes.'

'We actually have a policy that volunteers don't get involved in client services, in order to protect the privacy and confidentiality of our clients.'

'It might just be combating boredom, getting people out of the house, sitting in a room full of 20 other volunteers, and having pizza and stuffing envelopes. I think BGF's a fun place to work and the volunteers who work here on a regular basis tend to come back, so we hope that demonstrates a mutually rewarding organisation to work for,' she said.

If you're interested in volunteering for an organisation because you're planning to return to the workforce, BGF can provide support within the organisation.

'The first thing we'd want to do is to sit down and say, 'Have you accessed the Positive Employment Service at BGF? Have you spoken to the PES Officer? Is that something that you might find useful?'

BGF staff will also ask you about what you're interested in doing, and what your skills are, as well as finding out which skills you want to build on.

'We see volunteering as a donation to us. It's people donating their time. If we employed someone to do what our volunteers do, we wouldn't be able to help as many people. So, we have a responsibility to our volunteers to ensure that they're provided a safe and sensible working environment and that means we might provide some training, we provide lunch and we hope that we provide a nice environment in which people can not only build skills but build confidence,' said Georgina.

Volunteering for an organisation like BGF doesn't just help raise money. You can also build new skills. 'We're a community partner of the Positive Decisions Program and we've created two positions that we're looking for plwha to fill,' said Georgina.

One of these is an administration support position and includes IT and general office administration. BGF's Fundraising Manager Suzi Chinnery said this position will include filing, as well as 'assisting with the fundraising ... sending out letters, calling up people, doing a bit of research for trusts and foundations on ways to generate money, that sort of thing.'

The program offers opportunities with various host organisations, as well as training opportunities at PLWH/A (NSW) offices. Placements are currently within Darlinghurst and run for three months. Participants commit two days a week to the program, with another day a week committed to external training.

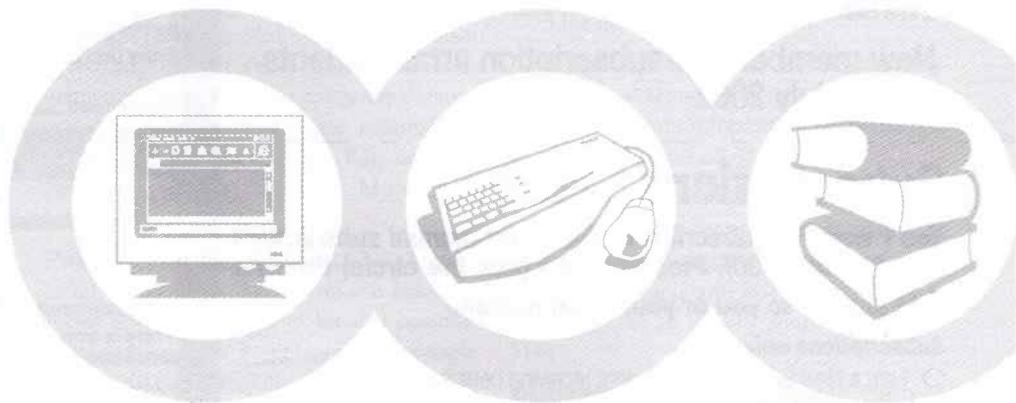
Positive+Decisions works with participants to focus on technological skills. Training options can be organised in the following areas: computers (Microsoft packages), internet and email, reception and administration, and self empowerment and presentation.

At the end of the three-month program, you won't be left alone. Ongoing assistance is available through the Positive Employment Support.

If you are interested, phone Will Klaasen on 02 9361 6011.

Positive Decisions at PLWH/A (NSW)

Daniel was four weeks into a 12-week placement at PLWH/A (NSW) when he spoke to **Susan Hawkeswood** about the Positive Decisions Program



'Being completely computer illiterate, I thought it was about time I learnt how to use a computer,' said Daniel. 'So I came and spoke to Will and, when he told me all about it, I thought, I'll just come and do it.'

'I haven't been ill, even though I've been HIV for about 15 years and just started on medication last year. I've never really been ill as such, so I've always worked. It's just that with my lifestyle, I just kept computers at bay.'

Daniel is doing a college-based computer awareness course two nights a week as part of the program. 'But I'm learning a lot here. It's hands on here.'

A yoga teacher at the Australian School of Yoga, Myrtle Place, and the Positive Living Centre, completing the Positive Decisions Program won't result in a change of direction. 'It will just enhance what I'm already doing. If somebody offers me a great job, maybe I'll think about it but at the moment everything I'm doing will just enhance what I'm doing.'

Wanting to get more involved with a PLWHA organisation was part of Daniel's decision to volunteer at PLWH/A (NSW). 'I didn't have any expectations but I just thoroughly enjoy being here.'

'I'm meeting other people. You get to see a lot more things that are going on.'

A third of the way through, Daniel thinks the program works to 'bring you out of yourself, realise your capabilities.'

'We're all capable of doing these things, and the plus of learning how to use a computer will really open up their world for them so much. Over at Myrtle Place, where I go on Fridays, they've got a computer room set up over there, and down at PLC they've got a computer room set up there. And they're free services.'

'We all know that your life doesn't stop because you're HIV and it's just the beginning for you, a new beginning for you. I think the benefits of learning the course is learning new skills, being out amongst people, realising that we've all got something to share.'

'It's a good environment to be in, you're very nurtured. Will's a good teacher, very patient. There's no stress involved in it. No-one's pushing you.'

'Obviously it can help you if you're looking at going back to work, or you've been out of the workforce and want to get back into the workforce, to have computer skills. That's obviously very important today. And you grow. We're all growing. I see people I work with all the time and they're forever growing. PDP is a generous opportunity to come to a friendly environment and learn new skills.'

I'm

meeting other people. You get to see a lot more things that are going on.'

Olga's personals

Mars seeking to align with his Venus, Heterosexual Male, 42 yo, hiv+, searching for a soulmate forever to support and grow in Love. Respecting differences, nurturing vulnerabilities and valuing each others friendship. Reply: 020802

39yo +ve, fit, good looking, 5'11, honest, genuine, live in Eastern Suburbs, dog owner, seek guy, late 30s-50, sincere, intelligent, warm, articulate, fit. Reply: 010802

Shy sincere loyal and hardworking 35 yo hiv + divorced and honest straight guy living in Sydney, seeks friendship with hiv+ lady in similar situation who wants to meet a true, loyal and down to earth friend. All letters answered. Reply: 020602

Central Coast, cute, slim & hiv+ (18yrs) 42yo passive bumboy. Seeks slim hung dickman, 35-50, for friendship, fun, and dirty sex. Reply: 010602

Good looking 30 yo straight + male, recently diagnosed, good health non-smoker social drinker, seeking honest, straight, single female aged 22-32, for serious relationship and love>. Please respond if you are genuinely interested. I am looking to hear from you. You will not be disappointed. Reply: 070402

Long Bay, 28yo hiv+, good looking, intelligent, kind hearted, country lad and straight acting. Like a drink, don't do gay scene very often, looking for good friends, pen pals, a real man is hard to find 'are you my knight in shining armour?' Reply: 060402

Guy 50s, Ryde area; active and in good health. Hiv+, 6'1, 85kg, blonde, likes home TV movies, going out GOSH no ties seeks person for companionship, relationship all replies answered so please write. Reply: 050402

24 yo gay guy hiv+ for 5 years, DTE, GOSH, comes from country. I am currently in gaol and looking for pen pals with other hiv+ gay guys with the same interests, all letters answered. Reply: 040402

Sth Sydney, 41yo Black gay guy, hiv & hep c. Hi, I've been hiv/hep c for 11 yrs. I'm 5ft 4" tall, tight body, ok looks, you similar 36-43yrs wanting same. Reply: 030402

Early 40s guy would like to meet with a genuine guy 35+. Preferring sincerity & understanding, id a must, so (please) don't waste our time; genitals are fun BUT I really need some heart. Heritage is no barrier. Reply: 020402

HIV+ guy, 53, 5ft 7", brown eyes, OK looks and physique, seeks similar female penpal! With view to whatever. I am prudent, compassionate, and monogamous, have learnt not to try and understand women but simply adore them. Resident in Gold Coast. Reply: 010402

HIV+ gay male 42, GSOH, caring, romantic, in good health, enjoys travel, dining, in/out, bushwalking. Looking for an intelligent, passionate, genuine active guy to 46 with a view to LTR. Not into drugs or the scene. Genuine replies only. Reply: 010202

How to respond to an advertisement Write your response letter and seal it in an envelope with a 45c stamp on it • Write the reply number in pencil on the outside • Place this envelope in a separate envelope and send it to Olga's Personals, PO Box 831, Darlinghurst 1300.

How to place your advertisement Write an ad of up to 40 words • Claims of hiv negativity cannot be made. However, claims of hiv positivity are welcomed and encouraged • Any letter that refers to illegal activity or is racist or sexist will not be published • Send the ad to Olga, including your name and address for replies. Personal details strictly confidential.

Sydney

StraightTalk Daytime support program by Pozhet. Straight Talk's objective is about getting people out where they can make new contacts, socialise and share information or insights. Barmuda Coffee Bar, opposite Newtown Railway station. More info, tollfree 1800 812 404.

Positive Living Centre, 703 Bourke Street, Surry Hills. The centre is a one-stop access point for a range of hiv and community based services. Programs for pos people to help develop new skills, interests and work opportunities.

Luncheon Club and Larder, Positive Living Centre, 703 Bourke St, Surry Hills.

Fit X Gym At the Community Pride Centre, Hutchinson St, Surry Hills. Positive Access Program (PAP) offers qualified instructors, free assessments, free nutritional advice, free individual programs and a free session to try out the gym. \$2.50 a session, or \$20 for a 10 visit pass. Contact Fit X Gym, 4-7pm Mon-Fri or PAP, 9.30 am-12 noon, Mon, Wed & Fri on 02 9361 3311.

Yoga for plwha Special weekly classes at Acharya's Yoga Centre Mon-Fri. Call 02 9264 3765 for more information.

The Sanctuary offers free massage, acupuncture, therapy information, social work and shiatsu services. Call Robert for details and bookings on 02 9519 6142. Also holds cooking programs. To find out more contact Sidney Leung (dietician) on 02 9395 0444.

Community Garden Learn how to grow your own vegies. Great opportunities at Newtown and Waterloo. Call Street Jungle on 02 9206 2000.

Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt. They'll pick you up from home, give you two hours to shop, then drop you off again. Price is \$4 and available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville and Darlington. Call Diana on 02 9516 4755.

Newtown Neighbourhood Centre has a

number of groups. Call Charlotte on 02 9516 4755 for details, including cost.

'Outings' from South Sydney Community Transport is always offering day trips and excursions. More information or bookings, call Jane or Robbie on 02 9319 4439.

Southern Cross Outdoor Group's website is full of details of their many up and coming social get togethers, including walks, dances and trips away. See the website www.scog.asn.au or call John on 02 9907 9144.

Dementia Support for Family, Partners and Friends. Telephone/group support for significant others of people with hiv associated dementia, cognitive impairment and/or mental illness. Meets last Wednesday of every month at the Tree of Hope, cnr Riley and Devonshire Sts, Surry Hills at 6.30pm. Contact Angela 02 9829 4242, Margaret 02 9698 3161 or ADAHPT 02 9339 2078.

Myrtle Place at Crows Nest offers massage services for plwha. For appointments and info about other services, call Dennis or Mark on 02 9929 4288.

Western Sydney

Pozhetwest offers peer support and education for men and women living heterosexually with hiv/aids in Western Sydney. Contact 02 9671 4100.

Blue Mountains

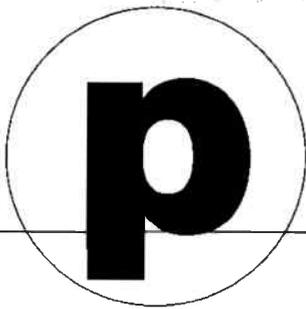
Drop in to the **Blue Mountains PLWHA Centre** at 2 Station St, Katoomba for informal peer support. Open Wed and Fri 11am-3.30pm. Lunch Wed 1pm, \$3conc/\$5waged. Ph/fax 02 4782 2119 email: bmplwha@bigpond.com

Hunter

Karumah A meeting place for positive people and their friends in Newcastle and the Hunter. Activities held each week. Pos-only space and open groups. Contact Karumah Inc, 47 Hudson St, Hamilton. Ph: 02 4940 8393. Email: karumah@kooee.com.au

Northern Rivers

Support Group for partners, family, friends, carers of people living with hiv/aids. Contact Sue on 02 6622 1555 or 1800



PLWH/A (NSW) Inc Privacy Policy

People Living with HIV/AIDS (NSW) Inc [PLWH/A (NSW)] is a non-profit community organisation representing the interests of people living with hiv and aids in NSW. Providing information, referral, advocacy and lobbying are our primary functions.

Our major projects include the Publications Unit, Positive Speakers Bureau, Community Development and Health Promotion and Education. These projects develop policies and community resources (for example, in peer education and hiv/aids awareness) through its volunteer working groups. We also have a volunteer board and program.

Protecting your privacy

Recent amendments to the *Privacy Act* require us to safeguard the privacy of personal information, including health-related information, we hold, collect and store on you and organisations with which we deal. We are committed to protecting and maintaining the privacy, accuracy and security of your personal information and give a general right of access to that information.

When we collect your information, we will tell you what we want to do with it and respect your wishes and views. All of our staff and volunteers sign confidentiality agreements in accordance with PLWH/A NSW's policy.

In this factsheet we set out policy on how we will handle your personal information.

What is personal information?

Your health information or information about your sexual preferences is very sensitive and the *Privacy Act* respects that. It gives a higher level of protection to sensitive information. This may also include other information such as racial or ethnic origin, political opinions, membership of a political association, professional or trade association membership, religious beliefs or affiliations, philosophical beliefs or criminal record.

Another type of sensitive information is health information and is concerned with your health or disability. This may include information about health services, and other personal information collected whilst providing advocacy referrals or any other assistance on your behalf.

How we collect and use your personal information

Your sensitive health information will only be collected where it is necessary to carry out the functions or activities of the organisation. These include the distribution of hiv/aids related material and publications, to keep accurate membership, subscription and volunteer details, and for purposes of advocacy or referral.

Wherever possible we will obtain consent from you before personal information is collected. We will only use your information or disclose it to someone else for the reasons we collected it and these are within reasonable expectations of what you expect, for example, service management or quality assurance.

When the law says we have to, disclosure of information may need to be made, for example, when someone's life is in danger, or when it is needed for court or legal proceedings, or for compassionate reasons.

Is your personal information stored safely?

We will take all reasonable steps to ensure the security of your personal information held by us from such risks as loss or unauthorised access, use, modification or disclosure. Access is restricted to staff of the organisation that require information to perform their job functions and your requests.

We use up-to-date processes, which meet professional and ethical codes and standards to ensure that your personal information is kept secure and confidential.

You can access your personal information

You have a general right to access and to correct or update your personal information.

Your access is subject to some exceptions where it would be against the law, or where someone else's privacy may be seriously invaded, or it may pose a threat to life and health. If this is the case we will let you know why we have withheld access.

What to do if you want to access or make changes to your personal information

We will provide the means for you to manage and control the information that you have provided us. We will take all reasonable steps

to correct the information so that it is accurate, complete and up to date. This service is free unless the information you request requires significant research or preparation time. Before we act on requests of this nature, we will inform you in writing how much this service will cost.

You also have the right to withdraw your personal information from mailing lists, including service updates, subscriptions and membership details.

To get access, or to update or correct your information you will need to complete a 'Privacy Inquiry' form. This form can be obtained by contacting the administration section via telephone, in writing or on our website.

If you have a complaint about the way we manage your personal information we will promptly acknowledge and investigate that complaint.

We will respond to your written request within 15 working days of receiving it.

Changes to this Privacy Policy

We may review and update our Privacy Policy. Revised versions will be posted on our website.

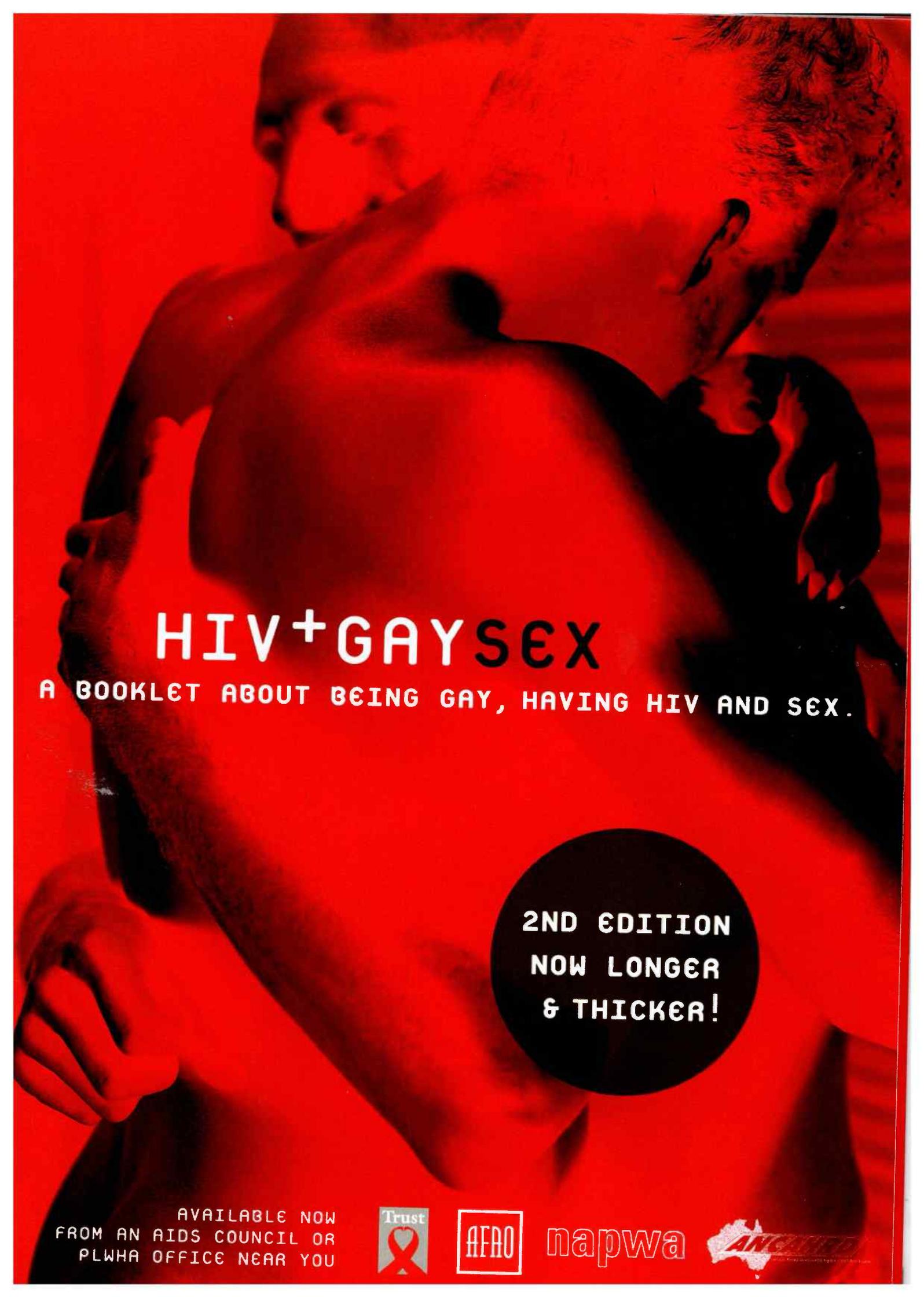
How to contact us

PLWH/A's Privacy Policy is available by factsheet or on our website – www.plwha.org.au. Copies are available on request.

If you have any questions or comments about this Privacy Policy, or wish to request access or update or correct your personal information, please contact PLWH/A NSW's Privacy Officer:

email research@plwha.org.au
telephone (02) 9361 6011
freecall 1800 245 677
fax (02) 9360 3504

The Privacy Commissioner's website contains detailed information on privacy obligations including a copy of the *Privacy Act* and the Guidelines On Privacy In The Private Health Sector. The URL is <http://www.privacy.gov.au/>. The Guidelines are at <http://www.privacy.gov.au/health/guidelines/index.htm#1>. These Guidelines set out the standards for collecting, storing, using and disclosing personal information.



HIV+GAYSEX

A BOOKLET ABOUT BEING GAY, HAVING HIV AND SEX.

2ND EDITION
NOW LONGER
& THICKER!

AVAILABLE NOW
FROM AN AIDS COUNCIL OR
PLWHA OFFICE NEAR YOU



napwa



Planet positive Christmas in July

