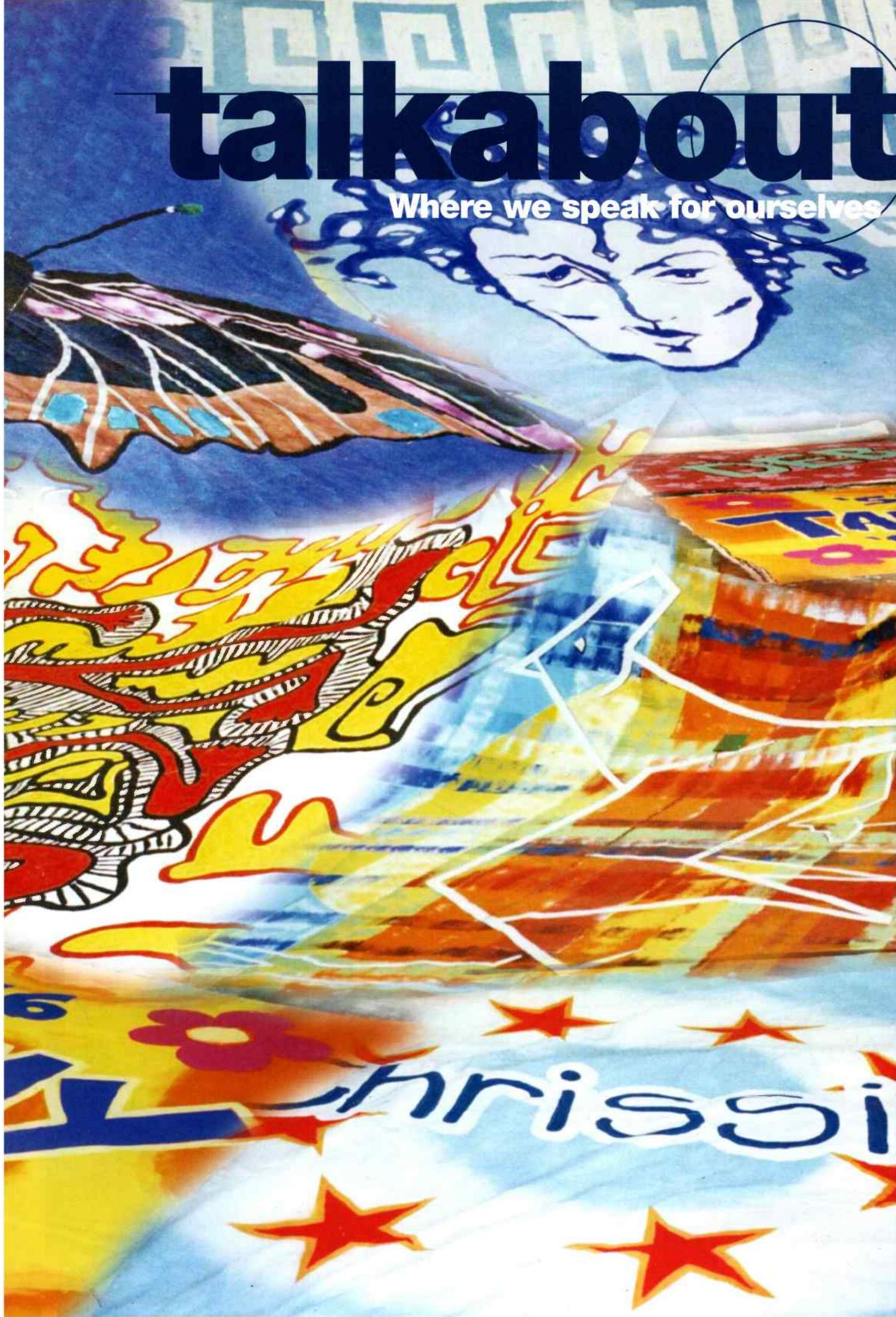


# talkabout

Where we speak for ourselves

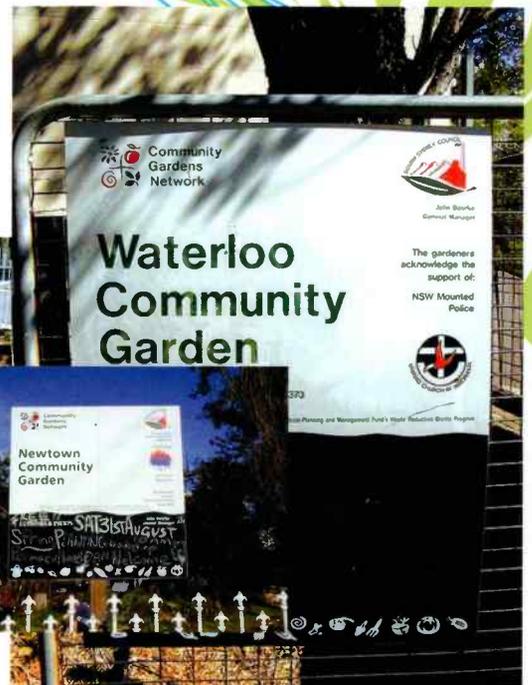
#124 | december 2002 - january 2003 | The Magazine of People Living With HIV/AIDS NSW Inc.





# Street Jungle

Started in 1999, Street Jungle has gardens at Newtown and Waterloo. Learn about gardening, or build on your knowledge of organic produce. Street Jungle is a community initiative of South Sydney Council, South Eastern Sydney Area Health Service, Central Sydney Area Health Service and the AIDS Council of NSW. The gardens are a peaceful place where you can get your hands dirty and be rewarded by the outcomes — free, fresh organic produce (and yes, even the free range eggs are free). Contact Street Jungle @ ACON on 9206 2000, or email [streetjungle@acon.org.au](mailto:streetjungle@acon.org.au).



# talkabout

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Cover: Volunteers re-created the quilt for the Sydney Gay Games.  
Pics: Ray Hansen. Design: Slade Smith

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#### CONTACTS

Office Suite 5, Level 1, 94 Oxford Street  
 PO Box 831, Darlinghurst 1300  
 Phone (02) 9361 6011  
 Talkabout (02) 9361 6750  
 Fax (02) 9360 3504  
 Freecall 1800 245 677

It's post-Games for some readers, so hopefully a speedy recovery from all that exertion. Congratulations to entrants – the crowds in a few locations have been unbearable but I guess it was worth it. I made it to Health In Difference 4 (HiD4), held as part of the Games conference program. The interest in hiv issues, judging from the attendance at these sessions, was minimal. Participants missed out on some great papers. The Quilt was re-created for an unfolding ceremony to celebrate the Games. Volunteers spent hundreds of hours over a series of weekends creating a copy of the original Quilt – a mammoth undertaking. The photographs on this issue's cover were taken at one of those workshops.

World AIDS Day and associated events will have been celebrated by the time this is in most readers' hands. In keeping with the tradition of World AIDS Day, which grew from the action campaigns of the 1980s, this issue of *Talkabout* includes an interview with three plwha from Papua New Guinea who visited Sydney recently. Their future depends on access to treatments – currently non-existent in Papua New Guinea – and services. Most of the AusAID funds allocated to Papua New Guinea are being directed to hiv prevention campaigns, with precious little going to plwha.

Also in this issue, an article from the Multicul-

tural HIV/AIDS and Hepatitis C Service profiles a two-year project for people from culturally and linguistically diverse backgrounds who present late with hiv. Fears about testing, lack of knowledge about hiv and its effects, and a scarcity of information about hiv in relevant languages are reasons why people from some communities are presenting late. Many of these people may be more likely to die as a result – another access issue.

Christmas will be on us in less than a month. Whether you celebrate the festive season or ignore the whole thing, have a great time and try to stay sane. This issue's Diary includes information about service closures over Christmas and New Year.

What's the drought got to do with me? If you live in Sydney, the water level of Warragamba Dam for a start. Capacity is down to about 70 percent, according to television reports in early November. When the water level drops that low, the nasties in the water become more concentrated. The increased concentration doesn't have dire consequences for anyone with an immune system functioning at 100 percent but if your immune system is compromised, the difference is enough to knock you off your feet, especially in summer. If this applies to you, buy your water bottled this summer, or filter tap water before you drink it.

Have a great holiday this summer.

*Susan Hawkwood*

## in this issue

#### TALKABOUT

is published by People Living With HIV/AIDS (NSW) Inc. All views expressed are the opinions of the authors and not necessarily those of PLWH/A, its management or members. Copyright for all material in *Talkabout* resides with the contributor. *Talkabout* is made possible by subscriptions, advertising revenue, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* thanks the many volunteers without whom its publication would not be possible.

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#### DISCLAIMER

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

Geoff Honnor on body positive representation and advocacy in NSW in response to PLWH/A (NSW) Executive Officer Antony Nicholas on **pages 12-13**

Although funds are being provided to Papua New Guinea through AusAID, Max describes getting services when you're positive as 'a bit hard'. Max, Helen and Margaret are three plwha from Papua New Guinea interviewed by Susan Hawkwood for 'Positive

in Papua New Guinea' on **pages 14-17**. Also an interview with Dr John McBride, an infectious diseases specialist based in Cairns.

People who are diagnosed late with hiv do not get treatment early in their illness and may be more likely to die earlier as a result. Masha Eisenberg and Mohamed Keynan, of the Multicultural HIV/AIDS and Hepatitis C Service profile a two-year project on **pages 18-20**.



# p os action

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

**Well, another holiday edition has arrived and the end of another year, and what a year it has been for all the staff and board here at PLWH/A (NSW). Some of the highlights for me have been:**

- \* Assisting in the planning, participation and presenting at the Rural HIV Forum in Nelson's Bay, an opportunity for rural plwha and workers to meet and discuss issues affecting rural plwha.
- \* The launch of a re-designed PLWH/A (NSW) website, which includes the Contacts Service Directory online for the first time.
- \* Receiving NSW Health funding for three new Health Promotion Projects.
- \* The Health Promotion Project of PLWH/A (NSW), which produced the postcards seen around town during the Gay Games and a 6 metre billboard at Town Hall station. Over 140,000 people a day will pass by, being questioned on hiv discrimination.
- \* Healthy support in donations from The Harbour Party and Malcom Stewart's Woof Party; as well as support from ACON through its final Hand in Hand Disbursements.
- \* The completion of those seemingly boring, but very important submissions on sub-

jects as diverse as clinical trials, medicine use, privacy legislation, welfare reform, housing issues, infected person control, review of the national research centres – and the list goes on. Most of this work is invisible and unacknowledged but leads to most of our most important outcomes.

- \* The re-launch of the 2002 expanded version of the HIV Traveller's resource, which was distributed nationally.
- \* Seeing another half a dozen people complete PLWH/A (NSW)'s Positive Decisions Program, which gives plwha the chance to retrain and make decisions about return to work, study or volunteering.
- \* After many months of negotiation with the Department of Housing about SASS, getting a positive result eventually to protect the rights of plwha to safe, secure housing.
- \* The well attended PLWH/A (NSW) Integrative Therapies Forum held at the Powerhouse Museum with 60 participants, 8 speakers and the ability to supply free copies of Dr John Kaiser's book.
- \* The success and growth of the Positive Speakers Bureau in its eighth year.
- \* And finally, six excellent editions of *Talkabout* distributed throughout NSW – and

across Australia – to those affected and living with hiv.

A lot of this work is completed with the assistance of dedicated Board Directors and other volunteers who assist PLWH/A (NSW) in numerous ways. Recently, several volunteers raised over \$1,600 dollars in just four days for the organisation. Thank you Glenn, Daniel, Kevin and John. To all our volunteers THANK YOU.

John Cumming and Kirsty Machon examine the claims about hiv made in World Without AIDS – and counter with a few facts – on **pages 20-12**.

Just who exactly are SASSters doing it for, asks James Peterson on **pages 22-25**.

Tim Alderman on hiv-related impotency, and some of the remedies, on **pages 26-27**.

Mary Bayldon, formerly of the Ankali Project, shares her experience of a teleconferencing support project for mothers of hiv positive adult children on **pages 30-31**.

Most of our usual regulars are included in this issue. Check for Xmas closures in the Diary on **page 32**. Agony aunt on **page 4** gives readers a few tips on surviving the festive season. Treatment Briefs are on **page 5**. News roundup, on

**pages 6-11**, includes interviews with volunteer, Tony Kay, and World AIDS Day Coordinator, Douglas Knox, at the Quilt workshop during the lead-up to the Gay Games. Apologies to all Olgas – she's going through a re-vamp and will return next year, better than ever.

**Correction: The PSB column in #123 was written by Angelo Stasos, of East Hills Boys Technology High School**

## Jennifer Gracie

**Q** At Christmas, I will visit my family. I'm worried because I can't afford to spend much on presents. There are about six adults and several children. I am not sure if I am expected to bring food or contribute money towards buying food. I really want to go but am stressing out!

**A** Perhaps you could speak to all the adults before Christmas and agree that there won't be any gifts but you will all just enjoy each other's company. You could also agree that there will only be presents for the children. If the children are young, you could look at a bundle of small things from the discount shops with each present wrapped separately in cheap paper and put into a small carry bag. Little ones love things such as a few balloons, bright plastic balls, colouring books and pencils, and chocolate Santas. If the children are older, you could buy books of crossword puzzles or a game for the whole family – again, the discount shops have some of these for less than \$10 each.

If you need to give gifts to the adults, consider joint ones such as a tin of biscuits or chocolates. You could try cooking a cake or cookies. It doesn't need to be an expensive Christmas cake.

**Q** I find Christmas very depressing because I have no-one to spend it with. Everything on TV is about happy families and I feel left out. Why can't Christmas just go away this year?

**A** Unfortunately, it doesn't go away but there are things you can do to make it more enjoyable.

Many charities put on special Christmas lunches. You could phone a few of them and offer your services on the day to help serve meals or provide entertainment. The Positive Living Centre sometimes puts on Christmas lunch, so contact them on 9699 8756.

The Metropolitan Community Church has Carols on Christmas Eve in the Sydney Town Hall at 8pm. There are lots of people there and everyone has a lot of fun.

Maybe you could ask your neighbours to see if anyone else is going to be alone on the day and see if they would like to share the day with you. You could each take a picnic lunch to the park or go to the beach.

*Jennifer Gracie is a financial counsellor with the Bobby Goldsmith Foundation. If you have any questions for agony aunt, email [jennifer.gracie@bgf.org.au](mailto:jennifer.gracie@bgf.org.au)*



PLWH/A (NSW) Community Development Officer  
**Glenn Flanagan** profiles what's happening in NSW

## Thanks to Will

Thanks to Will Klaasen for his hard work and enthusiasm during the last 12 months as Community Development Officer. As well as his work on many committees, at the HIV Rural Forum and managing volunteers, Will coordinated the successful expansion of the Positive Decisions program into several new sites. This has been a very important development for positive people who have wanted to explore their capacity for work and learning new skills in a range of workplaces. Positive people who are interested in testing their energy levels and interest in a number of friendly and understanding environments can ring us on 9361 6011 and discuss the possibilities. Thanks again Will.

## Time to make changes in your life?

Everyone who is hiv positive will have reflected on their lives at some point and the direction they have taken. Sometimes you may have thought of making changes and moving on. Often, even when you have decided you want to make changes in your life, even small ones, it can be difficult to know how to take that first step. To assist us in identifying these goals and following through on a decision we have made, BGF is starting up a new project based on life coaching principles.

To participate in this initiative you don't have to be a current client of BGF. All positive people looking for a change in their lives are welcome.

The project will be run by Maree Crosbie. Maree has been at BGF for five years and began the financial counselling project there. Lots of thought and planning has been going into this new project to make sure that it will be just as successful when it begins.

## Wanting to meet other positive people?

There can be a real benefit and empowerment in meeting other positive people who have had many of the same experiences we have had. Planet Positive is one of the best opportunities to meet and get to know other people living with hiv in a friendly and comfortable environment. We have been meeting now at the Positive Living Centre for more than a year for this bimonthly event. Planet Positive will be having a street party on Friday 6 December at 703 Bourke St Surry Hills. The night will start at 6pm, with free food, refreshments and entertainment.

## It's better to treat

Some form of complementary therapy, which can include everything from vitamin supplements and massage to acupuncture, can have a real impact on our sense of wellbeing. Combining these complementary therapies with antiretroviral therapy to manage hiv is a very common practice among positive people. To better inform us of the treatment options, the Integrative Treatments Working Group of PLWH/A (NSW) recently organized the HIV Integrative Treatments forum at the Powerhouse Museum. The forum was well attended and there was a range of speakers with diverse expertise, including a fitness trainer, a herbalist, a reflexologist, a dietician, an acupuncturist, and a kinesiologist. Treatments Officers and a medical practitioner also spoke at what was a really interesting event.

Contact PLWH/A (NSW)'s Community Development Officer, Glenn Flanagan on 9361 6011 or 1800 245 677.

# treatment briefs

## AZT, 3TC, efavirenz best first line combination

A large US/Italian trial has concluded that AZT, 3TC and efavirenz is the best first-line combination in people who have not previously taken antiretroviral medication. The study (ACTG 384), presented at the 14th International AIDS Conference in Barcelona, involved 980 antiretroviral-naïve people and was designed to answer 3 questions: 1) Is it better to start with d4T+ddi or AZT+3TC? 2) Is it better to start with a regimen that included a NNRTI (in this case efavirenz) or a protease inhibitor (in this case nelfinavir)? 3) Is it better to start the combination with three drugs (from two classes) or with four drugs (from all three classes)?

On entry to the trial, all participants had an average viral load of 80,000 copies and an average CD4 count of 278 cells. They were randomised into one of 6 groups, each receiving a different drug combination.

The trial concluded that there was no significant advantage in starting antiretroviral therapy with a four-drug regimen over a three-drug regimen. Taking into consideration the durability (time to drug failure) and the side effects experienced by trial participants, it was concluded that AZT+3TC+efavirenz provided the best therapy for people who had previously not taken antiretroviral therapy.

This trial adds further weight to the results of several other trials (most including efavirenz) – that first-line NNRTI-based drug regimens are as effective and as durable as regimens based on a protease inhibitor.

[www.aidsmap.com](http://www.aidsmap.com)

## Integrase inhibitor unveiled

So far, drug therapy has been successful in inhibiting two of the three enzymes that hiv uses to infect CD-4 cells – protease and reverse transcriptase. Now scientists have developed a compound that interferes with the third enzyme called integrase. Integrase is used by hiv to ‘integrate’ itself into the

DNA of the host CD-4 cell. Several integrase inhibitors have been studied over the years but have not proved successful due to their toxicities. The new compound, synthesised by Merck, is called L-870,810 and was found to be highly active against HIV-1 in laboratory studies. It is also active against hiv that is resistant to all currently available classes of antiretroviral drugs. Phase I trials are currently underway and it is hoped that Phase III trials could take place within the next two years.

Young, S.D., et al. L870,810: Discovery of a potent HIV integrase inhibitor with potential clinical utility, Presented at The XIV International AIDS Conference, Barcelona, Spain.

## Women at increased risk of NNRTI rash

A British study has shown that women who are taking either of the non-nucleoside (NNRTI) drugs nevirapine or efavirenz are more likely to develop an allergic rash than men. The retrospective study, reported in the journal AIDS, was designed to determine if there was a link between the development of an allergic rash in people taking NNRTIs and gender and ethnicity. The study involved 337 participants including 285 people treated with nevirapine and 52 people treated with efavirenz.

Development of a rash occurred in 19 (6.7%) people treated with nevirapine and 3 (5.8%) treated with efavirenz. Female gender was found to be significantly associated with the development of an allergic rash with an incidence of 14.6% compared to 3% for men.

It is unknown what factors predispose women to the allergic rash, although steroid hormones, oral contraceptives, menstruation, pregnancy and differences in the way that women process antiviral drugs in the liver may play a role.

[www.aidsmap.com](http://www.aidsmap.com)

Treatment Briefs are written by ACON's Treatment Information Officers. Phone 02 9206 2036/2013, tollfree 1800 816 518, email [treatinf@acon.org.au](mailto:treatinf@acon.org.au)

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## Europeans investigate resale of drugs

Police and investigators from the Netherlands, Germany, Belgium and France were scheduled to meet on 29 October at Europol, Europe's police agency in the Hague, to exchange evidence about a wide web of trafficking schemes in which deeply discounted AIDS drugs meant for Africa were resold in Europe at huge profits. In addition, the European Commission is set to publish new enforcement guidelines that it hopes will put an end to the smuggling. The investigations came to light this month after the discounted GlaxoSmithKline drugs Eпивir and Combivir were intercepted at airports in Paris and Brussels.

People close to the investigations said the intercepted drugs were resold to several big, respected European importers. One of them, Kohlpharma, bought some of the drugs from a Dutch company called Asklepios, and paid fair market price for them, a company spokesperson said, adding that Kohlpharma had no idea the drugs had been discounted for use in Africa. The investigations resulted in two arrests last week: that of a German businessman working out of a garage near Bochum and of a French pharmaceuticals trader.

Dutch authorities are investigating Asklepios, a tiny import-export company run by a husband and wife out of their home, according to Raymond Salet, General Health Inspection Service spokesperson. The couple's attorney said the couple bought the drugs from yet another trader, not in Africa, and that the sale to Kohlpharma generated a profit of 2-20 percent of the medicine's value. One person close to the Dutch health authorities expressed concern that companies under investigation may have functioned like money launderers who move their transac-

tions through several companies.

Some pharmaceutical companies were leery of discounting precisely because a two-tiered pricing system is such an easy target for fraud. Glaxo estimated it lost EUR16 million (US\$15.75 million) in the last year from the drug reselling, a figure supported, said law enforcement officials, by shipping documents and invoices that investigators collected. 'We can only continue this two-tier pricing if the diversion stops,' said Glaxo official Chris Viehbacher. Glaxo is considering changing discounted drugs' labels, but that requires regulatory approval.

*New York Times, 29/10/02, Gregory Crouch. [CDC News] CDC HIV/STD/TB Prevention News Update 29/10/02*

## New statement

The Statement on Consumer and Community Participation in Health and Medical Research was developed jointly by the Consumers' Health Forum of Australia (CHF) and the National Health and Medical Research Council (NHMRC). It provides the key to developing stronger partnerships between consumers and researchers at all levels of health and medical research, according to CHF Executive Director, Helen Hopkins.

The Statement was scheduled to be launched in Brisbane by Ms Teresa Gambaro MP, Member for Petrie, on behalf of Senator Kay Patterson, Minister for Health and Ageing.

Chief Executive Officer of the NHMRC, Professor Alan Pettigrew, said that the primary purpose of the Statement is to encourage researchers to involve the community to a greater degree. An involved community, he said, is likely to be better informed, recognise the value of research and have a greater understanding of research strategies.

Ms Hopkins said research was a very powerful tool and those who controlled it had a great influence over the health care systems

and a profound effect on the lives of all health consumers and their families. Health consumers believed that those most affected by these issues should be involved with its ongoing development.

'This partnership will mean a community that is more aware of current health research activities,' Ms Hopkins said.

In 2000, the NHMRC agreed to fund the CHF's proposal to develop the Statement. The project was conducted as a partnership between consumers and researchers, who were represented on the Reference Group for the project, responded to the consultation paper and participated in roundtable discussions.

'Health consumers have a great deal to offer and many researchers agree that the methods and results that are open to informed public scrutiny and debate ensure integrity and accountability,' added Professor Pettigrew.

A copy of The Statement on Consumer and Community Participation in Health and Medical Research is available for download at [www.nhmrc.gov.au/publications/synopses/r22syn.htm](http://www.nhmrc.gov.au/publications/synopses/r22syn.htm)

## What makes your party?

Early next year, the NSW Users and AIDS Association (NUAA) *User's News* will focus on how, what, where, when, why and why not people are doing drugs. NUAA is looking for first person stories written by people with experience using party drugs, including speed, GHB, special K, crystal, coke, ecstasy, Viagra, smack, pot, benzos, alcohol, mix 'n match, or any other drug that makes your party. NUAA pays 10 cents a word for published stories. Authors can be anonymous. Send your work by 15 December to *User's News*, PO Box 278, Darlinghurst 1300, fax 02 9557 1736, or [usersnews@nuaa.org.au](mailto:usersnews@nuaa.org.au). For more info, call the Editor on 02 9557 1476.

## Quick testing

The US Food and Drug Administration is expected to approve OraQuick – a new test that will tell people within 20 minutes whether they are hiv positive – soon, although the exact date is unclear. Some doctors praise OraQuick as an easy way to reach high-risk people who might never visit a health clinic – or return to one to collect their results. Critics, however, say many people actually benefit from a days-long wait for test results because it gives them time to reconsider their high-risk behaviour. OraQuick works like a pregnancy test and costs \$US10 to \$US15. Johnn Young, director of prevention at Colorado AIDS Project, said he is uneasy about how the traditional counselling of hiv patients will be folded into the quick-test process. In fact, Colorado officials plan to hold a summit next month with national experts on how to begin using the test in Colorado's clinics and doctors' offices.

Hiv prevention officials at the CDC say OraQuick will allow health workers to test a broader spectrum of people. It also may eliminate the portion of patients, 30%, who get tested but never come back for the results. Twenty-five percent of those with hiv in the United States do not know they have it, said Rob Janssen of the CDC's division of hiv/aids prevention. Proponents say the test is so hard to misuse that aids workers and even volunteers could test prostitutes on street corners and men going into bathhouses. But a 1999–2001 study by Dr John Douglas with the Denver Health Medical Center found that patients who underwent rapid hiv testing were 12% more likely to contract an STD later, compared to those who had slower testing. Because the quicker tests also have higher false-positive rates, doctors will recommend

patients go through more rigorous blood work to ensure accuracy. Colorado health officials are working to set up a 24-hour phone bank whose counsellors will be on hand for people whenever they learn their test result – even if the result comes from a health van at 2 am.

*Denver Post 13/10/02, Allison Sherry. [CDC News]  
CDC HIV/STD/TB Prevention News Update 21/10/02*

## Merck cuts cost of drugs for poor countries

Merck & Co has said it will cut the price of its new once-daily pill Stocrin to less than \$1 a day in the poorest and hardest-hit countries – a reduction of more than 30% from the present price. Stocrin, known generically as efavirenz, is frequently used in triple combination cocktail therapy for hiv patients. Activists welcomed the price cut but questioned the timing of the announcement, suggesting it is linked to a public relations campaign surrounding Merck's launch of the new one-pill dose in 52 nations. Doctors Without Borders spokesperson Rachel Cohen pointed out that big drug companies only began significantly discounting their aids medications two years ago after generic competition arose and activists began clamoring for price cuts. On September 5, GlaxoSmithKline announced price reductions of as much as 33% on several aids medicines in the developing world.

But Merck spokesperson Jeffrey Sturchio said the recent reductions, which bring the cost of the new Stocrin down to \$US346.75 per patient per year, show 'it simply isn't a case of generics leading the price decreases.' Indeed, four Indian

generic companies make Stocrin for \$438–658 a year, according to DWB.

The new move cuts the price of Stocrin to 95 cents a day in poor and hard-hit countries (down from \$US1.37). In middle-income nations like Brazil, Mexico, Jamaica and China, Merck is offering the medicine at \$US2.10 a day (down from \$2.52). Under an agreement, Bristol-Myers Squibb sells the same drug as Sustiva in the United States, Canada, Italy, France, Germany, Spain and the United Kingdom. In the United States, where the new 600-milligram dose has been available since February, the price is \$US12 a day.

*Wall Street Journal 23/10/02, Rachel Zimmerman, Mark Schoofs. [CDC News] CDC HIV/STD/TB Prevention News Update 23/10/02*



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## STIGMA: Testing guidelines for gay men

Outbreaks of sexually transmitted infections (STIs) such as gonorrhoea, syphilis and chlamydia have been documented among Australian gay men. Infected men frequently have no symptoms and therefore may not seek treatment. These infections can increase HIV transmission and infection. In 2000, responding to the increasing incidence of STIs in gay men, the sexually transmitted infections in gay men action group (STIGMA) was formed in Sydney. STIGMA aims to facilitate education and health promotion activities for STIs among gay men. Member organisations of the group include the AIDS Council of NSW, GPs specialising in HIV, the National Centres in HIV Epidemiology & Clinical Research and HIV Social Research and the South East and Central Sydney Area Health Services.

STIGMA has developed STI testing guidelines for gay men, which were publicly launched in Sydney on 31 October, 2002. The guidelines recommend that all sexually active gay men have, at the minimum, an annual screen for STIs and more frequent screens for men who change partners or frequent sex-on-premises venues. Speaking at the launch, Dr Chris Bourne from the Sydney Sexual Health Centre noted that for some years the USA's Centre for Disease Control has recommended the early detection and treatment of STIs as part of a HIV/AIDS prevention strategy but that, to date, Australia's National HIV/AIDS strategy has given less priority to this area.

## Syphilis campaign comes to Sydney

An award winning syphilis campaign from the Terrence Higgins Trust, which started in October, was a key component of ACON's public health messages during the Sydney 2002 Gay Games.

'Syphilis is making a comeback in many cities around the world with large gay male populations like Sydney although we are yet to see similar increases here,' said ACON President Adrian Lovney.

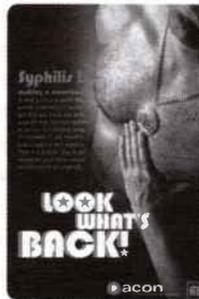
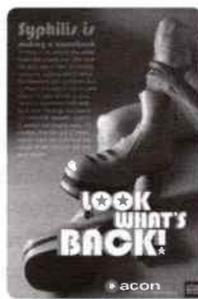
'Many people may have mistakenly thought syphilis was no longer an issue. It has been rare among gay men since the 1970s but we have witnessed recent outbreaks in the UK, the USA and across Europe.

'Syphilis poses a serious risk to people living with HIV/AIDS with the symptoms being more severe and taking longer to treat. A weakened immune system can also increase their risk of picking up syphilis.

'It's quite common for the symptoms of syphilis to be mistaken as something to do with having HIV so it is important to check STIs during regular check ups.

'We hope to raise awareness around the resurgence of syphilis, its transmission, symptoms and treatments so we can encourage more men to go out and get tested.

'If syphilis is not treated it can cause real damage to your heart, brain, eyes, bones, liver and nervous system.



## Zambia to provide drugs for 10,000

Zambia has announced that an adult antiretroviral therapy program for 10,000 adults will begin before the end of the year, according to Zambian Health Minister Dr Brian Chituwo. Access to treatment will be funded by a grant from the Global Fund to Fight AIDS, TB and Malaria, as well as funds from the World Bank.

Treatment is currently available at a cost of \$US300 a year in the private sector, which places it beyond the reach of all but the wealthiest members of a society where the average income is around \$US280. More than 80% of the population are living at subsistence level with no permanent job, so the government scheme will only require a contribution towards costs (as yet undefined). It is estimated that more than 500,000 people in Zambia already have HIV infection.

The pilot scheme will begin at eight sites (the capital, Lusaka, together with Ndola, Livingstone, Kasama, Mukinge and St Francis) using generic antiretrovirals procured in bulk. Initially, mothers with HIV identified through sites offering treatment to prevent mother to child transmission of HIV will be prioritised, along with fathers and infants born with HIV disease. National guidelines on clinical eligibility for treatment are due to be published shortly. It is likely that these will draw heavily on recommendations made by the World Health Organisation earlier this year, discussed in detail elsewhere on this website.

A package of care that will include not only antiretroviral treatment but also treatment and secondary prophylaxis of common opportunistic infections is planned, together with provision of food supplements (critical in a country now experiencing severe food shortages), treatment information and counselling and access to home care, income generation programs and support groups.

Keith Alcorn, [www.aidsmap.com](http://www.aidsmap.com), 21/08/02

# Vitamins affect pos women

Multivitamin supplements may help some hiv positive pregnant women reduce the risk of transmitting the virus to their children and improve certain aspects of their babies' health, according to US and African researchers. However, Dr Wafaie Fawzi of Harvard School of Public Health and colleagues also found that supplements of vitamin A alone actually increased mother-to-child hiv transmission during pregnancy or while breastfeeding. Their report, 'Randomized Trial of Vitamin Supplements in Relation to Transmission of HIV-1 Through Breastfeeding and Early Child Mortality', was published in AIDS (2002;16:1935-1944).

As to why vitamin A supplements may increase the risk of children acquiring the virus from their mothers, Fawzi noted that past studies have shown the same result. Previous research found that vitamin A may increase the replication of hiv in infected cells, while another study reported that people with low levels of vitamin A in their blood were less likely than others to transmit the virus via heterosexual sex.

Half of the 1,078 pregnant hiv positive women in the study received vitamin A supplements, while the others were given multivitamins without vitamin A. The researchers followed the women and their children from when they were 20 weeks along in the pregnancy through breastfeeding. Women who took vitamin A supplements were 38% more likely to transmit hiv to their children than women who received multivitamins. Multivitamins appeared to offer no benefit in preventing mother-to-child hiv transmission, except in women with low levels of white blood cells – an indication of advanced disease – who were 60% less likely to infect their children while breastfeeding than women

with low levels of the cells who were not given multivitamins.

In addition, mothers given multivitamins who had relatively low hemoglobin and gave birth to low-weight babies – both signs of poor maternal nutrition – were also less likely to transmit the virus to their babies. Children born to multivitamin-treated women with relatively weak immune systems and poor nutrition also appeared more likely to survive past two years of age and, if infected, live longer with the virus. Fawzi explained that vitamins B, C and E may have reduced the risk of hiv transmission by boosting the immune system in both mothers and babies.

In an interview, Fawzi said that providing pregnant hiv positive women with multivitamins throughout their pregnancy could potentially be a cost-effective means of keeping their children healthy. 'Prices of vitamins would be driven to a low level if mass production is undertaken for all women at risk,' Fawzi said.

*Reuters Health 10/10/02, Alison McCook. [CDC News] CDC HIV/STD/TB Prevention News Update 25/10/02*

## Woman sues clinic

A woman who claims an hiv test was done without her consent while she was pregnant is suing the clinic that performed it. The woman, identified only as Jane Doe in the lawsuit, discovered she was infected with hiv as a result of the test. The lawsuit, filed in Milwaukee County Circuit Court, was brought by the AIDS Resource Center in Wisconsin. The woman, who was about eight weeks pregnant, went to the former Aurora Health Care Clinic for treatment on June 28, 2000. A physician ordered that various lab tests be conducted, the lawsuit said. The woman said she signed a form that indicated she was not giving consent for an hiv test, but blood was drawn specifically for the hiv test. Three weeks later,

Dr Laroyce Chambers told the woman she tested positive for hiv. After discovering the woman had not given her consent for the test, Chambers summoned an office manager, who apologised for the mix-up. The lawsuit seeks unspecified damages for invasion of privacy and emotional distress.

*Associated Press 22/08/02*

## Deal on cheap drugs

Trade ministers reached agreement on how to supply cheap drugs to developing countries to fight diseases such as aids and malaria at a meeting in Sydney on 15 November. An Australian Department of Foreign Affairs and Trade official said the 25 ministers, including representatives from several African nations, reached consensus at their meeting at Sydney Olympic Park, as protesters gathered amid tight security outside.

The intellectual property of the drugs is held by European and American based drug companies. Non-government officials say the deal includes an agreement on which countries will be given rights to manufacture cheap, generic versions of widely-available Western medication. They say it's also likely to include a longterm waiver of any formal trade legal action against countries which allow the manufacture of generic drugs.

*15/11/02. www.smb.com.au*

## Fundraiser

Blue Mountains PLWHA are holding a charity auction at 5pm, Saturday, 14 December, at The Carrington Hotel in Katoomba. Anyone who can donate items for auction can contact the centre on 02 4782 2119. The centre is on the lookout for books, games, furniture, bikes, cars – anything to raise a few dollars (and hopefully more) for Blue Mountains PLWHA.

## The Quilt

A part of positive culture in Sydney since 1988, the Quilt was unfolded for the Gay Games

**On 3 November, the Quilt was unfolded at a ceremony at Darling Harbour as part of the Sydney Gay Games celebrations. Too fragile for so much public exposure, the original Quilt was re-created through the efforts of volunteers at a series of weekend workshops. Susan Hawkwood spoke to volunteer, Tony Kay, and World AIDS Day Coordinator, Douglas Knox, at a workshop in October.**

### Tony Kay, Volunteer

Tony Kay: I was at the first meeting in September 1988. That's where it all started.

Susan Hawkwood: Where was that meeting held?

T: In Andrew's flat, in Elizabeth Bay, Roslyn Gardens, which was a notorious block of gay units back in the late 80s, early 80s. [Andrew got the Order of Australia for his involvement.]

S: And where did the idea for doing the Quilt come from?

T: From America. Andrew went to America and he saw the Quilt in Washington and he was so overcome that he thought he'd bring it back in Australia and that's what he did. And the rest is history.

S: Do you know how many panels there have been in Australia?

T: There are 120-something blocks I think, the last time I heard, but I haven't been involved for a while.

S: So, what made you get re-involved?

T: I didn't know the Quilt was part of this, so I just came to volunteer. I retired earlier this year and so I just came to get involved in helping out. It's going to be good.

S: Why is it [the Quilt] being re-created?

T: Because it's such a big part of gay history. Maybe even the biggest, who knows. What happened in Germany, back in the 20s and 30s, and what happened with hiv/aids. You know, how do you compare the two?

S: Why not use the original quilt? Why is it being re-created rather than use the original?

T: Possibly it could be very confronting for some people who are not expecting it. That's one reason.

S: How many people have been involved in re-creating the panels?

T: I think about half a dozen altogether. I've just done bits and pieces. The artists are here. They come on Saturdays usually, the weekends, because most people are working. I'm not working anymore.

### Douglas Knox, World AIDS Day Coordinator

S: Douglas, is the Quilt Project excited about the Gay Games?

D: It certainly is because we're going to be able to do a display with a lot of international blocks that's going to become the biggest display that's ever happened, probably in the Southern Hemisphere, certainly in Australia, and I'm looking forward to having all these guests with us.

S: Why was the Quilt re-created for the Games? Why isn't the original Quilt being unfolded?

D: I think probably the reason was because of the possibility of rain or whatever else. The problems of keeping the Quilt safe.

S: How many quilt blocks are coming?

D: There's up to 50 international blocks coming from as far afield as Sth Africa, Venezuela, Canada, Denmark, Spain and the US, Netherlands, Belgium, New Zealand. The ceremony's going to be a traditional unfolding ceremony. Justice Michael Kirby, who has been the patron of the Quilt from early days, is going to be there. The main speaker. There'll be a couple of international choirs taking part in it and there'll be the actual unfolding of the Quilt, the presentation.

**A**ndrew went to America and he saw the Quilt in Washington and he was so overcome that he thought he'd bring it back to Australia.

didn't know the Quilt was part of this, so I just came to volunteer. I retired earlier this year and so I just came to get involved in helping out.



ACON West's Community Development and Education Officers, (l-r) Teresa Clonan, Jonathon Street and Belinda Munn.

## ACON West officially open

The Minister for Western Sydney, Kim Yeadon, officially opened the new premises for ACON's Greater Western Sydney Branch in Westmead on 8 November.

'This is an important day for ACON and for the communities of Western Sydney who now have access to a wide range of services for people living with and affected by hiv/aids including gay men, lesbians, Indigenous people and sex workers,' said ACON President Adrian Lovney.

'ACON West's original office in Parramatta was destroyed by fire and they spent more than a year in our Surry Hills central office before finding these wonderful new premises.

'Programs and services have continued with little disruption and the new office here in Westmead will act as an important community centre providing new and improved services.

'Communities in the Greater Western Sydney area now have better access to staff specialising in gay men's health, education, community development and lesbian health.

'ACON West is a central point of call for Community Support Network (CSN) in Western Sydney and the Positive Employment Service (PES) as well as the Corrective Services Inmate Support Project. We also work closely with FPA Health on youth support through the Way-Out Young Men's Sexual Health Program.'

## Govt to re-introduce Bill

On 13 November, the Federal Government re-introduced its Budget measure to increase co-payments on prescriptions. Under the legislation, concession cardholders will pay an extra \$1 for each script, from \$3.60 to \$4.60. The maximum increase in costs faced by single and married pensioners before reaching the safety net will be \$52 or \$1 a week for a year. After reaching the threshold, they need not pay anything for PBS prescriptions.

General patients would pay an additional \$6.20 a script with the co-payment rising from \$22.40 to \$28.60. Families in the general patient category will pay a maximum of \$188.50 more, or about \$3.60 a week. Once they reach the safety net threshold, they need pay only \$4.60 for PBS prescriptions.

In an interview on 13 November, the Shadow Minister for Health and Ageing, Stephen Smith, said the Government's proposed changes were a 'way of whacking pensioners, whacking families under financial pressure for the cost of their essential medicines.

'It's got nothing to do with the health care of Australians and everything to do with the fact that in the run-up to the last election this Government splurged the budget bottom-line.'

'We will oppose this legislation as we did before and as we rightly should.'

The Minister for Health and Ageing, Senator Kay Patterson, said that despite the Senate's rejection of the Government's Budget measure, the Government was determined to pursue its policy to ensure the sustainability of the \$4.8 billion PBS scheme.

'Sitting back and doing nothing to tackle

the unsustainable growth of the PBS is simply not an option,' she said.

'Ensuring the future of the PBS will require a whole of community approach and we are asking consumers to make an increased contribution to the scheme.'

## Cheap test kits

The Royal Free Hospital in London has recently agreed to discount the sale of CD4 test kits destined for Thailand, in recognition of the country's efforts to fight hiv by producing the lowest-priced antiretroviral drugs, according to Dr Thongchai Thawichachart, the director of Thailand's Government Pharmaceutical Organization. The discount will bring down the cost of the CD4 test from about Bt500 (\$11.50) to only about Bt100 (\$2.30), he said. Due to the high cost of the test, doctors have been conducting CD4 count tests only twice a year; CD4 tests need to be conducted every three to four months. As a consequence, much treatment has failed, even when good drugs were administered by well-trained doctors. Many patients who could not afford the cost of the CD4 test have died before they could see a doctor.

The GPO will also offer Saquinavir, which is out of patent, in the next few months as a more affordable choice for those who are resistant to the existing formulas produced and distributed by GPO. The drug has yet to be priced, though the GPO says it will be slightly more expensive than the cocktail of antiretroviral drugs, which range from Bt3,000 to Bt5,000 (\$69-\$115) per person per month.

*Nation (Thailand) 13/11/02, Arthit Khwankhom. [CDC News] CDC HIV/STD/TB Prevention News Update 11/14/02*

# Body positive representation and advocacy in NSW

body positive

**Geoff Honnor**

I had to read Antony's 'Pos Action' (Talkabout #121) a few times before the message began to form for me. The worry, I guess, is that I would have missed it if I'd just focused on what looked to be an irresistible opportunity to counter the challenges that Antony seemed to be offering the body positive. Are people living with hiv complacent? And if so, what exactly is it that we're complacent about? Do we really lack advocates and activists? I counted off 100, whose names came to me immediately, in about 1.5 minutes ... but then it dawned on me that my analysis was a tad superficial and was kind of missing the point.

By now it's odds on that Antony will have heard from more than a few people disputing some of his more muscular assertions. But I think it would be unfair in terms of both the 'real' issues I'm reading here and what I see as Antony's motivation in raising it, if that's where it ended. From my perspective, Antony's commentary offers a golden opportunity to ask some difficult questions about both the here and now and, importantly, also the future of body positive representation and advocacy in NSW. The clear message that came through to me was this: 'What do you guys want this, your organisation, to be in 2002 (and beyond) and why?'

And that discussion is crucial for all of us – and long overdue.

I'm hardly offering a news flash to the 8,500ish plwha who call NSW home by stating what I see as the key issue here: disease is basically about change, adaptation, success, failure. Movement, up, down, all around, is the constant. The Australian hiv experience has been, and will continue to be, anything but static. Therefore it seems to me that any ongoing engagement with it, by whoever, has to be based on – and in – a change dynamic. Words that come to mind are flexible, responsive, adaptable. To put it another way, after nearly 20 years we've learned that

static, monolithic service and advocacy provision structures have a tendency to be ... well, static and monolithic. That can in turn risk a provider perception of an equally static, uniform 'community' of plwha with a collective experience of disease that neatly coincides with just the service provision we've designed for them! Lucky break!

But the reality is that most plwha don't generally see themselves as the totality of their respective disease experiences any more than people with Cancer see themselves as Cancer People. Nor do plwha identify a role for themselves in being a passive provider-friendly, collective disease experience. We show a marked tendency to pick and choose – or not – as part of the ongoing business of creating our own life engagements. And relatively few of us seem to regard 'having hiv' as, in any way, a useful coverall encapsulation of our hopes, dreams and ambitions. I certainly see how 'complacency' could emerge as a description of what's going on here. But I'm not at all sure that it would be usefully applied to the body positive.

The drive to survive, to live – and to live as far as possible in some approximation of normality – is a powerful human instinct. None of us can sustain 'life as crisis' indefinitely. As far as disease goes, we're physiologically equipped to confront the 'invader', deal with it – or vice versa – and move on in to something that approximates 'normal'. Hiv has other ideas of course and the result for most of us now is a sort of individually created 'normal' between virus, wellness, treatment, desire and options which, for many, could be described as something like that scary and threatening term, 'chronic manageable illness'.

Like 'Post-AIDS', 'chronic manageable illness' gets a bad rep. It tends to be read as 'over it'. But should it be? My interpretation is: 'chronic' – meaning always there; 'manageable' – meaning 8,500 variations of manageable at any given moment; and, 'illness' – meaning, I guess, not 100% well.

Many of us no doubt wish that sector expertise at identifying 'complex needs' could be matched with similar expertise in terms of the complexity and effectiveness of our response to the situation.

How you get 'over it' out of that is a mystery to me. But then I find the 'Post-AIDS' confusion that Antony mentioned equally mysterious. 'Post AIDS' was never about the position of plwha specifically. It was offered, (by Gary Dowsett) as a gay-specific cultural construct, describing the effect of the hiv change dynamic in and on gay community as that community moved from hiv crisis engagement to hiv disease-as-continuum engagement. A quick scan of surveillance data reveals that the annual rates for aids morbidity and mortality peaked in 1994, hence his timing was pretty much spot on. The opportunity that emerges for us here is maybe to identify the need for clarity as another key issue on a par with recognising change as an epidemic constant.

And let's start our commitment to clarity by acknowledging that crisis can still be part of the individual hiv experience. Because, let's face it, if I'm in crisis, it pretty much is a crisis as far as I'm concerned. But if we've learned anything at all, it's surely something

important about the fact that identifying and working with the individual nature of our crises – and most other issues in and around hiv – offers the best chance for an individually-appropriate solution. One of the key points that begins to emerge from this is that disease is ultimately individually experienced. And the longer the experience runs, the more individualised it becomes. Maybe there's something in that about eventually having to recognise the limits of the ability of community-based health response to deliver collectively appropriate solutions. And adjust accordingly.

Which brings me to the third key issue: 'hiv lived realities – increasing diversity and range of.'

I'd argue that the huge and individual range of hiv lived experience that continues to emerge after nearly two decades of the epidemic has put paid to any useful notion of a unified 'positive community' that's inextricably and eternally linked by the same shared, disempowerment – framed disease experience. What's become pretty obvious is that the ability to normalise the ongoing disease experience has inevitably meant, for most positive people, less association with the notion of being centrally defined by and with disease and hence less ongoing regular contact with positive service delivery.

Whether or not this is a 'good' or 'bad' thing is perhaps less the issue than the fact that it is, a thing. Once people have a chance of structuring their own destiny, as imperfect as it might appear, they seem much less likely to find value in a continuing association with a form of service provision that appears increasingly representative of a time and place that for them is past. That doesn't mean that they don't need support, information, advice and encouragement. But it probably does mean that they're going to be more selective and specific about what they need and when they need it and from whom. And for service delivery and advocacy to assume that they'll just call us when they need us would be to assume a continuing relevance that looks increasingly hard to sustain. And unless we're prepared to acknowledge that times continue to change, that people move on, and adjust our own focus accordingly, then we're simply not going to be relevant.

Uncertainty remains. The maintenance of wellness is by no means guaranteed but you just get on with it, regardless. Life isn't ever, satisfactorily, put on hold to wait for some

elusive certainty. Life is maybe less, finally, about certainty than it is about risk and uncertainty. Whatever your serostatus.

The Futures II Study published in 2000, was the broadest take on Australian positive life that we'd had up til that time. It was clear however that, overwhelmingly, study participants had been drawn from the minority of the body positive who had retained regular service delivery contact. There were good practical reasons why this was so – as it is largely again with Futures III – despite significant efforts on the part of ARCSHS (the study's publisher) to spread the net wider.

The fact remains however that the study isn't, finally, the comprehensive picture that it's sometimes assumed to be. BGF and ACON client contact data have shown a steady positive service delivery uptake rate of about 1,200 separate client accessions annually. Over the same period, the total NSW body positive has numbered around 7,500 – 8,000. So it looks like roughly 15/20% of plwha form the bulk of the ongoing service delivery client base. We also know that virtually everyone with hiv has some form of ongoing contact with general practice and just over 60% of us are currently prescribed combination therapy. Is this shift towards Docs as major point of ongoing contact the dreaded 'medicalisation of aids'? Life defined by clinical markers? Or is it just life. And change? Or maybe both.

Then NAPWA president, Peter Canavan, made this point very effectively two years ago when he offered the view that we'd evolved to a point where a new understanding of positive community was necessary. Not because the hiv sector thought it was a good idea, more that the body positive had long been adapting, changing and creating their own understandings of what the conjunction of disease, life, and normalisation might mean and it was high time that the sector bought into this. The subsequent success of NAPWA/AFAO in reinventing their relationship as an equity based co-partnership has given accountability-based guts to the notion of positive centrality, given the world it's first and only community-based and owned full span of engagement from prevention to care and support, and given Peter's view a strong supportive evidence-base.

Peter specifically offered the view that instead of one positive community we had a range of communities in which serosta-

tus-challenge continued to have specific importance for poz and neg alike. Positive people could and would reclaim prime identity as women, gay men etc who also lived with hiv. Hiv is ever-present for all of us but the extent to which each of us manages in and with its effects is increasingly variable against a huge range of co-factors. What this means for providers is an acceptance of the fact that the ask is more complex, more specific, more sophisticated. It means that the position of those whose journeys into self-defined normalisation are delimited or constrained for whatever reason – and often the reasons are multiple and may have little to do with hiv disease progression – are at risk of being an increasingly marginalised minority, locked into, and with, a disease centrality that neither reflects the reality of their life challenges nor offers any obvious solutions to them. Many of us no doubt wish that sector expertise at identifying 'complex needs' could be matched with similar expertise in terms of the complexity and effectiveness of our response to the situation.

Combination therapy is generally regarded as the prime catalyst for this shift and its crucial importance is undeniable. But wellness has never been just about the pills. It's been more about using the opportunity offered by therapy to build our own understanding of wellness, in our own terms. In so doing, we've arrived at a form of normalisation, to whatever extent we're able, against whatever odds present. The achievement created in so doing is of pretty major proportions but it remains pretty much unheralded and unccelebrated.

You might think that a lot of this is pretty obvious. You might also think that PLWH/A (NSW) itself might have sat down a while ago to think some of this stuff through and respond accordingly. But it's not easy. The range of agendas and interests amongst all the providers of hiv positive service delivery and advocacy, and hence their stakes in defining and preserving their takes on 'real' constituency needs, is huge and often conflicting. So again, it's not easy. But it has to happen.

Were PLWH/A (NSW) to disappear tomorrow, the only noticeable effect for the vast majority of positive people would be the absence of *Talkabout*. The challenge for PLWH/A (NSW) is clear, time is long overdue for grasping it, and time is running out.

# Positive in Papua New Guinea

positive in PNG



## A positive voice

**Margaret, Helen** and **Max** visited Sydney recently and spoke to **Susan Hawkwood** about their work in Papua New Guinea

**Originally from the Southern Highlands in Papua New Guinea, Margaret completed an advanced hiv/aids counselling and care course at Madang in 2002. She has visited Lae, Madang, Kavieng and Port Moresby to speak to people about living with hiv.**

Margaret has also visited Shalom Haus, a respite care centre for women and children affected by hiv/aids, in the Western Highlands town of Banz. Established by the Order of the Sisters of Notre Dame, Shalom Haus is one of the few services for positive people available in Papua New Guinea. Accommodation is available for up to four women, for one week. Women staying at Shalom Haus have access to counselling.

Helen was born in Port Moresby and completed a counselling and care workshop in Goroka. She has spoken at Mt Hagen, Goroka, Kerema Popondetta, Lae and Buka Madang, and works at Shalom Haus with Sister Rose Bernard.

Margaret and Helen visited Sydney in October with Max, here on his third visit. Funded by AusAID, Margaret, Helen and Max use Sydney as a base to travel to other parts of the Pacific region, including Fiji and New Zealand, and to Trinidad for an international conference to lobby for more funds for all Pacific islands.

A \$12 million program to build, renovate and equip clinics to treat STIs, including hiv, across Papua New Guinea was announced in May this year by the Parliamentary Secretary to the Minister for Foreign Affairs, the Hon Chris Gallus MP. The three year program will eventually cover all 20 provinces of Papua New Guinea. An earlier AusAID project built or renovated 12 clinics in the PNG Highlands.

The rate of hiv infections in Papua New Guinea is estimated at one in 312.

Australia is providing \$60 million over five years (1998–2003) to support the Government of Papua New Guinea's National Plan for hiv prevention and care.

The program will also provide medical equipment and work with other Australian Government aid projects to train health care workers.

Although funds are being provided to Papua New Guinea through AusAID, Max describes getting services when you're positive as 'a bit hard'. He attributes the difficulty largely to 'the government and people working in aids consultancies. They are the worst, with holding the money.' He acknowledges the services that are starting to be provided, such as home based care.

'It's a bit like, they're playing politics at the same time. There's too much corruption.'

He describes himself and Margaret as 'brave enough' to take on the public speaking roles funded by AusAID, in spite of the stigma and discrimination positive people face in Papua New Guinea.

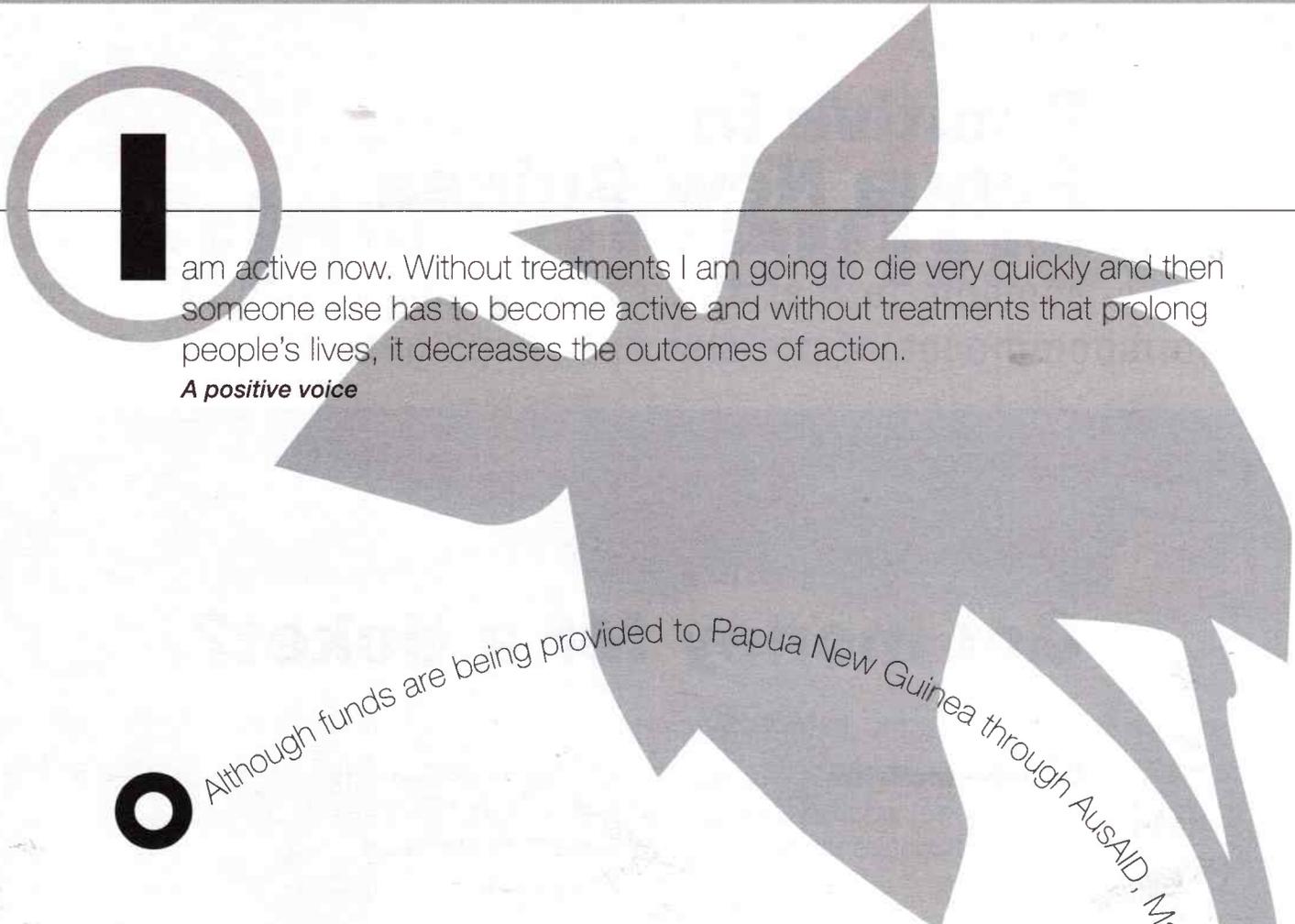
Positive people are often forced to 'go away,' says Max, 'but not violence. Chase them to stay out somewhere, not to come close or something.'

Through their work, which includes public speaking in the main markets in Port Moresby and provincial centres, people in Papua New Guinea are becoming more educated about how hiv is spread.

Free condoms have been available in Papua New Guinea for two years, but not always when and where people need them. 'We are the ones giving [them] out. It's free but sometimes, in the middle of the night, [when people go] to a party, to clubs, there are always some people who are selling those condoms. They can sell them for \$5 because [there's] nowhere to find it so the clients have to buy it for \$5.'

'Daytime they can find them. But night time it's hard for people to find it.'

Margaret describes the number of posi-



I am active now. Without treatments I am going to die very quickly and then someone else has to become active and without treatments that prolong people's lives, it decreases the outcomes of action.

**A positive voice**

Although funds are being provided to Papua New Guinea through AusAID, Max describes getting services when you're positive as 'a bit hard'.

tive people in Mt Hagen as 'second to Pt Moresby'.

As Helen explains, 'It's because of the double marriage. Men get married to plenty wives. They can get married to more than 10, and upwards.'

Margaret is quick to point out that no services for positive people exist in the Southern Highlands.

Pt Moresby also has a respite care centre run by a Catholic order of nuns, but Max wasn't sure how many people could be accommodated.

According to Max, the biggest need of positive people in Papua New Guinea is drugs. 'We need drugs. Drugs is the big problem we face. Most people, they can live but they don't have drugs.'

People with money, such as businessmen and politicians, can access antiretroviral treatment in Australia.

For some people, even access to antibiotics in Papua New Guinea is too expensive. Although prescription medicines are available through hospital pharmacies, patients are referred to private pharmacies when the hospitals run out of stock.

'It's too expensive for some of the people. They cannot afford to buy this,' said Max.

He explained that a prescription for an

antibiotic from a private pharmacy costs a bit more than \$20, sometimes as high as \$50. With an average income of \$200 – and sometimes as little as \$100 – many people cannot afford to buy medicines.

Max has no idea when antiretrovirals might be available in Papua New Guinea, but he is hopeful that, through the work he and others are doing, that drugs might be available soon.

Helen thinks that the incidence of discrimination is decreasing because people, through education, now have a better understanding of how hiv is spread. Through their daily public speaking in markets and in villages, people now understand the difference between hiv and aids. What is needed, she says, is 'testing in the community.'

Positive people in Papua New Guinea are, according to Helen, 'hiding themselves, instead of coming out and talking.'

People hide, she says, because of fear, including fear of change. She believes that, if positive people in Papua New Guinea had a government funded day centre, like the Luncheon Club and the Positive Living Centre, where they could share their stories, 'that would bring more positive people out instead of them hiding themselves.'

# Positive in Papua New Guinea

positive in PNG

## Got money for a ticket?

**Dr John McBride** is an infectious diseases physician and microbiologist who works at Cairns Base Hospital. He visited Sydney for the ASHM conference and spoke to **Susan Hawkwood**

**Dr McBride thinks that, up until recently, positive people in Papua New Guinea were not getting much news about the possibility of hiv treatments.**

'I think the people who have access to the internet, who read a little bit more widely, basically the middle classes are aware now of the possibility of treatment,' Dr McBride said.

Although a small number of people have received treatment at Cairns Base Hospital, Dr McBride believes that it would be more appropriate to provide services in Papua New Guinea.

People from Papua New Guinea being treated at Cairns have to pay their own way, including the cost of travel.

'There is a fairly strong kinship system in Papua New Guinea that [means] friends, particularly relatives or wider family, pay for treatment. This is not just a cost on the person themselves, this is a cost on the wider community, or the wider family. We've had patients come down where the whole wider family back in the village are raising money to buy treatments for this person.'

This means that the money professional people would have spent on their

children, for example sending them to university, is being spent on treating hiv. 'This is a really big problem for people who work hard to get where they are,' said Dr McBride. 'They're middle class, and now they're having to drift back in their economic circumstances because of this disease.'

Positive people who don't have extensive financial resources have 'no chance at all' of accessing treatment. Apart from the cost of medications, which is the biggest impediment, Dr McBride also identified the lack of people in Papua New Guinea who are experienced in monitoring and administering treatments as another major hurdle.

'It's a fairly complex area. A medical degree is not enough. There has to be additional training, postgraduate training, for people who want to give treatment safely to people,' he said. 'There's no-one who's specifically trained in the area of hiv.'

'People training isn't that much of a challenge. We train GPs here in treatment, prescribing hiv to s100 standards, over a weekend so it's not impossible.' He believes a one-week course would be popular, given the level of interest

among GPs, both expatriate and Papua New Guinea citizens. Because most of the medical practitioners are in large towns, Dr McBride believes hiv treatment efforts need to be located in the large centres where hiv infection is concentrated.

'There are very few practitioners out in the bush where most of the people live. Fortunately, there's not a lot of hiv out there although there are pockets of it so we might end up getting to the stage where treatments, if they are going to be made more available, might have to be administered by health care extension officers rather than medical practitioners or nurses.'

Dr McBride acknowledges the extent of planning and the changes within the PNG AIDS Council, which has resulted in policies, but points to 'almost an inertia in Papua New Guinea to moving ahead' that is the main barrier to practitioners being trained, and subsidised antiretrovirals being made available.

Coupled with this, AusAID programs are currently focusing on prevention efforts. 'I think there's been a realisation throughout the developing world that you can't just concentrate on prevention efforts,' he said.

# Discriminate...do you?

People living with HIV and AIDS. 1 in 3 people have experienced discrimination; 1 in 5 have experienced harassment and live with fear of violence; 1 in 5 have been discriminated against in relation to accommodation.



Photo: Jamie Dunbar

Team that promoted inclusiveness and an active lifestyle. Our members. Discrimination of HIV/AIDS is one of the most common forms of discrimination and behaviour". *Wett Ones, Swim Team, September 2002*

[www.plwha.org.au](http://www.plwha.org.au)

(02) 9361 6011

# **hiv doesn't discriminate... do you?**

Issues of discrimination remain central to the life of many people living with hiv and aids. 1 in 3 people have experienced discrimination in relation to medical treatment; 1 in 5 people have experienced harassment and live with fear of violence; 1 in 5 have experienced discrimination at work and more than 1 in 10 have been discriminated against in relation to accommodation.



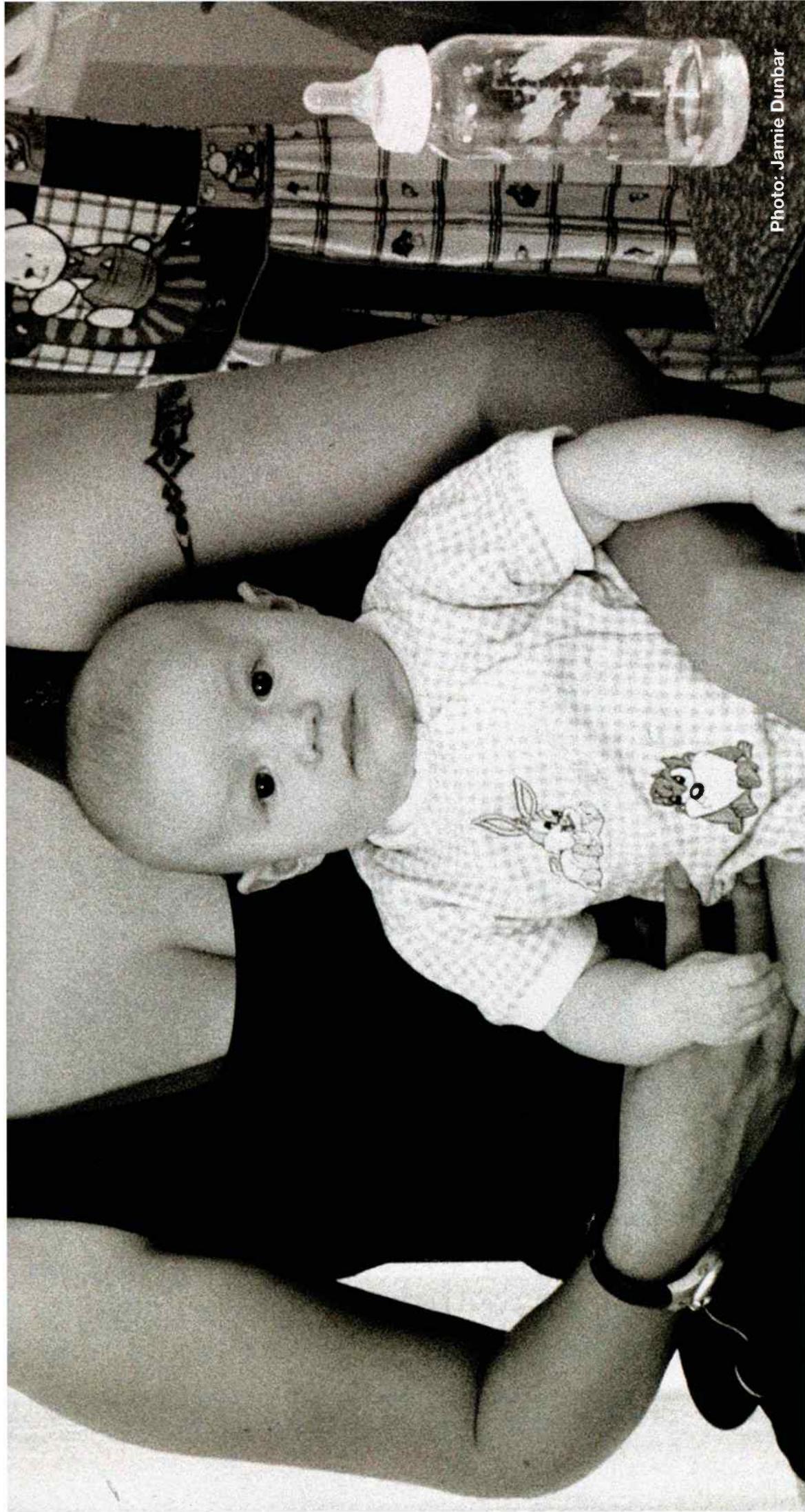


Photo: Jamie Dunbar

“I’m a woman with a life. I’m a mother ... I’m a wife. hiv doesn’t discriminate ... neither should you. ... I don’t want my son to suffer discrimination because I’m hiv positive”.

*Elaine and her son, September 2002.*

# hiv doesn't discrimi

Issues of discrimination remain central to the life of many people living with HIV/AIDS. 1 in 5 people have experienced discrimination in relation to medical treatment; 1 in 5 people have experienced discrimination at work and more than 1 in 10



“Coming out of the 'AIDS daze' of 1991 we formed a swim team now includes gay, lesbian, heterosexual, hiv positive and the key issues inhibiting changes in perception, attitudes

**People Living With HIV/AIDS (NSW) Inc**

# W oman

People from Papua New Guinea being treated at Cairns have to pay their own way, including the cost of travel.

Positive people who don't have extensive financial resources have 'no chance at all' of accessing treatment.

'One of the things I've seen as an impediment in New Guinea is that there are no prominent hiv positive people who have been prepared to stand up and become champions to the cause.

'It would be lovely if positive people could get together and form an equivalent organisation to the hiv/aids organisation that we have in Australia, and I would really love to see an equivalent organisation to ASHM getting off the ground in Papua New Guinea.

'I think those sorts of agencies outside of government, maybe putting a bit of pressure on government, are necessary to boost this forward.

'Looking back historically in Australia, you have ActUP who really did push things forward in Australia.'

'There's a need for a little bit of agitation.'

Dr McBride believes that, once capacity is built up, positive people receiving treatment can become an advertisement for treatment. Someone 'who's prepared to stand up and tell people, 'Yes, I've got hiv. I'm on treatment. I'm healthy and this is a viable option.'

*Centuries come and go,  
Generations come and go,  
But you are still known as Woman.*

*Woman, you are the beast of burden.  
You carry bilum load after bilum load.  
You fetch water buckets one after the other.*

*You are abused, beaten and insulted  
But you never retaliate.  
Your heart is full of love for your little ones.*

*You are the early morning bird  
and the evening star.  
The household machine is what you are  
WHO RESPECTS YOU?*

*Your man comes home, drunk and crazy,  
demanding his needs to be met.  
You give in out of fear, not love.  
Was that why you were created?*

*Then you find out later that you are  
the innocent victim of HIV/AIDS virus.  
What a blow!  
How my heart goes out to you because you  
are still a WOMAN.*

Reproduced with permission from 'Positive Reflections' by Maura Elaripe Mea. Self published, plwhapng@hotmail.com

Maura Elaripe Mea, Port Moresby, Papua New Guinea 2001

'My poems are personal reflections, dedicated to all people living with HIV/AIDS (PLWHA) and appealing to people all over the world, especially to people in Papua New Guinea. Please do not discriminate against PLWHA.'

# Late hiv presentation project

People who are diagnosed late with hiv do not get treatment early in their illness and may be more likely to die earlier as a result. **Masha Eisenberg** and **Mohamed Keynan** give an update on a two-year project

**People from culturally and linguistically diverse (CALD) backgrounds are more likely to present late with hiv compared to people born in Australia, according to several recent Australian studies. In other words, people from CALD backgrounds are more likely to find out they are infected with hiv when they are diagnosed with aids.**

Late presentation has important public health implications. It also has personal implications for people from CALD backgrounds who may not access treatment early in their illness and may be more likely to die earlier as a result.

In mid-2001, NSW Health provided funds to the Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) to focus on late presentation and people from CALD backgrounds.

The late presentation project began by consulting with service providers and people from CALD backgrounds living with hiv/aids (plwha). The consultations covered parallel, though not identical, issues and plwha from CALD backgrounds were consulted using the Telephone Interpreter Service.

Service providers noted African languages, Khmer, Spanish, Thai, and Vietnamese as the major languages of late presenters. They also indicated that heterosexuals were most likely to be late presenters, with gay men less so. Many women discovered their status during antenatal screening.

The identified barriers to early presentation were poor knowledge of hiv and hiv services as well as fear of test results. Other contributing factors were insecurity of status and language difficulties.

Strategies to promote early presentation suggested by service providers, included: multilingual recorded hiv information lines, better links with ethnic GPs, greater use of ethnic media, and work with community and religious leaders.

The small group of plwha from CALD backgrounds came from Asian, South American and European backgrounds, and included three women. Half the group knew no-one else affected by hiv.

Plwha from CALD backgrounds associated three factors with late presentation: people from CALD backgrounds don't know hiv can affect them, there is not enough information about hiv specifically for them, and they have fears about hiv and hiv testing, which are linked to their country and culture of origin.

Plwha from CALD backgrounds found it difficult to suggest ways to increase early presentation in their communities. However, some noted early education and vigorous promotion in the ethnic media and in targeted locations (saunas, bars) as ways to reach the community. Almost all agreed that recorded multilingual information lines on hiv, which anyone could ring anonymously, would be useful.

While the consultation with service providers and plwha from CALD backgrounds had common themes, plwha were more likely to emphasise the contribution of culturally linked attitudes to late presentation.

The project's current objectives are to provide:

- Community development initiatives with four prioritised CALD communities: African languages, Khmer, Thai, and Vietnamese speaking

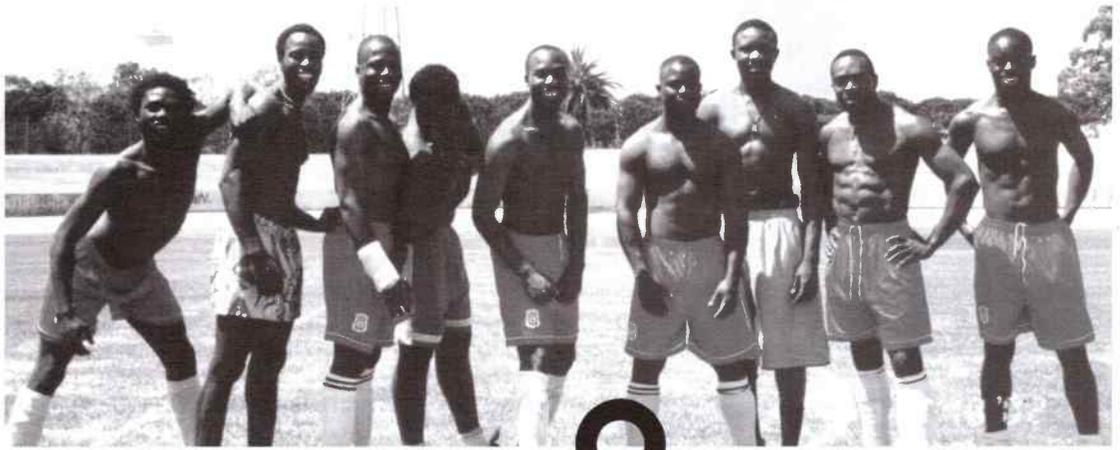
- An Ethnic Media Campaign in the prioritised communities focusing on early testing
- A campaign on hiv information and hiv testing for CALD background GPs from the prioritised communities
- Update and re-launch of the NSW Health HIV/AIDS Recorded Information Lines
- Forums on late presentation for mainstream hiv/aids service providers

So far, the two-year project has included initiatives with the African community and the Vietnamese speaking community.

The African community is not one community and includes people from many culturally diverse countries, including Eritrea, Ethiopia, Ghana, Nigeria, Sierra Leone, Somalia, and Sudan, to name only some. These communities have had no hiv/aids information directed specifically to them until a recent MHAHS workshop. The workshop, which targeted community workers drawn from the African Communities Council and several Migrant Resource Centres, included a client of the MHAHS as speaker and focused on basic hiv/aids information as much as on early testing.

Participants from the workshop helped develop an hiv/aids poster and were also involved in organising a soccer competition in their communities to raise hiv/aids awareness. The poster has four basic messages: protect your partner's life; use condoms; never share needles; be tested for hiv now!

The poster was recently launched and distributed at the final of the soccer competition in which teams from Eritrea, Ethiopia, Ghana, and Sierra Leone competed, together with an accompanying media campaign.



**T**

he best thing is education. We should have campaigns in the media with more information and pushing for testing. For instance, SBS could advertise testing and so could the ethnic press. People from my country will always have to be pushed hard to test early.

The MHAHS initiative with the Vietnamese community involved a radio drama in four three-minute segments, which was repeated over six weeks on the Vietnamese Radio Station 2NVR. The drama involving several characters, acted by Vietnamese speaking actors previously well recognised in Vietnam, focused on hiv awareness and testing issues. There was a talkback session at the end with a Vietnamese coworker from the MHAHS.

A before and after evaluation in Vietnamese with listeners of the radio drama showed that while they already knew the slogans about hiv transmission before, almost all the changes demonstrated after concern social and attitudinal aspects.

After listening to the radio drama, the

number of people taking part who understood that their hiv is not a disease of homosexuals or drug users was halved, and that it cannot be transmitted by social contact. The number of people who stated that people with hiv/aids should be kept away from other people also halved after listening to the radio drama.

The number of people who stated they did not know how to prevent hiv infection also halved. There was a notable decrease in the number of people who stated that hiv could be prevented by having 'one partner only' and 'avoiding contact with hiv positive people'.

*Masha Eisenberg, Research Officer, and Mohamed Keynan, Late HIV Presentation Project Officer, work for the Multicultural HIV/AIDS and Hepatitis C Service, Sydney.*

## African-Australians tackle hiv/aids

The African community in Sydney kicked off a weekend soccer tournament at Lidcombe Oval in October to increase awareness of late hiv diagnosis in the community.

Organised as part of its Late HIV Presentation Project by the Multicultural HIV/AIDS and Hepatitis C Service, the competition included teams from the communities of Ghana, Ethiopia, Sierra Leone and Eritrea competing for the coveted African-Australians Against AIDS Cup.

'Soccer provides a familiar playground on which to engage the community in discussing such a sensitive topic as hiv/aids,' Late HIV Presentation Project Officer Mr Keynan said.

The Late HIV Presentation Project sees early hiv diagnosis as a priority.

According to the National Centre in HIV Epidemiology and Clinical Research (NCHECR) people from non-English speaking background, including people born in Africa, are less likely to be diagnosed with hiv on time. 'Many people from non-English speaking backgrounds are hesitant to find out if they have hiv because of the shame and blame which can be associated with aids,' Mr Keynan said.

# The truth is out there

**John Cumming** and **Kirsty Machon** examine the claims about hiv made in *World Without AIDS* by Steven Ransom and Phillip Day

The myth that hiv is not the cause of aids is one of the most potent health conspiracy theories of our time. Aids is a condition which lends itself particularly to the perpetuation of such myth, for several reasons. For a start, hiv is often transmitted via acts which are considered private, and often, socially unacceptable or marginal. The visible symptoms of hiv infection may not develop for many years, and will almost certainly be very different between individuals, so it may seem logical to conclude that hiv has no apparent relationship to aids. The hiv-does-not-cause aids theory took off at a time when there was no effective treatment for aids but it has persisted, despite the relative successes of antiviral therapy and perhaps because of the limitations of these treatments, like toxic side effects. The authors of this book play cruelly on the understandable hope, and fear, and anger around hiv/aids: the hope for a 'cure', the fear of longterm treatment, and peoples' understandable anger that so many people continue to die from aids around the globe. In doing so, however, they perpetuate a dangerous myth, which continues, for some of the reasons suggested above, to thrive.

What follows is not a book review but a comparison of the book's claims with known facts:

#### **Claim**

No-one has ever found or isolated hiv.

#### **Fact**

Hiv has been repeatedly isolated from people with aids; the virus has been cultivated in

human CD4 cells, and hiv can be cultured in test tubes for replication.<sup>1,2</sup>

#### **Claim**

Hiv antibody tests [the aids test] are so inaccurate as to be meaningless. In investigating this claim, the authors point to the manufacturers' own disclaimer, which reads, 'This test for the existence of antibodies against aids-associated virus is not diagnostic of aids and aids-like diseases. Negative tests do not exclude possibility of contact or infection with the aids-associated virus. Positive tests do not prove aids or pre-aids disease status nor that these diseases will be acquired.'

#### **Fact**

There is no such thing as an aids test. And the manufacturers are quite right: a positive antibody test to hiv tells you nothing about aids or the likelihood of developing it. Whether you have aids does not depend on a positive hiv test result, but on the amount of damage which hiv has done to your CD4 T-cells. It can take up to three months for antibodies to hiv to develop in your blood following contact with the virus, so during this period, it is possible the test may not show positive even if you have been exposed to hiv. This does not mean that the test is inaccurate, simply that there are no antibodies for it to detect. If there is any doubt about the results, in Australia, Canada, the USA and Europe, a second kind of hiv antibody test is used to confirm if a person is positive to hiv.

#### **Claim**

A flu or cold can cause a 'hiv positive reading'.

#### **Fact**

Influenza vaccination can cause a false-positive result, but this is extremely rare. In a study of 133,000 individuals who had flu shots prior to testing for hiv, only 10 false-positives were found, and half of those reverted to negative within six months.<sup>3</sup>

#### **Claim**

There's no evidence aids is caused by a transmissible agent. Aids cannot be an infectious illness, because infectious illnesses always spread equally among the sexes and across the age range, whereas in the early years, aids cases were being reported almost exclusively in younger males.

#### **Fact**

It is true that aids was first identified among gay men. But aids was also identifiable in other people: people who had had blood transfusions, people who injected drugs and shared needles, sex workers, and people who were the sexual partners of people in these risk groups. In Australia, access to needle and syringe exchange programs early in the epidemic largely prevented the wider spread of hiv into heterosexual communities, through the sexual partners of hiv positive injecting drug users. The incidence of hiv among Australian injecting drug users is extremely low: less than three percent injecting drug users.<sup>4</sup> Consequently, Australian rates of heterosexual infection have also remained much lower than many other parts of the world. In the United States, where no such programs exist, about 25 percent of hiv infections are among injecting drug users. In Russia and much of Eastern Europe, with almost no access to clean injecting equipment, and very high

rates of injecting drug use, infection rates have exponentially increased.<sup>5</sup>

Further evidence that hiv is a transmissible agent is demonstrated by the experiences of couples in which one partner is hiv positive. These couples use condoms to prevent infection but if condoms are not used, or if they break, infection can happen. Such real-life events offer unequivocal evidence that hiv is transmissible, primarily by blood, semen, breast milk and less commonly, vaginal fluids. Hiv has been isolated repeatedly in each of these body fluids.

Finally, infectious disease does not always spread 'equally among the sexes and across the age range', but is mediated by a range of factors like geography, poverty, general health, and the presence of other illnesses or conditions. Older people and very young children, for example, are considered much more at risk from some infections, such as influenza, than healthy adults in their 20s or 30s.

#### **Claim**

Lifestyle factors such as promiscuity and recreational drug use, not hiv, cause aids.

#### **Fact**

This claim infers that essentially all people with hiv/aids have a history of injecting drug use on a scale significant enough to cause massive immune damage. In fact, as has already been noted, hiv/aids affects only a small percentage of Australia's injecting drug use population because the majority prevent infection by using clean needles.

In Australia, before the introduction of routine blood screening for hiv antibodies, there were 515 diagnoses of hiv attributed to blood transfusions or the receipt of blood products (eg for haemophilia treatment). In the absence of antiviral treatment, many of these people developed aids. Following the introduction of hiv antibody screening in the blood bank in 1985, only one case of hiv transmission through this route has been reported (in 1999).

There can be no other logical explanation for hiv positive babies born to hiv positive women than that it is an infectious agent. There is not a shred of evidence that maternal recreational drug use or bad 'lifestyle' causes babies to develop aids. In vast parts of the world, babies are born hiv positive to mothers who do not use illicit drugs. Their babies are infected because their mothers are not on treatment and may consequently have a high hiv viral load, or through breastfeeding. Without antiviral treatment, it is estimated that between 20 and up to 30 percent of the babies of hiv positive mothers will be hiv positive. With antiviral treatment

and other interventions this figure has been reduced to about 3 percent.<sup>6</sup> Babies with hiv/aids are also a bit of an inconvenience to the 'aids lifestyle' argument, since babies tend on balance to prefer feeding and sleeping rather than circuit parties and life in the fast-lane.

Nearly everyone who has aids has antibodies to hiv. A survey of 230,179 aids patients in the United States showed only 299 hiv negative people out of that total. Further tests showed 131 of these people were indeed infected with hiv. A further 34 died before their antibody status could be confirmed.<sup>7</sup>

The specific immunological profile of hiv-related aids – a persistently low CD4 count – is extremely rare in the absence of hiv infection or other identifiable, explicable causes of immunosuppression. The National Institutes of Allergy and Infectious Diseases in the United States (NIAID) supported a study of 2,173 hiv negative gay and bisexual men and found only one of these men had a CD4 T-cell count persistently less than 300. This man had been receiving a treatment known to suppress the immune system. Similar results have been found in other studies.<sup>8</sup> Hiv-related aids is defined by a CD4 T-cell count of less than 200.

#### **Claim**

AZT is a toxic drug that causes aids symptoms. Protease inhibitors have been a 'dismal failure'.

#### **Fact**

By the time this book was published in 2000, combination therapy (using drugs from several different antiviral classes to treat hiv) had been standard of care in Western medicine for five years. The authors' statement that when someone gets a hiv positive test result, 'early intervention treatment with AZT and/or its derivatives is generally recommended' is simply not correct. AZT was only used by itself in the late 80s and early 90s, when it proved to be a woefully inadequate treatment. The doses used then were extremely high, leading to unacceptable toxicity. But hiv and its treatment have changed dramatically since the early 1990s, when only AZT, and two other drugs from the same class (ddI and ddC) were available. In Australia there are now seventeen licensed hiv drugs to choose from, divided into four classes or types, depending on which part of the hiv replication process they inhibit. It is now standard practice for doctors to prescribe a combination of at least three drugs from two of these classes.

The demonstrable success of combination therapy provides probably the most obvious nail in the coffin of the authors' argument that protease inhibitors are a failure:

In one study of more than 7,300 people with hiv in 52 separate European hiv clinics, rates at which aids-defining illnesses developed declined massively between 1994 (prior to the availability of hiv protease inhibitors) and 1998, when the majority of these patients were receiving combination hiv treatment including protease inhibitors.<sup>9</sup>

In Australia, the numbers of once relatively common aids-related illnesses in people diagnosed hiv positive plummeted following the availability of hiv protease inhibitors and other new antiviral drugs. In 1991, for example, there were 1,205 cases of the aids-related pneumonia called PCP, compared to just 165 cases in the years 1998-2000. This disease was about 7.3 times more common before widespread treatment for hiv. In 1991, a total of 3,420 opportunistic infections were diagnosed in people with hiv. By 1998-2000, this had dwindled to 689, a decline of just about 80 percent.<sup>10</sup> All of this corresponded with the rapid uptake of hiv treatments among Australians with hiv.

Hiv positive people, their clinicians and anyone else involved in hiv or aids know that these drugs can be toxic and must be used very carefully indeed. Increasingly, clinicians and positive people are becoming rightly more cautious about the use of these treatments. All of the treatments available to treat hiv have long and short-term side effects. Many of these are serious; in a small number of cases, they have been fatal.

Just about any potentially fatal or immediately life-threatening illness has risks and benefits associated with its treatment. Treatments for cancer can be notoriously toxic. Antibiotics are commonly used to treat some infections, but in a small number of people they can trigger dangerous, and rarely fatal, reactions. The authors make much of hiv antiviral toxicity. But they misrepresent and distort the facts unacceptably. The issue is risk and benefit.

*World Without AIDS is published by Credence Publications, 2000*

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# SASSters are doin' it for who?

**James Peterson** comments on the changes to the Department of Housing's rental subsidy for plwha

SASSters might be doin' it for themselves, but, thankfully, they weren't doin' it for everyone on the DoH Special Assistance Subsidy/Special. I've been observing the group via their website (<http://www.angelfire.com/indie/sasster>) since its instigation. The problem I have with them isn't what they were fighting for. I totally agree with their intention to ensure that the roof over their heads is secure. That battle has, to all intended purposes, been won. I am a bit concerned that their website hasn't been updated since 22 September - obviously they don't feel that any sort of follow-up is required now that they have won their ground. Too bad if this is your main means of communication with the group - you probably don't even know the results of the community forum held by the Department of Housing on 21 October! If SASSters were there - and they should have been - then they were very quiet. Not what I would have expected at all, considering the tone of the website. That's a bit bloody rude, in my opinion. However, my concerns go a bit deeper than this.

It's obvious the group was formed by people concerned about problems arising out of the possible loss of the SAS/S, though somewhere along the line they have either forgotten their original purpose, or have just decided that bitchiness and mudslinging are

better bargaining tools than the plain old 'two commons' - courtesy, and sense.

I've also been on SAS/S (or Special Rental Subsidy, as it was then known) since the early 90s. I must have been fortunate because, unlike what is stated on the SASSters website, I was told when I went on it that it was a temporary measure: an option, not a choice. Although insecure, I chose this option anyway because it suited me at that time. This being the case, I have now been waiting, with baited breath, for its abolition for some time, and I am, in fact, surprised that DoH have kept it going for as long as they have. The department may have made a decision in favour of keeping the subsidy for now, but rest assured it is an issue that will raise its head again. Eventually, DoH will get rid of it. The reprieve is, I believe, temporary at best.

The original SASSters website was actually a very sane attempt to put across a valid argument, before degenerating into a hodge-

**T**he original SASSters website was actually a very sane attempt to put across a valid argument, before degenerating into a hodge-podge of inanity and bitchiness.

podge of inanity and bitchiness. In the heat of passion when first accessing the website, I sent off the requested emails to various government and community bodies, ensuring they were all sent from the safety of a free email account, something that would ensure my privacy and confidentiality. However, after this initial response, I decided to sit back and watch what went on before immersing myself any more deeply into this organisation. I have to admit that my only dealings with, and the only correspondence I have seen from the group to date, either on their site or otherwise, has been signed with a first name and initial only. I realise people feared retribution from DoH for the amount of interest aroused by the issue, but the group has to realise that the very people they want to take them seriously - the people on SAS/S - would have to be concerned about this lack of visibility from the people organising the group. Do they really want to be dealing with a long list of disembodied names;



ne has to question if this is the sort of argument that SASSters want to be remembered for, especially if they want to be taken seriously.



hese are very derogatory statements about other groups in society, and do nothing to benefit what was being attempted.

faceless people making a lot of demands, with fuck-all credibility? In fact, with people who want to change the world, but don't want it known who they are. For the fight to be valid, somebody has to be willing to make a sacrifice. Without names, the whole argument loses its validity. This anonymity causes problems in other areas as well. Take a look through the letters page, if you really want an example of how NOT to go about arguing a case. There were 32 letters, by 32 people at my last count. A closer observation shows that six of these people have written between two and three letters. Of this group, Steve B has three letters, and Herman one. One has to question if this is the sort of argument that SASSters want to be remembered for, especially if they want to be taken seriously. Loose cannons running around using words, phrases and language such as:

'that I find the mechanics of this operation disturbingly like events in Europe in the late 30's and early 40's'; 'Sixty years

ago, minorities were rounded up and forced into ghettos'; 'holocaust'; 'Nazi'; 'disinfection, transportation and special treatment'; 'They rounded up our forebears and put them in camps.'; 'The "SAS Police" in WWII Germany, were those NAZI henchmen who conducted this rounding up of victims. They, too, hired real Jews to administer the "processing of their own kind?"; and 'is also typical of the authorised intimidation of the NAZI regime. There has been no secret made either of the plan for these DOH "SASS" henchmen to be sent'.

These are very derogatory statements about other groups in society, and do nothing to benefit what was being attempted. It is embarrassing enough as a gay man to realise that this diatribe was published in a community newspaper, let alone that someone with hiv wrote it. Any letters using bitchy and catty comments should not be there. You cannot really call this sort of thing 'support'. As for Tina T's little bit of input: 'The

last scheduled meeting (June 26) which hundreds of terrified PLWHA's ... was called off. Not by the department, by the lobbyists. Well, I suppose one of them was off to the Hunter Valley to scrub up for his Pride award for Sexiest Male, while another was relishing jumping into the ritzy stilettos of his senior, herself away in sunny Barcelona for nine weeks. And his understudy was, well ... chucking a sickie? ... These lobbying divas are far too fabulous and high-flying to think about where you are going to end up living. Honestly, you bitches are so damned selfish sometimes. Anyone would think these celebs get paid for being your voice in such menial affairs as your housing' is just not helping anyone.

There are other issues as well. In a letter to Carol Mills, Acting Deputy Director of DoH, SASSters claim that 'Nothing about our health, our lives or our personal needs has changed since SAS/S inception.' This is just blatantly untrue. SAS/S was originally

instigated about 1993. The whole scope of hiv was different then to now. To even compare 1993 to 2003 is ludicrous. In 1993, most people with hiv thought they would be dead by 1996. The 10 years in between has brought many changes. Sure, not everyone is jumping through hoops with good health, but many are.

There is also an inference in the letter to Ms Mills suggesting that one of the criteria for keeping SAS/S is the 'finite' lifespan of people with hiv. To my knowledge, every single person living on this planet has a 'finite' lifespan. If they mean a reduced lifespan, I don't agree with that. Like many others, I have used the experience of hiv and aids to change my lifestyle, to create, literally, a new life for myself. Indeed, my experiences with others – both personally and through community organisations – shows I am not the only one adopting this ideology. The possibility of living out whatever may have been our allotted time is quite possible.

Another issue I have with SASSters is more serious. They wanted, as part of the negotiated result, a guarantee that will ensure that if you had been receiving SAS/S since its inception, that you would retain it. In the letter to Ms Mills, SASSters again claim 'we urge you to consider the feasibility of applying the post-review SAS/S conditions only to those of us already on SAS/S alone.' In other words, everyone else can go to bugger. If you are diagnosed with hiv tomorrow, well, don't look to SASSters for support, or to the DoH for handouts. Surely this is pure elitism, and is something to be deplored by all people living with hiv. Have we survived for this long; fought the battles we've fought; people living with hiv. Have we survived for the whole 80s experience to not even having been ill), to many hiv doesn't necessarily give

you a shared experience. I align myself now with general disability groups. I realise that this is not hiv versus disabilities. It must be a shared experience, an experience whereby benefits achieved for one group feed through to others. This is where true empowerment is. We must acknowledge that it is not just hiv+ people who suffer from discrimination, and take combination therapy and are therefore affected by changes to the PBS. Just ask someone with leukaemia or diabetes. These are shared experiences across many levels of society, including other people with disabilities, and the aged. It is no longer good enough to say that we are a special group, and should be treated with special conditions. There are many who could argue the nature of these claims, and considering the current funding climate, it is probably only a matter of time before they do. Government funding no longer stretches itself to benefit every subculture in the community, and fundraising within the hiv community no longer brings in sufficient money to cover necessary. One only has to look at the last Baker's Off and the extremes groups like BGF and The AIDS Fund go to for funds, to realise that the financial climate has changed – drastically. As to their claim, again in the letter to Ms Mills that 'We have had to form unique subcultures to survive socially and live with everyday persecution. It is a mistake to believe we are no different to those with "other conditions"'. We are very different indeed.' This is only one person's perception of the hiv community, though indeed, this is often the case, and is one of the greatest challenges facing the hiv community. As long as this subculture exists, there is no moving

Then, we get to societal perceptions of hiv, and current funding. Let's be honest. Hiv is not the frightening disease that it was even 10 years ago. Treatments have improved greatly, as have life expectancy. Getting hiv now is no longer a death threat. Hiv is no longer in the news on a daily basis (not even in the gay rags), and we no longer see pages of memorial notices. This doesn't mean that it has gone away, or that people suffer any the less from it. It does, however, show a shift in the way it is perceived. To argue now that people with hiv should be treated any differently from other people in the community with disabilities does not wash. This is no longer an 'unknown' disease, it no longer has a mystique. People are very aware of it. Like many others, I chose to move myself from hiv circles just after my illness. Being hiv+ with disabilities did not give me security or understanding amongst other hiv+ people, despite whatever claims they tried to make about comradeship. I find more empathy amongst people with the same disabilities as me. A friend of mine confined to a wheelchair for a while as a result of aids has had the same experience. He found himself drawn to others in wheelchairs, as they had a shared experience. Because of the huge differences in our hiv experiences (from aids, and experiences in our hiv experiences (from aids, and the whole 80s experience to not even having been ill), to many hiv doesn't necessarily give

ident in their arguments.  
 SASSters do not recognise equity, hiv+ is frightening, and worse – discriminatory! SASSters have been gated on the length of time they have been very thought that people should be segregated of haves and have-nots created. The world of hives and have-nots created. The gained benefits for ALL hiv+ people to see a

Let's be honest. Hiv is not the frightening disease that it was even 10 years ago.

I put this challenge to SASSters. Don't desert your supporters, as you have appeared to do, judging from your lack of updates.

forward. It is really a subculture that is its own worst enemy, as it promotes the theory that there is only safety for these people in that environment. This is just not true, and is certainly not the experience of people who have moved themselves away from the subculture.

I put this challenge to SASSters. Don't desert your supporters, as you have appeared to do, judging from your lack of updates. Reinvent your group to provide support and information to people who require housing alternatives. Provide information on a range of sensible alternatives for people who are going to have to change the situations they are currently in. If I saw these lines adopted by SASSters, then maybe I would think they were an organisation worth supporting, that they were really attempting to sort out a problem that is going to affect a number of people eventually. Nobody wants to see what are legitimate problems being countered by sneakiness, bitchiness, nonentity and mudslinging. Get your acts together guys. If you choose to alienate the negotiating power the hiv community has through the ACON/BGF/PLWHA lobby (which is a group that DoH is more likely to deal with than the current group of SASSters), then you are just cutting off your nose. Show the people who are depending on you that you really do care, that your group isn't just a flash in the pan.

However, if you want your group to be taken seriously, then get serious. Show some names (FULL names), and faces. If your battle is won, what do you have to fear? Ensure that you show some access and equity, and don't create an 'us and them' community. Is this what the old guard have reduced them-

selves to? As the argument stands, anyone who speaks out against you is classed as 'the enemy'. As much as there are arguments for what you did, there are also arguments against. At least accept that there is, and will be, criticism not only of your motives, but your course of action. ACON was quite right when they stated that you were just a group of people hiding behind false email addresses AND a website (not a false website, as you chose to interpret the statement!). There is also a very definite 'vendetta' feel coming through in a lot of the SASSters statements. This, 'We were hampered by the resistance of government funded lobby groups (the so-called "community alliance") who had other goals according to their own agenda and which supported the review though a complex programme of rhetoric and subterfuge. The "community alliance" turned out to be agreements between the lobby groups, the government and the community paper media which has seen SASSters silenced, discredited and attacked' (from the website) is so full of inaccuracies that one doesn't even know where to start (and no, I have nothing to do with the alliance!). With rhetoric like this, there was no longer an objective argument. This is nothing short of some individual having an issue with ACON, and using the group as a means to vent their spleen.

So what now, SASSters? An unused website taking up room in cyberspace, or a place for something new to be born? If you really dislike the so-called 'alliance' so much, if you don't want people to use the available methods to get housing, then provide them with an alternative.

The ball is now in your court!

# Keep it up!

**Tim Alderman** on you know what

**When I first decided to write a piece on hiv related impotence, I thought to myself 'Hey, this is a pretty serious subject, and maybe you should treat it that way.' However, a visit to a sexual health clinic changed my mind on taking it too seriously, so here is a more tongue-in-cheek view on coping with impotence.**

Firstly, don't go onto the internet and hope to find any information. I visited all my regular, usually reliable sites, and found absolutely nothing. There is plenty just on general impotence, but nothing on the hiv related. As usual with a lot of the more 'delicate' subjects (let's face it, nobody likes admitting that 'they can't get it up'), there is bugged all information. As usual with a lot of hiv related problems, nobody thinks it is really important, or perhaps that, given the right length of time, the problem will just go away. But as we all know by now, that isn't necessarily the case.

Visiting a sexual health clinic on the advice of my doctor – and clutching a referral – did come as a bit of a surprise to me. I don't know what I was expecting, but it sort of seemed like the sort of place where you would tell people that you were Mr X, and you are just here to inquire for a friend who is having problems.

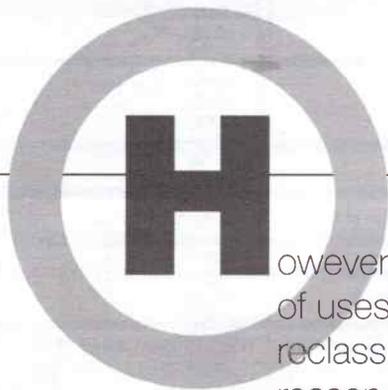
It wasn't tucked away in a dark alley, nor was the impotency problem treated as something only related to very old men, nor just one of nature's aberrations. It was treated like a serious medical problem, and perhaps this was the one huge realisation. There was almost a blasé flippancy associated with the consultation. Now, as to the real reasons for hiv related impotency, I'm probably no more an expert than the guys who are trying to assist those of us with this problem. Everyone does seem to agree that as people live longer and longer with hiv, it is becoming a more widespread problem, irrespective of your actual health status. The fact that

there don't seem to be any studies covering this area at the moment should be of some concern, as the one thing we can be relatively sure of is that the problem is not just related to hiv. Some experts think it is just a natural progression of advanced hiv disease; others see it as being a side-effect of combination therapy (plus all the other drugs needed to handle hiv); some think it is related to having had aids (if you have had aids; or that it is related to peripheral neuropathy, especially long-term PN). For some of us, it is a problem of having lived with hiv for 20 odd years, and getting older. My neurologist doesn't seem to concur with the PN idea, but personally I know that it is a distinct possibility. If PN can affect the way I move and get around, if it can cause other sorts of neurological disorders, I see no reason why it could not be related to impotency. Let's be real. Those of us who have lived with hiv for as long as the disease has been around, are still coming up with things that nobody has even considered, let alone know what to do with. And as we all know, we don't usually fit into any of the general categories, and what happens with us, health-wise, is often unexpected. So, it is a bit of 'by guess or by God' at the moment, in trying to pin down the causes of this type of impotency.

The clinician proceeded to ask me the usual questions – are you in a relationship? Yes! How does your partner feel about this? Well, I don't think anybody would be really happy with this problem, from either side of the fence! Have you considered an open relationship? Well, that helps his problem, but it doesn't really help mine. It wouldn't exactly be a situation where you could go home and compare notes later on about your trade! Have you considered using a cockring? Now, I don't know about anyone else, but I always thought these gizmos were more about aesthetics than practicalities, you know – visual stimulation and all that

(not to mention adding a sizeable amount to the actual dimensions of a cock), but here it was, out of the world of sex shops and mail order, and onto a clinician's desk. Talk about taking the erotic appeal, and the mystique, out of an object! To be told that the good old studded leather contraptions are just not good enough for this sort of problem was very disheartening. Now as to the suggested alternative, well I have to say that perhaps we should go the way of eroticism instead of commonsense. A very wide rubber band – I was given a sample to take home and try – or a 'medically authorised' cockring, which I have to say, still being the owner of black rubber and leather rings, left a lot to be desired. I could see the purpose to it, but God, was it ugly! A flesh-coloured ring with a small handle on each side of it, so that it can be stretched over the erect penis, it almost looked like some bizarre love-handled item, or perhaps a sighting feature for those who can't aim straight.

There was also a plethora of information on 'Viagra' and 'Cavaject'. Now, both these are good products, and anyone having used them as prescribed will attest to this. However, there are drawbacks. 'Viagra' is not on the PBS, and at \$55+ for 4 tablets, is very expensive if you are on a pension. You also have to be careful with it if you are on protease inhibitors. If you buy the larger size tablets, you will need a tablet cutter to split them, as they are very hard to break. But perhaps their biggest drawback is that you have to – sort of – plan your sex life, which kills any hopes of spontaneity with sex. It takes anywhere from 30-60 minutes to work (depending on your metabolism). Once you've taken it, you'd better hope your partner's still in the mood when it kicks in, or that there are plenty of available partners, or that everyone doesn't suddenly change their mind, and go back to sleep, because if that happens, there goes \$15 down the drain!



However, when the PBS definitions and classifications of uses for 'Viagra' and 'Sustenon' went through reclassification, hiv disease was NOT defined as a reason for being able to have them prescribed.

On the upside, if your partner is in the mood, you are about to give them one hell of a good time, but there is always that element of the unexpected. And waiting can be frustrating. It's fine to tell your partner that you have just taken the tablet, but if he is ready to get into it after 20 minutes of foreplay, you could be left well behind in the stakes.

Similar problems exist for 'Cavaject', although it works a lot quicker than 'Viagra', being injected directly into the penis. If you are needle-shy, forget this! You probably also don't want to see the video the sexual health clinics give to help you decide. To start with, they use a female doctor in it. Now, don't get me wrong! I know female doctors are every bit as good as male! It is just disconcerting that in a scenario where it is a male problem being discussed with men, it is slightly off-putting to see this poor guy in the video stretching his penis out, holding it as though it is about to spit poison, then aiming a needle at it as a female voice in the background goes 'Very good. You are going well'. The fact that she looks a bit like everybody's mother probably doesn't help either (no offence to whoever she is). Now, if this doesn't put you off, the price, and the procedure, probably will. I managed to do a bit of stockpiling just before it went off the PBS, thankfully. It went from \$3.50 for 5 injections to \$80+ overnight. Again, you wouldn't want to be wasting it on frivolous events. It does have the added plus, as I mentioned earlier, of working instantly. And boy, when it works, it works! We are talking rock hard to the point of impressive here! However, just make sure that you don't hit any veins or capillaries on the way in, as a gusher of blood can be a bit of a passion killer. They show you how it is done to avoid this, but as with all things, we weren't all cut from the same pattern. You also have to be careful with the needle, as you can get a bruise from a misplaced shot (or perhaps

an over-eager shot!). It is a simple procedure, and it really doesn't hurt, though I encountered a slight stinging for a few seconds just after the initial injection.

I'm also sure that a lot of you hiv guys are now familiar with regular injections of 'Sustenon', a testosterone topper-upper. It is very effective if you have depleted testosterone levels, but doesn't serve much purpose if you fall into the normal reading range, and your impotency is caused by other factors. 'Sustenon' is not cheap either, being in the \$30+ range. I think this is a major concern with 'Viagra', 'Cavaject' and 'Sustenon'. None of them are available on the PBS (unless, in the case of 'Sustenon', you can show depleted levels of hormone). Okay, if you are a vain person with no medical problems, and you just want to show off your sexual prowess, then you should have to pay for these products! However, when the PBS definitions and classifications of uses for 'Viagra' and 'Sustenon' went through reclassification, hiv disease was NOT defined as a reason for being able to have them prescribed. The definitions have never changed, despite research that shows these are problems often associated with hiv. So, to be hiv+, and to want a healthy, normal sex life means you have to pay through the nose. If you are on a pension, consider joining a monastery! The choice is 4 or 5 ecstatic sexual encounters, or starvation. On second thoughts, I may have to think about that!

Now, this brings me back to the brochure I walked home with after that little visit to the clinic. Not only pictures and order form for a natty little injection kit for 'Cavaject', and the love-handle cockring, but also a vacuum pump. Now, last time I saw one of these items – and it was recently – was on an 'adult only' site (you know the sort I mean! The ones that require adult verification!), and the use it was being put to was not medical. Hell, when I used to manage

'Numbers' Bookshop (a lifetime ago), these were amongst my bestselling items – from the cheapest, through to the elite models. I have to say that on the particular site I was on, they did show budget-wise reasons for using this device, as two guys were using it at the same time. You could time-share with a friend I guess, but the fact of both of you wanting sex with different people at the same time is probably pretty remote, so it probably isn't convenient to do it this way. I can see that they have a certain erotic appeal, and would probably be fun as foreplay, but imagine the extreme situations that could possibly occur. Over-pumping to start with, or getting the old boy stuck! Try explaining that in A&E, let alone telling them that you bought it through a medical catalogue.

Though, ideally, I don't see any of these things – apart, perhaps, from 'Viagra' – as totally expedient ways of overcoming impotency, it is a 'different strokes for different folks' scenario, and in a lot of cases, doing something is better than doing nothing. We'd all like a reasonable sex-life, and if it means going to some sort of extreme, I guess most of us would be willing to swallow a little pride, and use whatever props we have to. On the upside, on ACA recently, there was a story about this guy who has been successfully trialling a capsule that dissolves under your tongue, and guarantees pretty quick results. I did ask my pharmacist about this, and he claims it will probably be a couple of years before it is available. I say let's try and get on the trial! In the meantime, I guess we are going to have to either scrape up the money to go down the 'Sustenon'/'Viagra'/'Cavaject' road, or stock up on appliances. Whichever way we choose, as hiv+ people we are used to being creative, and I'm sure our imaginations won't let us down in the sex department.

Go for it, people!

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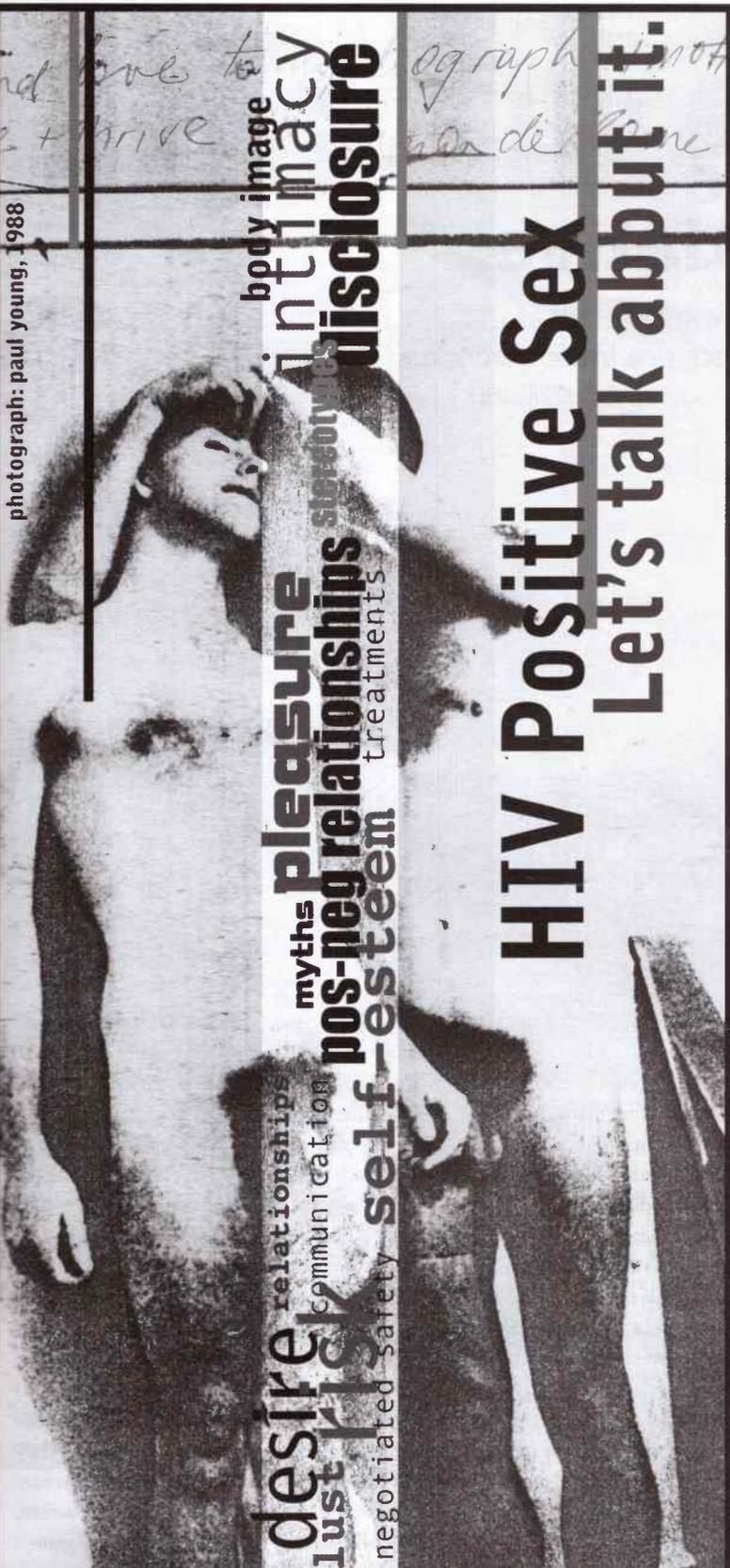
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People Living With HIV/AIDS (NSW) Inc. [www.plwha.org.au](http://www.plwha.org.au)

PLWHA (NSW) is facilitating a seven week workshop looking at HIV positive sex. We will meet once a week to find out what has changed for us and why? As part of our Health Promotion Program we aim to improve awareness and understanding of the diversity of risks, practices and sexual health issues associated with HIV positive sex. If you are interested in participating in the workshop (or a confidential interview) please contact us on 02 9361 6011 or e-mail: [healthpromotion@plwha.org.au](mailto:healthpromotion@plwha.org.au).

## OPTIONS



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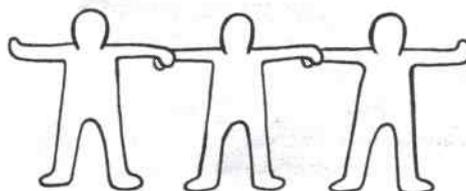
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# A worthwhile initiative

**Mary Bayldon** shares her experience of a teleconferencing support project for mothers of hiv positive adult children

**I**t reached out to clients who were living in isolation, both geographical and emotional, and helped to link people with similar problems so that they did not feel so alone.

**In 1990, shortly after I joined Ankali as a volunteer, one of my fellow volunteers, a 26-year-old man, died as a result of aids. It was my first experience of an aids-related death and I felt very concerned for his mother who had come from a rural area to care for her son in the last few weeks of his life and who would be returning home where nobody outside her family knew the details of her son's death. I wished I knew of another mother in a similar situation who could be a telephone contact for this mother but I didn't and she was left to deal with her grief on her own. However, she stayed in my mind and I often thought of her isolation brought about largely by her loyalty to her son and her fear of what people might say about him as an hiv positive person.**

In the mid-90s, I joined the staff of the Ankali Project, which has been operating in the Sydney metropolitan area since 1985 and which provides emotional support to people infected and affected by hiv/aids. Over the years we have supported a number of parents, most particularly mothers, of seropositive adult children. Despite improvements in treatments, all seem tied to an emotional rollercoaster as they try to respond to whatever is

going on for their child – a ride which is aggravated for them all by experiences of isolation, fear of stigmatisation, anxiety about the future often fuelled by a lack of information about their son or daughter's condition and the hiv+ person's own feelings of ambivalence around issues of dependence and independence.

It was 1997/98 that I heard of a project sponsored by the Australian Red Cross which used teleconferencing to link families of organ donors scattered throughout the state. The group 'met' on the phone every week for about an hour and it was, it seemed, a very positive experience for the participants. Attracted by the idea, I explored the concept further to discover that teleconferencing offered a number of benefits particularly relevant for our client group.

It overcame the kinds of difficulties in access often caused by geographical distance, disability, transport arrangements or availability.

It reached out to clients who were living in isolation, both geographical and emotional, and helped to link people with similar problems so that they did not feel so alone.

It offered anonymity and allowed people to come together who might not be willing to participate in a face-to-face group.

In addition, my research indicated it had

already been used successfully with people infected and affected by hiv in other countries.

With support from the Albion Street Centre, we ran our first teleconferencing group in 1999. It consisted of five mothers scattered throughout the Sydney metropolitan area, some of whom had almost daily contact with their 'child', some of whom had more than one infected family member and some of whom had difficult relationships with their sons. The program consisted of eight weekly sessions which lasted approximately one hour and followed a particular theme each week, such as whom do you tell and when, the effect on the wider family, sources of support, and how they might look after themselves. The attrition rate was high and there were three deaths before, during and shortly after the end of the group. Understandably, these affected group participation and only two women stayed with the program right to the end when all elected to share their full names and phone numbers and who have maintained some degree of contact and speak on the phone every month or so providing support and comfort to each other.

In 2001, I publicised the possibility of another group, this time for rural mothers but this was much harder to get off the ground. I spoke to rural health workers who were very



**W**

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These experiences have convinced me that mothers are very much a neglected factor in the hiv equation.

enthusiastic, I advertised at the rural health forum and I was lucky to be given some publicity on local radio stations, but referrals were very slow and in the end I ran the group with a mixture of mothers from both city and country. Participation was much better than previously and only one woman dropped out and then only for the last session.

Feedback from both groups was very similar. All the women described feeling isolated and trapped by their particular situation. 'I feel so frightened and alone,' said one mother, and another, 'Neither my husband or my other children seem to want to know.' Yet another described her situation as 'a continuing nightmare we cannot get out of'. Disclosure and fear of stigmatisation was an issue for all of them, 'frightened because of what they might think of me', 'easy to shut myself off rather than tell lies'. They all felt there had been little support or information for them as mothers and that was the aspect of the group they found the most helpful. 'To be able to speak to other women in a similar situation as me', 'I found I didn't feel so alone as the ladies understood', 'Honesty in the way we could talk to each other', 'I could feel free to talk whereas I can't talk to anyone else as, to me, nobody else understands', 'I found myself looking forward

to the calls every week. Good companionship, some sad stories, lots of good constructive talks and some laughs.'

These experiences have convinced me that mothers are very much a neglected factor in the hiv equation. Most mothers have a special attachment to their children even when their relationship is poor or apparently broken down completely, and this imbues them with an enduring sense of responsibility and concern even when their children are leading quite separate lives. In the case of hiv, I think, this has been compounded by the stigma surrounding hiv, the degree of public misinformation still prevailing and the confidentiality between a doctor and his/her patient which often excludes mothers. Add to all this, the inevitable tension when a son or daughter who has led an independent life for years, returns home to live. Not easy stuff – especially for women who on the whole admit they are more comfortable taking care of other people than taking care of themselves! Yet they are the ones who are most likely to be there for the long haul and they deserve our support. As one of the group members put it, 'It is nice to know that someone cares!' It seems so simple!

*I would like to acknowledge the help and support I received from Dr. Sandy Regan from the School of Social Work at the University of New South Wales.*

# diary

## Sydney

**Positive Living Centre**, 703 Bourke St, 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.

**Comp therapies at the PLC** Shiatsu – 10am, Th. Acupuncture – 4.30pm Th, 12.30pm Sat. Massage – Th. Yoga – Th evening & 2pm, Sat. 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 assessment, 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, 9.30am-12noon, 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, social work, social activities and shiatsu services for gay men. Call Robert for details and bookings on 02 9519 6142. Also holds cooking programs. For more info, ph Sydney Leung on 02 9395 0444.

**Community Garden**, Newtown and Waterloo. Learn how to grow your own veges. 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 and Petersham. Ph Gavin on 02 9516 4755.

**Newtown Neighbourhood Centre** has a number of groups. Ph Charlotte on 02 9516 4755 for details, including cost.

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

**Shopping service** for residents of South Sydney City Council area. Cost is \$4. Trips are to Marrickville Metro, Eastlakes and Eastgardens. Ph Jane or Eunice on 02 9519 4439.

**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. No group meetings Dec/Jan. Ph Margaret 02 9698 3161.

**Myrtle Place** at Crows Nest offers massage services for plwha. Also lunch M/W/F, 12.30pm. \$2.50 donation M/W; \$3 donation F. For appointments and info about other services, call Dennis or Mark on 02 9929 4288.

**Southern Cross Outdoor Group's** website has details of their social get togethers. [www.scog.asn.au](http://www.scog.asn.au) or phone John on 02 9907 9144

## Western Sydney

**Pozhetwest** offers peer support and education for men and women living heterosexually with hiv/aids in Western Sydney. Ph 1800 812 404.

**PozWest Women Support group** for women living with hiv in Western Sydney. Fun and friendship, social activities and newsletter. Ph Maxine or Pat on 02 9672 3600.

## Blue Mountains

Drop in to the **Blue Mountains PLWHA Centre** at 2 Station St, Katoomba for informal peer support. Open W/F, 11am-3.30pm. Lunch W 1pm, \$3 conc/\$5 waged. Ph/fax 02 4782 2119.

## 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.

## Northern Rivers

**Peer support for plwha** Ph Sue on 02 6622 1555 or 1800 633 637. Treatments by the sea for plwha, 7 Dec, Byron Bay. Ph Treatments Officer on 1800 633 637.

## Closed for Xmas

### The Haven, Western Sydney

Check answering machine for message. If in need call Gwen on 9672 3600 or 0414 796 809

### The Sanctuary

Closed 18 Dec – 7 Jan

### Positive Central

Closed public holidays

### BGF

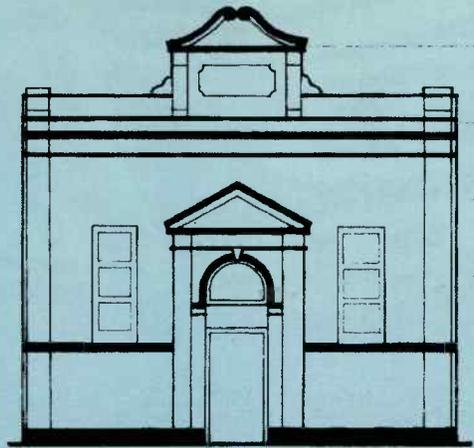
Closed 24 Dec – 2 Jan

### Myrtle Place

Closed 20 Dec – 6 Jan

### PLWHA Blue Mts

Closed 21 Dec – 14 Jan. Check answering machine for emergency contact.



## THE SANCTUARY SEXUAL HEALTH CLINIC

FOR MEN ONLY



**FREE AND CONFIDENTIAL SERVICE  
NO MEDICARE CARD REQUIRED.**

For an STD check, he  
patitis A & B vaccination, HIV testing and counsel-  
ling, HIV treatments ...

Drop in to The Sanctuary at:  
6 Mary Street, Newtown  
(opposite Newtown Post Office)  
or make a booking on  
**9560 3057**

Hours of Opening: Wednesdays, 2pm-6pm.

