

# talkabout

Where we speak for ourselves

#131 | February - March 2004 | The Magazine of People Living With HIV/AIDS NSW Inc.

 PEOPLE LIVING  
WITH HIV/AIDS  
NEW SOUTH WALES



**POSITIVE CENTRAL**

# Chill out without trying

**Discover how to tune in to your body, mind and breath**

**When:** Thursdays 1-2pm, March 4 - April 22, 2004

**Where:** The Sanctuary, 6 Mary St, Newtown  
Limited places - contact Kylie to register on 9395-0444

## Keep that New Year's Resolution to do some exercise!

**The physiotherapy gym at RPAH is open for business for 2004**

Hydrotherapy starts on 3 February for 2004  
Enquiries/Bookings - contact Andrew on 9395-0444

## The Sanctuary needs a hand or two

If you've completed a basic massage course and can spare a couple of hours to help your community, give us a call.

The Sanctuary, 6 Mary St, Newtown

For information, or enquiries, contact Robert on 9519 6142.

Hello! Can I speak with someone who understands my culture and what it is like to live with HIV/AIDS.



HIV & AIDS  
VIH/SIDA  
الايدز  
AIDS

HIV i

ជំនួយនិងការដឹងច្បាស់

ΑΡΧΟΥ Υ ΚΟΜΠΡΕΝΣΙΟΝ HIV AIDS Assistenza e Comprensione

ХИВ/СИДА YARDIM VE ANLAYIS PODRŠKA i RAZUMIJEVANJE

ΣΥΜΠΑΡΑΣΤΑΣΗ ΚΑΙ ΚΑΤΑΝΟΗΣΗ HIV-AIDS الايدز

ช่วยเหลือและเข้าใจ Trợ Giúp Thông Cảm VIH/SIDA

التفهم... والمساندہ HIV & AIDS 支持與理解 เอ็ช.ไอ.วี/เอดส์

ПОДРШКА И РАЗУМЕВАЊЕ ПОМОС I ZROZUMIENIE

HIV/AIDS 愛滋病病毒/愛滋病 APOIO E COMPREENSÃO

나는 몰랐었다고 말하지 마십시오. ជំនួយនិងការដឹងច្បាស់

AIDS는 예방될 수 있습니다.

អាត់អែដស៍និងជំងឺអែដស៍ الايدز ខ្ញុំខ្លាចហេតុនិងផ្លូវ

For HIV/AIDS information in ten languages go to [www.multiculturalhivhepc.net](http://www.multiculturalhivhepc.net)

**YOU ARE NOT ALONE**

Phone 02 9515 3098 Freecall 1800 108 098

누구나 AIDS를 유발하는 바이러스 HIV에 감염될 수 있다. PODRŠKA i RAZUMIJEVANJE  
Support and Understanding HIV & AIDS i AIDS

YARDIM VE ANLAYIS

التفهم... والمساندہ

ΣΥΜΠΑΡΑΣΤΑΣΗ ΚΑΙ ΚΑΤΑΝΟΗΣΗ

ជំនួយនិងការដឹងច្បាស់

愛滋病病毒/愛滋病

เอ็ช-ไอ-วี / เอดส์

Trợ Giúp Thông Cảm

ПОМОС I ZROZUMIENIE

HIV i AIDS

支持與理解 VIH/SIDA

Dukungan dan pengertian

ВИРУСОТ HIV И СИДА-ТА

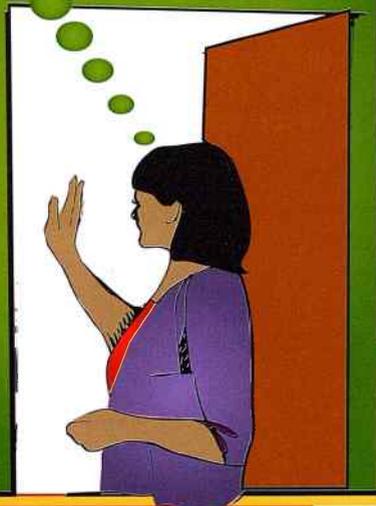
Assistenza e Comprensione الايدز

ПОДРШКА И РАЗБИРАЊЕ

나는 몰랐었다고 말하지 마십시오.

AIDS는 예방될 수 있습니다.

I am so happy my support worker is someone I can trust who does not talk to other people about my situation.



Illustrations by Annie Stashbury

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Grose Street Camperdown NSW 2050  
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Multicultural HIV/AIDS and Hepatitis C Service

# Art of Living

see page 22



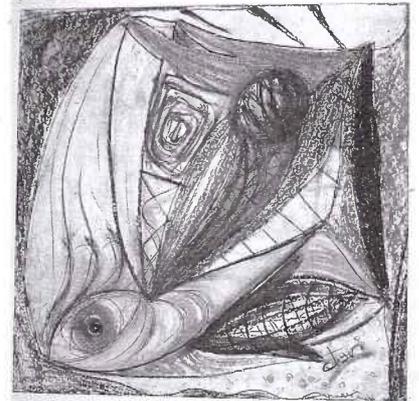
# talkabout

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Cover: 'Face Me' by Dori. The Art of Living exhibition was held during World AIDS Awareness Week. More pics on pages 22 & 23.

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## TALKABOUT

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## DISCLAIMER

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

If a person discloses their hiv status in *Talkabout*, either in a submitted article or in an interview for publication, that personal information is in the public arena on publication. Future use of information about such a person's status by readers of *Talkabout* cannot be controlled by PLWH/A (NSW) Inc.

This issue of *Talkabout* – the first for 2004 – includes details of the people, and organisations, who received World AIDS Day Awards awards. Posthumous awards went to Colin Ferguson, a Bundjalung man who founded the Indigenous Family and AIDS Council; Phillip Medcalf, the longest serving President of People Living With HIV/AIDS (NSW); and Kath Vallentine, one of the women who spoke frankly about her life in the 1992 video 'Positive Women, Women with AIDS speak out'.

'Hiv positive and applying for Australian residency' by Community Development Officer Glenn Flanagan includes interviews with Danny, Andrew, Matt and John, who all have hiv, and want permanent Australian residency. After four years and \$6,000 in legal expenses, Danny's application for residency, which included an application to waive the health requirements for permanent residency, was successful. Health requirements apply to all classes of permanent residence and people with hiv automatically fail these requirements. People born overseas with visas based on personal relationships, for example partners, can apply to have the health requirement waived so they can live perma-

nently in Australia. Glenn is setting up an email network of positive people who would like to share information about immigration. If you're interested, email him at glennf@plwha.org.au.

A bus stop poster campaign - 'Condom on paper behind glass' - is the next step in People Living With HIV/AIDS (NSW)'s response to increases in hiv. Planned for February 2004, this health promotion campaign has been made possible through an agreement between South Sydney City Council and JC Decaux that gives community groups access to bus shelter poster panels. The bus stop poster campaign is linked to the 'words to say it' campaign, which raises the awareness of people with hiv of the importance of regular sti testing for all sexually active people, especially people who have changed sexual partners, as part of hiv management. Watch out for the poster at bus stops in South Sydney Local Government Area.

Positive Central's most recent art project, 'Art of Living', was exhibited during World AIDS Awareness Week. Supported by City of Sydney Council and Pine Street Creative Arts Centre, some of the artworks – and the workshop process – are featured in this issue of *Talkabout*.

## In this issue

Positive Speakers Bureau Project Coordinator, **Paul Maudlin**, spoke to Maria Neill, who coordinates the Queensland Positive People's Public Speakers Bureau, at last year's NAPWA Conference, **page 12**.

'Hiv positive and applying for Australian residency', by **Glenn Flanagan**, includes interviews with positive people, and their partners, about their experiences applying for permanent residency in Australia. One of the people interviewed, Danny, has been successful and has been granted permanent residency. **Pages 14-16**.

**Ian Thompson** shares his recent experience after admission to St Vincent's for cardiac surgery on **page 18**. The response of St Vincent's Hospital Executive Director, Ms Kerry Stubbs, is on **page 19**.

# Pos action



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

As many members, partners and readers will be aware, during 2003 People Living with HIV/AIDS (NSW) completed a major strategic planning process. The resulting Strategic Plan was completed and launched in late 2003 and in early 2004 the organisational restructure attached to that plan has begun. The aim of the restructure is to meet the priorities identified through consultations with people living with hiv/aids, our members, communities and stakeholders, current best practice and the needs identified through the excellent range of hiv research car-

ried out in NSW and Australia. Our key partner organisations, such as NSW Health, Bobby Goldsmith Foundation, ACON, Area Health Services and many smaller grass roots hiv positive organisations, have been fundamental players throughout this process over the last 12 months and continue to be so.

Unfortunately, as with any organisational restructure, some staff redundancy is possible and the staff team has been informed and involved in these discussions over the past months. By the time you are reading 'Pos Action', some changes will already be in the process of implementation, with the organisation in the early stages of a major restructure to create a new organisational structure. Our staff team has been informed and given notice exceeding statutory requirements. However, redundancy and restructures are never easy and create considerable stress for staff and our communities. Change is often stressful and difficult.

To counter some of this stress, we have offered all staff affected by changes access to counsellors and a redeployment consultant,

as well as assisting those being made redundant by providing time to look for other employment. This may impact on our key partners, organisations and people because our attendance at other organisations, working groups, meetings and social gatherings will be reduced throughout this period. This is just a temporary stage to assist staff with changes and allow the organisation time to adapt to the changing structure.

In the coming weeks, I am sure that you will hear more about these events and we wish to inform you directly and ask for your understanding during this time of change. Most importantly, we will be maintaining our adage that part of our role is getting hiv positive people to do it for themselves and maintain strong, dynamic and heard positive voices. Please, if you have any concerns, don't hesitate to contact me through this time as we adapt, grow and evolve. What we are aiming for is a more people focused and friendly organisation, working with more hiv positive people, having greater quality contact and achieving more for hiv positive people across NSW.

**Victor Shepherd** reports from the Northern Rivers on **page 19**, and includes a review of World AIDS Day events in the region.

How sexually transmissible is hepatitis C? The answer could depend on the presence of other sexually transmitted infections. **Susan Hawkwood** reports on two London studies of acute hepatitis C associated with unsafe sex and syphilis, and a third Indian study on **pages 20-21**.

'Art of Living', a positive art project supported by Positive Central, City of Sydney Council and Pine Street Creative Arts Centre, is featured in colour opposite **page 1**, with more pics **pages 22-23**.

**Susan Hawkwood's** report of the progress of Matthew Cusick's discrimination com-

plaint against Cirque de Soleil, who fired him because he has hiv, is on **pages 24-26**.

**Kathy Triffitt** profiles the latest health promotion campaign from People Living With HIV/AIDS (NSW) - 'Condom on paper behind glass' - on **page 27**.

Regulars appearing this issue include 'Treatment Briefs', by **ACON Treatment Information Officer**, which reports on the results of a New-Fill pilot study and the benefits of HAART for people co-infected with hiv and hepatitis C, **page 4**. Jennifer Gracie's 'Agony Aunt' gives some tips on budgeting the income from casual work, **page 4**. **Glenn Flanagan's** 'Talkshop' appears on **page 5**. 'News roundup', **pages 6-12**, includes an update about Medicare reforms by **John Cumming** and a report of a visual

arts workshop held at last year's NAPWA Conference by **Kim Gotlieb**. World AIDS Day Award recipients are listed **pages 10-12**. **Tim Alderman's** cooking column this issue has some great summer food recipes, **page 13**. The Talkabout 'Diary' is on **page 32**. Anyone who's ever had a little question, a situation, or something that is downright wrong, turn to **page 31** for 'Dear Miss Bitch'.

**Pozhet's 10th Anniversary Writing Competition:** The closing date has been extended until 31 March.

# Treatment briefs

# A gony aunt

## Study shows usefulness of New-Fill

The goal of a pilot study conducted in Paris, France, was to evaluate the efficacy and safety of facial injections of poly-L-lactic acid (New-Fill) in hiv positive people with severe facial lipoatrophy. Fifty participants were enrolled in the study and received four sets of injections initially, and then every 2 weeks for 6 weeks. At entry of the study, the average facial fat thickness was equal to zero. The average total cutaneous thickness increased by >10 mm and was observed in over 19% of participants over the initial six weeks of the study and then was maintained for 96 weeks in 43% of the participants in that group. The benefit of New-Fill for the correction of facial lipoatrophy in hiv positive individuals was clearly demonstrated, with an evident aesthetic and quality of life improvement. The efficacy, safety profile, and the simplicity of the injection schedule make New-Fill a potentially attractive treatment.

Source: *AIDS* 2003; 17(17):2471-2477

For some time NAPWA, People Living with HIV/AIDS (NSW) and ACON have been collaborating with the National Centre in HIV Epidemiology and Clinical Research (NCHECR) with the aim of developing a national trial of New-Fill. NCHECR advised in December 2003 that a draft trial protocol should be available for comment by mid-January 2004. A trial protocol provides the reasons for the trial, its concerns and aims, details about how participants in the trial receive treatment, the criteria for selecting participants and for making comparisons in treatments. Once the New-Fill trial protocol is available, all the groups involved will develop a strategy to find funding for the trial.

John Cumming, Research & Policy Officer, PLWH/A (NSW)

## Treatment with HAART beneficial for HIV/HCV positive individuals

A German observational study of 285 hiv/hcv positive people was conducted from 1990 to 2002. The study was divided into three groups: individuals on HAART, those not on treatment and those taking either a dual or mono analogue treatment. None of the participants were treated with interferon, either alone or with ribavirin as anti-hcv therapy, during this time. Overall mortality rate from liver related disease was less in those individuals receiving some sort of antiretroviral therapy. Severe drug related liver toxicity was seen in 13.8% of individuals taking HAART with no deaths resulting. Investigators conclude 'analysis of long-term survival in our cohort of 285 patients with co-infection shows that in addition to improving overall survival, effective antiretroviral therapy also lowers mortality from HCV-associated chronic liver disease.' An editorial in the same edition of *The Lancet* stated 'the risks of hepatotoxicity, although real, should not diminish the use of HAART, but should encourage more widespread use of pharmacokinetic testing and development of new agents against HIV-1 that have less effect on liver metabolism.'

Source: *aidsmap.com*

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

**Q I am on the Disability Support Pension but have been getting a bit of casual work each fortnight. I am finding it very difficult to budget my money when I don't know how much I will be getting from fortnight to fortnight. How can I make my budget work better?**

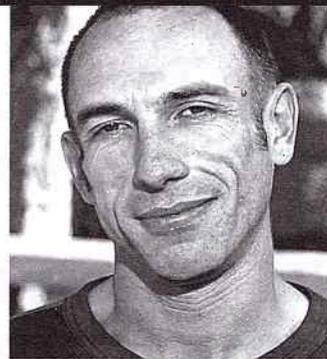
**A** It is always more difficult to manage your money when you do not get a regular income but there are a few things you could try to make it easier. The most important thing is to let Centrelink know each fortnight how much you have received so they can adjust your pension if necessary. If you are working part-time or casually and do not notify Centrelink every fortnight, your pension will be stopped until you contact them.

When it comes to managing your budget there are a few things you could try:

1. If you have any debts, such as loans or credit cards, it can be helpful if you make a part payment every fortnight. This means that you won't have to find a lump sum when each payment is due and you may have only received a small income for that fortnight. Also, if you make fortnightly payments to your electricity, gas and phone you will not have a large bill coming in at any one time.
2. Another option is to work out an average of your income

**Jennifer Gracie**

# Talkshop



over a period of about 6 – 8 weeks. You then budget your money based on that average and, when your income is higher, you leave the money in the bank to cover the weeks when your income is lower.

3. The third option is to work with the lowest amount you usually get and budget with that plus your pension. When your income is higher you can leave that extra money in the bank to cover the monthly, quarterly and yearly bills as they come in. It is important to remember that the extra money building up is already allocated for bills and not spend it on other things.

If you have difficulty working through these options you can make an appointment with one of BGF's Financial Counsellors who will work with you over a period of time to help find the best option for you.

*Jennifer Gracie is a financial counsellor with the Bobby Goldsmith Foundation. If you have any questions you want agony aunt to answer, 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

### **Your help (really) needed at MG Launch**

The Mardi Gras Launch is Friday 6 February in Hyde Park. This is the most important fundraising night of the year for People Living with HIV/AIDS (NSW). Lots of our work is only possible through fundraising. The more people who help us, the more money we can make on the night. So we need all the help we can get! If you can join us for an hour (or whatever you can spare) to shake a bucket in Hyde Park, we would really appreciate it. Call Glenn on 9361 6011 to lend a hand.

### **Planet Positive**

Planet Positive is back for 2004. This social night is for all hiv positive people and their friends, and is organised by ACON's Positive Men's Project, the Positive Living Centre and People Living with HIV/AIDS (NSW), with music by DJ Ruby. About 100 people came along to the last Planet Positive in October. Our (almost) Valentine's Day Planet Positive will take place on Friday 13 February, 6–10pm, at the Positive Living Centre, 703 Bourke St, Surry Hills. Food and refreshments are provided.

### **Come and join us at Fair Day**

People Living with HIV/AIDS (NSW) will be having a stall at the Mardi Gras Fair Day on Sunday 22 February. We'll be giving out *Talkabout*, brochures and information on what we do. If you can help us for an hour, contact Glenn on 9361 6011.

### **Would you like to be in the Mardi Gras Parade?**

The Mardi Gras Parade is on Saturday 6 March. If you would like to be part of the PLWH/A (NSW) float in the Parade this year, contact us on 9361 6011.

### **Mardi Gras Party: Take a break in the Chill Out Room**

If you're going to the Mardi Gras Party this year, you will be able to relax as usual in the Chill Out Room organised by People Living with HIV/AIDS (NSW) with the assistance of New Mardi Gras. Our friendly Chill Out Room is located in a room in the corner of the Hordern Pavilion, where you will always find a comfy beanbag and a warm welcome. If you still can't find us, ask at the ACON Information Stall.

### **A new exhibition**

Ambiguity is a collaborative art exhibition to be held at *Queer as Flowers*, 430 King St, Newtown, from February until April. The exhibition includes artworks from hiv positive and hiv negative people to highlight the effects of hiv on everyone in the community. Coordinated by the Ankali Project in Surry Hills in collaboration with People Living with HIV/AIDS (NSW), Positive Living Centre, ACON, South Eastern Area Health Service HARD Unit, Positive Central, Pine Street Creative Arts Centre and the Luncheon Club.

### **After Hours – Meeting up with other newly diagnosed men**

Our monthly drop-in night for newly diagnosed gay men got off to a successful start in December. It's been a good opportunity to meet other people in the same situation in a relaxed environment. We're meeting for snacks, chat and chilling out every third Thursday of the month. New people are always welcome. For more information, call Glenn on 9361 6011 or the Positive Men's Project on 9206 2000.

# N

## ews roundup

## Switched on Living

The HIV/Allied Health Department of St Vincent's Hospital is running a free monthly program – Switched on Living – at Sacred Heart Hospice throughout 2004. Coordinated by dietitian, Julia Kent-Hughes, social worker Patrick Dunn and occupational therapists, Katie Lemont and Elizabeth Abraham, the program's first session, scheduled for 21 January, covered nutrition. Subsequent sessions will be held on the second Wednesday of each month, from 3–5pm. Already planned are 11 February, when Michael Dash teaches meditation and mindfulness, and 10 March, when Jennifer Gracie, of the Bobby Goldsmith Foundation, covers finances.

The session's topic will be covered from 3–4pm, followed by a half-hour break, with refreshments provided, and an optional half-hour relaxation class.

The program's sessions are run on a 'drop in, drop out' basis – participants don't have to make a regular monthly commitment but can come to the sessions that appeal to them.

The program aims to provide education, support and practical information to people infected with and affected by hiv/aids in a group environment, focusing on everyday issues facing people living with hiv/aids. Throughout the year, the program will use the expertise of various professionals in the HIV Team at St Vincent's, as well as drawing on the skills and knowledge of professionals from hiv organisations, for example the Bobby Goldsmith Foundation.

*For more information about the program, or to book, contact Julia Kent-Hughes on 8382 2072, email jkhughe@stvincents.com.au, or Patrick Dunn on 8382 3296.*

## Medicare reforms update

Currently under consideration by the Australian Parliament is the draft Health Legislation Amendment (Medicare) Bill 2003. Colloquially known as the Medicare Plus Package, the bill proposes safety net measures for people whose doctors do not bulkbill. When a person spends more than a certain amount on medical costs in a calendar year, the bill guarantees reimbursement of 80 cents in the dollar for all subsequent medical expenses in that calendar year. However, eligibility for these measures depends on a person's income, whether a person has dependent children and whether they have a Health Care Card, as this table explains:

Who are you?	Eligible?
A couple with dependent children and an income of less than \$115,000	These people become eligible when they spend \$500 per year in medical costs. They will be reimbursed 80 cents in the dollar for all subsequent medical expenses in that calendar year.
A couple with dependent children and an income of more than \$115,000	These people become eligible when they spend \$1,000 per year in medical costs. They will be reimbursed 80 cents in the dollar for all subsequent medical expenses in that calendar year.
Individuals and families without dependent children	These people become eligible when they spend \$1,000 per year in medical costs. They will be reimbursed 80 cents in the dollar for all subsequent medical expenses in that calendar year.
Anyone with a Healthcare Card	These people become eligible when they spend \$500 per year in medical costs. They will be reimbursed 80 cents in the dollar for all subsequent medical expenses in that calendar year.

'For people living with hiv and aids, this is a disastrous package,' said David Menadue, President of the National Association of People With AIDS (NAPWA), in a November 2003 media release. 'The 14,000 Australians living with hiv infection, most of whom are gay men and many of whom are already struggling to meet medical and prescription drug costs, are being ignored by a package that provides a safety net only to those with children.'

In a submission to the Senate Select Committee on Medicare, NAPWA have urged that the safety net thresholds be urgently revised to take into account the needs of people with chronic illnesses on low incomes and with high health care needs. Among other recommendations, the submission calls for the introduction of a Chronic Illness Card for people struggling to meet their ongoing health care costs who would be inadequately protected by the safety net and bulkbilling measures proposed in the Medicare Plus package. NAPWA argues that a Chronic Illness Card would provide assurance for people with hiv who are working but on low incomes that the costs of their medical care can be adequately met. This, in turn, will help ensure that people remain well enough to stay in the workforce for viable periods of time, and that people are not forced to cut vital corners in their health care, or seek support from charity to meet costs as basic as doctors' visits or prescription drugs. The Senate Committee is expected to deliver its recommendations on the Medicare Plus Package to Parliament on 11 February 2004.

*John Cumming, Research & Policy Officer*

## In Your Hands

These photographs were created at a workshop, led by Visual Arts Educator Peter Fenoglio, at the 2003 NAPWA Conference in Cairns. Our aim was to use our hands to express different aspects of living with hiv. We began with some exercises, exploring using our hands and relating with one another. We then formed small groups and were given good quality 35mm cameras to work with. Each of us had the opportunity to choose poses and situations which had meaning for us – these are a few I came up with. The atmosphere was bristling with vitality and everyone seemed to really get into it. It was a great way for a diverse group of people to interact and enjoy working on a creative project together. By the end of the session, we quite organically merged into one big group. The entire collection was put on display for other participants to enjoy for the rest of the conference. I appreciated both the facilitator and conference organisers for including this session, which used creativity to build bridges and develop community, while providing each of us with the opportunity to engage with the challenges of living with hiv/aids.

Kim Gotlieb

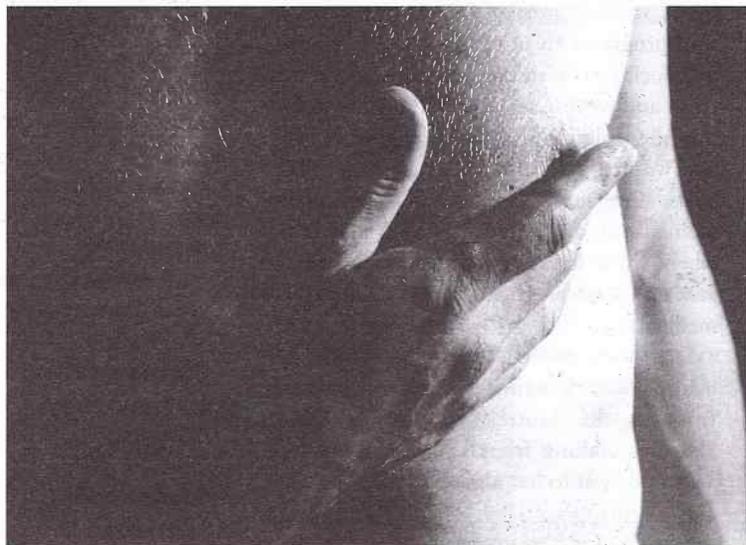
## TAFE teachers protest

NSW TAFE teachers planned to protest against increases in student fees on enrolment day by refusing to sign enrolment forms. NSW Teachers Federation president Maree O'Halloran said TAFE teachers would complete paperwork about courses students signed up but would not sign enrolment forms for fees. She said TAFE directors and the NSW government could still enrol students without the teachers' signature on the form. 'They have the authority to enrol students without the fee being paid,' she said. Ms O'Halloran said teachers also planned to hand out forms for students to seek fee exemptions. Enrolments for most TAFE courses began during the last week of January, she said.

Source: 'TAFE teachers protest fees hike', 23/01/04, news.com.au



Community



Sensuality



Sanctuary



New Growth

## Pozhet welcomes Nandini

Pozhet is giving a very big welcome to a new fulltime women's worker in 2004. Nandini Ray will be working with positive women and women partners of positive men. Nandini has already worked with many positive people in all areas of Sydney, including out west. She's also worked with the Multicultural HIV/AIDS and Hepatitis C service.

Besides being a qualified social worker, Nandini's work has included hepatitis C and intravenous drug use as well as developing, and delivering, training and education programs to other health care workers and social work students. She's worked with rural and remote services and has an insight into the isolation that many positive women and women partners have to face on a daily basis. Overseas, Nandini has helped with a women's organisation in New Delhi, India, where these issues are compounded by the lack of affordable treatments and inadequate medical care.

So as you can see ... she's enthusiastic and busy. Nandini's main occupations outside of work are the theatre, yoga and gardening. She says making friends and cooking food are important to her also.

*Nandini will be meeting many of you at events on the 2004 Pozhet calendar. She can also be contacted on 1800 812 404 or by email at [Nandini.ray@email.cs.nsw.gov.au](mailto:Nandini.ray@email.cs.nsw.gov.au).*



## Options closes

Following the closure of Options Community Enterprises Ltd, the Deputy CEO of Job Futures, Phillip Greenwood, has advised People Living With HIV/AIDS (NSW) that services provided by Options will be provided by other providers in the Commonwealth's Job Network. Job Futures is the national network of community-based employment service providers within the Commonwealth's Job Network. Options – a Sydney based provider of specialist employment services to people living with hiv/aids, hepatitis, the deaf and the hearing impaired – has gone into voluntary administration. Job seekers will be contacted directly and advised of the new arrangements. Contact details for specialist replacement services for people with hiv or hepatitis in Surry Hills, Chatswood, Parramatta and Newcastle are below.

- **Surry Hills** (previously Darlinghurst): Job Futures/WorkVentures, Level 10, 418a Elizabeth St, Surry Hills. Ph 9282 6995. Contact: Baden
- **Parramatta**: Job Futures/WorkVentures, Suite 402, Level 4, Macquarie House, 169 Macquarie St, Parramatta. Ph 9633 9644. Contact: Jackie
- **Chatswood**: Job Futures, 61 Archer St, Chatswood. Ph 9412 3122. Contact: Felisa.
- **Newcastle**: Job Futures/Life Activities, Level 4, 50 Hunter St, Newcastle. Ph 4929 7003. Contact: Lisa

These new providers will be maintaining the commitment to people living with hiv/aids and hepatitis and will be working to retain and develop community links.

Option's collapse, which had seven offices in NSW and two interstate, with 120 staff, was reported on Christmas Eve. The chief executive of Options, Bill Gye, told his 120 employees they would be stood down while the non-profit organisation went into voluntary administration by the accountants Ferrier Hodgson.

*'Fears for jobless as agency collapses', Lauren Martin and Tim Dick, Sydney Morning Herald 24/12/03. Media Release: Job Futures, 6/01/04*

## Work plan

Under a six-month, \$840,000 pilot scheme to encourage people with a disability into the workforce, Job Network providers will be offered cash to run advertising campaigns and employ staff to contact disability pensioners. Providers will also be paid an incentive for each person placed in a job under the scheme.

Employment Services Minister Mr Brough said he did not know how many of the 670,000 Australians on disability pensions would return to the workforce.

'That's a very difficult question to answer at the moment because this is a pilot program and what we're trying to do here is ascertain how effective our communication can be and how we can see what sort of attitudes are held within this wide group of people,' he told ABC radio. No type of disability would be targeted and participation would be voluntary, he said.

'That will help the labour market because we are at a 22-year-low in unemployment and we are requiring more people into the workforce so this is a win-win situation,' Mr Brough said.

*The Australian* newspaper said the Government believed as many as 150,000 disabled pensioners would move off welfare and into jobs if the pilot scheme were expanded, potentially saving \$1 billion a year in welfare payments.

[www.news.com.au](http://www.news.com.au), 12/01/04.

## Support for families

The ACON Family Support Project works with families living with hiv/aids to achieve positive health outcomes and ensure that ongoing care is provided by a Family Support Worker who understands the family's needs. 'Family' includes non-traditional families and single parents. It may be a parent who is hiv positive or a child (up to 18 years old). The project also assists people expecting a child when one or both partners are hiv posi-

...tive. Any member of the family can request assistance.

Maintaining a family unit focus, and ensuring access to services regardless of a client's background, gender, sexual identity or religious beliefs are important aims of the project.

The project provides support, information, referrals, advocacy and links to services. The extent of assistance is determined by the client's needs and wishes. Some people access the project for assistance on a 'one off' basis; for others, the project provides ongoing support. Some clients access the service for assistance regarding one specific issue, and others contact the project to seek assistance for a whole range of needs. The Family Support Worker can work with other support services, which may already be providing assistance to the family, or can approach support services that might be able to provide assistance. Clients from culturally and linguistically diverse backgrounds are encouraged to access the service. A sensitive approach is offered and an interpreter can be arranged.

The project has also organised a couple of small social events in collaboration with CSN West and will start to promote future events more widely. The next gathering, at the Positive Living Centre, will include child-minding to make access to the free services offered easier. The Family Support Worker is open to suggestions of activities that a number of families might see as a gap in services. Families who want to receive information about the event planned at the Positive Living Centre and other upcoming events can be included in the mailing list by contacting the Family Support Worker.

According to the results of a survey distributed in May last year, 50% of respondents had used ACON services. We want to encourage more families to access ACON services, by either contacting the relevant ACON staff member directly or getting a referral through the project. The Family Support Worker is happy to meet in an environment that is easy to access for the families.

*If you would like to speak to the Family Support Worker, or be added to the mailing list, contact Marina Suarez on Monday, Wednesday or Thursday on 9206 2079 or 0419 120 260, or email [family@acon.org.au](mailto:family@acon.org.au).*

## World AIDS Day Awards

Among the people and organisations that received awards at last year's World AIDS Day ceremony was the Positive Decisions Project of People Living With HIV/AIDS (NSW), which received an Innovation Award. Glenn Flanagan, Community Development Officer at People Living With HIV/AIDS (NSW), accepted the award on the association's behalf. He is pictured (right) with Stepan Kerkyasharian, recently appointed President of the Anti-Discrimination Board of NSW, and Chair and CEO of the Community Relations Commission. For other award recipients, see page 10.

Pic: Geoff Friend

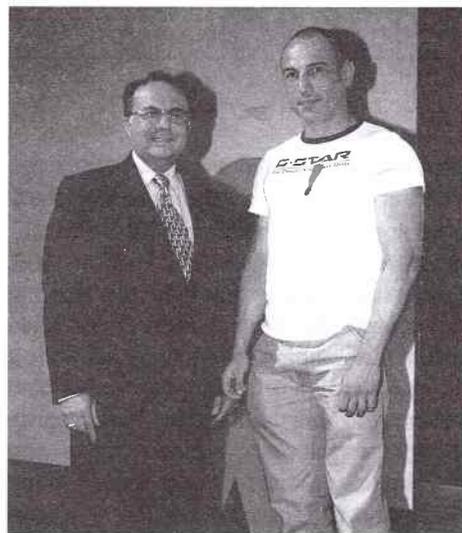
## Resident concessions

City of Sydney residents on low incomes can get a Resident Concession Card to use at the City's Aquatic and Leisure Centres. These include:

- Andrew Boy Charlton Pool in the Domain Gardens
- Cook & Phillip Park Aquatic Centre
- Victoria Park Swimming Pool
- Prince Alfred Park Pool
- Juanita Nielsen Leisure Centre
- Ultimo Community Centre
- Pyrmont Community Centre
- King George V Recreation Centre
- Pine Street Creative Arts Centre

The concession cards are available from the One Stop Shop or our Neighbourhood Service Centres. Proof of address and receipt of Commonwealth benefit will be required.

For more information, contact Desi Katsores on 9265 9595 or [dkatsoros@cityofsydney.nsw.gov.au](mailto:dkatsoros@cityofsydney.nsw.gov.au).



## New president for AFAO

Dr Darren Russell was elected president of the Australian Federation of AIDS Organisations (AFAO) late last year, taking over from Bill Whittaker who has been president for three terms. Russell has been president of the Victorian AID Council/Gay Men's Health Centre for three years. He has 10 years community and clinical experience as a sexual health physician and GP focusing on hiv/aids and sti in inner Melbourne. He has also had regular locum experience among Indigenous people around Cairns as well as international experience, primarily in Thailand. While maintaining these clinical roles, Russell's primary appointment is Senior Lecturer in Sexual Health at the University of Melbourne's Department of Public Health.

'Australia's hiv response needs revitalisation in the face of rises in hiv infections nationally and waning commitment by many in government, in the bureaucracy and in the community,' Russell said. 'I look forward to leading the community sector in driving the revitalisation needed both at the national government level and particularly within our own affected communities.'

'My predecessor, Bill Whittaker, has done a sterling job in his three years as President of AFAO and I am greatly heartened by his willingness to continue on AFAO's Board,' Russell said.

# W

## World AIDS Day 2003

**Awards presented on World AIDS Day are in three categories: Outstanding, Partnerships, and Innovation. The Posthumous Roll of Honour, conceived in 1995, recognises openly hiv positive people, nominated by their peers, who have given outstanding service in advocacy, care, education or support and have died during the previous year. The Awards recognise voluntary service above and beyond expectation, and are judged according to length of service, depth of service including contribution in diverse fields, service in particularly challenging environments, and service that has been previously unrecognised. The 2003 World AIDS Day Address was delivered by Mr Stepan Kerkyasharian AM, President, Anti-Discrimination Board of NSW. Each Award was introduced by Mr Ray Hansen and presented by Mr Stepan Kerkyasharian. Music was by harpist Marshall McGuire and countertenor Peretta Anggerek.**

### **Outstanding**

**Nicola Addison** A CSN volunteer for almost 18 years, Nicola has contributed hundreds of hours of personal care to plwha, and provided training and support to other volunteer carers by facilitating weekend training programs and running support groups for carers. Nicola's contribution is highly regarded by people with hiv, by CSN staff and other CSN volunteers and colleagues.

**Andrew Bredin** A CSN volunteer for almost 18 years, Andrew has contributed personal care to people living with hiv/aids, and volunteer support to individuals with aids. Andrew has also facilitated weekend training programs and run support groups for carers. President of CSN for the last three years, Andrew stepped down from this position in December 2003. Andrew has been President during a particularly challenging time in CSN history when members of affected communities have been less motivated to volunteer for CSN. Andrew has worked to ensure that CSN meets its financial and legal obligations. He has also worked to pro-

vide social and learning opportunities for volunteers including movie nights, bingo, theatre events and parties, and has helped produce a regular newsletter. His contribution is highly regarded by people with hiv, by CSN staff and other CSN volunteers.

**Ingrid Cullen** A qualified fitness instructor, Ingrid has been a longstanding member of Fit-X gym (the gay and lesbian community gym). Ingrid recognised the needs of hiv positive people to exercise to help combat aids wasting, re-energise and re-engage with other people in a safe and supportive environment. She designed, and volunteers her time, to run a program called the 'Positive Access' program, which has been running for nine years. Ingrid also designs exercise programs for positive clients, gives individual nutrition advice and attends the Positive Access Committee Meetings. Ingrid also helps the 'Positive Men'.

**John Robinson** has a long history of many roles including President, PLWHA (NSW), and Secretary/Treasurer/NSW Rep, NAPWA. John was instrumental in recreating and revitalising PLWHA (NSW) through its Governance changes and its recent Strategic Plan. He has volunteered on numerous working groups across many organisations, and participated in workshops and seminars with ACON, PLC, and World AIDS Day, as well as travelling around NSW to meet and talk with positive people. 2003 was John's final year as President of PLWHA (NSW). Truly an outstanding achievement as a volunteer.

**Geoffrey Spinks** A very quiet and unassuming person, Geoffrey only discussed his involvement with those rostering shifts. When he became involved 10 years ago, it was not unusual for plwha to deprive themselves of much needed assistance because 'they did not want everyone to know they needed help' and this would have been known when they were seen with a carer. Geoffrey overcame this by appearing to become a close friend and attending hospital or helping in the home as a friend. When his own partner became ill, Geoffrey withdrew from caring outside and concentrated on the

needs at home. Geoffrey lost his partner after a hard struggle. When The Haven moved to Blacktown, Geoffrey took on some overnight shifts, providing respite care and daytime cleaning shifts. For the past 42 months, Geoffrey has committed lunchtime Sunday until lunchtime Monday and overnight Tuesday to caring at The Haven. This is a man who tries to go unnoticed, and is clearly deserving of an Outstanding Award.

### **Partnerships**

**Andrew Coote** A volunteer with the Ankali Project for over 10 years, Andrew has provided emotional and social support to four different clients. Andrew has been matched with the same client for over seven years. Andrew is very aware and sensitive to the needs of his clients and has improved their quality of life. His gentleness, compassion, enthusiasm and humour have made him popular with both his clients and fellow volunteers. Andrew uses his extensive experience to assist and support new and less experienced Ankali volunteers.

**Janice Fewin** A consistent volunteer with the Ankali Project since June 1997, Janice has supported five people living with hiv/aids in the most professional way. She has shown a deep level of compassion and understanding towards her clients and maintains warmth, openness and honesty through their difficult times. Janice has been a role model volunteer with regard to supporting her fellow volunteers. She is a volunteer group leader, and brings invaluable support to newer, less experienced volunteers. Her contribution and participation within this project is outstanding and commendable.

**HUGS** (HIV Understanding and Group Support) is a peer run social support group for plwha on the Central Coast. Initially established in 1999 with the assistance of Central Coast Health, the group has been self-supporting and run by the members for three years. The group is the only one of its type on the Central Coast. It conducts fortnightly meetings and frequent social outings. HUGS provides an important advocacy role and has lobbied effectively for consumer rep-

resentation on the local NGO board. HUGS provides mentoring for members with newly diagnosed hiv. HUGS has developed strong links with ACON and is a crucial part of the community and plwha services on the Central Coast.

**Julia Moors** A volunteer with the Ankali Project since June 1996, Julia has supported two plwha, one since 1997. Her support is a constant in her client's lives and her qualities of genuine warmth, openness and a keen sense of respect is apparent. In addition to her role with positive clients, Julia has been a committed and generous member of her support group with fellow volunteers. She is truly deserving of this Partnership Award.

**George Pavlides** A client and volunteer of the Positive Living Centre (PLC) for at least four years, some of his duties include reserve bus driver and regular kitchen duties (including cooking, cleaning and serving food). Everyone knows that George is always there to lend a hand. He is also on the PLC Working Group and takes PLC clients grocery shopping on Friday afternoons. He is also doing a TAFE course, learning how to be a better volunteer cook at the PLC.

**Ray Sarsin** A tireless volunteer for ACON for more than three years, Ray helps distribute information resources and newsletters and is always keen to assist with special events like the Red Ribbon Campaign. A familiar face to all ACON staff and volunteers, he is a true 'behind-the-scenes' quiet achiever.

**David Scarlett** Known as 'Davo' and a member of the Positive Living Centre since it opened in the 1990s, David frequents the PLC on a regular basis. He helps out in the kitchen on Fridays: serving food, setting tables, cleaning and lending an understanding ear to those in need. He also attends the monthly PLC working group. He also volunteers at the Luncheon Club. Between the Luncheon Club and the PLC, Davo makes an invaluable contribution.

**Dan Webb** One of the original volunteer participants in the Street Jungle Community Garden Project, a joint program run by ACON, SESAHS, CSAHS and South Sydney

Council – Dan has been a major figure. He welcomes, supports and encourages other plwha to participate in the program, which provides gentle exercise, and reduces food costs and isolation. Dan was offered a limited paid position at ACON to facilitate this program. After funding was withdrawn, Dan went back to being a volunteer. Street Jungle could not have been successful without Dan's past and ongoing contribution.

**Elizabeth Worrall** and her two daughters have been some of ACON's most dedicated and committed Red Ribbon Volunteers. Each year, they hit the streets rattling buckets, selling ribbons and helping to raise awareness of hiv/aids. We can always rely on the Worrall family to help raise much needed funds for ACON's care and support services. Their reliability and commitment is truly deserving of a Partnership Award.

## **Innovation**

**Positive Decisions** began in 2000 and assists hiv positive people to make choices about returning to full or part-time work, study or volunteering through practical experience. Trainee placements are two days a week for twelve weeks and include vocational counselling sessions and external training courses. Participants are given the opportunity and support to discuss long and short-term goals, training needs and issues of disclosure. Since 2002, the program has expanded into a range of community organisations. All the participants have stated that Positive Decisions has given them more confidence and self esteem and has assisted their ability to make choices about their occupation and futures. Many participants have been able to proceed to part-time, fulltime or casual work in new areas. All have reported a stronger sense of connection to community. An innovative project that responds to the changing needs of plwha.

## **Posthumous Roll of Honour**

**Colin Ferguson** Raised in South Grafton, Colin was born on 15 August 1962, the son of Wilfred and Frances Alma 'Roach' Ferguson. A Bundjalung man with strong spiritual

beliefs, he will be dearly missed by his brothers and sisters: Kay, Karen, Wilfred (Buddy), John, Kerry, Kim, Ian and Lee-Anne. During Colin's short life, he made a considerable contribution to the Aboriginal Community through his involvement with the Aboriginal Land Council. He also established many lasting friendships due to his generous and friendly personality. He was always there to offer support and guidance, even when he was feeling down or unwell. Colin was the Founder of the Indigenous Family and AIDS Council (IFAC). Very quietly and anonymously, he assumed the role of an Aboriginal carer and devoted much of his latter life to caring for others living with hiv/aids in the Aboriginal community. He suffered a ten-year battle with the knowledge that hiv would some day take him. Colin was a quiet achiever who brought much joy to many people's lives.

**Phillip Medcalf** was well known to many in the hiv/aids sector before his sad passing away in February 2003. He served for many years in several positions, most notably as the longest serving President of PLWH/A (NSW). Phillip represented the needs of positive people on the NSW Ministerial AIDS Advisory Committee on AIDS Strategy, was an ACON Board member who contributed to moving the Positive Living Centre to Bourke St, a Bobby Goldsmith Foundation (BGF) Board member, and rotated between various working groups and Committees including World AIDS Day. He was instrumental in setting up Positive Heterosexuals and was passionately interested in the real lives and living conditions of BGF clients.

Many people will sadly miss his generous, caring and compassionate nature. Phillip brought these qualities to his role as Vice President of NAPWA (from May 1999 – 2002). He was elected President in April last year. The significant contribution of Phillip Medcalf in advocacy, care and support is being recognised by including his name on the Posthumous Roll of Honour.

**Kath Vallentine** During the nearly 20 years that she was aware that she had the hiv virus, Kath Vallentine offered support,

friendship and inspiration to many. One of the first group of positive women, Kath was instrumental in setting up a Positive Women's group, working to establish peer support, so that women did not feel so alone in the extreme discrimination experienced in the early days of the aids epidemic. Kath was part of a group of plwha who became the visible faces of hiv/aids. In 1992, Kath took part in making the video 'Positive Women, Women with AIDS speak out', and was one of the women who spoke frankly about her life. With PLWH/A (NSW), she worked very hard to establish Health Promotion to facilitate new ways of disease prevention. In 1996, Kath helped establish a support group for women called Screamlane, which provided telephone counselling and support. This group of volunteers offered instant access to support and information, often during the frightening hours of the night. She contributed to *Talkabout*, and *HIV Herald* and one of her articles was published just before her death. On World AIDS Day 2002, Kath was one of the three speakers at St. Vincent's Hospital, telling her story.

Her continuing battles against debilitating setbacks and infections astounded all who knew her. She offered hospitality to many when they visited Sydney for medical appointments and hospital visits. A frequent visitor when other women were in hospital, she offered information, inspiration and friendship. As with many women, she was willing to test out new procedures because she realised that clinical trials were mainly based on male responses and women's bodies responded differently. She was gravely ill many times, yet she fought on, overcoming critical illnesses and debilitating infections.

How she found the will to continue is a tribute to her determination not to be overcome by the hiv virus. She was an inspiration to us all, hiv positive or not. Kath died on 19 July 2003. She was a valiant champion for Positive Women, an advocate, an inspirational woman, a dear friend to many, a spirited and spiritual leader in the fight against hiv/aids.

# P ositive people speaking in public

**Paul Maudlin** Positive Speakers Bureau Project Officer, People Living With HIV/AIDS (NSW), spoke to **Maria Neill** at last year's NAPWA Conference

**I have been the Project Officer in charge of PLWH/A (NSW) Positive Speakers' Bureau for almost seven years and a speaker in my own right since the project's inception on World AIDS Day, 1 Dec, 1994. I attended the NAPWA Biennial Conference in Cairns last October and while there met up with several of my interstate counterparts. Some I already knew, others became new acquaintances.**

One such new acquaintance was Maria Neill who is responsible for coordinating the Queensland Positive People's (QPP) Public Speakers Bureau which operates in the Sunshine Coast and Gold Coast. Maria was one of four eager panelists in my conference workshop 'Telling your story ... How to decide' and provided an interesting insight on how she decided to become involved in a speakers bureau. Afterwards, Maria and I spoke together and agreed to the following interview:

**PM:** How long have you been involved with QPP Speakers' Bureau and how many speakers does the project have?

**MN:** As a part of my job of 18 months as QPP Coordinator, I organise our Public Speakers Bureau (PSB) talks. I enjoy engaging positive people to talk about their lives as people living with hiv/aids in public, and believe that public speaking is one of the most effective ways to change the general perception of positive people for the better. We currently have three female and three male speakers available.

**PM:** Are there any major changes you'd like to implement during your tenure as coordinator of your Public Speakers Bureau?

**MN:** QPP's first priority for the PSB over the next eight months will be to provide a training program for new speakers. Secondly, we'd also like very much to unify all

of QPP's speakers across the state and have the diversity needed to encourage booking clients to utilise our positive people for speaking engagements in schools, universities and other community organisations. We have undertaken speaking engagements in a number of school and university settings, scout groups, Volunteering Australia and Royal Brisbane Hospital.

**PM:** Does QPP have a promotional project brochure?

**MN:** This is another area that QPP intends to explore further. We want to develop a promotional plan for the project and a good way to do this is to have a recognisable project brochure.

**PM:** What have you liked most about the NAPWA Conference?

**MN:** I have enjoyed the opportunity to meet people from similar backgrounds and also had lots of informal talks with other positive people. I particularly enjoyed the opening plenary speech by Justice Marcus Einfeld. He addressed a range of human rights issues and in particular hiv and other social justice and women's issues globally. I found the information provided in the sessions and workshops to be valuable and interesting. More time could have been allowed for these. I would like to have seen more facilitated discussions take place as this was a one-off opportunity for positive people from all over Australia to express some of their views. This was a missed opportunity ... maybe next time?

**PM:** Overall, what is your lasting impression of the conference?

**MN:** Overall, the conference content was really good. There was always something of interest that I could get involved in and I was generally happy with my choices of workshops.

# S

## o, Can You Cook?



The multi-talented **Tim Alderman** shares some expertise with readers

## Aubergine & Marrow in Banana Leaves

- 2 tablespoons peanut oil (or other, if allergic)
- 3 cloves garlic, crushed
- 3cm piece ginger, peeled, grated
- ½ banana chilli, deseeded and cut into strips
- 2 medium banana eggplants, cut into fine strips
- 200g marrow or squash, peeled, deseeded, cut into fine strips
- 1 tablespoon spice paste (recipe provided)
- Salt to taste
- 6 pieces banana leaf, each 20cm square (available from Harris Farm or quality grocer)

Heat a wok or heavy-based frying pan. Add oil. When smoking, add garlic, ginger, chilli, eggplant and marrow. Sauté for 2 minutes until golden, then add spice paste. Stir, season, then remove from heat. Wash and dry banana leaf. Soften for 5 minutes in a moderate (180C) oven, so they will fold without splitting. Set on a bench, and divide mixture between them. Fold ends of leaf in, then roll to seal the parcel. Secure with a toothpick. Steam for 20 minutes and serve as a snack.

**NB** Banana leaves are not eaten. They are used to protect the contents, and give a subtle flavour. Wrap and freeze extra parcels for later use.

Makes 6 parcels  
Approx \$2.00 per parcel

## Spice Paste

- 8 shallots, peeled
- 10 cloves garlic, peeled
- 1 teaspoon coriander seeds
- 10cm piece fresh turmeric, peeled (try Asian grocers, or use dried to taste)
- 6 lge red chillies, deseeded
- 5cm galangal, peeled (Asian member of the ginger family. Substitute ginger if unavailable.)
- 1 teaspoon salt
- ¼ teaspoon white pepper
- 2 kaffir lime leaves (Harris Farm grocers)
- 100g candlenuts (try a health food store, or Asian grocers. 'Herbies' at Rozelle stock them. They are used to thicken the paste.)
- 1 stalk lemongrass, bruised (use the flat of your knife)
- 2 tablespoons peanut oil (or other, if allergic)

Coarsely grind all ingredients except lemongrass in a mortar and pestle (preferred), or a food processor. Heat oil in a heavy-based pan, add the paste. Add lemongrass and cook over a LOW heat for 30 minutes. Cool completely before using.

This will keep in the fridge for 1 week, or freeze small quantities.

## Fruit Salad with Tamarind & Palm Sugar Syrup

I adore the flavour of tamarind. It's so sweet/sour. You can get it from Asian grocers, or from 'Herbies' at Rozelle.

Fresh fruit, such as papaya, mango, pineapple, lychees, rambutans, pawpaw, berries and passionfruit

For the sauce:

- ¾ cup palm sugar, chopped
- ½ cup water
- 1 pandanus leaf (Harris Farm or Asian grocer)
- 4 tablespoons tamarind paste (no seeds)
- 4 red birds-eye chillies, whole
- Pinch of salt

Bring palm sugar, water and pandanus leaf to the boil and simmer for 5 minutes. Add tamarind paste, chillies and salt and simmer 5–10 minutes. Cool before drizzling over fruit salad for an unusual hot-sweet-sour dressing.

Serves 4–6 (depending on size and quantity of fruit)

Approx \$2.80 per head

# HIV positive and applying for Australian residency

## Glenn Flanagan

PLWH/A (NSW) Community Development Officer

**Imagine not knowing where you might be living this time next year, or whether you will be able to stay with your partner or make plans for the future? Moving to a new country can be a stressful experience – forming new social networks, looking for work, dealing with bureaucracies and paperwork – but if you're hiv positive and trying to get Australian residency, it is even more stressful.**

Everyone who applies for permanent residency in Australia must have a health check (part of which is a blood test), and people with hiv will usually fail Australia's health requirement because of their status. Based on the results of the health test, the medical officer must estimate health care costs for that person for the rest of their stay in Australia (ie over their lifetime). If the cost is over a certain amount then, according to the legislation, residency cannot usually be granted. The reason for this is the alleged burden on the health and welfare budget.

People applying for residency in certain categories can apply for a 'health waiver' from the Department of Immigration and Multicultural and Indigenous Affairs (DIMIA) to allow them to remain in Australia indefinitely. Most people who apply to the department for the health waiver are not successful and need to appeal to the Migration Review Tribunal (MRT). This process can be an expensive, nerve-wracking and distressing experience.

Some people with hiv who have been going through this process of simply wanting to live with their partner have been willing to share their experience. One of them has been successful and, after initially being rejected, has been granted a health waiver and residency, while the others are still waiting on the outcome of their appeals.

**Danny** was on a round-the-world trip: 'I had closed my general practice in Toronto and had decided to take a year off. First stop was California, then Cairns, then Sydney. I met someone and I didn't go past Sydney. And that was the end of the world trip. Six months later I returned to Canada and we had a relationship back and forwards six times for close to a year. Then we made a decision to be together and it would be in Australia. We actually hadn't thought it out very well. It was more about us being together rather

than any of the practicalities of immigration or much of the knowledge about hiv restrictions.' Applying for an interdependency visa 'was a difficult choice, and it was a big step for both of us. We used to joke and call it the marriage licence.'

Danny was initially surprised at the difficulties he encountered. 'I had an understanding that it wasn't very difficult to come into Canada. I had no idea how difficult it was to come into Australia.' After finding out more, he knew that the application he had submitted would be rejected because he was

Except for protection visas applied for by refugee applicants within Australia, health requirements apply to all classes of permanent residence.

hiv positive. 'We weren't expecting anything but that. The lawyer told us that. It was everyone's experience.' However after the initial rejection and a lot of expense (Danny's lawyer's bill was about \$6,000), paperwork, stress and time (four years), Danny's subsequent application for a health waiver was recently approved. He is now able to stay in Australia with his partner, Richard.

Except for protection visas applied for by refugee applicants within Australia, health requirements apply to all classes of permanent residence. People with hiv automati-

Matt he must use a lawyer to get this information to support his application for residency.' In fact, the cost of treatment is a medical question, and the MRT only accepts medical evidence on that point. It has not been very easy to get information from DIMIA either. Heather and Matt have just waited until the Immigration Department has contacted them, and followed their instructions regarding the evidence of their relationship. 'I phoned Immigration in October to find out the status of Matt's application as a follow up to our health waiver interview in July. I

Going through something like this really does prove the strength of relationships.

left a message and this was answered with another message saying someone would call me. No one has followed up this call. I have not called Immigration since.'

The process has taken Heather and Matt three and half years so far. 'We have not used lawyers and have not hassled Immigration.'

Peter says, 'Most of the information we have had is from our lawyer, and we know a couple of other people who have gone through the process. Most of our support comes from each other.'

Andrew agrees, 'I run into people going through this process every so often and they

seem to be doing it on their own. It would be really nice if PLWH/A were to organise an immigration support group or something. I know at least four other couples who are going through this at the moment. And I think that sort of support that you could lend to each other in a peer way is important in order to make it through this process. It is exhausting.'

John says he has found some helpful support, particularly through the Multicultural HIV/AIDS and Hepatitis C Service. He has known two other positive people applying for residency but their experience was different because they were applying under the refugee category.

It is very hard for people to know the best way to approach the complexities of the process, while always being aware that their future together relies on making the right decisions. As Peter says, 'There's no kind of manual: 'do this, this and this and you'll get it'. You have to keep banging your head away until you hopefully succeed.'

Andrew adds, 'No one really knows what to put in their health waiver application for example. No one really knows what to say at the Migration Review Tribunal. You just hope that you're putting together a good package of information.'

Going through something like this really does prove the strength of relationships. Danny felt it was good for him to see how his partner took on the battle for him to stay in the country. 'I knew that he really wanted this to happen. We would get letters of rejection. And throughout the whole process whenever we would talk to our friends and supporters, he'd always say, 'You're not going anywhere'. And to see him fight really instilled the belief in me that I wasn't going anywhere.'

He does acknowledge, however, what a difficult process it was. 'There were probably three times when I called the airlines [to go home].'

Andrew agrees that, 'if a relationship is able to make it through this process then it's a stable relationship.' But he adds, 'It brings couples closer together but it also causes enormous stresses and everyday strains. Not knowing where you're going to exist is a very destabilising thing for people.'

Peter agrees, 'A lot of people who go into this process don't make it through because of the degree to which the process affects your relationship. And we're fortunate that our relationship is very strong but even so, as you go through the various stages, there are

Heather and Matt also continue to live with uncertainty, and the fact that Matt's parents are elderly adds more stress to the situation.

frequently times that are quite stressful and challenging.'

Danny points out the power imbalance, 'One person is a citizen and the other person hasn't any rights, and it's quite clear to that person that without the other person sponsoring them to be here they could be on the next plane home. That tests the relationship as well.' Peter's words underline the fact that the Australian partner does share a lot of the frustrations and stress of this process: 'The decision we're dealing with is about my future happiness. I've never met the people who are going to make the decisions about

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Body shape change (lipodystrophy) can be a challenging experience. It is important to support personal well-being and establish a sense of control over the situation by drawing on a range of useful resources and strategies. Lipodystrophy may or may not be a concern for you personally. Either way, you might like to find out more about how some people experience and deal with body shape change. The voices presented here highlight important themes and issues, but should not be seen as representing all the diverse experiences of people with HIV and lipodystrophy.

## Lipodystrophy

Since its introduction in 1996, highly active antiretroviral therapy (HAART) has significantly reduced AIDS related deaths and greatly improved life for many people with HIV/AIDS, but some also experience a range of side effects from antiretroviral drugs, including *lipodystrophy syndrome*. This metabolic disorder involves an unusual process of fat redistribution which can manifest in a variety of body shape changes. The most common of these include: fat loss (*lipoatrophy*) in the arms, legs, buttocks, and face, and fat accumulation on the abdomen, breasts, shoulders, and back of the neck. Prominent veins on legs and arms are also common due to loss of subcutaneous fat. Other symptoms include metabolic abnormalities such as elevated levels of harmful fats in the blood and insulin resistance, which can increase the risk of heart disease and diabetes.<sup>1</sup>

## It's different for everyone

It is important to emphasise that lipodystrophy does not happen to everyone who takes antiretroviral drugs. There is still a great deal that is unknown about lipodystrophy in terms of its causes, mechanism and prevalence. Nor is it clear whether lipodystrophy is one or several overlapping conditions. The dominant theory is that protease inhibitors play a role in lipodystrophy, and possibly the nucleoside analogues as well, particularly in relation to lipoatrophy. However, two people taking the same HIV drugs do not necessarily experience the same kind or degree of symptoms, if any at all. It is also unclear to what extent these symptoms are caused by

living with body shape

# change

antiretroviral drugs or by HIV itself, or a combination of both. In addition, some changes in body fat are a common feature of normal ageing. Generally, most experts agree that the possibility of developing lipodystrophy increases with age and length of HIV treatment. On the whole, it is likely that lipodystrophy is a result of a number of complex co-factors that are yet to be fully understood.

Having lipodystrophy often means having to adjust to a new body image and a new way of being HIV positive. Because of different personal circumstances, this experience is not the same for everyone. Certain circumstances may lessen the impact of lipodystrophy, such as being openly HIV positive, engaging with the HIV sector or peers, being in a supportive relationship, and being older.

**Ludwig:** Well, to me it's a bit like a badge of honour in a way because it says that I'm positive and I'm out and all that sort of business ... I think it's important that positive people be seen as out there. And this is a side effect of being HIV positive and taking medication.

But it is also important to acknowledge that body shape change can sometimes be a challenging experience that may affect personal well-being and everyday life in numerous ways.<sup>2</sup>

## Talking about lipodystrophy

Little is understood about the lived experience of body shape change. Social avoidance and silence are common, and for those who are affected, finding support or people to share their experience with can be difficult:

**Max:** We talk about it happening, but we don't necessarily talk about how we feel about it happening. I haven't experienced a lot of discussion, really meaningful discussion.

**Adam:** I think the effects of lipo have to be factored into this whole sort of approach to managing HIV ... I think there is all this avoidance about it. You don't have any role models and positive people with lipo coming out and saying, you know, I have lipo and this is the effect it's had on me. You hear about what it's like to be positive and all that stuff. But you don't hear about what it's like to have lipo, you know ... There is a silence around it. Get the community to talk about it in some way. Maybe, you know, some education campaign.

## Body image

Body shape change can have a negative impact on body image, making you feel you look different, unattractive, 'bizarre', or prematurely aged, a feeling that might be triggered by comments and looks from others:

**Matthew:** The fact that I get comments all the time means there's something about my appearance that looks out of place. So, I'm sure I look abnormal in some way ... It's just the fact that they know that you're different. I don't want to be different. I just want to be one of the crowd, you know.

**Duncan:** I feel like the ageing process has been sped up. It's just suddenly happened. I mean everyone is organic, you have to age. But to have it happen so quickly and so bizarrely is quite deeply psychologically horrible, you know, even something you can hardly talk about.

Living with a body that does not conform to cultural ideals can be a challenge. Society saturated with images of young, healthy looking, buffed, and largely unattainable bodies. Messages that play on fears and insecurities are everywhere in the visual and print media and feed a hugely profitable industry.

**Ann:** Lipo can really sort of knock you around self esteem-wise as a woman, particularly the belly thing, because women are not supposed to have bellies, or so I've been told.

**Mandy:** When [lipodystrophy] started to happen, it just kind of flipped me straight back into being a teenager and being totally unattractive and being the wrong shape and not being what society says is beautiful.

Advertising in the gay media and the body-conscious Sydney gay 'scene' can be particularly unhelpful and may exacerbate the difficulties of lipodystrophy:

**José:** The community seems to be geared towards people with beautiful bodies ... All the ads for call services and sex, and ads for the saunas, they're all people that have got beautiful bodies and they're all youthful. I don't think that helps at all in trying to come to terms with something like lipodystrophy. It just makes it that much worse.

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**Damien:** As long as you're still on the 'scene', they're going to judge you on the way you look. So, that's really disappointing and it makes those little things, like the lipodystrophy, far more significant than they should be. You know, it's not a really big problem except in this context, in this body beautiful competitive scene. It's sad the way it is.

### Personal reminder of HIV

Regardless of individual health and viral load, lipodystrophy is sometimes experienced as a visual manifestation of HIV on the body. This may force you to confront or reassess your HIV status:

**Rick:** It's something you can't hide anymore, you know, whereas for a long time you could just sort of bury it or be in denial about it. It brings about a change where it leads you to recognise 'I do have something'.

**Ann:** What I look at is the disease in my body. The way I look is like a visual reminder that I actually do have HIV ... I've never looked like a person with HIV until I got lipodystrophy ... There was no visual thing on my body that related to HIV, you know, apart from a band-aid from a blood test. Like that was as much as my body expressed HIV.

### Forced disclosure of HIV

It is also common to experience concerns that your body shape change (in particular facial fat loss) makes it obvious to others that you are HIV positive:

**Jim:** It just makes you feel like, you know, the face of HIV. It's like people can look at you and know that you're HIV positive. It sort of decreases my self-worth.

Feeling 'outed' by your own body can undermine the sense of control over your HIV status in social situations or the timing of disclosure to friends, workmates, or family:

**Adam:** I'm quite close to my family, but I want the choosing to be mine, like when I choose to tell and if I've got lipo bearing down on me then I lose a bit of that decision making ... like my decision to disclose my status and not have it sort of overrun by physical appearance.

Concerns around HIV disclosure and identification may be strongest in relation to gay community because of an assumption that lipodystrophy is well-known among gay people:

**Rick:** I mean people know what's going on, you know, people in the gay community know what lipodystrophy is and pretty much know now what it looks like.

This sense of forced disclosure of HIV within gay community can increase feelings of social stigma. While overt discrimination is relatively rare, many experience a subtle division within gay community between HIV positive and HIV negative people:

**José:** You see in adverts, in the personals: 'clean, healthy'. Well, I'm healthy. I just happen to be carrying a virus around with me. Yeah, so there's a lot of discrimination there and that doesn't help. If there was more support in the community, I think it would be easier to adjust to [lipodystrophy].

If you live in a regional area, disclosure can be a concern in relation to the local population as a whole because of the higher degree of visibility and 'talk' that comes with living in a smaller community:

**Vincent:** There's less people like you around and so maybe you're a bit more visible. And there's less people around overall, so you probably are more visible than you would be if you were walking around Oxford Street.

### Social life, relationships and sex

Poor body image and low self-esteem can impact negatively on quality of life and lifestyle, such as avoiding particular social interactions and places like the beach, saunas, parties, or the gym, to escape potential stares and questions:

**Matthew:** Well, it puts a lot of restrictions on my life. Things that I would like to do, but I won't, like going to the beach ... I love swimming and stuff like that. But I haven't been swimming for three years and that's a direct result of lipoatrophy.

**Eddy:** Certainly, at the end of the day, if you feel uncomfortable about your looks it doesn't assist your social interaction skills and all those sort of confidences.

Feeling unattractive, and fearing rejection by potential partners, can sometimes become an obstacle to relationships and sexual intimacy:

**José:** I remember one day looking in the mirror and I'd lost a lot of muscles and fat from my legs and I've got very prominent veins in my legs and in my arms, and my face. And I remember looking in the mirror and I just broke down and cried because I thought, 'who is going to want me?' I mean, I was just horrified.

Wanting to protect yourself from potential hurt and rejection may even lead to self-imposed social and sexual isolation:

**Duncan:** I've isolated myself. Things are switching off bit by bit in my social life. Feeling like, you know, kind of non-sexual and like I'm not really 'part', you know ... You have to feel good to go out and I never feel good. I never feel I look good.

**José:** It's all part of this feeling of not wanting to be hurt. It's protection, not wanting to put myself in a situation where I can be rejected, you know. I'm afraid of that.

## HIV therapy: weighing it up

The lack of a cure for lipodystrophy is a concern for many. Several substances, such as steroids, human growth hormone, and rosiglitazone (a diabetes treatment), have been tested with mixed results.<sup>3</sup> **Before you consider these therapies, you should consult your doctor about their effectiveness and suitability for you.**

In some cases, changing those HIV drugs that contribute to lipodystrophy may alleviate some symptoms, but is unlikely to reverse them fully.<sup>4</sup> Furthermore, stopping or switching drugs is not an option for everyone:

**José:** I've had a long history of treatments and monotherapy and dual therapy. I'm concerned about how many changes I can now make and for the drugs to work as well as they are working. And at this late stage, how reversible is it anyway?

Body shape change can cause resentment or ambivalence towards HIV therapy:

**Max:** I just think it increases the mental work of taking the medication because, you know, it's that paradox of taking something that is supposed to be good for you and yet you're also witnessing some stuff that shows that the body is also being really damaged at the same time ... You're taking really, really powerful drugs to have a desired outcome and there are costs to that outcome.

In light of these present limitations, you may have to consider lipodystrophy in a broader health context and weigh the adverse effects of HIV therapy against its more positive outcomes:

**Leroy:** I know a lot of people say to me, 'oh the side effects with these drugs', and I say, 'yeah one of the big side effects is that it keeps you alive'. You've got to look at it like that as well.

**Ludwig:** I think containing the virus is number one. Lipodystrophy is sort of, you know, a bit further down that list. Provided I can have the current quality of life and contain the virus, I'll put up with lipodystrophy.

## Dealing with body shape change and taking control

**A**nger or frustration can be common reactions if you feel you have little choice but to 'put up with it'. Making a conscious decision to come to terms with the experience of lipodystrophy or to actively deal with it somehow can be a useful way to establish a sense of control over your situation:

**Trevor:** I think I was quite traumatised at the beginning and now I think I've grown into it more. So, yes, it had a major impact, but I think the impact has lessened with time as I've grown used to the face I see in the mirror, as I've grown used to the person that I am ... I mean, I don't think I could stand spending all my time hating myself, because that's all I am. So, I've grown to accept it to a large extent.

**Walter:** Time was the cure and also empowering myself to do something about it ... So it was a bit of a road to discovery, because I wasn't willing to think you can just change body shape and not do anything about it.

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## Diet, exercise, and making friends with your body

There are a number of non-medical strategies that you can use to deal with body shape change, the most common being a healthy diet and exercise. A nutritionist can help you work out a suitable diet to maintain your weight and reduce cholesterol levels. While lack of money and energy levels can be an obstacle, a regular exercise routine, such as walking, swimming, yoga, or the gym, can help to counteract some of the body shape changes, to maintain cardiovascular health, to change your body image, or simply to 'feel better':

**Jim:** Doing exercise, especially doing exercise with a group of guys who are HIV positive, you know, it's almost like adding a different dialogue, you know, the internal dialogue that you're having with your body. After a while, when you can say, 'oh gee my biceps are getting bigger', that increases your self-esteem, you know, so then you're not so overly critical of other bits that aren't so good. You can sort of try and push your attention a little bit more to things that are good and happening, you know ... It makes you feel better about yourself.

**Matthew:** I feel a lot less fatigued and have a lot more energy because I go to the gym regularly, which probably has been my number one treatment since I've been diagnosed ... I know that if I don't go to the gym on a regular basis my weight just starts to plummet very quickly. I can't put on weight, but I can maintain where I'm at ... Going to the gym keeps me stable at least.

Physical contact and touch can also be helpful, especially if there are feelings of physical isolation and discomfort. Massage for example can be a great way to relax and to care for your body and yourself.

**Lisa:** Massage is a natural therapy that I always do, because I think it's very important that people with this virus be touched ... Just that element of touch is really, just really important.

## The cosmetic option

In terms of facial fat loss, some find cosmetic procedures such as the New-Fill<sup>®</sup> injections into the cheeks effective and are generally pleased with the results.

**Ben:** Oh it makes me feel like I look younger. It makes me feel like I've got a fuller face. It makes me feel fabulous. Like in the last few months, wherever I've been, people say how well I look and they haven't said that for a long time. So, yeah, self image. Worth it. Worth having it done.

**George:** Whoever sees me now says, 'oh you're looking much better'... I know that I don't like people looking at me and that's why I never go out. But if my face fills up I think I will start going more to the pictures, even sitting down having a coffee in the open air.

The effect of New-Fill on self-esteem is promising. Currently, the cost of this procedure, which requires repeated treatments, makes it out of reach for many. It is important to remember that while New-Fill can have very positive effects, it is a temporary solution and it may not resolve every issue related to lipodystrophy, HIV or body image:

**Alf:** I think that things like New-Fill are incredibly important. But, you know, what I am saying is that, it's not going to fix all the inadequacies and all the probs. It's just going to fix the cheeks ... I think if we actually looked more at why people felt uncomfortable about it and dealing with some of the basic behavioural stuff around it and looking at people's anxieties and the reasons why they're so anxious about it, we'd actually achieve a hell of a lot more.

### Covering all bases: the broad approach

Because of the impact that lipodystrophy can have on self-esteem and well-being, it is important to consider a broad approach that takes emotional and social needs into account along with physical strategies:

**Jim:** I use techniques to actively make sure I'm not sliding into depression. So I stop negative thoughts and, you know, 'my glass is half full rather than half empty' stuff, and that's important. And, you know, trying to make a strategy against social isolation, so remaining engaged by doing volunteer work and seeing community groups and organisations and stuff. And physiologically, I think going to the gym keeps you as fit as you can be, you know ... Also, I go to the metropolitan community church periodically so that spiritually my needs are met. So, you know, I really keep working at it, keep it in check.

### Friends and peer support

It may be difficult to find people to talk to about your experience, and you might feel hesitant to approach others with lipodystrophy in case you 'touch a raw nerve' or draw attention to it. Taking steps to break down that barrier can be rewarding, as friends and peers can provide a valuable source of support:

**Ann:** I have a couple of female friends who are also unhappy about their bodies. My HIV negative female friends are just as good to talk to, because women are just good at talking about bodies ... So there's a level of peerness that I find from other women, like just around the body image stuff. That's helpful.

**Rick:** I discuss it with friends who are HIV that have [lipodystrophy] as well. The way it looks. You don't need to go there with your friends as far as how it's feeling, because you know what they're feeling ... Quite often it's a subtle acceptance, you know. It's like, 'you're okay, it doesn't change the way I feel about you. It doesn't change the way I look at you', yeah.

### Humour and focusing on the positive

Maintaining a sense of humour, and staying focused on the positive, including positive aspects of lipodystrophy, can put things into perspective and make it easier to cope:

**Ann:** It's not all grimness. Like if I go out anywhere I'll wear mini skirts and take great delight in the fact that I've got these gorgeous thin thighs for the first time ever in my life. But that's really kind of playing around the edges of it.

**Jim:** I actually try and jolly myself and maintain my positive optimistic nature with telling myself things like 'look at this fantastic six pack of abs, you know, I barely needed to work on it all, all thanks to lipoatrophy'. Because like to me humour is a way of coping, you know. Yes, it's grim and gallows humour, but that's just my nature, to try and be optimistic.

### Take me as I am: resisting negative messages

Actively resisting those cultural body ideal and negative messages that contribute to the difficulty of lipodystrophy is another valuable strategy, either by refusing to participate in the beauty industry or refusing to let lipodystrophy stop you from doing what you want to do:

**Ann:** Having other women to talk to helps. Having cartoons on my bathroom wall which take the piss out of that whole thing. Not going shopping in stores that I know won't have anything that I can [wear] ... I don't buy fashion magazines or stuff. Yeah, just refusing to participate.

**Jacob:** I still walk around in a pair of shorts as though I've still got footballer's legs, even though I don't ... I still walk up the street as though I was the same as yesterday ... I've always had the attitude that if you can't take me the way I am, then don't take me at all. I'm not going to do somersaults to try and impress you. What you see is what you get.

It is important to remember that lipodystrophy is not necessarily something negative in and of itself. It is the culture we live in that makes it so. The language around lipodystrophy is loaded with words like 'disfiguring' and 'abnormal' which can make it easy to forget that beauty is very subjective.

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**Alf:** There's a lot of discussion about lipodystrophy always being bad and I don't think it is always bad. I think there are a lot of men who look heaps better with a bit of lipodystrophy than they ever did before they got it, to be perfectly honest. I mean it's an aesthetic thing which is in the eye of the beholder ... I don't necessarily think it makes people look worse. I think that in many cases it makes people look really interesting.

ow lipodystrophy is seen and represented also linked to the ongoing stigma of HIV, another important reason to challenge negative messages:

**Alf:** I have survived and I am a middle aged gay man who is out and is known to have HIV. I mean, it's just part of having the disease and people know that I have the disease and, you know, in a way it's a statement, a confirmation of who I am and what I am ... I'm pretty comfortable about it, you know. I don't care who knows I'm positive ... I'm pretty upfront about all that sort of thing. If people have a problem with that, that's their problem. It's not my problem. I refuse to take that sort of stuff on.

While the emotional and social effects of body shape change are increasingly acknowledged, there is a need to further develop support systems and strategies to assist people dealing with these effects. The personal stories in this factsheet describe how some people deal with body shape change by using a number of positive strategies that are well worth considering and building on.

### Remember that help is available.

- Talk to your doctor, nutritionist, counsellor or ACON Treatment Officer.
- Peer support – talking to another HIV positive person can help.
- ACON has developed Healthy Life +, a twelve week gym program for HIV positive gay men around exercise, general health and diet that runs regularly during the year. Phone ACON to find out when the next program starts, or ask for the accompanying booklet.
- The Positive Access Program at FitXGym (ACON) is a program exclusively for HIV positive clients. Call ACON (02) 9206 2000 or Ingrid Cullen on 0400 712 964.
- Contact the Positive Living Centre, the Sanctuary or a community health centre for information on their lifestyle enhancement programs (yoga, exercise, nutrition).

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- 5 New-Fill (polylactic acid) is a cosmetic intervention and procedure, which is injected into the cheeks or temples, to 'fill out' the trademark hollows caused by lipodystrophy.

### The Side Effects and Lipodystrophy Project

The discussion presented here is based on interviews with research participants in The Side Effects Project, a study by Dr Asha Persson at the National Centre in HIV Social Research at the University of New South Wales. This qualitative study documents and explores how some people experience and manage lipodystrophy and other HIV treatment side effects, with particular focus on body image, social and sexual relationships, and decisions around HIV treatment and health priorities. All names have been changed.

## For support and information

### Services provided by the AIDS Council of NSW (ACON):

- **Counselling and Assessment Team** ☎ (02) 9206 2000. Outside Sydney 1800 647 750 between 10am–6pm Mon–Fri. Trained and professional staff offer a free & confidential service to people living with, affected by or at risk of HIV/AIDS as well as gay men, lesbians, bisexuals and transgender people, regardless of their sero-status.
- **Treatment Information Officers** ☎ (02) 9206 2013 or (02) 9206 2036. Freecall 1800 816 518. Call for up-to-date information about treatments for HIV.
- **ACON's Women's HIV Peer Support** ☎ (02) 9206 2012. Information, education, support and referral services for women living with HIV/AIDS.
- **Men's HIV Support** ☎ (02) 9206 2037. Information, education, support and referral services for men living with HIV/AIDS. They will also have information on Healthy Life +.

### Services from other organisations:

- **People Living with HIV/AIDS (NSW) Inc.** ☎ (02) 9361 6011. Freecall 1800 245 677. A non-profit community organisation representing the interests of people living with HIV/AIDS in New South Wales.
- **Heterosexual HIV/AIDS Service (Pozhet)** Project Coordinator ☎ (02) 9515 3095. Freecall 1800 812 404 (national) between 10am–5pm Mon–Fri. Peer support, workshops, social activities and retreats, freecall phone counselling for positive heterosexual men and women, their partners and family members.
- **Multicultural HIV/AIDS Service** ☎ (02) 9515 3098. Freecall 1800 108 098. 9am–5pm Mon–Fri. Bilingual/bicultural co-workers providing emotional support, advocacy and information to PLWHA from non-English speaking backgrounds.
- **Albion Street Centre Psychology Unit** 9am–7pm Mon–Fri Psychology Unit Manager ☎ 9332 9600. 24hr Crisis call 9382 2222 (ask for Albion St counsellor on call). Free and confidential psychological and counselling services to HIV positive people, their partners, carers, family and friends.
- **Albion Street Centre Nutrition Department** ☎ (02) 9332 9600 Customised services for health care workers and people affected by HIV/AIDS and Hep C.
- **Positive Living Centre (PLC)** offers programs on complementary therapies for people living with HIV/AIDS. ☎ (02) 9699 8756.
- **The Sanctuary Newtown** offers massage, shiatsu, meditation, yoga and social activities. ☎ (02) 9519 6142 (Mon–Fri by appointment).

- **FitXGym** Call ACON ☎ (02) 9206 2000 or Ingrid Culle (Positive Access Program instructor) on 0400 712 964. The Positive Access Program offers positive people a opportunity to exercise in a comfortable, supportive environment, where individually tailored programs are implemented for HIV positive people who may not feel comfortable in the commercial gym environment.

### For regional NSW HIV/AIDS and related services:

- **Contacts. A Directory of Services for People Living With HIV/AIDS.** Available from People Living With HIV/AIDS (NSW) Inc. ☎ 02 9361 6011. Freecall 1800 245 677.

### Useful websites:

- AIDS Meds: HIV+ owned and operated [www.aidsmeds.com](http://www.aidsmeds.com)
- Team Sydney: Contacts for gay and lesbian sports groups in NSW [www.teamsydney.org.au](http://www.teamsydney.org.au)
- Aidsmap [www.aidsmap.com](http://www.aidsmap.com)
- Amfar AIDS Research [www.amfar.com](http://www.amfar.com)
- The Body: An AIDS and HIV Information Resource [www.thebody.com](http://www.thebody.com)

### Produced by the Health Promotion Unit of



**PEOPLE LIVING  
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NEW SOUTH WALES



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us. And it can give you a sense of powerlessness which is hard to deal with.  
Hearther and Mart also continue to live with uncertainty, and the fact that Mart's parents are elderly adds more stress to the situation. Hearther says, 'His father is quite ill and without permanent residency, Mart is concerned about leaving Australia. He also refuses to travel into Zimbabwe on his Zimbabwean passport because he is afraid the government will take it off him. Under Zimbabwe law, if a citizen has been out of the country for more than a year that citizen effectively loses their

The problem is that according to the legislation, the government's cost must be taken as being correct.

citizenship. This means Mart is now a non-citizen. It also means we cannot travel overseas, even for a short holiday.

DIMIA's rationale for rejecting hiv positive people's residency applications is based on the belief that a positive person will cost the Australian taxpayer somewhere in the region of \$240,000 for a lifetime of care.

Peter says, 'We've argued every single step along the way that that's just not true. The costs are out of date. It's a weird kind of legal limbo where you're constantly mounting this argument, which you know you can't

win but you also know you're right about.' Danny believes his GP's submission to the process was very important in his being granted a health waiver. Danny's GP argued that it is very unlikely that hiv or its complications will impinge his ability to work in the foreseeable future or render him dependent on community support, including income support.

As David Puls from HALC argues, 'The estimate of \$240,000, or close to it, seems to be applied in every single hiv case, but we know that different people require different care. The cost can't be the same - so when the estimate is done they're not individualising the cost. The problem is that according to the legislation, the government's cost must be taken as being correct. So you can argue that the real cost of health care is less, and even have your doctor prove it, but the legislation won't let the decision maker use your own doctor's estimate. At the same time the government doctors won't use a realistic cost estimate, so you're stuck in this limbo where you've proved the cost being used to deny your residency is incorrect, but you can't do anything about it.'

Even if a person has hiv, they can still be a productive member of society and contribute to the country. While to some degree these matters are taken into account when applying for a health waiver, the current process is definitely weighted towards seeing applicants as a burden rather than as a possible asset to the country. Not enough emphasis is placed on applicants being assessed at the moment. Ultimately, Danny thinks that his lawyer's submission was successful because it concentrated more on his Australian partner, Richard and why Richard 'has the right to stay in Australia as an hiv positive man himself and choose to be with whomsoever he wants just like any other Australian citizen regardless

Danny believes his GP's submission to the process was very important in his being granted a health waiver. Danny's GP argued that it is very unlikely that hiv or its complications will impinge his ability to work in the foreseeable future or render him dependent on community support, including income support.

\* Names have been changed to protect the confidentiality of the people concerned.

If you are interested in being part of an email network of positive people who would like to share information with each other on this issue, email Glenn Flanagan at glennf@plwha.org.au

Even if a person has hiv, they can still be a productive member of society and contribute to the economic wellbeing of the country.

Danny but you also know you're right about.' Danny believes his GP's submission to the process was very important in his being granted a health waiver. Danny's GP argued that it is very unlikely that hiv or its complications will impinge his ability to work in the foreseeable future or render him dependent on community support, including income support.

To reasonably minded people that would seem to be a clear cut and just argument, rather than one which people have to spend many stressful years working on, not sure whether they'll be successful.  
'I would not have gone through this if my partner and I had decided I wasn't here for that reason. I would have gone home. I love Australia but I also love Canada. There's really no reason to be in Australia other than to be with Richard and that's why I'm here and that's why I stuck with it.'

# Inpatient experience

**Ian Thompson** shares his recent experience after admission to St Vincent's for cardiac surgery

**At the time I was admitted to the ward, I handed a comprehensive list of all my medications to both the registrar and the pharmacy representative who attended me. I told them that the hiv drugs I was on were trial drugs and that it was important that I received my doses at particular times. This they appeared to understand. Apart from two of the hiv trial medications which need refrigerated storage, I keep all my medications in two dosette boxes – one for my morning medications and the other for my afternoon meds. Both these boxes were taken from me by the ward sister and placed under lock and key in the cabinet next to my bed. The medications that need to be refrigerated were taken and I was told that these were being looked after.**

This was the last time I saw any of my prescribed hiv medication for nearly three days. I had my operation and, soon after surgery, was given new medications, which did not include any hiv medications. These new medications were those the Registrar had decided I needed. This was done without any thought being given to complications that might arise from possible harmful interactions with my regular medication regime. In fact, the Registrar admitted to me that she knew nothing about hiv drugs or anything about contraindications with different medications. By this stage, I was very disturbed and I demanded to see an hiv doctor. This request was refused for reasons unknown to me.

When I was eventually given my regular medications, as well as the new ones prescribed for me, I was distressed to find that two of my regular drugs were not to be administered to me. One was the antidepressant Zoloft and the other was Ordine, a form of liquid morphine, both of which I have been taking for at least the past decade. When one stops taking these drugs, the rule

of thumb is to gradually withdraw and not just stop 'cold turkey'. My objections to this once again fell on deaf ears despite my reminder to the Registrar that, because of my prolonged use of Ordine, my pain tolerance would be very different to a 'normal' patient when it came to post-operative pain control. And, sure enough, I had to endure an unreasonable level of post-operative pain when the hospital-prescribed medication proved inadequate.

I also had major problems with the administration of my medications because some of my medications were not in stock in the hospital pharmacy, and medications in stock not being administered on time. My dose of 3TC was one example. I had to go without this medication for several days because the pharmacy said there were no stocks of it. When staff realised my prescribed medication was required, they agreed to use the medication I had brought with me in my dosette boxes but the nursing staff had difficulty recognising some of the pills. Because the hospital is severely short of nurses, administration of my meds was extremely erratic. Several times, medications were administered up to three hours after my due times. Some staff had trouble locating the refrigerated pills I needed. This prevented me from taking the meds when they were due. I was not allowed to self-administer my hiv drugs to keep within optimum timeframes for the drugs to work correctly, even though I had them all in the dosette boxes beside my bed. This was also a cause of conflict with the Registrar, who refused to believe that absorption and effectiveness of any medications could be affected by timeframes of administration.

When I began inquiring as to why I was not allowed to self-medicate my hiv drugs I was told that it was a NSW Health Department policy that patients were not allowed to self-medicate. I later found this to be incorrect: it was a hospital policy rather than

a blanket policy, and other wards allowed patients to self-medicate. It seems obvious to me that this policy urgently needs changing. I have been told that patients in the hiv ward are now allowed to self-medicate and believe that this should also be extended to hiv+ patients in surgical and other wards. It would save people much anxiety and fear. From a personal perspective perhaps I would not have ended up with the extremely high viral load and many depleted T-cells that I had to deal with because of my experience as a result of the hospital's policy. Registrars and nurses obviously have much to learn when it comes to their education and understanding of hiv management, despite this disease being around for more than 20 years.

Two weeks after being discharged after my surgery, I was again admitted to the hospital's Intensive Care Unit, where I spent the following four days in a critical condition. This time I was diagnosed as suffering 'septic shock' – the cause for this was never found but it came very close to killing me. I wonder if the debacle over my medications had anything to do with this response?

I believe that my post-operative recovery has been compromised to a marked degree because of the complications arising from the interruption to my hiv medications and I urge others about to enter hospital to take steps to ensure that their medical team is aware of their particular needs at the time of their pre-admission assessment, and that these people agree to respond accordingly. I now believe that a failure to do so could have devastating (life-threatening?) consequences.

I would be interested in hearing of another hiv+ person who has had trouble in hospital with their medications, and as them to contact me with their story at [jamie@triode.net.au](mailto:jamie@triode.net.au).

# Northern Rivers

**Victor Shepherd:** I was born in the year of the monkey, and readily admit that I don't know what it all means, but the Chinese certainly seem very excited. So I've decided to try and be excited and positive about the year ahead, and hope some of you will join in this enthusiasm.

Dear Ms Hawkeswood,

Thank you for providing St Vincent's Hospital with the opportunity to respond to an Thompson's letter.

Due to privacy laws relating to patient confidentiality, the Hospital is unable to comment in relation to Mr Thompson's specific management at St Vincent's.

The Hospital has thoroughly investigated the issues raised by Mr Thompson and is confident that his management was appropriate throughout his treatment at St Vincent's. We would encourage Mr Thompson to make contact with the Hospital to discuss the issues he has raised.

Importantly, we would like to encourage patients who may have any clinical issues with their treatment at St Vincent's to utilize the various complaints mechanisms both within the Hospital or externally, through independent review panels such as the HCCC.

The Hospital regards patient complaints and suggestions as an important aspect of providing evidence-based medicine and ensuring that we continuously improve on our outcomes. Many patient complaints have led us to review our patient protocols and treatments. Accordingly, we would encourage your readers to utilize these complaint mechanisms.

Yours sincerely,

Kerry Stubbs, Executive Director

**Editor's note:** The Health Care Complaints Commission (HCCC) can be contacted on 9219 7444 or 1800 043 159, tty 9219 7555

## 2004 - Year of the Monkey - Happy New Year

Over the past few months, the media (gay and otherwise) have given lots of space to the increasing numbers of people testing hiv positive. Words like apathy and complacency were widely used and of course there has to be someone to blame.

Is there apathy and complacency in the Northern Rivers, and do we ever blame others when we should be looking at ourselves?

People constantly make comments like:

'No one does anything for me.'

'There's nothing to do.'

'Nothing happens socially.'

'I feel isolated.'

How about, this year, we all club together and make an effort to overcome some of the problems with being hiv positive.

I'm currently the area representative for People Living With HIV/AIDS (NSW), so if anyone has any bright ideas, burning issues, or just wants a chat, please contact me.

Messages can be left at ACON Northern Rivers, ph 02 6689 9352 or email me at [ausvicross@yahoo.com](mailto:ausvicross@yahoo.com)

To all you monkeys, goats, rats, tigers, dogs, snakes and any I've missed, a very happy New Year, one filled with fun and excitement and of course good health and wealth.

*Cheers, Victor Shepherd*

## Review: World AIDS Day events in the Northern Rivers

Excellent coverage by the media, especially TV, of the Quilt unfolding ceremony. Yours truly even featured as the face of positive people in the local paper (*The Northern Star*, 1 December edition) in an article called 'Life goes on for Victor'.

The two functions to raise funds for the local hiv crisis fund were well advertised but poorly attended. compounded by the fact that the local cry - 'there is nothing on for us to go to' - only compounds the organisers' disappointment.

'The Audition' at Nimbin was a terrific show with excellent performances from the nine performers. One of the performers suggested trying out the final rehearsal as a fundraiser for ACON. Sadly only 20 people turned up.

The World AIDS Day trivia night was also a huge effort by a few people working their butts off to find prizes and come up with ways to make the night interesting and fun.

There were about 60 people, who all had a fantastic night. Entrance fee was only \$5, but with provision to bribe and challenge the judges, and several raffles, we were all amazed to hear that \$800 had been raised for the crisis fund. The mind boggles at what amount a bigger crowd could raise?

However, we have a new year and just maybe, maybe, this will be the year when everyone realises that they can make a difference.

*Victor*

# Hepatitis C and other STIs

How sexually transmissible is hepatitis C? The results of three studies – two in London and one in the Indian city of Chennai – indicate that the presence of other sexually transmissible infections increases the chances.

Talkabout Editor, **Susan Hawkwood**

**Two studies indicating an epidemic of acute hepatitis C associated with unsafe sex and syphilis infection in London were recently reported in *HIV Treatment Bulletin* (Vol 4 No 10 December 2003/January 2004). The epidemic is reportedly sexually transmitted among hiv positive men who engage in high risk, unprotected sexual activities with other men. A high percentage of individuals spontaneously cleared the infection.**

One study carried out at the Chelsea and Westminster Hospital reported that, 'In recent months we have seen an epidemic of acute hepatitis C, probably sexually transmitted, with individuals reporting unsafe sex and a higher rate of recent syphilis infection.'

The second study, carried out at the Ian Charleson Centre at the Royal Free Hospital reported that, 'recent findings suggest that hcv is being increasingly sexually transmitted, particularly among hiv positive men who engage in high risk, unprotected sexual behaviours with other men', rather than the major risk factors of sharing needles among intravenous drug users (ivdu) and receiving blood and blood products more usually reported.

S. Fletcher of the Ian Charleson Centre reported that 16 hiv positive patients were diagnosed with sexually acquired hcv infection. All were homosexual men with no history of ivdu 'who had been involved in high risk, unprotected sexual behaviours, which included active and passive anal intercourse, fisting, rimming and oral sex.' Of these 16, six spontaneously cleared the infection. The remaining ten were treated with combination treatment (pegylated interferon alpha-2b and ribavirin). Three of the patients who received treatment achieved a significant reduction in hcv rna after 12 to 14 weeks of treatment.

M. Nelson and colleagues at the Chelsea and Westminster Hospital identified 44 individuals between January 1997 and June 2003, 38 in the last 18 months. All were homosexual men and one had a history of recent ivdu. Fifteen were diagnosed with syphilis in the year before hcv seroconversion. Twenty did not receive treatment – ten of them because they spontaneously seroreverted to pcr negative. Those who spontaneously seroreverted to pcr negative were more likely to have a cd4 count >500 and had higher ALT at diagnosis. Having a higher ALT can indicate a stronger immune response to the presence of the virus. Twenty-four patients were treated. Fifteen of these patients have finished treatment and nine are continuing treatment. This group was treated with interferon and ribavirin, or pegylated interferon alone, or pegylated interferon and ribavirin. Of this 15, ten have been successfully treated to the point of testing pcr negative, and treatment failed for five (one due to toxicity, four because of lack of response). The researchers reported that treatment response to interferon was lower among this group of hiv positive men than in the hiv negative population.

At a presentation at the 9th EACS at Warsaw in October 2003, Professor Brian Gazzard, of the Chelsea and Westminster Hospital, said, 'It is clear there is an epidemic going on within the London gay community of acute hepatitis C infection and this is also being seen in a number of other units across London.' Modes of transmission have not been identified in four co-infected gay men, and another four also injected drugs (two of whom also had unprotected anal intercourse).

As well as barebacking, associations have been made with fisting, sharing drug-snorting paraphernalia and, particularly, syphilis

but, according to Professor Gazzard, receptive unprotected anal intercourse was the single common factor among the 44 out of a total of 50 gay men seen at the London hiv/hcv co-infection clinic since it began in January 1997.

'They all had passive anal sex,' he told aidsmap, 'but many of them were also fisting. We did ask about [snorting drugs] and we didn't find any association, so I don't think that was a risk factor.' The Chelsea & Westminster also found that around 40% of the men had been diagnosed with syphilis in the year prior to hcv seroconversion.

It is not known whether acutely or chronically co-infected hcv/hiv positive men are most likely to transmit hcv to their sexual partners, but extremely high hcv viral loads are seen during acute infection and, just like hiv, hcv is more likely to be transmitted when viral loads are high, and possibly in the presence of an sti, like syphilis. The next step will be to do 'DNA fingerprinting, to see if it comes from a common source or many different sources,' Professor Gazzard said. 'The suspicion is that it may well come from a common source.'

The Chelsea & Westminster has learned lessons about identifying and treating new cases of hcv co-infection from its past experiences, and now does routine liver function tests every three months on all of their hiv positive patients. If they are abnormal, they are then screened for hcv antibody and hcv pcr (viral load). Thirty-nine of the 50 co-infection cases reported so far in the epidemic were picked up in this way, another three told their doctors they had barebacked with a known hcv positive sexual partner, four presented at the clinic with jaundice, and the rest were screened for hcv during seroconversion for hiv antibodies.

# H

## ow is hepatitis C passed on

Sharing or reusing other people's needles and syringes	extremely high risk
Sharing or reusing other people's injecting equipment	very high risk
Unsterile tattooing and body piercing	high risk
Mother to baby, before or during birth	moderate/low risk
Health care worker, needle-stick and sharps injury	moderate/low risk
Sharing of razor-blades and toothbrushes	moderate/low risk
Blood transfusion and blood products, before Feb 1990	low risk
Sexual activity (without blood to blood contact)	very low risk
Blood transfusion / blood products, after Feb 1990	extremely low risk
Breastfeeding	extremely low risk

Source: Hepatitis C Council of NSW

Although treatment with pegylated interferon/ribavirin is standard practice at the Chelsea & Westminster, they now wait 12 weeks to see if the hcv co-infection spontaneously clears. So far, 12 out of the 22 patients who did not take any treatment spontaneously converted to hcv pcr negative within that time. 'We were surprised by the relatively high rate of spontaneous conversion to pcr negative,' said Professor Gazzard.

However, of the nine individuals presently receiving treatment, four have a poor anti-hcv response. Professor Gazzard reported that they had found that the short-term success rate of treatment of acute hcv co-infection 'was close to 60%'.

In a separate study of Indian slum-dwellers published in *Clinical Infectious Diseases* in July 2003 and reported by [aidsmap.com](http://aidsmap.com), women who have had a history of genital ulcers and men who reported sex with other men were found to be at increased risk of being infected with the hepatitis C virus through sex.

In a study involving more than 1,620 slum-

dwellers in the Indian city of Chennai, investigators hypothesised that individuals with ulcerative sexually transmitted infections and men who had sex with other men would be at increased risk of acquiring hepatitis C from sex. The study excluded injecting drug users.

Hepatitis C was detected in 2% of men and 3% of women. Most of the study participants (53%) were women, and 71% were married. The number of reported life-time sexual partners was low (between one and six), although 95% of sex was unprotected.

None of the hepatitis C-positive individuals was coinfected with hiv, or the bacterial sexually transmitted infections trichomonas, gonorrhoea, or chlamydia.

Twenty-four women tested positive for hepatitis C. Women reporting a history of genital ulcers were more likely to be infected with hepatitis C compared to women with no genital ulcers.

Compared to men not infected with hepatitis C, the 15 hepatitis C-positive men were over three times more likely to report sex with other men, and over three times more

likely to have antibodies for herpes simplex virus-2.

The investigators conclude that their data suggests that although hepatitis C is not easily transmitted sexually, 'genital ulcers and anal trauma may increase the risk'. They recommend that health care providers should stress the importance of using condoms and lubricants.

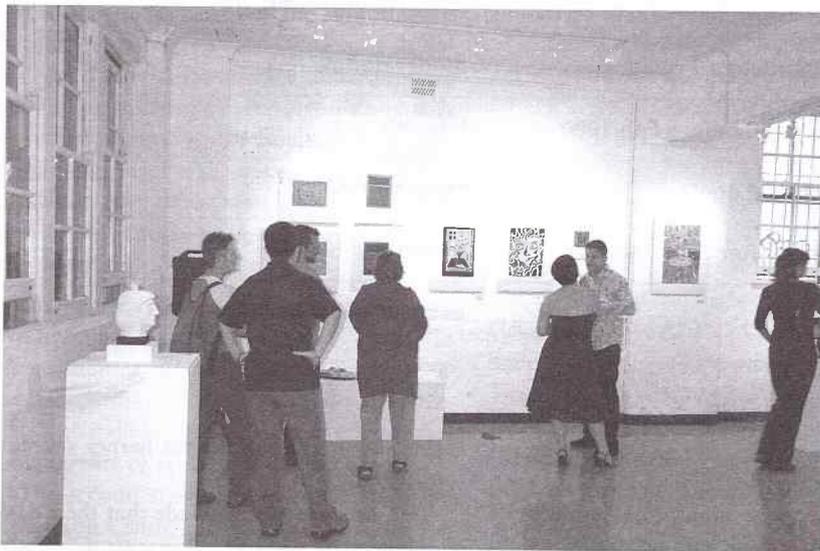
Sources: 'Sexual transmission of HCV seen in Indian women with genital ulcers and men who have sex with men', Michael Carter, 30/07/03, [aidsmap.com](http://aidsmap.com). 'London epidemic of sexually transmitted hepatitis C', Graham McKerrrow, HIV I-base, HIV Treatment Bulletin, Vol 4 No 10 December 2003/January 2004. 'Barebacking the sole common risk factor in London's sexually transmitted hepatitis C epidemic', Edwin J. Bernard, 28/10/03, [www.aidsmap.com](http://www.aidsmap.com).

Editor's Note: I haven't been able to find any comparable studies conducted among large city populations in Australia to include however in discussion with researchers they had confirmed the need for further studies before comments can be made in an Australian context. Currently there are only very few documented cases reported of Hep C being transmitted sexually in Australia, and it is generally considered that sexual activity without blood to blood contact is very low risk.

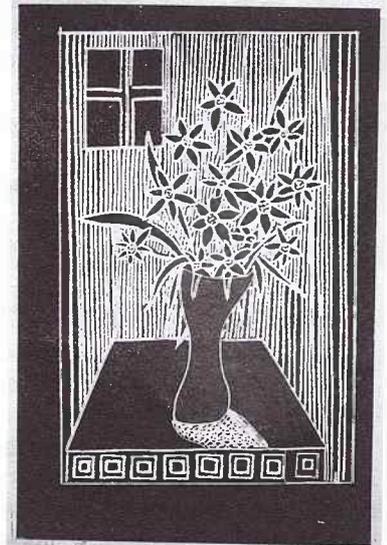
# A rt of Living

An exhibition of works by positive artists held during World AIDS Awareness Week, 'Art of Living' was supported by Positive Central, City of Sydney Council and Pine Street Arts Centre. For information about other arts activities in inner Sydney, contact Kylie Tobler on 9395 0444.

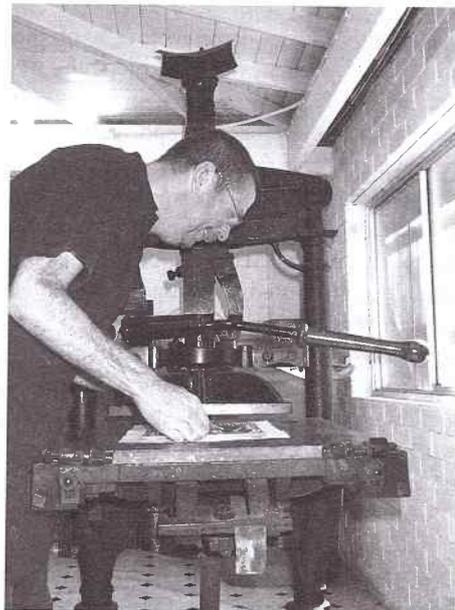
'The Joker' David McIntyre



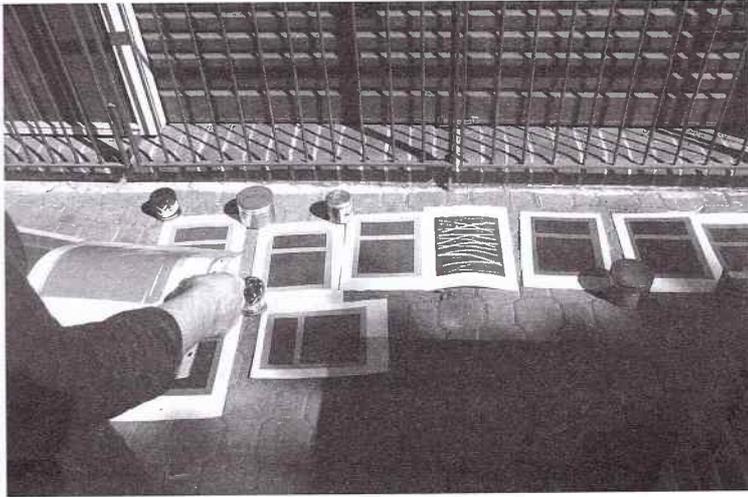
'Stick Em In A Vase' David McIntyre



Peter McGrath printmaking



'Rothko has Myopathy' & 'Rothko has Neuropathy' by Blair



'Ganesh has Lipodystrophy'



Peter McGrath with Scratchboard and woodblock prints



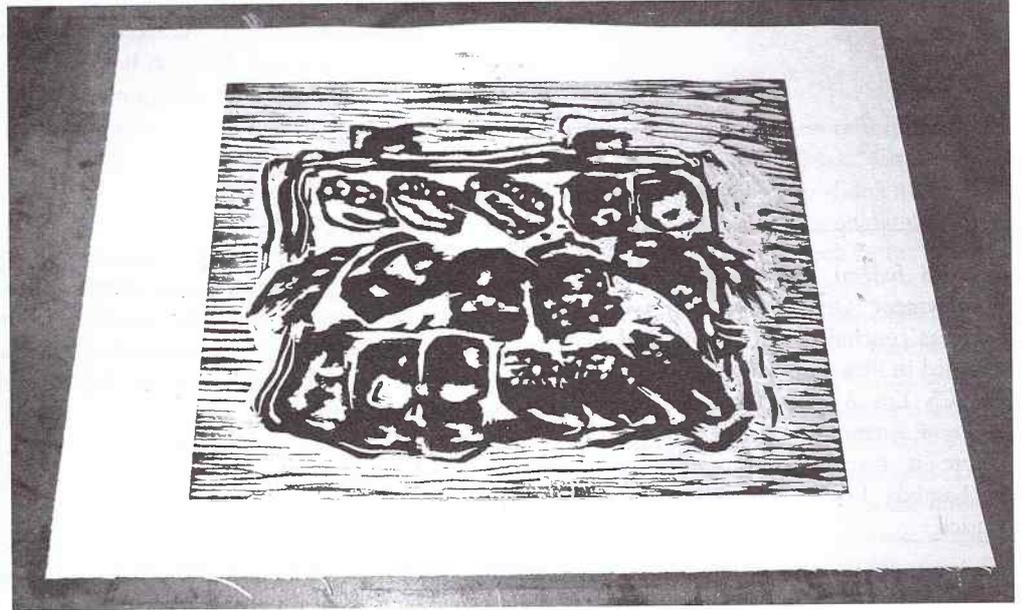
Blair with 'Mandala with K.S'



Using the press



'Boiled Rice' Peter McGrath



# Discrimination: At Cirque du Soleil

In November last year, Lambda Legal and activists launched a campaign with protests at Cirque de Soleil's show in San Francisco, a nationwide petition drive and plans protests in the months ahead at other Cirque shows across America.

Talkabout Editor, **Susan Hawkwood**

Some of America's most accomplished performers, artists and celebrities are joining a nationwide campaign against Cirque du Soleil for firing a gymnast because he has hiv, Lambda Legal announced on 20 January. Increasing protests and public opposition to Cirque du Soleil stem from a federal discrimination complaint filed by Lambda Legal in July against Cirque on behalf of Matthew Cusick, who was fired because he has hiv. Although the company's own doctors cleared him to perform safely, top executives at Cirque du Soleil contend that he poses a safety risk. In formal filings, letters to the public and dozens of media interviews, Cirque has said that Cusick was fired solely because he has hiv.

The US federal government's Equal Employment Opportunity Commission has concluded that Cirque likely engaged in illegal discrimination. The EEOC's Los Angeles District Office will now attempt to resolve the matter before it reaches court, according to Lambda Legal, which represents Cusick.

Los Angeles, 30/01/04, [www.lambdalegal.org](http://www.lambdalegal.org)

'Today, the entertainment community is sending Cirque du Soleil a strong and clear message that hiv discrimination is unacceptable,' said Michael Adams, Director of Education & Public Affairs at Lambda Legal. 'Cirque du Soleil is on the wrong side of the law and stands in direct opposition to a growing consensus in the entertainment industry.'

'Some of our nation's best and brightest performing arts voices stand against Cirque du Soleil because people with hiv can safely perform and shouldn't be relegated to desk jobs just because they have hiv.'

The supporters of the campaign against Cirque du Soleil announced by Lambda Legal include: Nathan Lane, Tony and Emmy award-winning actor and singer, currently starring in *The Producers* on Broadway; Chita Rivera, award-winning actress and singer for the last 45 years, who recently received the Kennedy Center Honors; Rosie O'Donnell, six-time Emmy Award-winning actress, producer and former talk-show host; Bebe Neuwirth, Emmy and Tony award-winning television, film and theatre actress, singer and dancer; Tony Kushner, Pulitzer Prize-winning author of *Angels in America*; BD Wong, award-winning television, film and theatre actor; and the Actors' Equity Association, the first American actor union, founded in 1913, which is one of the most influential performing arts organisations in the nation, representing more than 45,000 members working on theatrical stages nationwide.

They join dozens of organizations and individuals who joined the campaign in late 2003, including: Rudy Galindo, US men's

figure-skating champion; David Pichel, Olympic diver 1992, 1996, 2000; Patrick Jeffrey, Olympic diver 1988, 1996; Eric Anderson, first openly gay high school or collegiate male sports coach; Dr Paul Volderbing, MD, leading national and international authority on hiv since the first days of the epidemic; and Dr John Stansell, MD, also a leading authority on hiv; the Stop AIDS Project; the National Association of People with AIDS (USA); the San Francisco AIDS Foundation; the San Francisco Lesbian, Gay, Bisexual and Transgender Community Center; the Asia & Pacific Islander Wellness Center; Parent Families and Friends of Lesbians and Gay Lyon-Martin Women's Health Services; the Horizons Foundation; the National Center for Lesbian Rights; Bay Area Physicians for Human Rights; Broadway CARES/Equity Fights AIDS; Dancers Responding to AIDS; the Gay and Lesbian Medical Association; HIV/AIDS Legal Services Alliance; Beir Alive/People with AIDS Action Coalition; Pride at Work, AFL-CIO; The Project to Eliminate Homophobia in Sport; International Action Center; and the AIDS Service Foundation of Orange County.

'The story of Matthew Cusick's firing by Cirque du Soleil is only the most recent chapter in the long, dismal history of discrimination, but it's especially shocking – and disgraceful – to find bigotry and ignorance about the aids epidemic manifest in 2004 by an organisation with so many connections to the performing arts,' Kushner said in a statement released on 20 January by Lambda Legal.

Despite Cirque du Soleil's written claim that it fired Cusick after extensive training,

for a highly choreographed show because it has an obligation to avoid 'known safety hazards', Lambda Legal AIDS Project Director Hayley Gorenberg, who represents Cusick, said, 'There has never been a case of a performer or an athlete transmitting hiv during a performance or competition.'

Dozens of other artists, actors, playwrights and entertainers are joining the campaign against Cirque du Soleil, Lambda Legal said. They include Michael Kearns, the first openly hiv-positive actor in Hollywood, who has appeared in dozens of television shows, movies and plays, including *Body Double* and *The Waltons*. 'Cirque du Soleil's actions are disturbingly ignorant, shockingly inhumane and decidedly illegal. When I first came out as hiv positive, this is the kind of discrimination many people expected to see. But today, in Cirque du Soleil's own field,

Over the last two months, a wide range of leading local, state and national groups have joined the campaign against Cirque du Soleil.

there's a consensus that this discrimination is wrong,' Kearns said in a statement released by Lambda Legal.

Moises Kaufman, award-winning author of *The Laramie Project*; Tim Miller, award-winning author and playwright, and one of the 'NEA Four' who fought rightwing attempts to strip federal funding from controversial artwork; Chad Allen, actor, formerly starring in the hit television series *Dr Quinn, Medicine Woman*; and Rod McKuen, bestselling author, singer and songwriter, also joined the campaign on 20 January, along with bestselling authors and community leaders Betty Berzon, Malcolm Boyd,

Bernard Cooper, Sam Harris, Cleve Jones and Mark Thompson.

As Lambda Legal's federal discrimination claim on behalf of Cusick proceeds, the campaign against Cirque du Soleil has intensified in recent weeks with protests outside Cirque shows in San Francisco and Los Angeles, and another protest, which Cusick will attend, set for Thursday night outside Cirque's performance of 'Varekai' in Orange County, California. Several thousand people have signed petitions and sent letters to Cirque du Soleil to complain about Cusick's firing. Cirque du Soleil has come under fire from local governments in recent weeks, as well, with the San Francisco Human Rights Commission launching its own discrimination investigation and the Los Angeles City Attorney writing a strongly worded letter to Cirque du Soleil's founder and CEO, Guy Laliberte, to express concern.

Over the last two months, a wide range of leading local, state and national groups have joined the campaign against Cirque du Soleil.

In addition to community action at Cirque's Orange County show on the evening of 22 January, Lambda Legal and local leaders will protest Cirque du Soleil performances in a number of cities, including Atlanta (in March and April) and New York (in May and June).

For more information, go to [www.lambdalegal.org](http://www.lambdalegal.org)

Lambda Legal delivered petition signatures and notes from people in all 50 states of America to Cirque du Soleil on World AIDS Day, the day before Cirque de Soleil was required to respond to an investigation opened by the San Francisco Human Rights Commission in mid-November. Cirque leases public property for its San Francisco 'Alegria' show and must abide by local non-discrimination laws, or the commission can levy fines, terminate Cirque's contract, or disbar the company from future city contracts.

'Cirque du Soleil is learning that discrimination is bad business,' said Michael Adams, Director of Education & Public Affairs at Lambda Legal. 'A growing consensus of organisations, athletes, artists, medical experts, government officials and communities are sending Cirque a clear message that this discrimination is outside the mainstream and won't go unnoticed. We're delivering that message to Cirque's doorstep at these local shows and with the first batch of petitions on World AIDS Day.' Some petitions are signed papers gathered by local activists,

while others are submitted from around the country online at [www.LambdaLegal.org](http://www.LambdaLegal.org).

'When I first heard that Cirque du Soleil fired this gymnast, I was horrified and knew I had to do something about it,' said Jackie Mathis of Orange County, who is working with Lambda Legal to coordinate the protests there. 'Cirque du Soleil markets itself to the gay community so much, and hiv is a very big issue within our community. It's callous and wrong for Cirque to try to separate the two issues - taking our money with one hand while discriminating against us with the other.'

One Bay Area resident, Sylvia Sokol, requested a refund for 'Alegria' tickets she was holding for 20 December, writing to Cirque that she 'cannot continue to support your company if you treat people in such a discriminatory fashion. Please let me know

'When I first heard that Cirque du Soleil fired this gymnast, I was horrified and knew I had to do something about it,' said Jackie Mathis of Orange County, who is working with Lambda Legal to coordinate the protests there.

as soon as possible how to return my tickets to receive my money back.' Cirque du Soleil responded, saying she didn't need to mail the tickets because the company had simply refunded the charge back to her credit card and cancelled the tickets.

At the protests, community members distribute leaflets with information on Cusick's case to people entering and leaving the shows. They also distribute stickers for people to wear into the performance to show their support. While the organised campaign seeks to educate Cirque du Soleil rather than boycott the company, a number of individuals from San Francisco, Southern California and elsewhere say they won't attend Cirque's

performance because of the company's hiv discrimination.

Cirque du Soleil was required to file a formal response with the San Francisco Human Rights Commission by 2 December. Cirque's response had to include copies of any policies it has on employing people with hiv, documents written by medical authorities that recommend not hiring people with hiv, copies of precautions the company's employees take to prevent transmission of communicable diseases and a list of titles and descriptions of positions for which people with hiv would not be hired.

In an attempt at damage control amid growing public outcry over Cusick's case,

The Stop AIDS Project, which was founded in 1984 and is an internationally recognised model for community organising and education about hiv and aids, got involved with the campaign, in part, because Cirque du Soleil is spreading inaccurate information about hiv transmission.

Cirque du Soleil has been sending a letter to members of the public – admitting that it fired Cusick solely because he has hiv, but claiming that such action is not 'discrimination'. In the letter, Cirque du Soleil says Cusick was fired 'solely for safety reasons'. Cirque's letter and its other public statements on the issue offer no explanation for how a highly trained gymnast could transmit hiv while performing in such a heavily rehearsed and choreographed show. Mainstream medical, scientific and athletic organisations say that athletes with hiv should not be restricted from performing or competing.

'Cirque du Soleil may have thought Matthew Cusick would just go away when they

fired him for having hiv, but this growing alliance of groups fighting back on his behalf cannot be ignored,' said Michael Adams, Lambda Legal's Director of Education & Public Affairs.

The Stop AIDS Project, which was founded in 1984 and is an internationally recognised model for community organising and education about hiv and aids, got involved with the campaign, in part, because Cirque du Soleil is spreading inaccurate information about hiv transmission. 'It is important to tell the truth when we talk about hiv,' said Darlene Weide, Executive Director of the Stop AIDS Project. 'Not only is it our responsibility to discuss what life is like with the virus, but it is our ethical duty to talk about stigma against people who live with hiv, who face horrible discriminations in every walk of life that aren't based on the science of the epidemic. Whether it's a popular company or an individual community member that acts unfairly because they don't know the facts of transmission, I know the people of San Francisco will not tolerate these actions.'

The National Association of People with AIDS (USA) said it applauds Cusick's courage in coming forward to fight Cirque du Soleil's discrimination. 'A community of people with hiv and aids all across the country stands behind Matthew Cusick in demanding that Cirque du Soleil stop discriminating against people based on their hiv status,' said Eric Ciasullo, Chair of the Board of Directors of the National Association of People with AIDS and Manager of the San Francisco Department of Public Health's HIV/AIDS Return to Work Initiative, who will speak at Thursday night's event. 'Cirque du Soleil's discrimination represents every hiv positive worker's worst nightmare – that disclosing hiv status on the job will lead to discrimination, despite their employment experience, the wisdom of science and medicine, and the mandate of the law.'

In an attempt at damage control in November, Cirque du Soleil began sending a six-paragraph letter by senior staffer Renee Claude Menard to members of the public – admitting that it fired a gymnast solely because he has hiv, but claiming that such action is not 'discrimination'.

Menard's letter and Cirque du Soleil's other public statements on the issue offer no explanation for how a highly trained gymnast could transmit hiv while performing in such a heavily rehearsed and choreographed show.

#### Matter of Matthew Cusick

Nevada Equal Employment Opportunity Commission

Lambda Legal filed a complaint with the Equal Employment Opportunity Commission on behalf of Matthew Cusick, charging Cirque du Soleil with hiv discrimination.

Lambda Legal represents Matthew Cusick, who was fired from his job as a High Bar Catcher from Cirque du Soleil because he is hiv positive. Cirque du Soleil hired gymnast Cusick in Summer 2002 and would eventually be assigned to train for its popular Las Vegas-based show, 'Mystere'. Cusick spent several months training for the performance and went through extensive medical exams with Cirque du Soleil's own doctor, whose notes said Cusick was a 'healthy athlete' who 'should be able to perform.' But shortly before he was scheduled to begin performing, Cirque du Soleil told Cusick that because he

The National Association of People with AIDS (USA) said it applauds Cusick's courage in coming forward to fight Cirque du Soleil's discrimination.

has hiv, the company would not continue to employ him.

Lambda Legal argues in its complaint that Cirque du Soleil denied Cusick a job without a valid reason, since he does not pose a health risk or safety threat to himself or anyone else. Federal and state laws prohibit discrimination against people with disabilities if they pose no real risk to themselves or others and if the illness doesn't interfere with their ability to do the job.

In a letter this spring responding to Lambda Legal's formal request to reinstate Cusick in the performance, Cirque du Soleil's attorneys said the company was acting as a "socially responsible employer" that has an obligation to avoid 'known safety hazards.'

Hayley Gorenberg, Lambda Legal AIDS Project Director, is handling the case.

# C

## ondom on paper behind glass – Sydney – Australia 2004

A bus stop poster campaign is the next step in our response to increases in hiv.

**Kathy Triffitt** Health Promotion  
Officer PLWH/A (NSW)

A bus stop poster campaign planned for February 2004 establishes links between our recently launched 'words to say it' campaign and The Inter-agency's response to increases in hiv in NSW. The Inter-agency is a collaboration between hiv community organisations, Area Health Services and NSW Health. The campaign has been made possible through an agreement between South Sydney Council and JC Decaux to give community groups access to bus shelter poster panels.

'The words to say it' is the first campaign in NSW to raise the awareness of people with hiv of the importance of regular sti testing for all sexually active people, especially people who have changed sexual partners, as part of hiv management. A factsheet for people with hiv on the extra health risks associated with having an sti was published in the last issue of *Talkabout* and is available on our website at [www.plwha.org.au](http://www.plwha.org.au).

In addition, campaign themes are the focus of a series of community forums and discussion groups. A partnership with ACON, Central, South Eastern and Northern Area Health Services, the community forums are designed to raise awareness and support discussion about some of the issues that have an impact on sex, relationships, and sexual health. These include communication strategies, disclosure of hiv, negotiating sexual health and discrimination. (See forum ad on page 29.)

These opportunities for personal contact place plwha, community and healthcare professionals at the heart of health promotion. We want to facilitate safe environments that support discussion of relevant topics with peers, the development of new networks, exchange of experiences and opinions. To find 'the words to say it', to name, to define and to intervene in relation to hiv/aids has relied on personal experiences to achieve visibility for specific issues and people affected by them.

In 2004, People Living With HIV/AIDS (NSW) and partners want to continue to build individual and communities skills, capacity and ownership of health promotion activities by supporting a culture of participation, learning and collaborative decision-making.



*Condom on paper behind glass. Sydney, Australia, 2004*

## STI testing and treatment are easy.

Sexually transmitted infections (STIs) often show no symptoms  
• STIs can be more serious for people with HIV • Having an STI  
can increase the risk of passing on or getting HIV

### Decrease your risk.

Regular STI testing and using condoms are the best ways to look  
after your health and to prevent passing on or getting HIV.

People Living With HIV/AIDS (NSW) Health Promotion [www.plwha.org.au](http://www.plwha.org.au)  
For more information look for our 'WORDS TO SAY IT' brochures and factsheets  
at service providers or our website [www.plwha.org.au](http://www.plwha.org.au)

If you have any questions call the info line: 1800 009 448 or 1800 009 HIV



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South Sydney City Council

Sexually transmitted infections (STIs) like  
gonorrhoea, chlamydia and syphilis.



# O lga's personals

**Hiv+** man seeking pos or neg man for LTR. Age 30-40 yrs. Looking for me? I'm into leather, bodybuilding, movies, handholding, nights at home, motorbikes, pos community. Love dogs. Hate cats. **Reply: 100023**

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

**Hiv+** guy, 53, 5ft 7, brown eyes, OK looks and physique. Prudent, compassionate, monogamous, I have learned not to try and understand women but simply adore them. Gold Coast resident. Seeks similar female penpal with view to whatever. **Reply: 010402**

**Central Coast.** Cute, slim, Hiv+ (18yrs), 42yo, passive bumboy. Seeks slim hung Hiv+ dickman, 35-50, for fun, sex and compassion. **Reply: 010602**

**39yo, +ve,** fit, goodlooking, 5'11, honest genuine, live in Eastern Suburbs, dog owner, seek guy, late 30-50, sincere, intelligent, warm, articulate, fit. **Reply: 010801**

**Shy,** sincere, loyal, hardworking 35yo hiv+ divorcee. I'm a straight, honest male living in Sydney. Seeks friendship with hiv+ lady in similar situation who wants to meet a true loyal and down to earth true friend. ALA. **Reply: 020602**

**Hiv+,** 36yo male, ok looking and DTE. I have good friends and a GSOH but need that someone to share my life with to love and spoil, 18-40yrs. **Reply: 021002**

**South Sydney,** 41yo, black, gay, hiv hepC man. Hi, I've been hiv, hep C for 11 yrs. I'm 5'4" tall, tight body. Good health. OK looks, you similar 36-43yrs wanting same. **Reply: 030402**

**Hiv+,** 38yo, goodlooking, GSOH, living Western Suburbs. Seeking fun and fair dinkum bloke for friendship and maybe more. Love horseriding, breed dogs and cats, love the bush and love a drink. My first advert. Genuine guys only please. **Reply: 031002**

**24yo,** gay guy, hiv+ for five year, DTE, GSOH, come from the country. I am currently in goal and looking for penpals with other gay, hiv+ people with the same interest. ALA. **Reply: 040402**

**Hiv+,** gay man, early 50s, still in good health and shape, enjoys home life, reading, theatre and travel, excellent cook, have my own business, looking for a companion, or more, with similar interests. **Reply: 041002**

**Guy, 50s,** Ryde area, active and in good health, hiv+, 6'1", 85kg, blonde, likes home, tv & videos, going out, GSOH, no ties, seeks person for companionship, relationship. ALA, so please write. **Reply: 050402**

**Long Bay,** 28yo, hiv pos, goodlooking, intelligent, kindhearted, country lad, straight acting, like a drink, don't do gay scene, looking for good friends, penpals. A real man is hard to find. Are you my knight in shin-

ing armour. **Reply: 060402**

**Hiv+,** 45yo gay guy, 16 yrs survivor, NS, SD, enjoying good health, would like to meet and see a guy younger or up to early 50s on a regular basis for drinks, dinner, coffee ... nationalities open. **Reply: 061002**

**Goodlooking,** 30yo, straight + male, recently diagnosed, good health, NS, SD. Seeking honest, straight, single female 22-32 yrs for serious relationship and love. Genuine responses only. Looking forward to hearing from you girls. You will not be disappointed. **Reply: 070402**

**Looking** for boyfriend! I enjoy good company, good conversation and good wine. Looks, physique ok. Interests: health, hiv+ & rebuilding immune system. Holistic wellness. WLTM interesting, personable guy, age open, social status unimportant if sincere. Seek monogamous friendship. **Reply: 071002**

**Hiv+** gay male 30, GSOH and responsible. With view to LTR for the best in life, love and happiness. Enjoys cosy nights in, seeking fun and healthy relationship without the use of drugs and alcohol. Only genuine replies. **Reply: 100000**

**Active,** horny male seeks: totally passive male, 18-40yrs, quiet, gentle, softspoken, caring, non-scene & likes lots of loving & TLC. Good looks not important. Prefer reasonably solid build guy who is unattached & wants a longterm relationship. **Reply: 100001**

**Very goodlooking** hiv +ve guy, good body, very healthy. Professional, NS, GSOH, 5'9", olive complexion, brown eyes, 32yo, seeking guy up to 40yo, for fun, sex, companionship. Preferably North Shore area. **Reply: 100002**

**Hiv+,** 38 yo guy, lives in the country. I'm 183cm, slim/average build, hairy chested and DTE. Seeking someone (18-50s) for fun and maybe more if compatible. I like country life, animals, art, food and a good time. **Reply: 100004**

**Surry Hills.** Black, gay guy. Late 30s, DTE, hiv+ with a GSOH. Versatile. WLTM Mr TLC. View LTR. Welcome all nationalities. **Reply: 100005**

**Heterosexual** male. 42yo, hiv and positive that he will one day find a friend who is heterosexual, female, hiv and positive in complementing each other's life journey in love, health to becoming free. **Reply: 100006**

**Hiv+** male, 31yo, tall and muscular, motorcycle enthusiast, seeks female 28-40. I'm hardworking and searching for companionship/relationship, genuine replies. **Reply: 100008**

**Young** country guys, are you coming to Sydney? Goodlooking, 34yo, hiv+ guy from the bush ISO DTE country lad looking for LTR. NS but will do the odd party. R U non-attitude? Straight acting? Beach/bush walks, horseriding, cuddling. **Reply: 100009**

**Nthn NSW** male. 27yo, hetero pos, single Dad of 1,

seeks female to write to, and/or meet. Any nationality age. **Reply: 100010**

**Joe,** 42yo, poz guy. 6'3", tall, dark hair, blues, seek 1-1, easygoing, honest, sincere, handsome for fun & better thinking. I'm attracted to stocky, solid guys into wrestling, massage, laughter & life. Will travel, let's chat. **Reply: 100012**

**Attractive,** Sydney, 35yo +ve male. Seeking attractive lady 20-45 yrs for f/ship, r/ship, love. I'm sincere excellent health, athletic build, olive skinned, and a hopeless romantic. Enjoy theatre, music, fine dining deserted beaches, GSOH, live bands. Discretion assured. ALA. **Reply: 100013**

**Attractive Asian** (hiv+ but undetectable viral load) seeks genuine, masculine, hairy-chested, active, well hung men for fun, friendship perhaps LTR. I am smooth, tan, petite and healthy with witty sense of humour. Photo and phone number ensures prompt reply. **Reply: 100015**

**This guy** is in need of love. 42yo +ve with good looks, very fit and financially secure. Looking for a high spirited man with me in a new beginning. **Reply 100016**

**Tall,** usually 85kg, smooth, uncut, tattoo. Met too many liars and timewasters. Want guy who is manly, like body hair. I'm 30s, cooking, animals, nature, movies, can adapt for right guy round 40. **Reply: 100017**

**Hiv+** gay guy, 39 yo, fun-loving, who loves life and wants to enjoy it with someone who is easy going and friendly, 18-50 yrs. Enjoy music, video games, fine food and intelligent conversation. **Reply: 100019**

**Straight guy,** 42 yo, hiv+, in Sydney, moving to mid North Coast. Seeks hiv+ girl for longterm life and to start a family. Must be genuine about this and have gsoh. I'm easygoing and want to have children (with a little help), so if you're interested, drop me a line. **Reply: 100020**

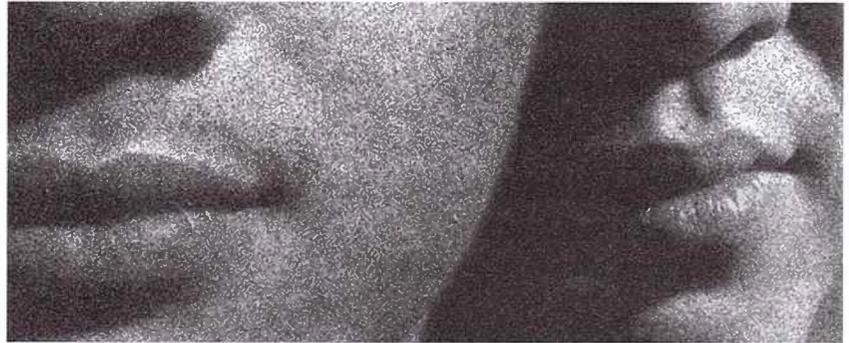
**Aust hetro** male, hiv+, early 40s, very fit and healthy, genuine personality, lots of hobbies, likes outdoors, N/S, lives in Sydney. Looking to start friend/relationship with a female in similar position. Age/nationality open. Kids ok. **Reply: 100021**

**24yo straight + female,** recently diagnosed. Looking for love, friends and/or penpals. Enjoy alternative music, live bands, photography and movies. ALA. **Reply: 100022**

**Hiv+** man seeking pos or neg man for LTR. Age 30-40yrs. Looking for me? I'm into leather, bodybuilding, movies, handholding, nights at home, motorbikes, pos community. Love dogs. Hate cats. **Reply: 100023**

**Venus!** Male, closeted, playmate. Not worker. Seeks unattached, non-scene guys for intimate f/ship or r/ship. Don't have problem about being laid, no strings casual sex, especially, those living with hiv+ & extra big tool, naturally. Tired of trying to meet perfect match in all the wrong places. **Reply: 100024**

# THE WORDS TO SAY IT



## When placing and answering personals

Be clear about who you are and what you are looking for. Too much detail can be boring, and too little may be too vague. Be honest to avoid disappointment for you and your correspondent.

Do not give out your work or home address, telephone number or email address until you think you can trust the person. Use a Hotmail or Yahoo address.

Like you, other people may be anonymous. You can't always believe everything you are told.

## When meeting someone

Have reasonable expectations. Don't let your fantasies run away with you – how somebody seems might not be who they are face-to-face.

Meet for the first time in a busy public place, like a bar or club, or with friends. You can go to a private place after you have met the person and think you can trust them. Don't rely on the other person for transport.

Let someone know who you are meeting and where. You can leave a note, keep a diary, email a friend, or ask someone to phone you on your mobile to make sure you are alright.

Apply commonsense and the basic rules of personal safety. Maintain a healthy degree of suspicion: if anything seems odd, be careful.

## How to respond to a personal

Write your response letter and seal it in an envelope with a 50c stamp on it – Write the reply number in pencil on the outside – Place this envelope in a separate envelope and send it to Olga's Personals, PO Box 831, Darlinghurst 1300.

## How to place a personal

Write an ad of up to 40 words – Claims that you are hiv negative cannot be made. However, claims that you are hiv positive are welcome and encouraged – Any personal that refers to illegal activity or is racist or sexist will not be published – Send the personal to Olga, including your name and address for replies. Personal details strictly confidential.

## A forum on disclosure, sex, relationships & sexual health.

### NorthAIDS

41 Alfred St Sth, Milson's Pt (next to Milson's Pt train station) t 9929 4288  
Saturday 31 January 10.00am–1.00pm  
RSVP 28 January. Brunch.

### The Sanctuary Centre

6 Mary St, Newtown t 9515 3217  
Saturday 7 February 3pm–5.30pm  
RSVP 5 February. Light refreshments.

### Royal Prince Alfred Hospital

Missenden Rd, Camperdown  
John Greenaway Room, Medical Education Centre  
t 9515 3217  
Saturday 28 February 2.00pm–4.30pm  
RSVP 26 February. Light refreshments.

### Positive Living Centre

703 Bourke St, Surry Hills t 9699 8756  
Saturday 17 January 2.00pm–4.30pm  
Thursday 26 February 2.00pm–4.30 pm  
Saturday 20 March 2.00pm–4.30 pm  
Thursday 22 April 2.00pm–4.30 pm  
RSVP 3 days before each forum.  
Light refreshments.

### Albion Street Centre

Corner Crown St & Albion St, Surry Hills  
t 9361 6011  
Sunday 15 February 2.00pm–4.30pm  
RSVP 12 February. Light refreshments.

### Waratah Clinic, St George Hospital

2 South St, Kogarah t 9350 2959  
Monday 9 February 6.00pm–8.00pm  
RSVP 6 February. Dinner.

For more information please call the above numbers or Kathy Triffitt, Health Promotion, People Living With HIV/AIDS (NSW) 9361 6011 [www.plwha.org.au](http://www.plwha.org.au)



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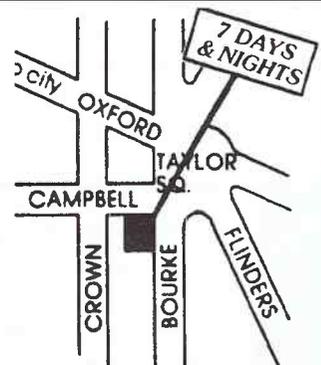
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You can use this form to apply for membership and/or subscribe to *Talkabout*. Please remember to sign the form. A statement about our privacy policy is below. Please read it. Our contact details are below.

## Membership costs nothing!

**Yes, I want to be a member of  
People Living with HIV/AIDS (NSW) Inc**

### Please tick

- Full member (I am a NSW resident with hiv/aids)
- Associate member (I am a NSW resident)

**Disclosure** of positive hiv status entitles you to full membership of PLWH/A (NSW) with voting rights. Members' details are confidential.

**Membership** entitles you to *Contacts*, the Annual Report and a biannual newsletter.

If you want to receive *Talkabout*, you need to fill out the subscription section of this form (below).

Sign below



## Subscriptions

**Yes I want to subscribe to *Talkabout* (annual subscription July 1 to June 30). Please select (tick the circle) the rate that applies to you or your organisation.**

### Subscriptions only

- I am a New South Wales resident receiving benefits – \$5 (Please enclose a copy of your current health care card)
- I am a New South Wales resident living with hiv/aids who does not receive benefits – \$20
- I am an individual and live in Australia – \$33
- I am an individual and live overseas – \$77

### Organisations:

- Full** \$88 (includes all business, government, university, hospital, and schools either for-profit or government-funded)
- Concession** \$44 (includes plwha groups and self-funded community owned organisations)
- Overseas** \$132

Members of PLWH/A (NSW) Inc who want to subscribe to *Talkabout* but are experiencing hardship are urged to contact PLWH/A (NSW) Inc to discuss their circumstances.

## Personal Information Statement

We collect this information to add you to our database and to notify you of information and events relating to PLWH/A (nsw) Inc. We store this information either in hardcopy or electronically or both. Access to your information is strictly limited to staff members who need it to act effectively on your behalf. Your information will not be passed on to any other organisation. You can access and correct your personal information by contacting our Privacy Officer, phone 02 9361 6011 or freecall 1800 245 677, email [research@plwha.org.au](mailto:research@plwha.org.au)

## How to contact People Living with HIV/AIDS (NSW) Inc

Office: Suite 5, Level 1, 94 Oxford Street, Darlinghurst  
Mailing address: PLWH/A (NSW), Reply Paid 831, Darlinghurst NSW 1300

**You do not need to put a stamp on the envelope.**

Phone: 02 9361 6750  
Freecall: 1800 245 677  
Fax: 02 9360 3504

**A membership form is available online at: [www.plwha.org.au](http://www.plwha.org.au).  
Please use the 'text only' version if you need to use a text reader.**

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

I would like to make a donation of \$ \_\_\_\_\_

If you are paying the concession rate for *Talkabout* subscriptions, please enclose a copy of your Health Care Card.

You can pay by cheque/money order/credit card.  
There is a \$10 minimum for credit card payments.  
Please enclose your cheque or money order or give us your credit card details.

Please charge my  Bankcard  VISA  MasterCard  AMEX  Diners

Expiry Date \_\_\_\_\_ Signature \_\_\_\_\_

Name on card \_\_\_\_\_

Cash payments can be made at our office.

Total payment \$ \_\_\_\_\_

I acknowledge the Personal Information Statement and consent to my information being collected and stored for the current financial year.

\_\_\_\_\_  
Signature

# D

## ear Miss Bitch



I know there are a lot of you out there who have something to say to Miss Bitch – a little question, a situation, something that is downright wrong. Send questions to Miss Bitch, PO Box 831, Darlinghurst 1300

### A few hot tips for surviving Mardi Gras

#### 1. Leave town

For some of us, leaving town is the best way to deal with Mardi Gras ... abandon all that 'gay community' stuff and quasi-activism to those lost in the 70s. Perhaps it would be a good time to visit your Aunt in Albury ... or that internet liaison in the Dandenong Ranges ... Whatever, try and work out what's right for you before you find yourself overwhelmed by MG madness without a t-shirt and matching cap!

#### 2. Create a fantasy lover

Whatever your sexual preference ... it is impossible to survive Mardi Gras alone. Everywhere you look there are girlz and boyz arm-in-arm, tongue-in-mouth, cooing ... and doing what cums naturally ... so make sure you are not missing out. Get a picture of your favourite hunk or dame and put it up in the kitchen, toilet, bedroom ... talk to him/her. Imagine that they wink back at you. And especially when you get home and when you go to sleep – make sure you have a little chat with them. Tell them about your day ... let them into the intimacies of your life. Maybe they know that secret place you like to be caressed ... Go on ... they're as far away as your imagination ... and it can feel soooooo good.

#### 3. Get into it!

Be the one who is seen at every event possible – especially the free ones. Just turning up is very good for the soul ... and who knows what experience might be awaiting you. Whether you find yourself a-fly-on-the wall, watching the passing parade ... or whether you get involved in a little eye contact and intrigue ... Mardi Gras is a time when you can let it all hang out ... and maybe broaden

your horizons. It's also a great time to go through that address book and hook up with some friends you haven't seen for a while.

#### 4. Sex and Drugs and Rock & Roll

Go For It! and have fun ... but someone has to think about the consequences ... try and make strategies to enjoy yourself while maintaining some decorum and a modicum of concern for your own body ... and those you may be bumping into – in one way or another. Keep the condoms nearby and some nice fresh produce to munch on between outings ... and don't forget your friends.

#### 5. Do something different

The atmosphere during the month of Mardi Gras is not like any other time – and there are so many opportunities to try new things ... be with new people ... think differently ... wear different clothes ... try a new style of walking ... or hair colour ... or make up ... or dress down ... It can be lotsa fun doing the most mundane things ... but from a different perspective. And there are plenty of places to strut your stuff – from Fair Day to theatre ... to that queermobbing thang ... and of course the ultimate strut-your-tail-feathers event ... all the way up Oxford St on March 6.

#### Happy Mardi Gras Everybody...

Let yourself sink into the VIBE of warmth and caring and sharing ... Let the season be like a giant bubble bath for your soul ... Lap up everything Mardi Gras has to offer ... Even Miss Bitch has gone all mushy ... What can I do with my hair??  
Kissee Kissee  
See youse all out there!!



### HOLDSWORTH HOUSE GENERAL PRACTICE

- Dr Mark BLOCH
- Dr Dick QUAN
- Dr David AUSTIN
- Dr Andrew GOWERS
- Dr Kate BESSEY
- Dr Ercel OZSER
- Dr Gail LYNEHAM
- Dr Damien MERGARD

32A Oxford St, Darlinghurst NSW 2010  
Phone 9331 7228 Fax 9360 9232  
Email reception1@hhgp.com.au

### halc

HIV/AIDS Legal Centre Incorporated

### FREE LEGAL ADVICE

HALC provides free legal advice, information and referral to people living in NSW with an HIV related legal problem.

To make an appointment please call us on  
**02 9206 2060**

All information is kept strictly confidential.

9 Commonwealth Street,  
SURRY HILLS NSW 2010  
Freecall 1800 063 060  
Fax (02) 9206 2053  
Email halc@halc.org.au  
10am to 6pm Mon to Fri

# D iary

## Sydney

**Positive Living Centre**, 703 Bourke St, Surry Hills. The centre is a one-stop access point for a range of free hiv and community based services. Programs for pos people to help develop new skills, interests and work opportunities. Calendar of events available from the PLC.

**Comp therapies at the PLC** – Acupuncture – Tu 2 – 4pm. Massage – Tu 6 – 8pm (for employed and volunteers), W 10am – 2pm, Th 6 – 8pm, Sat 10am – 12noon. Yoga – Sat 9.30am. Reiki – Th 7.30 – 8.30pm, Fr, 10am – 4pm. Lomi Lomi (Hawaiian massage) – Tu 6pm, W 6pm, Sat 11am. Bookings essential for all therapies. Ph 02 9699 8756.

**Social lunch at the PLC** – Fri 1 – 2pm, Soup, main meal, dessert. Breakfast Sat 11.30 – 12.30.

**Gone Shopping** – weekly shopping trip by bus from PLC to Marrickville Metro, Fri 2.30 – 4.30pm. Bookings advisable. Ph 02 9699 8756.

**Basic Computer Skills at the PLC** – Fri 11am – 4pm (no booking required). Sculpture – Th 6 – 8pm. Ph 02 9699 8756 to book.

**Luncheon Club & Larder relocates** – for people living with and affected by hiv/aids, Gordon Ibbet Community Centre, 77 Kellick St, Waterloo (near Elizabeth St). M/W noon – 4pm. Ph 0416 040 074.

**The Breakfast Group** offers hiv positive gay men who are working a chance to network and support each other through a monthly breakfast meeting. Ph Positive Men's Project at ACON on 02 9206 2000 for more info.

**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. Call Robert for details and bookings on 02 9519 6142. Also holds cooking programs. For more info, ph 02 9395 0444.

**Gay Vietnamese Social Support Group** meets every last Sat at The Sanctuary in Newtown. Ph John on 02 9515 3138.

**Community Garden** – Learn how to grow your own vegies. Ph Street Jungle on 02 9206 2000. ACON Western Sydney: Ph 02 9891 2088.

**Newtown Neighbourhood Centre** runs a shopping service for Marrickville LGA residents Tu, Th, Fri to Marrickville Metro. They'll pick you up from home, give you two hours to shop, then drop you off again. Price is \$4. Ph Gavin on 02 9516 4755.

**'Outings'** from South Sydney Community Transport is always offering day trips and excursions. More info or bookings ph Jane 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. Individual service for shopping available after assessment. Also medical transport available. Ph Jane on 02 9319 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. Ph Margaret 02 9698 3161.

**Silk Road**, social and support group for Asian men, meets the first Friday of each month. Ph Matthew on 02 9206 2080 for more info.

**Asia Plus** for hiv+ Asian men, meets the second Friday of each month. Ph Matthew on 02 9206 2080 for more info.

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

**Queer Spirituality Group** A group is being formed for gay guys to explore aspects of spirituality. An opportunity to share our ideas and our humanity. For more info, phone Kim on 9310 0931 or email: kimgot@ozemail.com.au

## Western Sydney

**Western Suburbs Haven** – M-F 9.30-4.30. Drop-in, support, food service, respite care. Ph 02 9672 3600, 9671 7110, 8807 4697.

**Community Garden** - Learn how to grow your own vegies. Wed Emerton. Tu ACON Western Sydney: Ph 02 9204 2400.

**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, and social activities. Retreat to the Beach, 6-8 Feb. Ph Pat on 02 9672 3600.

## Blue Mountains

**Drop in to the Blue Mountains PLWHA Centre** at rear of 2 Station St, Katoomba for informal peer support. W/F 11.30-3.30. Lunch: W 1-3. 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.

**McKillop Centre** Training, peer support, counselling, drop-in. M-F, 9am-5pm. Ph 02 4968 8788 for more info.

## Illawarra

**ACON Illawarra** at 47 Kenny Street, Wollongong provides drop-in, care and support, advocacy, and referrals for positive people. Positive support group meets last M each month. Contact Craig on 02 4226 1163 or email cyeates@acon.org.au.

## Central Coast

**HUGS** (HIV Understanding Group Support) A support and social group for hiv positive people on the Central Coast. We meet at PSN (Positive Support Network) in Gosford every week on pension Thursdays 12.30-3pm for support, discussions, outings and lunches. Please call Leslie @ PSN on 02 4323 2905 for upcoming dates and more info or Sean @ ACON Hunter on 02 4927 6808.

## Port Macquarie

**ACON Mid North Coast** 4 Hayward Street, Port Macquarie. Ph 02 6584 0943.

**Port PLWHA** Support group for plwha. Lunches, social events, fundraising activities, peer support. Ph 0418 207 939 or 1300 658 878, email HYPERLINK <mailto:portplwha@optusnet.com.au> portplwha@optusnet.com.au. Postal address: Port PLWHA, C/- PO Box 5648, Port Macquarie NSW 2444.

## Northern Rivers

**Peer support** for plwha Ph Sue on 02 6622 1555 or 1800 633 637.

**Shopping Bus Service** Door to Lismore Square or Lismore Central and return, Tu/Th \$6 return. Individual transport to medical appointments, \$9 within local area, M-F. Ph Northern Rivers Community Transport on 02 6624 7070.

**Tropical Fruits** – Annual General Meeting planned for February. For more info: HYPERLINK "<http://www.tropicalfruits.org.au>" [www.tropicalfruits.org.au](http://www.tropicalfruits.org.au).

## Canberra

**PLWHA** - dinner Tu @ 6pm. Massage Wed (woman masseur for women) \$10 (some discounts). Ph Marcus 02 6257 4985.

# Late HIV Presentation Among African Communities

**Mohamed Keynan** reports on the work carried out with identified African communities

In mid 2001, NSW Health funded the Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) to focus on late hiv presentation and people from culturally diverse backgrounds as a demonstration project. The work is being carried out with African communities identified in the consultation process as a priority population for the service.

## African Communities in NSW

Hiv/aids remains one of the dominant public health problems for most countries in sub-Saharan Africa for the foreseeable future, with many countries experiencing large hiv epidemics. UNAIDS data and other research indicates that the main mode for hiv transmission in Africa is through heterosexual relationships.

The 2001 census shows a significant increase among African communities in NSW compared with the previous data from 1996. This means many African people migrated to Australia since 1996. Some of these people may come from areas where hiv infection rates are very high and many may never have been tested for hiv, except for applications for permanent residency or refugee status.

According to the 2003 Annual Surveillance Report, almost 6% of all hiv notifications in Australia concerned people born in Sub-Saharan Africa. People born in Africa are also more likely to be late presenters.

'In Africa, hiv/aids is very bad thing in the community. People don't like to hear about hiv virus infections and ways of prevention. Although many people are dying every day because of hiv infections, some African governments and community leaders continue to deny the existence of the disease.'

Positive African people in NSW are less likely to disclose their hiv status to others because of the fear of rejection among their own communities. For this reason, many

of them lose their friends and families and become isolated. These people also have poor knowledge of hiv/aids testing, treatment, and health services available in NSW.

Most of the hiv positive people from African communities in NSW speak English as a second language and are less able to access hiv/aids information. They are also scared to use interpreters as they feel that interpreters may disclose their hiv status to the community.

## Hiv/aids workshop

Most of the African people in NSW are from Western and Eastern Africa, such as Nigeria, Ghana, Sierra Leone and Sudan, Eritrea, Somalia, Ethiopia. There is no African umbrella organisation that represents these diverse African communities. However, there are community workers, funded by the Department of Immigration, representing many communities in different Migrant Resource Centres in Sydney.

My first approach to community workers last year was difficult because:

- stigma and fear around hiv/aids issues exists
- their experience of hiv/aids in Africa
- never had contacts with the hiv/aids sector before my visit

Many African workers were uncomfortable discussing hiv/aids in their workplace. Sometimes they did not even like to receive a phone call or a message from an hiv/aids service. In general, African people prefer face-to-face meetings rather than phone conversations. Sometimes it was hard to explain things on the phone. After long negotiations, most community workers agreed to meet with the project officer.

Consequently, I had to spend more time with the African communities than other target communities. I consulted with health, welfare or settlement organisations who

work with African communities in NSW to find out general information about the community, contacts of African workers, and their workplaces.

Over the last two years, we have held two hiv/aids workshops for African community workers. The workshops aim to improve the African workers knowledge of hiv/aids and develop their understanding of hiv/aids services.

A guest speaker from a sexual health clinic presented information about hiv/aids in general, history, hiv/aids situation in Africa and Australia, prevention, transmission, hiv testing and treatments. An hiv positive speaker shared his experience with the African community workers. During the workshop, the participants exchanged their views and experiences of hiv/aids and the difficulties facing positive people in their original countries.

It was also an opportunity to explain why the project targets identified African communities in NSW and how the community can benefit from this project.

## African Advisory Group

After the second workshop in June 2003, the African community workers agreed to set up an advisory group to support project work with the African communities. The group consists of eight African community workers and the Project Officer. Their role is to assist in providing appropriate strategies to reach the community; to advise and assist the Project Officer in the implementation of project strategies among the African communities; to recommend appropriate activities to promote the project among the African communities; and to make recommendations for future activities.

The group meets once every two months to discuss issues relating to hiv/aids and the African communities.

Initially, the project consulted with the African community workers as well as com-

munity leaders to develop an African-Australians Against AIDS poster. The aim of the poster was to promote hiv testing information among African communities in NSW.

'The African people in NSW are from different parts of Africa. They have different languages, cultures and traditions. The only thing they have in common is the African continent they all come from.'

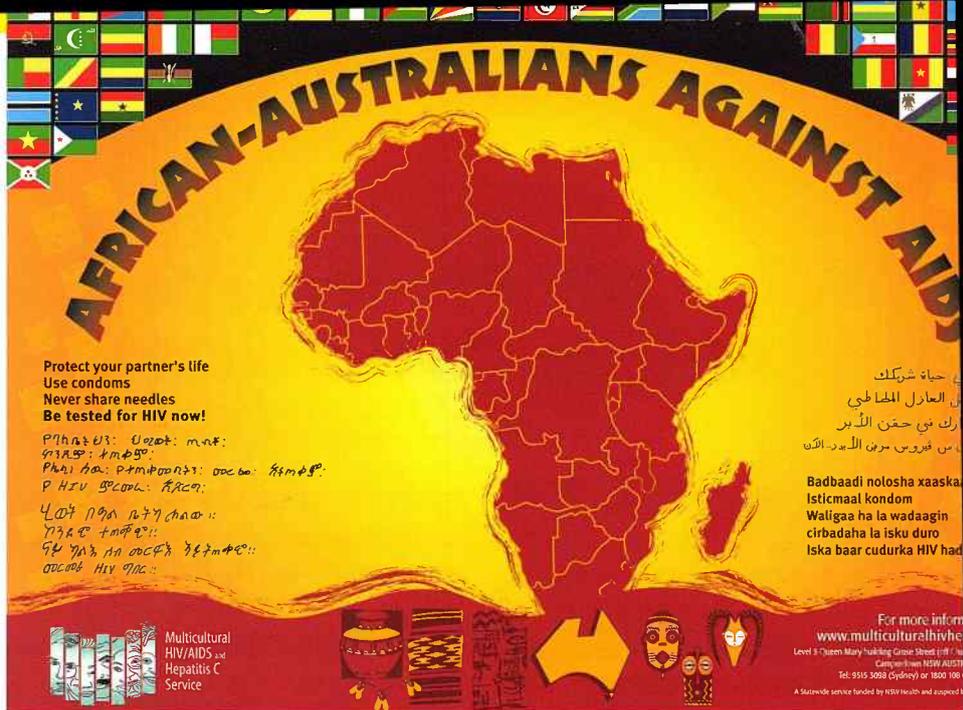
I consulted with various community workers to find a picture common to Africans to use on the poster. The community workers suggested using the map of Africa, which would attract the eyes of all African people. They also suggested that African flags displayed at the top of the poster would make the poster more attractive to every African person. Although some community members suggested pictures of African faces, other community workers rejected this idea because they – believed that it would be offensive or insulting for some African community members. They said some African people would feel uncomfortable seeing African faces associated with hiv/aids and felt that other people would misjudge the rest of the African community.

The majority of community members agreed to name the poster 'African-Australians Against AIDS'. This means that all members of the African communities are committed to fight against hiv/aids disease and are ready to participate in any campaign to prevent the HIV/AIDS disease.

The other messages on the poster included: 'protect your partner's life; use condoms; never share needles; be tested for HIV now!'

Because most of the African people in NSW are from countries where English is not the official language, the message of the poster was developed in four different African languages: Amharic (Ethiopians), Tigrinya (Eritreans), Arabic (Sudanese and other north African communities) and Somali (Somalis). 1,500 posters were printed and 800 have been distributed since October 2002.

The poster has been distributed in different African community places, such as community centres, African hairdressers, African shops, restaurants, soccer clubs, Migrant Resource Centres, medical centres, Sexual



Health Clinics, and members of the African community. The poster was also distributed at the soccer tournament.

### Soccer cup: 'African-Australians Against AIDS'

For the second time, we organised an African-Australians Against AIDS soccer competition in Sydney. Another four teams from Ethiopia, Eritrea, Somalia and Sudan competed for the African cup. Advertised in community newspapers and radio in Sydney, the tournament was held at Philips Park, Lidcombe, in October 2003.

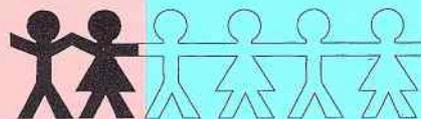
The project invited all African community workers, community leaders, the project advisory group, other health and welfare organisations who work with the African communities and members of the African communities in NSW. The project also distributed invitations to African community venues around Sydney.

An estimated 200 people from African communities attended the tournament. Most of these people were from the communities of competing teams (Ethiopia, Eritrea, Somalia, and Sudan).

Multicultural HIV/AIDS and Hepatitis C service presented the African Australians Against AIDS Cup to the Sudanese team, the winners of the 2003 competition. The service also presented small gifts including hiv testing information to each player and their coaches. African-Australians Against AIDS posters were distributed to the spectators.

The Multicultural HIV/AIDS and Hepatitis C Service would like to thank the Auburn City Council for their contribution towards the African-Australians Against AIDS soccer tournament.





HIV+ HETEROSEXUALS

Freecall 1800 812 404

What's new on Straight Street

January

**SATURDAY 17**

**Happynewyear Picnic**

Imax Big Screen, ferry trip & picnic

May

**TUESDAY 4**

**Straight Talk**

**MONDAY 10 to Friday 14**

**Pozhet Wheels: Heading north**

Outreach Lismore & Coffs Harbour

**SATURDAY 22**

**Pozhet Partners: Break time**

Guest: Patricia Austin, SVH

**FRIDAY 28**

**Fats 'n' Figures**

NEW

Pozgirls:Treatments Night In

September

**SATURDAY 11**

**Pozhet Partners: Break time**

Guest: Nandini Ray

**FRIDAY 24**

**Open House: Healing brews**

Complementary Therapy Night

February

**FRIDAY 6 to Monday 9**

**Bilgoa Ocean Breeze**

NEW

Pozwest Women's Retreat

**FRIDAY 27**

**Open House: Thai the knot**

Special guest

June

**TUESDAY 1**

**Straight Talk**

**SATURDAY 26**

**Absolutely Fabulous Pozhet**

**Clinic**

Complementary therapies

extravaganza

October

**SUNDAY 17**

**Mountain Blossoms**

NEW

Blue Mountains day trip

**SATURDAY 30**

**Join the crowd**

NEW

Walk 'n' Talk: Coogee

March

**FRIDAY 12 to SUNDAY 14**

**Pozhet-by-the-Sea**

Retreat at Shellharbour

**FRIDAY 26**

**Monsoon Wedding**

NEW

Film & Indian cuisine night

July

**TUESDAY 6**

**Straight Talk**

**FRIDAY 23**

**When a blokes**

NEW

**shed falls down**

Pozboys:Treatments Night In

Special guest: Gary Trotter, RPA

HIV Clinical Nurse

November

**SATURDAY 13**

**The Main Event**

Annual HIV/AIDS Workshop

April

**TUESDAY 6**

**Straight Talk**

**SATURDAY 17**

**Under the sun**

NEW

Walk'n'Talk: Cremorne

**FRIDAY 30**

**Open House: Crossing the**

**Liver**

Guest: Nurse liver lover

August

**SATURDAY 7**

**Heaven and Earth**

NEW

Cabramatta Temple & Tucker Tour

Tour guide: Walter Mason

**FRIDAY 27**

**Open House: South of the**

**Border**

Mexican food & travel fiesta

Guest: Jodie Partridge

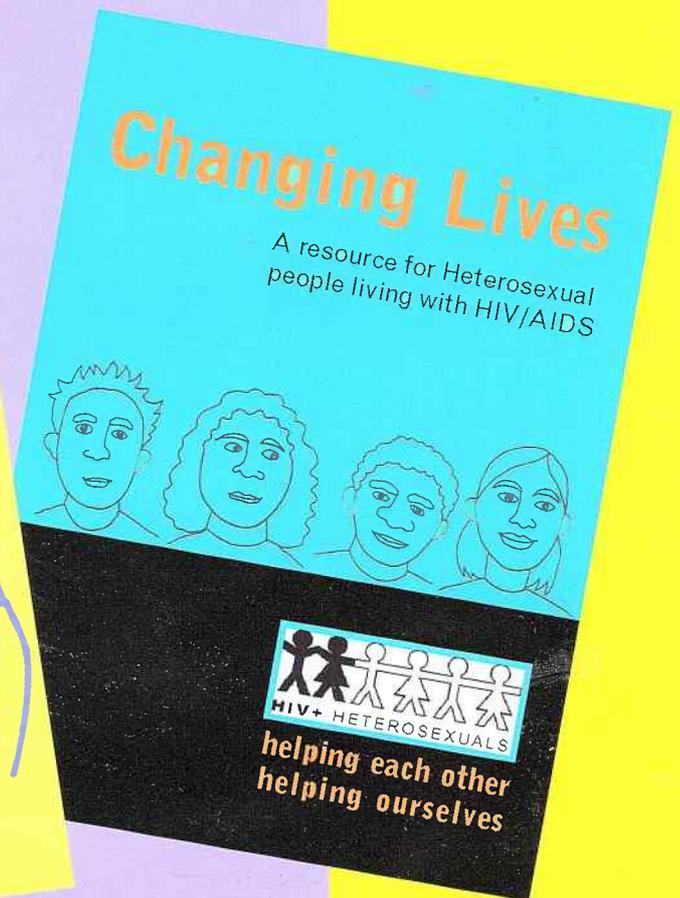
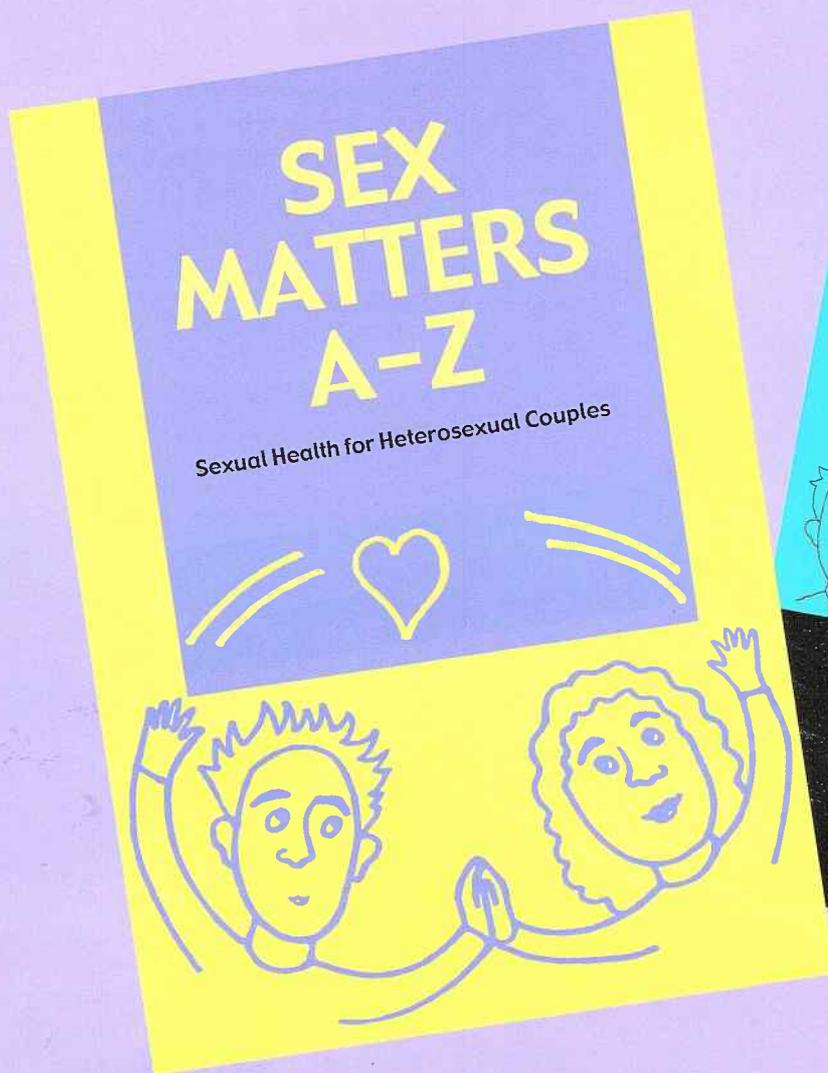
December

**FRIDAY 10**

**Open House: Champers &**

**hampers!**

Pozhet Xmas Party



**Something new**

**Freecall 1800 812 404** (national)

**Heterosexuality & HIV/AIDS Resources Kit**  
**Positive Men • Positive Women • Couples • Partners**  
**Telling Others • Family Matters • HIV Illness**  
**Talking Treatments • Tips for Living Well**  
**Getting Support • A-Z of Sexual Health**