

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

No.108 may/june 2000

Talkabout

◆ Where We Speak for Ourselves ◆



here, there and
everywhere

... travel and you

international round-up, durban bound, our arts update and more noztalk winners



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C O V E R

our ode to the adventure
that is travel



12

the highly commended
poztalk stories



16

here, there and everywhere



22

a progress report from acon

F E A T U R E S

- so near ... so far** 7
larry wellings reports on a recent study tour by Filipino PLWHA
- the fight for treatments** 8
in this month's **community briefing** *megan nicholson* reports that access to treatments is centre stage in the lead up to july's world AIDS conference in durban
- breaking the silence** 10
the international spotlight that comes with hosting AIDS 2000 may give South African PLWHA the impetus they need to strike back. *ken davis* reports
- poztalk's highly commended entries** 12
two more stories from our inaugural creative writing competition – highly commended entries from *keith jepson* and *robert baldwin*
- here, there and everywhere** 16
international travel is everyone's dream – but for positive people there are special considerations. we give you tips on your big trip; *brian* and *rhonda* share their stories; *dean murphy* reports on AFAO's new campaign and we launch our new travel factsheet
- the rocky road to change** 22
feona studdert reports on the progress of ACON's vision for a broader engagement with gay, lesbian and PLWHA communities and we publish ACON's future directions progress report

R E G U L A R S

Editorial 2 PosAction 3 Tell it like it is 4 Talkshop 5 Arts Update 6 Epistle-ette #5 25 Legal Update 26 Treatment Update 27 Glossary 28 Diary 31 Olga's 31 HyperActive 32

A D V E R T I S E R S I N D E X

contacts **inside front cover** HALC 15 Livingstone Road Medical Centre 20 ACON Illawarra 20 Family Medical Practice 20 Taylor Square Medical Centre 25 The Sanctuary 25 Wholistic Medical Centre 25 ACON Treat Me Right 29 ACON HIV Living 29 ACON Healthy + Life 29 ACON Services for Women 29 PozHetWest 30 Luxford Road Clinic 30 Ottoways Pharmacy 33 King Street Chemist 33 Trade Accounting and Taxation Service 33 ACON Healthy Life + **back cover**



"If you go to London", Gertrude Lawrence is reported to have told an American friend, "there's one place you must be sure of visiting". "Where is that?" asked the friend. "Paris," said Miss Lawrence.

Welcome to the Travel issue and the immediate anxieties of what to do with all these airports. Not even a good set of Louis Vuitton can disguise that noise and the worry that there's something you need to declare. Brian's story of 'love my credit card ... love my status' is a telling and witty exposé of how a positive person can manage their travel itinerary across three continents in one year. I'm already searching out a 'love my status' container for my next holiday.

This month *Talkabout* launches *International Travel for Positive People*, a factsheet about countries that have dodgy entry requirements for positive people, and a list of other important tips for trips. It's for one of the many who can't afford to pack their bags and feel that you're missing out. Always remember the best cure for restlessness for far places is to go there and find them full of other people who want to get back home again. Now if you're considering taking a drug free holiday you should check out the *HIV Treatment Breaks* factsheet from the AIDS Treatment Project (02) 9281 0555 before leaving strapless.

Still on the international theme, we look at the struggle of PLWH in the Philippines and South Africa and review the intensifying international focus on treatments that has emerged in the lead up to the 12th International AIDS Conference scheduled for Durban in June.

ACON's vision of change continues along a rocky road. This issue we update readers with a report on ACON's 'absolute commitment to HIV'. ACON will start to draft and redraft their vision based on the recent community consultations and *Talkabout* will keep you informed. There are obviously many views to be tapped about this big change. The rights and importance of the positive person is a basic value that must be acknowledged.

We also celebrate the first birthday of our internet review page 'HyperActive'. Tim Alderman has assessed well over forty sites for *Talkabout* readers, and tells us there's plenty more sites of interest to positive people. This is what we want - high quality resources for PLWH.

We hope you enjoy the read - remember our next issue is out July 1. June is the month that we hope you'll renew or start a subscription to *Talkabout*. Thanks for your support.

David Barton



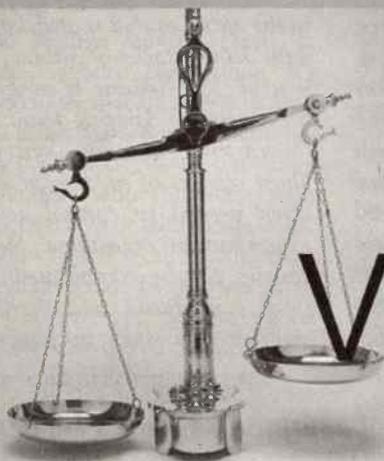
complementary therapies and treatments working group

treatments working group

legal working group

fundraising working group

publications working group



volunteer action

Douglas Knox – the convener of the PLWHA (NSW) Legal Working Group – reports on a team of volunteers working to improve legal issues for PLWHA.

The last six months has been an exciting and productive time for the Legal Working Group. This month *Talkabout* will launch **International Travel for Positive People**. The factsheet aims to address basic concerns of positive people planning international travel. It tells you which countries positive people can and can't enter and offers important tips to planning your trip.

The Legal Working Group (LWG) represents positive people on the Disability Advisory Council of the NSW Attorney-General's Department. This year we secured the Department's assistance to produce a revised Sentencing Kit, a resource for lawyers compiled by the HIV/AIDS Legal Centre.

PLWHA and prison

The Sentencing Kit ensures that all members of the legal profession involved in sentencing have access to up-to-date information on the law as it affects positive people. This revised edition reflects changes in the law and the role of combination therapies in the lives of positive people and will be launched by Mr Justice Kirby, during the NSW Law Society's Law Week this month.

Working together

We are a small working group and organisation without the resources to take on direct advocacy. Our aim is to work in constructive partnerships with government agencies, and other community organisations to address broader legal issues that affect PLWHA.

We have prepared joint submissions with the ACON Policy Unit on the Review of the NSW *Public Health Act*, and the South-East Sydney Area Health Service Code of Confidentiality that governs the way information technology is used to collect patient data. We will get a better result on these issues by speaking to government with a combined voice.

Amongst all this activity we also prepared independent submissions on the delivery of services in the Justice Sector for people with disabilities, the interests of older-positive people and the workings of the *Guardianship Act*.

We look forward to further challenges in the promotion of the interests of positive people in NSW. If you want to join us, you don't have to be a lawyer. Just call (02) 9361 6011 or (02) 9315 7215 to come to any of our meetings. ■

The Sentencing Kit ensures that all members of the legal profession involved in sentencing have access to up-to-date information on the law as it affects positive people.

Three drugs in one pill

Gilaxo Wellcome has applied to Australian regulatory authorities to license Trizivir, a single tablet formulation of their three licensed nucleoside analogue drugs. Each tablet of Trizivir contains FTC (150mg), AZT (300mg) and Abacavir (300mg). In Europe where the tablets are also still unlicensed, the new formulation is being made available under a special scheme in which a doctor applies for its use on behalf of a patient. This scheme is largely for people who have a major problem with adherence. One tablet of Trizivir is taken twice a day and there are no food or water restrictions.

Source: AIDS Treatment Update

Possible new treatment for peripheral neuropathy

L-acetyl carnitine may reverse peripheral neuropathy (nerve damage) that is caused by some nucleoside analogue drugs such as ddC and ddI. At a recent international pharmacology workshop, Dr Mike Youle from the Royal Free Hospital, London reported on a study of four patients with moderate to severe drug-related peripheral neuropathy who received L-acetyl carnitine therapy (1500mg twice daily) for six months. All four patients reported a reduction in pain symptoms. Skin biopsies, taken before and after carnitine treatment, showed significant re-growth of small sensory (pain) nerve fibres. A larger scale (100 people, randomised (control versus treatment) groups) trial is now planned to study L-acetyl carnitine in more detail as a treatment for drug-related peripheral neuropathy. L-acetyl carnitine is now available from ACON's Vitamin Service.

Source: Aidsmap News

News on Salvage Therapy

At a conference on salvage therapy on April 13, Dr Rafael Campo from the University of Miami School of Medicine reported on 27 patients who had previously experienced a substantial increase in viral load with on an average of two to three protease inhibitors. These people were switched to an indinavir (800 mg)/zidovudine (200 mg) combination which was taken twice a day. The average CD4 cell count and viral load levels of these people at the start of the switch were 239 cells and almost 200,000 copies of virus. Fifteen of the 27 achieved viral load levels below detection. In eight of the fifteen this was maintained 32 weeks after the switch. Three quarters of those who responded had viral mutations that indicated resistance to protease inhibitors. All four people who had virus that showed resistance to indinavir achieved undetectable levels of virus with the indinavir/zidovudine combination.

Source: aegis



Tell it like it is is your opportunity to get a straight answer to questions about health, treatments and side effects. Send your questions to Tell it like it is, *Talkabout*, PO Box 831 Darlinghurst 1300 or fax 02 9360 3504 or email feonas@plwha.org.au

Q I'm feeling blue. I should be feeling on top of the world. My doctor is happy with my results. But I'm still feeling blue. I can't get my act together or my life organised. What can I do?

Depressed, Surry Hills

A Your problem is very common. It does come as a bit of a surprise for some service providers that there is more to HIV than blood test results. Depression in PLWHA can have many causes. Firstly, depressed mood can be caused by antiviral medications or by over-use of recreational drugs. Secondly, 'clinical depression', due to poorly understood chemical imbalances in the brain, is common and probably under recognised in patients with HIV disease. This form of depression may respond to 'anti-depressant' medication. Finally you can feel depressed because of the difficulties you face adjusting to a new life with HIV. The first thing is to have an open and frank discussion with your doctor, treatments officer or nurse. If drug side-effects are ruled out then you should be reviewed by a psychologist or psychiatrist to establish if counselling and/or anti-depressant medications would help. Finally there are programmes to help PLWHA re-engage in life and/or the workforce. You can find out about these from your doctor, treatments officer or from PLWHA (NSW).

Q I'm on medication that needs to be taken three times a day and on an empty stomach. I try my best but it is not always easy. My friend takes his medications twice a day and doesn't have to worry about having an empty stomach. What can I do?

Hungry, Leichhardt

A Taking medications three times a day on an empty stomach is hard work. You should be congratulated for sticking to it. However, there may be alternatives, which could make your life a lot easier. By using combinations of protease inhibitors you can slow down the metabolism of the drug. This means that the drug stays in your

in the air tubes that is associated with acute attacks of asthma. If you like, prednisone is used in these cases to dampen down an 'overactive' immune system. Short courses of prednisone are often needed to control acute exacerbations of asthma. Such courses can be complicated by oral candidiasis and herpes simplex outbreaks in patients

It does come as a bit of a surprise for some service providers that there is more to HIV than blood test results.

Depression in PLWHA ... can be caused by antiretroviral medications or by over-use of recreational drugs.

Secondly, 'clinical depression', due to poorly understood chemical imbalances in the brain, is common and probably under recognised in patients with HIV disease.

body for longer. There are a number of advantages to this approach. You don't take the drug as frequently; you don't take as many pills and you don't worry about whether you have a full or empty stomach when you take your pills. This might not apply to your particular combination but you should explore these possibilities with your doctor or treatments officer.

Q My doctor wants me to take steroids for my asthma. I thought steroids were bad for your immune system. I am worried that the steroids will make my HIV disease worse. What should I do?

Paul, Potts Point

A The immune system is a complicated beast and simple rules do not always apply. Steroids, like prednisone, are used to reduce the inflammation

with HIV disease. However, in general they are safe and do no long term damage to your immune system. Long term use of prednisone, on the other hand is generally associated with complications and should be used only if no alternatives exist. Your doctor treating your asthma should know that you have HIV disease. Serious chest infections associated with HIV disease can mimic exacerbations of asthma.

Answers are provided by Virginia Furner and Mark Kelly - both Doctors at the Albion Street Clinic and members of PLWHA (NSW) Treatments Working Group. Decisions about treatments should be made in conjunction with your GP. Virginia and Mark can be contacted on furnerv@sesahs.nsw.gov.au and kellymark@sesahs.nsw.gov.au

Talkshop



PLWHA (NSW) staff and committee members are active in many projects, consultations and meetings that affect the interests of PLWHA. **Antony Nicholas** – our Community Development Project Worker – profiles what's happening in NSW this month.

Haven funded

The Western Suburbs Haven is now a funded organisation. It's good to see that after years of hard work funding is finally confirmed. They would also like any volunteers who can assist with practical help or with caring shifts. I know I put in a call for volunteers a couple of months ago but I put in the fax number, not the phone number. So try 02 9672 3600 if you want to help the Haven.

HACC project progress

PLWHA (NSW) along with numerous other community groups has been working with the Aging And Disability Department (ADD) and Home and Community Care (HACC) to ensure equal access and equity to services are available. The Positive Access Project in Eastern Sydney will be providing training to HACC services over April, May and June around issues related to servicing people living with HIV/AIDS. The Community Development Organisation is also running a HACC – HIV/AIDS Information and Training project in the inner west over the next

few months. Both have the same focus and are a direct result of ADD funding.

PES expands

Positive Employment Services are now operating in three locations, Northern, Western and Eastern Sydney. The project demonstrates the great work that can be achieved through well managed, effective collaboration between HIV organisations.

New financial help guidelines

Amanda Theobald has started at the Bobby Goldsmith Foundation as a second financial counsellor working with the lovely Maree Crosbie. Welcome to Amanda who has been doing the rounds of organisations and will be seeing clients from May. BGF will also release new financial guidelines this month. Watch out for promotional information or contact BGF on 02 9283 8666.

New coordinator on northside

Welcome to Dhanu River who is the new coordinator at Myrtle Place. Dhanu's past work and experiences are extremely diverse so pop in and say hello. He told

Talkabout he is looking forward to extending the program for alternative therapies and all things relating to enjoying life, stress management, social events, trips and educational forums. For information call Myrtle Place on 02 9929 4288.

Administrative training

PLWHA (NSW), with funding from the HIV/AIDS and Related Diseases Unit of South Eastern Sydney Area Health Service will embark on an exciting new project of training and on the job experience for PLWHA. Two days will provide on the job experience, assessment, interview skills and training; and one day each week will cover education programs. Return to work issues have been identified as a priority for positive people and our organisation. It is hoped the project will offer positive people an opportunity to see if they are ready to return to work, while updating their skills and accessing training courses. For further information contact Antony between 10am and 5pm on 9361 6011. ■



Sensible buzzing

Drag Queens continue to play a glamorous role in the community response to HIV/AIDS. Shown here receiving her award for Miss Sensible Buzzing 2000 is Miss Joyce Maynge. The campaign, devised by SWOP, promotes harm reduction in drug and alcohol – including safe sex and needle use – to show queens and their audiences. Photographed with Miss Maynge is norrie may-welby, coordinator of the campaign. She told *Talkabout* that Miss Maynge is delighted with her award and looks forward to educating her audiences on the benefits of controlled drug and alcohol use during her short reign.

Briefs

PLWHA to carry torch

A member of PLWHA (NSW) has been selected to carry the Olympic Torch relay in September. Luke Chipperfield was advised early this year that he had been selected to carry the torch from Bateman's Bay to Malua Bay on the New South Wales South Coast on September 9. Luke, who is 22, is the youngest speaker in the Positive Speaker's Bureau. He is a haemophiliac who has lived with the virus since he was four years old.

Treat yourself right

An updated edition of *Treat Yourself Right*, the comprehensive resource for positive women has been released nationally. "Written in conjunction with positive women from all over Australia, *Treat Yourself Right* is for both the newly diagnosed woman and women who have been living with the virus for longer," said Sonja Ristov, Chair of Positive Women Victoria. *Treat Yourself Right* provides information about treatment and care options from a holistic perspective and specific issues for positive women including menstrual and gynaecological conditions, pregnancy, childbirth and parenting. "Women with HIV in Australia are less likely to access treatment than men and more likely to be living in poverty, according to the *HIV Futures Report* released in March 2000. That means we face a different set of issues, both culturally and health wise," said Ristov. *Treat Yourself Right* will be launched in Melbourne this month and is available from PLWHA (NSW) and ACON.

Hep C campaign underway

The Hepatitis C Council of NSW have welcomed the hepatitis C public awareness campaign, launched in March by the Deputy Director General – Public Health and Chief Health Officer, Dr Andrew Wilson. Stuart Loveday, Executive Officer of the Hepatitis C Council of NSW, said the initiative was a welcome addition to recent activity to reduce the impact of hepatitis C. An estimated 90,000 people in New South Wales are living with hep C. In November 1998, a NSW parliamentary inquiry into hepatitis C delivered its report *Hepatitis C: The Neglected Epidemic*. The report found that hepatitis C was a disease largely neglected by decision makers, health planners, the media, health care workers and the public in general," Mr Loveday said. Health authorities agree that hepatitis C has become Australia's most commonly reported infectious disease. The Futures 2 Survey found that one in six participants were living with both HIV and hepatitis C. "Infection with both viruses creates greater complexities in treatment choices and more uncertainty about HIV progression rates", the authors noted in the report.

where roads intersect

Ernie Blackmore started writing in his fifties. Last month his story *Positive Expectations* was awarded first prize in our PozTalk writing competition. Ernie's story used a strong, original voice to explore an intersection of Aboriginality, gayness and HIV/AIDS. He hopes his first play *Buckley's Hope* – selected for both the Australian National and United States National Playwrights Conferences – will be produced in 2001. **feona studdert** asked Ernie how he balanced the intersecting themes of his life and stories.

My Grandfather and my Mum were Aboriginal. My Grandfather was a story teller from Moree and Mum was a story teller. Somehow that rubbed off because I've always loved books and theatre. I didn't learn to read and write until I was in my late twenties. Late in 1994, when I was 54, I was diagnosed with cancer. When you get diagnosed with a terminal illness it turns it all round. After the surgery I ended up at a Wollongong University. I enrolled in Creative Writing. I knew what I wanted to say, but I didn't know anything about grammar, syntax. All those things were a complete mystery. I was helped by the Aboriginal Education Centre. I got a degree in Creative Arts. I turned around from writing stories to writing for theatre because of my ability to write dialogue. That's how I got into writing.

So you're telling stories like your family?

It is culturally important for us to give back some of those skills that we have let go of. It's important to use whatever medium you can, so let's use technology to tell the stories – Grandfather would tell a story – you know a five, ten minute story and then he would look at us. If we hadn't understood, he would tell the story again and he may do it two or three times and then he might come back a few days later and tell the story again and then, the lights would come on and we would begin to understand. These circular stories, they have an in-built moral but he would just tell the story of some little kid who got lost in the bush and how he found his way back. He was a fascinating old guy and when he died, (my mum died very early)

that cultural bit of my family stopped and I guess I'm trying to revive that.

Can you incorporate your own life into your stories or do they have to be morals?

I think that there's a way that the whole thing can be told. I'd been a western suburbs closet queen visiting beats from bloody Bulli to Penrith; west of the George's River, you know, I was there. That went on for years and years; twenty-five years of unprotected sex. As late as 1986, when I was coming out, I was still having unprotected sex and never contracted HIV. A lot of people I knew disappeared off the scene and I didn't know what was wrong. They were no longer at Campbelltown on Friday or Saturday nights, they were no longer around. Of course, they were getting sick and their doctors were moving them

face to face with this battle with prostate cancer. It was about reconciliation with my own son, because although we're fine now, for about eight or nine years we had a terrible time. I was an embarrassment to him.

There is also another little bit that I didn't realise I wrote until I read it. It was anger about HIV. Years ago I was mentoring a young fellow, and he was diagnosed with HIV. I met him at the doctors up in Oxford Street and I chased him half way down Oxford Street, I was going to kill him, because he hadn't been practising safe sex. Twenty-four and in my mind, throwing his life away; I was bloody angry about it. So there's the whole range of things, my reconciliation with my own son, the young fellow sero converting and being angry about that.

I'd been a western suburbs closet queen visiting beats from bloody Bulli to Penrith; west of the George's River, you know, I was there.

around so they could get treatment because in the west of Sydney HIV/AIDS was still taboo. When I came out and sort of moved into the city, I got face to face with a number of people that I had known, and had been having sex with for god's sake. I must have gone to twelve or fourteen funerals in eighteen months for people that I knew. That was a pretty difficult period. There's a feeling of guilt you know, that my friends are dying and I'm not dying and I'm guilty for this. So there was a whole lot of new things for me to work through. I've yet to write that out.

What motivated your story

My cancer recurred last year and I've had radiation treatment. I was sitting at home recovering from treatment and it brought me

There's three of us in the house, my partner Phillip, me and another guy who's HIV positive. He and I do a lot of talking, because we're both early morning birds. We sit out on the verandah at four or five in the morning and talk. We were saying yesterday that I need to move through that anger. I use writing to find my way through whatever's bothering me. Sometimes you start writing a story and you realise you've got something more than what you thought you had. Then you start doing a bit of editing. It's getting to know at what point do I stop editing and give it to somebody else and let them edit out the dross and try to keep the spirit of the story. Because once I start editing I question every sentence and its value and I kill it. ■



recent statistics

In a population of 76 million, to date 1,325 HIV notifications have been recorded (791 male, 527 female and 24 children under 15). 203 AIDS-related deaths have been recorded 1984-2000. In 1998 UNAIDS estimated the number of infected adults and children could reach 24,000 this year.

so near ... so far

Members of the Philippines' two PLWHA organisations recently visited Australia to study models of Care and Support. **Larry Wellings** facilitated the tour and spoke to Joshua Formentera about the struggle of Filipino PLWHA to obtain HIV treatment.

With the passage of the Philippines AIDS Prevention and Control Act 1998 (Republic Act 8504 or 'AIDS Act') the Philippines now has a legislative framework covering many of the things Australian PLWHA take for granted including the provision of basic health and social services.

Joshua Formentera, is a leading policy advocate and President of the Positive Action Foundation Philippines Inc (PAFPI). He was one of the first people to get HIV medications in his country.

"I was able to access antiviral treatment in Australia in 1996, so I brought it home and started discussing this with doctors. I was hoping to have a trial but they didn't give it - there is none." Joshua has paid for his own treatments for the last three and a half years, but says without a government subsidy the cost is prohibitive.

"It really cost a lot of money ... about US\$1,000 a month. Treatments are available, but not affordable."

Failed trials

The use of clinical trials to get treatments to PLWHA in developing countries is problematic. Compassionate access protocols, for example, are not in place in the Philippines.

Filipino PLWHA now face a number of challenges, the most pressing being the need for a national strategy with appropriate care and support services. The National AIDS Council (PNAC) has been reconstituted as a means of guiding outcomes associated with the new legislation.

Joshua is frustrated by the difficulty of getting antiviral treatment.

"PLWHA are dying and we are reading a lot of news about the benefit of antivirals or alternative medicines so we

started asking doctors, volunteers and patients, but the doctors refused to give that information."

"Firstly, anti-virals are very expensive, patients don't have the money to pay for them and there is no government funding system. Secondly, doctors don't talk about the use of medications. There is concern that, because medications are not affordable, discussion may add to depression among PLWHA."

PLWHA are dying and we are reading a lot of news about the benefit of antiviral therapy or alternative medicines so we started asking doctors, volunteers and patients, but the doctors refused to give that information.

Emerging collaboration

A breakthrough came when PAFPI initiated a collaborative effort with a national research institute to approach a Government agency for funds. The joint project resulted in twenty-five PLWHA gaining access to antiviral treatments.

"PAFPI volunteers and allied health providers realised there was something we could do. We contacted the Philippines Charity Sweepstakes (sells Lotto) and requested a meeting. Together with the Research Institute of Tropical Medicine in Manila, we prepared a strategy to discuss with the Sweepstakes agency.

"We met with them and told them we needed support for our work in the wider

community. We were doing a lot of prevention work, dissemination of information on STDs and HIV/AIDS. We identified that this was the only way to get the information to our community.

"The Sweepstakes responded favourably and funded medications for about twenty-five PLWHA. We have to go back to them every year to report on what we have done, to prove that we are doing well."

Ground work

PAFPI's other activities include organising a training program for Filipino PLWHA as Health Educators for pre-departure Filipino Overseas Workers, and Speechcraft Training in Manila for forty-five PLWHA to assist with HIV/AIDS education in schools, affected communities and public companies. PAFPI has also conducted the first Pre-Assessment Social Survey of PLWHA covering General Health and Education Assessment, Self-Worth Assessment and Social and Infrastructure Support Assessment.

Joseph hopes the Philippine Government will come to fully embrace the partnership model that has proved so successful in Australia.

"We have identified a need for networking and partnerships, as well as the involvement of politicians in the Philippines, strong involvement. That's what we don't see, that there is a strong involvement from the Philippine Government perspective. That's why we are trying to work ourselves, to motivate a strong voice for people living with HIV/AIDS to prove that there are needs to be addressed for Filipino PLWHA." ■

Larry Wellings is a consultant to the HIV/AIDS sector. The Pasasalamat Study Fund sponsored the tour.

the fight for global activism in the lead up to durban

Make no mistake: the fight is well and truly on. AIDS activists globally have placed access to treatments centre stage in the lead up to the World AIDS Conference in Durban in July. **Megan Nicholson** reports.

The struggle is for governments to recognise the impact of AIDS on their people, for rich countries to go beyond a focus on prevention to fund health infrastructure and drugs, and for pharmaceutical companies to make affordable medicines available.

The global context

The recent International Conference for People Living with HIV/AIDS highlighted three priority areas for 2000–2001:

- access to treatment and care
- stigma and discrimination
- greater (and more meaningful) involvement of people living with HIV/AIDS.

Priorities on the ground are determined by regional, national and local factors. In the 'North' (the US, Europe, etc) the advent of effective treatments has dramatically changed the HIV/AIDS service and support sector. As Joseph Scheich of the Global Network of People Living with HIV/AIDS (GNP+) told *Talkabout*, the struggle in some centres is to keep HIV on the agenda and avoid complacency.

In the US, there has been some infighting amongst PLWHA representatives, with claims that pharmaceutical companies only deal with favoured individuals. Nevertheless, activists have launched a new campaign against drug price increases. In Western Europe, a cosy relationship between industry and 'community' has not emerged, in part due to a formalised and representative "European Community Advisory Board" of 20–30 activists representing most European Union countries.

In other areas such as Eastern Europe, Asia and Latin America, prevention of HIV and opposition to discrimination are central issues along with access to treatments. Injecting drug use, which is driving the epidemic in much of Asia and Eastern Europe, is a key focus for prevention activists advocating harm reduction strategies.

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According to Scheich, the top priority in Africa is access to care and treatment. "Unfortunately," he said, "the reality of the situation has lead PWA activists working in Africa to be more pragmatic in their focus and hopes".

Advances in treatments activism

Access to treatments for opportunistic infections and antiretroviral therapy has transformed the course of HIV disease for many individuals in wealthier, western nations. However, 90% of people with HIV have little access to basic healthcare and no access to any HIV/AIDS treatments. The outrage and activism this striking inequity has sparked has already produced changes in discourse and policy.

UNAIDS Executive Director Peter Piot has spoken of a moral imperative to provide treatment and care to people with

HIV, and countenanced the licensing and importing practices which would make cheap drugs more readily available to HIV positive people in resource-poor settings. Previously, UNAIDS had steered away from endorsing practices opposed by the pharmaceutical lobby. At a meeting of the UN Security Council Meeting on HIV/AIDS held in January, there was an acknowledgment from many speakers, such as the World Bank President James Wolfensohn, that treatment and care are priorities despite the focus on prevention and global stability. (See opposite page for recent victories in treatments advocacy.)

Ongoing activism

While the recent victories seem impressive, activists are far from satisfied. For example, while the Pfizer donation (see sidebar on page 9) has been regarded as a great victory, leading non-government organisations (NGOs) have demanded systematic price reductions for medicines in resource-poor countries plus changes to production and distribution monopolies by the big pharmaceutical companies. Such changes would pave the way for access to treatments generally, rather than a one-off gesture to a country with effective activists and a forthcoming World AIDS Conference.

Marie de Cenival from ACT UP Paris/Planet Africa said: "Our main theme this year is war against the pharmaceutical companies". The Planet Africa project has provided ten PLWHA associations in Africa with computers, and has facilitated the development of collective strategies. The network has been pivotal in victories around fluconazole and cotrimoxazole.

Some activists have been critical of the priorities and inertia of AIDS bureaucracies.

treatments:

Central American activist Richard Stern has provided a draft letter to pharmaceutical companies for activists to use to secure local production of HIV/AIDS medicines. In an attachment to the letter, Stern commented: "We lament the fact that well-funded international AIDS organizations in a position to facilitate efforts such as this ... continue to be mostly silent."

Our main theme this year is war against the pharmaceutical companies

Another problem in achieving access to treatments is that the debate often gets side-tracked by development issues of clean water and lack of infrastructure. Marie de Cenival was adamant: "If we wait for water to be clean throughout Africa, then Africa is going to die from AIDS." Hospitals and doctors able to provide AIDS care and treatment do exist in many parts of Africa, she said.

De Cenival argued that treatment is necessary to transform the meaning of AIDS in Africa. "If you give even a very little part of the infected population the means to be treated, and their families the means to care for them, you change this representation ... from fear to sickness".

The Durban Conference

The theme of the Durban conference is 'Breaking the Silences', indicating the commitment of conference organisers to effecting change in HIV/AIDS policy and practice. A 'March for Affordable Treatment', planned for the first day of the conference, certainly is likely to ensure a lot of noise about treatments.

Conference organiser, Richard Burzynski, from the International Council of AIDS Service Organisations (ICASO) said that he hopes the Conference will highlight key silences around HIV/AIDS such as the lack of resources for the community frontline. "We are tired of international agencies which keep large amounts of resources for their own promotion, administration and advocacy," Burzynski said. "ICASO believes strongly that most of the resources should go directly to those on the frontline."

We lament the fact that well funded international AIDS organisations in a position to facilitate efforts such as this ... continue to be mostly silent

Joseph Scheich said that GNP+ hopes that the Durban conference will focus world attention on HIV positive population with no access to treatment or care. GNP+ also hopes that the contribution of people living with the virus will be taken more seriously and that the "lofty words" of the Paris Declaration will come closer to becoming a reality. ■

Megan Nicholson is a freelance medical writer and editor. Thanks to all who contributed ideas to this article including: Dave Burrows, Keith Alcorn, Lars Kallings and Gary Dowsett.

As well as a change in discourse, there have been key victories in treatment access:

Pharmaceutical company Pfizer will donate the anti-fungal drug fluconazole to people with AIDS in South Africa. Fluconazole is used to treat a brain infection called cryptococcal meningitis which affects about 8% of people with AIDS. The decision announced on March 31 followed pressure led by the Treatments Action Campaign in South Africa.

A UNAIDS-WHO consultation in Zimbabwe endorsed the use of co-trimoxazole to prevent opportunistic infections throughout Africa. Known as Bactrim in Australia, co-trimoxazole is a cheap, generic drug effective at reducing rates of AIDS-related pneumonia, toxoplasmosis and tuberculosis.

The decision in early April followed pressure from African, French and US activists.

In March, the Inter-American Commission on Human Rights ordered the government of El Salvador to provide anti-HIV medications to 26 people with AIDS who petitioned the Commission. It is hoped that the decision will lead to general availability of antiretroviral drugs in El Salvador.

The Thai government recently announced local production of ddI, that will halve the cost to consumers. The decision followed pressure on the US government, which had been threatening Thailand with restricted access to US markets if local production of anti-HIV drugs occurred.

breaking the silence

As hundreds of international PLWHA, activists, and scientists gather in July in Durban for AIDS 2000, South Africa faces heavy odds against its struggle with HIV/AIDS. **Ken Davis** reports that the international spotlight may give South African plwha the impetus they need to strike back.

The AIDS 2000 Conference in Durban in July is shaping up as a unique challenge. This is the first time the international AIDS conference will take place in a country of the Southern Hemisphere, where 4 million people live with HIV. Just kilometres away from the beachside conference centre, millions of people live in townships such as kwaMashu and Umlazi, poor communities with tens of thousands of people with HIV.

South Africa has a highly developed medical system, but this was largely privatised during the last years of Apartheid. Most people with HIV-related illness can get only minimal primary health care and symptom control, treatment for just a few of the opportunistic infections, and no antiviral therapies.

Hospitals are overwhelmed, and often cannot admit patients with AIDS. The primary health care clinics are under extreme pressure. Nurses are rarely available for home care, even for the dying. With high rates of STDs and TB in South Africa, the rapid spread of HIV makes it vital to maintain and upgrade sexual health, TB and maternal/child health services. Yet in many areas, services are less accessible now than a decade ago.

Only the rich can pay \$1000 (Aust) per month for combination antiviral therapies at pharmacies in the most opulent suburbs of Cape Town and Johannesburg. \$1000 is twice the yearly income of the majority of the population.

Talkabout May/June 2000 ♦ Page 10

Background to a crisis

The South African epidemic emerged later than in other southern African countries. By the late 1980s Botswana, Zimbabwe and Zambia were reporting infection rates in young women of twenty percent but in 1990 South Africa still had less than one percent nationally. Almost eight percent of pregnant women tested HIV positive in 1994. Now in the eastern and northern provinces, twenty-five percent of young adults are HIV positive.

It is only in the last year that SA communities have begun to experience the trauma of significant numbers of people with serious illness and a noticeable increase in deaths.

system, the labour market and education since the early 1990s. Now all their worst predictions are coming true. For example, recent press reports estimate that a majority of mine workers and members of the SA Defence Forces are HIV positive.

The Apartheid legacy

The rapid spread of HIV was helped by the policies of the late Apartheid regime. A migrant labour system kept workers in cramped hostels and their families hundreds of kilometres away in ten Homelands. The regime also disrupted township life by sponsoring mass terrorist violence from right wing or anonymous 'third force' groups. In one instance, discussed in the Truth and Reconciliation

Only the rich can pay \$1000 (Aust) per month for combination antiviral therapies at pharmacies in the most opulent suburbs of Cape Town and Johannesburg.

\$1000 is twice the yearly income of the majority of the population.

Although 20 million of South Africa's 43 million people live in poverty, the country has one of the most developed economies in Africa. Half of all the motor vehicles, plane flights, electricity, and telecommunications for the whole continent are in Gauteng, the small province around Pretoria and Johannesburg. The implications of a devastating epidemic interacting with an advanced capitalist infrastructure are unprecedented.

SA demographers and economists have been predicting the impact of HIV on life expectancy, insurance, the health

hearings, the secret police deliberately recruited men to infect sex workers in Johannesburg, in order to spread HIV to the urban black community.

The Apartheid regime promoted condoms to lower the African birth rate. People saw HIV/AIDS as a racist plot, and the government's early fear-based anti-sex messages lacked any credibility.

The Apartheid regime also left an enormous international debt, so South Africa, like the countries to its north, now repays its creditors more money each year than it spends on keeping its citizens alive.



There were enormous hopes that the democratic transition would see an effective response to the epidemic. While still in exile the African National Congress leadership had mandated democratic resistance structures inside the country to begin work on AIDS education. Despite inspiring rhetoric from leaders, the record of the ANC-led Coalition Government has been poor.

to pregnant women has generated widespread anger. Local and international activists are also alarmed at Mbeki's public toying with American HIV-denial theorists (Duesberg and the schismatic ACT-UP San Francisco).

The new constitution guarantees legal protection against discrimination, but the economic polarisation of South Africa

solidarity. In every community non-government structures are trying to provide volunteer care and support for affected households.

A vibrant Treatments Action Campaign has emerged in the last year, spurred on by despair and frustration among PLWHA, health workers and community activists at the lack of access to health care. The campaign aims to take on the drug companies and their super-profits that stand in the way of Africans getting life-saving medicines.

The TAC has had a major victory, with the pharmaceutical company Pfizer offering to supply the anti-fungal fluconazole free to people with HIV and cryptococcal meningitis in South Africa. Until now it cost approximately \$60 (Aust) per tablet, and many people have been dying of meningitis or oesophageal thrush without effective medications.

The TAC is mobilising thousands of people to march on the Durban conference on July 9 to demand affordable HIV treatments and health care for all. The march has the backing of all three SA trade union federations, and several international non-government organisations. The Australian Council of Trade Unions and the Australian Council for Overseas Aid have also endorsed the march. ■

... it is important not to underestimate the commitment of vast numbers of ordinary South Africans. In each township, school, church and workplace, community activists have been involved in education to promote solidarity.

Worrying trends

Under President Mandela, Health Minister Nkosazana Dhlamini-Zuma built hundreds of clinics, offered free treatment to children under six and pregnant women, declared war on the tobacco industry and tried to introduce cheap generic drugs, provoking threats from the USA. But Zuma's record on HIV was tarnished by a scandal that allocated the bulk of one year's AIDS education budget to the play *Sarafina II*. Zuma was also responsible for the tragic declaration by Cabinet that SA had discovered a cure, Virodene, an industrial solvent that not only proved ineffective against HIV, but also was sometimes fatally toxic.

In 1998, Manto Tshabalala-Msimang became Health Minister, under President Thabo Mbeki. The refusal of this government to provide AZT or Neviripine

means that the situation of people with HIV in terms of employment, housing and health care is bleak. Most people attend traditional healers, and few believe in germ theory, so ideas that HIV/AIDS is a punishment or a dishonour remain strong. Those PLWHA brave enough to become publicly visible have often suffered violent persecution. One kwaZulu-Natal woman, Gugu Dlamini, who came out on World AIDS Day, 1998 was killed by her neighbours.

The fightback

On the other hand, it is important not to underestimate the commitment of vast numbers of ordinary South Africans. In each township, school, church and workplace, community activists have been involved in education to promote

Ken Davis works for APHEDA, the aid agency of the Australian trade unions. Visit the TAC website: www.tac.org.za

This month we present two of our five highly commended entries in the PozTalk writing competition. The judges and *Talkabout's* Editorial Committee congratulate Keith Jepson and Robert Baldwin for their original, lively and entertaining stories.

Thanks to our two judges, Robin Gornal, Executive Officer at the Australian Federation of AIDS Organisations (AFAO) and Marcus O'Donnell, Editor of the *Sydney Star Observer*. As well as key professional roles in the community both Robin and Marcus are, themselves, published writers.

Thanks of course to our many sponsors who have generously donated both and cash and in-kind prizes.

On page 6 you can read the first of our interviews with the PozTalk winners, this month featuring Ernie Blackmore, author of *Positive Expectations*.

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headwise (a fantasy)

By Keith Jepson

So everything is still fabulous Doc. Blood counts, liver functions, viral load all good. I still wonder which hit it was that allowed me to acquire Hep C when I was young and silly. I know it's as useless a reflection as wondering which sex hit gave me HIV all those years ago when nobody knew or wanted to know. It's such a fascinating condition you know, the way it keeps evolving; the way people have responded from the global to the local to the individual.

But there's something else Doc. Something (how can I put it?) not quite right with my head. I've been noticing a few wobbles lately out of the ordinary; and so have others. Yes: I know I can't expect to escape the legacy of decades of dipping into a drag bag of mind altering substances without some effect on the grey matter. And I am aware (and relieved) that, thanks to the wonders of modern profit taking, there are demented queens out there who do remember their names again and forget to die.

Anyway, it was the guy at the Centre where I do volunteer work who threw me – what he said that day. I know I do well there with the physical/emotional support stuff; a mixture of Dr Feelgood and realpolitic; the unfair, cruel, life's a bummer stuff. Makes me think of that bikie guy; seriously pissed off about being looked after by “you pofter bastards”. I'd catch him sometimes, screaming silently, like something out of a Munch or a Bacon painting. On one of his better days he showed me a photo of himself when he was younger – a rough muscled spunk, hanging off a Chopper, all long hair and golden. He probably got fucked up the

arse or a vein sometime when he was a guest of Her Majesty's Government. No clarification was ever asked for, or granted.

But it's ironic when I think back on it that towards the end he would sometimes quietly ask me to give him a massage; and I have to say the relief it gave him was palpable – calmed him right down. It was probably the only really human thing that was happening to him at that time – a primal need to be touched by another person: even though that person was a bloody pofter (with AIDS).

I felt OK massaging him; simply because I could. I'd been doing it for years anyway with all sorts of people, from strangers to lovers, and I knew what to expect – how they would feel. The bones just beneath the skin. Just like with my darling Charlie. I'd go frantic conjuring up interesting but innocuous foods that just might tempt him. I'd hold him, doped out, in my arms in bed and try to make time stand still. I succeeded too, until he died. “When you let go I'll catch you” I would whisper. One night he did, and left me – holding the pieces. Fortunately he'd left a healthy number of his pain killers behind, and they helped to soften – well, soften the fall.

Anyway, back to my head. So it seems like I'm functioning OK socially; and everything seems fine with the abstractions of life too: literature; the Arts; language; political and philosophical meanderings. All that stuff. I feel generally at ease in this mass hallucination called everyday reality.

I'm getting on well with my lover too, though his negative status rears its ambivalent head and causes hassles. Nothing beats skin to skin; and in spite of the best creative efforts of the Demigods of safe sex culture to eroticise latex and to promote staying alive as a desirable long term goal, the jury is still out. Sex and Death; what a recipe!

It gnaws at my guts to admit it but we fuck unsafely at times. I agonise about it less as time passes because, you see, we've constructed this shimmering mystique which we've allowed to morph into a set of received truths; like – "It's OK if he only fucks me" – "I don't have any pre-cum; and my viral load is undetectable anyway" Then there's that definitive article of faith, "No cum in bum – no worries". Shades of "Beauty is truth, truth beauty". Keats, you old romantic, if only it were as easy as that. I still don a condom, but hubris is a seductive creature; and the beguiling "next time – next time" apes the ultimate cop out that life anyway is nothing but a farrago of fate and chance.

He's remained negative through all the years we've been intimate; through all the refinement of our delusions. And yet there

he is day after night, solid, glowing and sparkling healthy, and it's the virus that has become the delusion.

But I need to deal with this more immediate problem which seems related to the concrete, cognitive processes, like short term memory, and money matters; or with trying to brand repetitive tasks on my brain, like deleting messages from the pager at the Centre. I nearly ended up in tears once, pressing "UP" and "DOWN" buttons in a mist of confusion. And I took this volunteer job on to rehabilitate myself, because I wasn't going to die after all.

But it was the guy I mentioned earlier at the Centre, when he pointed out to me that I had just asked him the same question twice in the past five minutes – well, that freaked me.

Thanks anyway, but I'll forego the

lumbar puncture for the time being, if you don't mind. (Like I've stonewalled that liver biopsy for years now.) I think I'll plump for the neuropsychological battery of tests instead; sounds much more exciting.

No, I haven't put the soap in the fridge or the butter in the shower yet, but I did 'mislaid' some diced meat I'd bought the other day for dinner. Searched the kitchen to make the stir-fry. Two days later the meat made itself known in the corner of the bedroom. Yeah, joke: should have told the meat to leave that night.

There is something else Doc. Any chance of a top up? Those monsters in my head are stuffing up my sleep hygiene again, as they say. And some more of those other pills would be much appreciated; the ones that help with, you know, the pain. And yes, I'll be careful. I always am. ■

future dreaming

By Robert Baldwin



It was dark in the bedroom. There was only a slight glow from the orange street lights filtering through the wooden venetian blinds, but Tony could still see the cobalt blue eyes and sandy hair of his one true love. Since meeting John two and a half years ago he had held the dreamy desire to bed this man, not a stand-up butt slapping quickie, but a romantic night of endless passion to make the heart flutter. Finally it was actually happening.

Although Tony and John were close work mates, they had shared different social lives much to Tony's regret. Finally a mutual friend had intervened and they began to spend more and more time together doing the things queer mates do - partying, dancing, playing hard and flirting. Their flirting developed into a strong mutual desire and bed was next, after an appropriate length of courtship.

They rolled, they romped, they rubbed their sweat soaked bodies together. They licked, they sucked and finally after what seemed like hours of foreplay, Tony whispered (panted) into John's ear.

"Would you like to ... ?"

"Would I like to what?" John asked.

"Don't make me say it. You know what I mean. God, my bloody Catholic background never leaves me."

Tony's erection was wilting slightly under the imagined gaze of a bedroom full of frocked men leering from the end of the bed.

"You mean, would I like to FUCK!"

Tony felt the rush of blood to his cock. "YES."

John, playing with Tony's obvious embarrassment, coyly replied.

"I thought you'd never ask. But only with the safety suit on."

Tony, with the blood once more departing from his genitals, felt his soul missing the moment as tears seemed to involuntarily fill his eyes. The thought of his perfect match not being all he seemed to be was too much to bear. John, spurred on by the obvious blanching of Tony's facial and cock blood felt a much needed reality kick.

"I'm sorry. I didn't mean to scare you. It's just hard to change the pattern. Yes, I've been vaccinated against the virus and my latest check-up last month was all clear."

The air of passion had departed the bedroom as the two men lay back and remembered. The names and bodies may have been different but what they both recalled at that moment was strikingly similar. Visions of vibrant young men struck down by an invisible threat. They had both experienced what many others in their community had lived through and what the outside world referred to as the making of victims or the scourge of god upon the evil.

John's hand reached for Tony's and their separate mind videos became physically linked. They had both survived, why, they did not know. John and Tony were no better or worse than their comrades, just lucky. Their avoidance of viral capture was not due to saintly virginity or a forgiving god.

Their linked minds recalled the day of freedom when the usual stuffy government television news reporter smiled with secret

memories of his hidden passions and announced to the country that the vaccine to this 'terrible scourge' had been discovered. The feeling of jubilation had been evident. An instantaneous 'Mardi Gras' happened on the strip as the embattled community celebrated the end of the war. However the partying was tempered by the lack of an effective cure for those already living with the virus. They could not be saved this time.

Tony and John remembered recently lining up at the makeshift clinic for their vaccination under the sombre gaze of the not so lucky ones. These people did not begrudge Tony and John their chance to avoid illness. However the division between the infected and the uninfected had developed. Although compassion and empathy flowed freely from the lucky to the not so lucky, it appeared as though nothing could stop the march of this microscopic terror. But hope would never be abandoned by this community.

Their watery eyes met in a moment of understanding. They knew tonight was not right for passion. It would happen, but not tonight. They hugged in an embrace of love and understanding as they reasserted their right to love and as remembrance of all those friends who had not escaped.

"I don't think I can go through another one of these." John whispered.

"What do you mean?" Tony asked.

"Well we had AIDS in the 1980s, now BOC in the 2010s. What's the next virus these right wing bastards will release?" John felt his anger rising.

Tony kissed his man lover and they drifted into a mind float of safety. Safe in the knowledge that in their newly formed island nation of Queermania the fearsome dyke warriors would protect their male comrades from further hurt. ■

Robert Baldwin is a member of the PLWHA (NSW) committee.

Got a story to tell?

Talkabout welcomes stories and letters from PLWHA.

In our combined July/August issue **Talkabout** looks at creative ways to make ends meet; a week in the life of BGF; the HIV Futures II Survey; a report from AIDS 2000 in Durban, an ACON update, more PozTalk winners, our regular features ... and much more!

For more information please call The Editor, feona studdert on (02) 9361 6750, or email your story to feonas@plwha.org.au.

Talkabout welcomes your feedback on future directions for the magazine - so get involved ... it's your magazine.

Deadline for the July/August issue is **10 June, 2000.**



Contributors fees available for PLWHA receiving disability pension or similar low income.

HALC

HIV/AIDS Legal Centre

The HIV/AIDS Legal Centre is a community legal centre. We provide free legal advice and referral to people living with and affected by HIV/AIDS in NSW. A staff solicitor is available Monday to Friday from 10.00am to 6.00pm. Alternatively HALC holds an information night on alternate Monday evenings where volunteer solicitors give free advice sessions. We deal with topics such as superannuation, discrimination, social security issues and more.

To make an appointment please call us on

02 9206 2060.

All information is kept strictly confidential.

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Travel restrictions that stop people entering a country because they are HIV positive are one of the failures of the international response to HIV/AIDS. In 1987 the World Health Organisation concluded that travel and migration restrictions relating to HIV/AIDS are "ineffective as a public health measure, impractical, and wasteful."

Of course travel restrictions do not stop PLWHA from successfully travelling internationally for fun, work or activism: there are few countries like the United States or China that actually give a toss. But there are specific factors to consider when you are travelling - and most of these revolve around treatments and dealing with the law.

Ask the right questions

So for our feature this issue we asked two people addicted to travel to share their experiences. Brian and Rhonda come from different cultures and lifestyles. Both are intrepid travellers who refuse to let their status come between them and their boarding pass. Both have found a way through the challenges facing positive people who want or need to travel. We hope you enjoy the road.

New resources

We also asked AFAO to tell us about a new campaign that will look at the special relationship gay men have with travel and how this is affected by their HIV status. And we celebrate the launch of *International Travel and HIV: Advice for the HIV Positive Traveller*. This fact sheet has been produced by the Legal Working Group of PLWHA (NSW) - a group of dedicated volunteers interested in the many legal issues that touch the lives of positive people. The brochure outlines the entry guidelines to over thirty popular destinations. It also offers assistance in how to charm those intimidating embassy bureaucrats and gives a list of handy resources and tips to ensure your plans get off on the right foot. Contact 02 9361 6011 to be sent a brochure.

love my credit card love my status,

If the United States won't party, take your credit card elsewhere. That's the word from **Brian** who has launched his own personal protest at America's intransigence to HIV-positive travellers.



Travel! I love it. I'm a gay man with no wife, no kids, and no mortgage so it's easy. Last year I went to the United States twice, New Zealand, Mexico and six European countries.

To keep up this gruelling schedule I save hard and spend well. My biggest problem is those pesky pills, and what to do with them when I leave home. When I visit my family in New Zealand I take my box of pills and declare them. It's never a problem because as an Australian citizen we have a right to entry and the New Zealand Government does not discriminate against HIV positive travellers.

Get to know customs

It's the United States that presents the difficulty. I have the face that says 'snap on the glove boys'. Being stopped and questioned by customs people is now a regular feature of my itinerary. I even know customs people at Kingsford Smith airport by name, spooky really.

Because of the current policy of barring positive people from entering the US I do not carry drugs with me. The end. Luckily, because I know people in the States I do have a few options.

My preference is to post the drugs to friends - I use a rattle proof container and post them four to six weeks ahead of my departure. I send them in a normal small box marked as a gift with a present inside for my kind hosts. I don't think this is lying, as it is a gift of health to me and some trinket for my friends. My doctor gives me a prescription for a month's medication - very handy!

Blondes get through

My second option is to take a drug free holiday. I did this last year on my trip to Mexico. I didn't want anything to interfere with my plan to climb the Temple of the Sun and Moon and then fly to Acapulco for Easter. I need not have bothered in Mexico. The Customs officials were far more fascinated by my passport and travelling companion - a tall, blond, loud Queenslander, need I say more?

The catch was flying through the US. To get to Mexico you travel via California and we decided to stay a week at Miami. The tall blond Queenslander sails through customs at San Francisco with flapping arms, and wiggling hips screaming, "a fag, I need to put a fag in my mouth", and heads straight outside to light up. Meanwhile I get the third degree. As it



new zealand

turned out Miami was a big mistake; it's like the Gold Coast with absolutely no nightlife. It was almost the first time in my entire adult life that I have gone a week without sex, thank god for other tourists – well, Norwegian since you asked.

My personal protest

Unfortunately every time you are in transit through America you have to go through customs and immigration. Curse them, more stupid questions and looking at my luggage. I have no idea what they would do if I was going to Canada or Europe via

some American city and they found HIV medication. Throw me out when I was leaving anyway? Most certainly list my name, nationality and passport number onto their black list of undesirable aliens. So if in transit, I tell them that I do not wish to visit and I want to leave as fast as possible. This throws them off balance and they wave me through with disgust.

My passport is stamped with many USA visas. I first went there in 1980 and yet they continue to make it difficult for me. Would they be the same if I was on a

Package Tour? With a wife and children? Do I really look that queer?

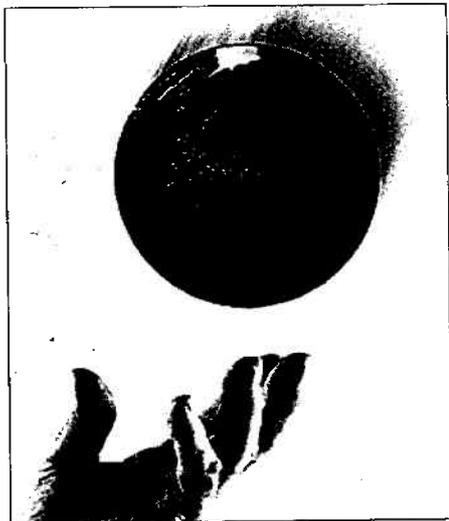
Who knows, but I've decided that the Americans do not deserve my money or patronage, so I won't be travelling to their shores in the near future. I can live without the stress of knowing that these pills, that have most certainly saved my life, mark me as unwelcome. For my money, I would rather visit one of the other 152 or so countries around the globe that seem to be more interested in the status of my Credit Card. ■

Brian is not his real name

It was almost the first time in my entire adult life that I have gone a week without sex, thank god for other tourists

when in rome ...

Dean Murphy looks at travel, gay men, and a new, national campaign



"Deep down we are little different from the ancient Greeks and Romans: we leave home and wander about the world to magnify our idea of who we are as human beings. It might not make us wiser, but leaving home unfailingly makes us feel more intensely alive." This was recently written by Robert Dessaix (appropriately for the Qantas inflight magazine) to suggest that we seek to find ourselves as much as to explore museums and monuments, by travelling. And the timelessness and freedom from the constraints of our usual lives allows us the opportunity.

The reasons people travel are many and varied. Positive people travel to experience new things, see famous sites, and experience different cultures. Many gay men talk about travel as an opportunity to be part of a larger gay community or world, or to seek the anonymity they need to try things that they wouldn't at home.

HIV treatments

Holidays also represent a change in routine and can be a time when PLWHA on antiviral therapy find it difficult to adhere to treatment schedules. Some people successfully develop routines around their travelling that are conducive to maintaining their treatments. Others may take treatment breaks because of the travel restrictions imposed by some countries on PLWHA. In some cases, however, treatment breaks may be taken for no other reason than fear or a lack of information.

Sex

In this country at least, travel or mobility does present a risk context for HIV transmission. In some Australian states a significant proportion of gay and other homosexually active men who become HIV positive believe that they acquired their infection outside the state—either in another Australian state or outside the country.

Moving outside the usual/home environment is sometimes associated with a freedom to abandon general practices. People often do more adventurous things when they are on holidays.

Some places offer opportunities for adventures and experiences that are not available at home, especially for those who live in small cities or regional centres. This is a strong theme among gay men. In fact gay men often choose travel destinations based on their sexual tastes or their own perceived sexual currency.

Introducing or suggesting condoms during sexual encounters can mean different things in different places. Not all countries have anything like the safe sex culture that we have become accustomed to in Australia. Access to condoms and lube is another issue. They are not always provided free of charge in many countries.

New campaign

The AFAO/NAPWA Education Team is developing an education campaign for gay men around HIV and travel. The campaign comes from interviews with positive and negative men in a number of Australian states.

The data will be used to document the range of meaning that travel has for Australian gay men. The project will also explore gay men's sexual decision-making processes and describe how sex occurs for gay men when they are away from their home environment.

We'll produce one resource for gay men (positive and negative) travelling overseas and another specifically for men from regional areas and smaller state capitals travelling to places like Sydney.

The campaign aims to assist gay men to maintain health while travelling. For negative men this means preventing HIV infection. For positive men this also means preventing the transmission of HIV, and avoiding other infections and maintaining your treatments.

For all gay men the campaign will look at making assumptions about your sexual partner's HIV status, negotiating sex and condom use, and some basic information that has been gleaned from other gay men's experiences.

Gay men will of course continue to travel far and wide. In the words of one of our interview participants: "This might sound a bit wanky, but I see myself as being on a mission to show ... HIV positive people that you can still get out there ... you don't have to sit down and just think 'well I'm going to die now'. Or even: 'I'm going to get old and then I'm going to die'. Boring." ■

Dean Murphy is a Positive Education Officer at AFAO

travel tips

The rule of thumb when planning a trip overseas is to be prepared - plan where you want to go as far in advance as possible. Here are a few tips.



Step One

It is very important that you find out about any entry restrictions that apply to the countries you are planning to visit. You can do this by phoning your AIDS Council or PLWHA organisation. You can also find out by contacting the local embassies or consulates of each country. If you do this, you should not reveal your HIV status or name to them. The information can change so it is important to double check. If restrictions do apply get advice from your local PLWHA organisation or AIDS Council.

Step two

Contact your PLWHA organisation, AIDS Council Treatment Officer for information and advice about:

- **Treatments** How do I adapt my pill schedule to different time zones and other tips for staying compliant? How do I transport my drugs; can I buy antiviral and other medications overseas; what do they cost; can I stock up before I go; do I need a letter of support from my doctor? Are there any legal issues I should know about taking medicines overseas?

- **Travel Insurance** What does it cost; where do I get it and what does it cover?
- **Eating sensibly** Boiling water and cooking and/or finding fresh food.
- **Me and my Medicare card** Which countries have Reciprocal Health Care arrangements with Australia and what healthcare is covered; what happens if I get sick in another country; what about private health insurance?

Step three

Talk to your doctor about any health precautions you should take while travelling. Your GP can give you advice on vaccinations, Malaria and other medications that might be required?

If you are quite ill, seek advice from your doctor about whether it is advisable to travel and whether you should inform the airline or an overseas doctor about any special requirements.

Step four

Make sure your power of attorney (someone to take care of financial arrangements while you are away) and wills are updated before you go.

A Medical Power of Attorney is a simple legal document that confers in many situations the authority to make medical decisions on your behalf to anyone of your choosing. Ask a lawyer to draft the document for you and carry notarised copies with you on your travels. Medical Power of Attorney is particularly useful if you are travelling with a same sex partner.

Get the phone numbers and names of AIDS organisations in the countries you are visiting. Your local AIDS Council can help you with this.

These two sites will answer most of your questions about travel, but if they don't, use the links and go surfing!

Travel Health on Line

<http://www.tripprep.com>

This is a site for everyone. It includes health and safety profiles for over 200 countries. If you're after facts about mundane and exotic travel-related ailments this is the site! There is also a comprehensive list of travel medicine providers in all major countries but be aware that the site producers offer no warranty on the credentials of any of those health providers listed.

Out and About

<http://www.outandabout.com>

A comprehensive gay travel site. Features destination information and a reference library that includes sections with all sort of advice and information on health.

Know the location of the Australian Embassy in each country that you visit.

Leave your travel plans and contact telephone numbers with a relative or friend.

Carry identification that clearly indicates the name of a person to contact in an emergency.

Step five

Be calm and confident at customs points.

Information compiled from resources including WHO, AEAO, and the Out and About website. Due to implications of HIV status when travelling to the United States the names of the two authors of our personal stories have been changed.

on the road again

Rhonda's involvement with international HIV/AIDS networks has meant international trips, talks and conferences. Now a sexual health educator, she is on the road and in her own country.

I refused any treatment for the first twelve years of my diagnosis. I believe the drugs that were available at that time were far too toxic for the human body. So getting through customs in countries like the United States was never a problem. I started combination therapy three years ago but still chose not to declare my medical status to immigration authorities. With one major exception I have travelled wherever I wanted without being questioned.

Walking Blues

In 1995 I was one of four positive women who travelled to Beijing to give workshops on AIDS at the International Women's Conference. When we arrived in Beijing the Chinese Government refused us entry, although the conference was sponsored by the World Health Organisation the Chinese held their ground. The Chinese Government finally agreed to waive the ban when the UN suggested withholding their sponsorship.

Through my travels I have met many women from different countries, exchanging ideas and learning about different peoples' specific needs. I've also attended many programs about ways to deal with government and the medical profession. These experiences have been enlightening, and by developing solidarity amongst positive women around the world, my sense of isolation has lessened. I have developed friendships and mourned the loss of many modern heroes who I would never have met if it weren't for my and my travels. I am saddened that most people with HIV (90%) do not have access to treatments or, for some, the most basic of health care. I often come home and feel how lucky I am; the universal health care system in Australia makes a significant difference to my quality of life. Unfortunately it looks as if Medicare is being cut, and the safety of our health care system is in jeopardy.

there is also a health care system to having a STD as a result of these indigenous people's diagnosis and treatment.

*... development
positive women
my sense of*

I am still rather than as new people, information, side effects, difficult to to have an months ago because of compromise, sensible to drugs for effects, health psychology, the course, cholesterol.

Gender Sex, education, elements, I have working and every

I would that's also person, committing people

Rhonda is a

Editor's note

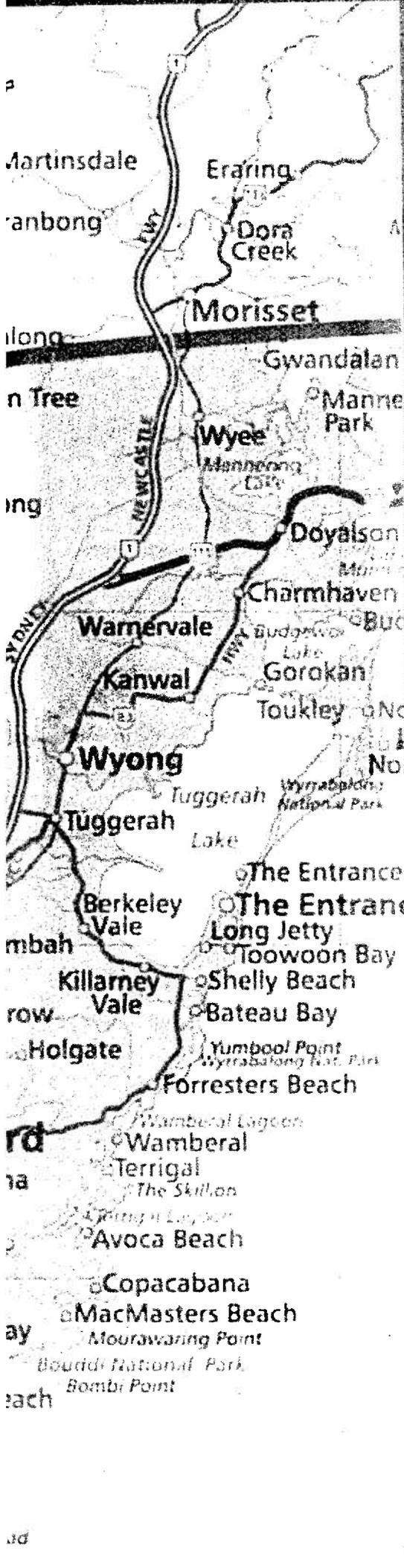
October 2000

The end

had

the

the



a message from the editor

The last nine months has been a period of intense change and growth for *Talkabout* and the Publications Unit of PLWHA (NSW). *Talkabout* has developed into a highly regarded magazine that aims to present the voices of PLWHA in all their diversity.

Many new subscribers have come on board and I thank each of you for your support. Community organisations work best when people on the street get involved in meaningful ways. Your subscription not only helps us financially but also gives us valuable feedback about the direction of the magazine's content and design.

Along the way there have been problems. Some of our subscribers have slipped through 'the cracks' and too many have had to ask us more than once to change their details. For this I apologise. We are doing all we can to fix the problems and I hope that by the end of 2000 our subscription database will be running smoothly.

Due to staff changes in 1999 we did not have our annual subscription drive. Consequently many of you may have forgotten to renew. In order to bring everyone into sync again we are introducing a change. All subscriptions will now cover the year from June 30 to July 1. From this year, you will receive a letter in late May/early June asking you to renew your subscription. We hope that you value *Talkabout* enough to renew or start your subscription as close to July 1 as possible.

For those of you who have already subscribed or renewed since January 2000, we will simply extend your subscription until June 30, 2001. An additional six months of delivering *Talkabout* to your door is our way of saying thankyou for your support.

A subscription to *Talkabout* is free for PLWHA who live in New South Wales and receive government benefits – but you should still renew your details and enclose a copy of your benefit card if you wish to continue receiving the magazine.

A word on the GST. We are still evaluating the effect of the new tax on the Publications Unit – so I have decided that subscription rates will stay the same for the next year. In June 2001 you should expect that the rates for organisations, overseas subscribers, and non-members living outside NSW would rise by up to ten percent.

Once again thanks for your support and interest in *Talkabout*. If you have any questions about subscriptions please contact me on (02) 9361 6750. The subscription form can be found on the inside back cover of this issue.

feona studdert
Editor

the rocky road to change



It is widely conceded that the HIV/AIDS sector must change to stay relevant in a tough political environment. But the road to change is rocky. **feona studdert** reports on the progress of ACON's vision for a broader engagement with gay, lesbian and PLWHA communities.

The AIDS Council of New South Wales (ACON) has given an absolute commitment to improve its HIV/AIDS services after a mixed response to the recent community consultations. The consultations centred on ACON's proposal to broaden the focus of the peak AIDS agency to include the wider health needs of the gay and lesbian community.

ACON President, Adrian Lovney, told *Talkabout* that the consultation process had demonstrated to ACON that PLWHA want an explicit commitment from the peak AIDS agency to maintain their HIV/AIDS care and support services.

"I can do that. I'm giving an absolute commitment to improve – not maintain, improve – HIV services in the short to medium term." Lovney said in an interview on April 14.

A mixed response

The commitment came after a meeting of eighteen community organisations on April 1 rejected the ACON proposal as "inappropriate and misconceived". The meeting was convened by PLWHA (NSW) at the request of care and support organisations in the Sydney metropolitan area. A Position Statement released after the meeting outlined the organisation's concerns and requested a response from the New South Wales Department of Health (DOH) which is yet to respond.

The Position Statement also raised concerns about ACON's existing service delivery, operational structure, funding, the consultation process, the leadership role of ACON and its relationship with the wider sector.

ACON held public consultations with the gay and lesbian communities and the HIV/AIDS sector throughout NSW to canvass reaction to a Vision Statement issued in February. The statement flagged the future of the peak agency as a "progressive health organisation, based in the NSW gay and lesbian communities." The vision statement went on to say that ACON's "continuing commitment to HIV will be complemented by an increased focus on the wider health needs of the gay and lesbian communities."

The Progress Report

A Progress Report (*see page 23*) outlining the feedback received revealed cautious support from the gay and lesbian communities for the ACON vision. The report also acknowledges that the process may have concerned some PLWHA.

"We have also heard some people tell us that they found our process unusual. Some people think ACON had already made up its mind and that we were just 'going through the motions' of consulting. We're sorry that some people thought that. Our intention was to do some preliminary research and thinking – then release a broad vision which people could engage with and debate".

The report also addresses some of the key concerns repeatedly raised in the course of the consultations.

"We need to make clear our commitment to political advocacy for all positive people and to strengthening the community and sector structures that support this", the report states.

"We need to make clear that one reason we want to 'do gay health' is because we think we can reach more positive gay men in that way and have a

better chance at improving their health. We think we can also prevent more new infections. We need to be much clearer that we are talking about the social dimensions of health, not creating a big medical centre model" continues the report.

The next step

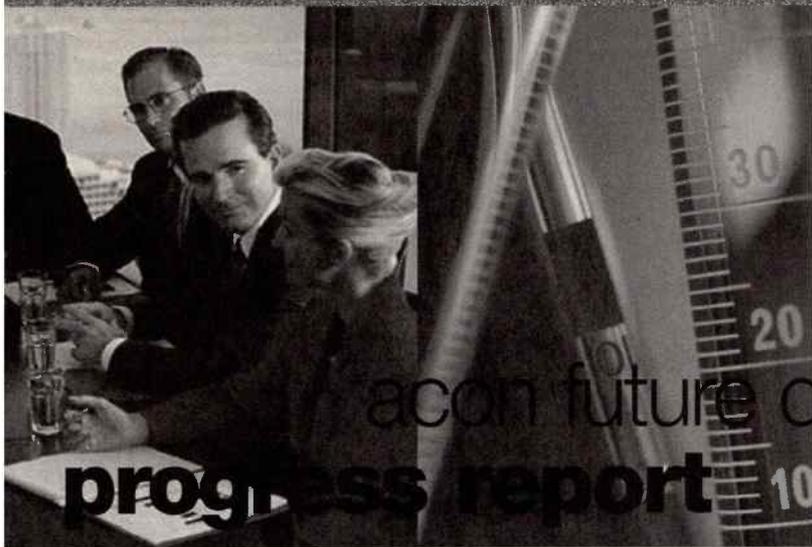
Lovney told *Talkabout* that the Board remains committed to the vision outlined in February but emphasised that the community response would be taken into account.

... I'm giving an absolute commitment to improve – not maintain, improve – HIV services in the short to medium term.

"We have heard people's concerns and have moved in our thinking – this is reflected in the Progress Report. We are now going to go away and think really hard about everything everyone has said and develop a new strategic plan which takes account of what we have been told, which we'll then consult on," Lovney said.

ACON expects to release its Strategic and Business Plans in June. ■

For details of the ACON consultations and a complete version of the Progress Report visit their website at www.acon.org.au. Copies of the community organisation's Position Statement are available from PLWHA (NSW) on 02 9361 6011. feona studdert is the Editor of Talkabout and coordinates the Publications Unit of PLWHA (NSW).



acon future directions progress report

ACON released a proposed Vision Statement in early February. Since then, we've been engaged in an intensive process of consultation. We've held meetings with our communities, our service partners, our clients, and our staff in six regional centres and in Sydney. We have also received many letters and emails.

This process is continuing, but now is a good time for the ACON Board to pause and reflect in detail on some of the things people have told us. It's not possible to capture everything but some of the main things we've heard include:

some people fear that ACON is saying that HIV/AIDS is over and positive services can now be downgraded. Many do not understand how, with limited funding, ACON can respond to new needs as well as improving existing services.

others fear ACON wants to establish a gay and lesbian health clinic, and will try to tackle all the health needs of gay men and lesbians.

people overwhelmingly value our lobbying and advocacy skills, and want those still to be committed to positive people and HIV issues.

people (including positive gay men) do not want ACON to weaken in any way our commitment to positive women and positive heterosexual men. ACON's work with Aboriginal people is starting to receive strong support. ACON needs to acknowledge that this work does not rely on gay and lesbian identity, even when working with Aboriginal gay men, lesbians and sisters/girls.

some lesbians fear we will promise too much and deliver too little.

outside Sydney, people have told us that they've been attempting to meet some of the broader needs of the gay and lesbian communities for some time now – even with stretched resources.

- people want to see our basic services improve and are worried we will try to take on too much and spread our resources too thinly – they do not want us to take on too many new things and fail.

We have also heard some people tell us that they found our process unusual. Some people think ACON had already made up its mind and that we were just “going through the motions” of consulting. We're sorry that some people thought that. Our intention was to do some preliminary research and thinking – then release a broad vision which people could engage with and debate.

We heard about some of the gay and lesbian health issues not currently addressed by the health system. A number of common themes arose:

- issues such as self esteem, depression, youth suicide, drug use and homophobia in health services, schools, and families affect our communities' health
- there is not the culture of sexual health testing (other than HIV) among gay men which existed before the epidemic – and these issues now underpin new HIV infections as much as a lack of safe sex and safe injecting knowledge
- issues such as mental health, poverty, violence, and poor access to appropriate health services also affect our communities' health – and addressing these things are now critical to a sustainable improvement in health for positive people
- the wider gay and lesbian community have largely failed to “welcome back” positive gay men and to embrace the diversity of their life experience
- almost all health settings are inappropriate for many lesbians, even some which are very women friendly
- ageing is an issue which affects the gay and lesbian communities: our community settings and structures provide little space for older people

- gay and lesbian experience is diverse and includes people with disabilities, people from non-English speaking backgrounds and others who are marginalised for a whole range of reasons, including drug use, sex work or just living rough.

So, how do we put all of this together?

We will start to draft, and to redraft, to distil our thinking and to respond constructively to what we have heard. We will do this but wanted first to try and make clear some basic points we are taking from all of this for our further thinking.

We remain fundamentally committed to HIV. We have not yet found the clearest way to say that. One commitment we want to make and to be held accountable for is to make our HIV services better. This doesn't mean just by doing new things but by improving the basics. That needs to be said loudly and clearly in our vision and for all positive people – regardless of their sexuality or gender.

We need to make clear our commitment to political advocacy for all positive people and to strengthening the community and sector structures that support this.

We need to make clear that one reason we want to “do gay health” is because we think we can reach more positive gay men in that way and have a better chance at improving their health. We think we can also prevent more new infections. We need to be much clearer that we are talking about the social dimensions of health, not creating a big medical centre model.

This isn't a money driven vision. We know people get nervous about funding. We have to be honest: there is no guarantee that any organisation working around HIV will keep receiving the same amount of government funding to do the work we currently do. Change will be careful and evolutionary. It will have to be negotiated with the government and communities, and based on our skills and history.

to page 24 ►

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from page 23 ►

ACON has spent the last 15 years growing new projects in new areas without jeopardising existing activities. Sometimes we've done this through voluntary energy, for low cost or without government funding. If we're clever, we can do this again and generate excitement and energy rather than fear.

Addressing the health needs of lesbians will be a challenge for ACON. But there is energy and input available from within the lesbian community and within ACON, provided we do not proceed in a rash way, or take on more than we can achieve and fail. We can envisage some partnerships with other agencies, around service delivery and advocacy, and we know we can be more inclusive in our gay and lesbian community health agenda.

Our commitment to Aboriginal people, to the diversity of regional NSW, and to being more effective with marginalised communities in and around inner Sydney each need to figure more prominently in our Vision. Now is not the time to weaken either our resolve or our accountability to these communities. This very consultation process, for example, has deepened our relationship with the Aboriginal Health and Medical Research Council of NSW. We are committed to pursuing these partnerships.

We also need to be clear that we support Aboriginal claims that land underpins health and that improving health in the Aboriginal community is not just a matter of specific disease strategies. We believe we can make a difference in partnership with Aboriginal communities and organisations.

We think we can continue to make a contribution to the health rights of illicit drug users and sex workers but we also

understand that this should never stop users and workers speaking for themselves.

We know people want detail and are frustrated that we don't have that yet. We're working on it. Based on these consultations, the Board will now do some more thinking - including talking more with those people who have indicated they want to be a part of that process. We will then draft a new Strategic Plan and seek some more input into that. By June we want to have a new Strategic Plan and a detailed Business Plan.

Overwhelmingly, what people have told us carries a lot of fear and mistrust. Some fear that a new program or service for some clients will mean a loss in service for them. Some of that fear is based in ACON's history. We know that we have a huge challenge in front of us but we are convinced that improved health for positive people and for our communities rests almost entirely in our ability to build bridges and overcome that fear and mistrust.

We want people to judge us against these commitments and hold us accountable for the most important part of all - the things we actually do.

Adrian Louney
ACON President

Robert Griew
ACON Chief Executive Officer

epistle-ette #5

Other Helen Highwater OPI (ret*) – on another thing that pisses her off



blessings and a Perpetual Indulgence
 gentle readers. Continuing on from
 y last bitch session, I bring you my
 nique perspective on one major
 convenience that I as a PLWHA
 ve had to bite my wimple and be
 lent about.

I received a letter from the
 ommunity Support Network (CSN)
 ntlining the reasons for the suspension of
 e PIN system of taxi travel. This service

allows PLWHA to book taxis for out of
 hour's medical-related appointments.
 Well, gentle readers, talk about a lot of
 bureaucratic gobbledey-gook. The PIN
 system, which had been in place for a few
 years, had now become unmanageable for
 the poor dears and the system was open to
 abuse. Please inform me, intelligent
 readers, of any system that isn't!

The small amount of people granted
 this freedom of mobility would not justify
 a statement such as "... the scheme had a
 negative impact on our budget ... " It was
 also suggested that for weekend
 emergencies the NSW Ambulance Service
 be used. Oh sure – for a private massage?
 For alternative therapies? Oh, if only I had
 one of those scanner thingies so that I
 could show you the letter, your blood
 would boil as well. This change in policy is
 tantamount to removing our access to
 after hours health service. The service was
 valuable to this nun because it gave me
 psychological freedom to lead as 'normal'
 a life as this wretched disease will allow.
 How about our mental wellbeing, CSN?

May I, in all humility, suggest that too
 many of our care organisations have
 succumbed to being budget instead of
 people focused.

Would it be a sin to even dare suggest
 that it's time for the CSN to become,
 again, a network of support for our
 community? And I've heard on my electric
 wireless that the State Government has
 increased funding to the local area health
 services. I look forward to seeing if there
 is any response to this lone nun baying in
 the wilderness.

Till next time, I love you all and care, in
 a motherly way, of course, for you as well. ■

* retired/retarded

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knock, knock ... let me in?

PLWHA must first jump through hoops if they want to call Australia home. **Chris Ward** surveys the fine print.

Anyone who applies to enter Australia is required to be in good health before they will be allowed to enter. In the case of short term visas, such as those for three or six months that tourists most frequently seek, this requirement will not prevent the entry of PLWHA. It is the practice to grant a visa even when an applicant discloses that they are HIV positive. When entering Australia with their medications, visitors with HIV are advised to carry with them copies of the prescriptions for their medications, or a letter from their doctor, listing the drugs the person will carry, and stating that the drugs have been prescribed for the person carrying them.

No business

For longer temporary visas HIV testing will be required, for example where a person seeks to enter Australia under a Business Sponsorship visa, to work in Australia for two years or more. If a person tests HIV positive, they will fail the health requirement, and will not be entitled to have the health requirement waived on compassionate grounds, in the way that some people who apply to migrate here are.

Migration to Australia

It is possible for PLWHA to migrate to Australia (that is, to move here permanently) in some circumstances. But it appears this is becoming more difficult. Australian immigration law requires that all potential immigrants satisfy a test of good health. All applicants for permanent residence aged fifteen years or over are

required to have an HIV test. In addition, children under fifteen are tested if they are to be adopted by an Australian resident, if they have a history of blood transfusions, or if it is clinically indicated.

A little compassion

Under the criteria used by immigration law, people with HIV will fail this test. However, certain classes of potential immigrants who satisfy "compassionate grounds" can apply for permission to move here permanently even though they have failed the health test. The recognised "compassionate grounds" are:

- having a spouse (including a de facto spouse) who is an Australian citizen or permanent resident;
- having a fiancé who is an Australian citizen or permanent resident;
- being in an interdependent relationship with an Australian citizen or permanent resident;
- being the dependent child of an Australian citizen or permanent resident;
- being a former Australian citizen; or
- being a refugee.

A significant proportion of PLWHA who apply to migrate to Australia are gay men in relationships with Australian citizens. Gay relationships are recognized by Australian immigration law under the "interdependency" class of applications. However, there is also a considerable number of applicants who are not gay.

PLWHA applying in one of the categories listed above must satisfy the Australian authorities that they will not:

- prejudice the access of Australian citizens to healthcare facilities;
- be a risk to public health or safety; or
- constitute an undue cost to the Australian community

The cost of your health

Satisfying the first two criteria is not a problem for PLWHA, but they are sometimes refused permission to migrate because of the projected cost of their health care. Costs are assessed for each applicant, and will include a lifetime estimate of all medication, hospital-based, and other medical care.

It appears that this criterion is being enforced more harshly than it used to be, and that more PLWHA are being refused permission to migrate because of the estimated cost of their healthcare. That is not to say that everyone who applies is refused. It appears that in the past, a cut-off point was set at \$240,000 in lifetime costs, but that the figure now used may be \$200,000.

It appears that ... more PLWHA are being refused permission to migrate because of the estimated cost of their healthcare.

Immigration authorities take into account a range of factors such as:

- the amount of social welfare, medical, hospital, or other institutional or day care the person is likely to require;
- the potential for the applicant's state of health to deteriorate;
- the willingness of a sponsor, family member or other person to provide care and support at no public cost;
- if there are any "compassionate grounds". ■

Chris Ward is the Legal Officer at AFAO. For further information contact Chris on 02 9281 1999

... except my genius i have nothing to declare

John Cummings and Graham Norton examine the perils of travelling with medication.



Although you may be clinically well and looking healthy, travelling overseas with HIV medication can require intensive pre-planning and nerves of steel. Passing through different time zones can interfere with your dosage schedule. One way of overcoming this is to maintain your original dosing times until you reach your destination. Then you can gradually reconfigure the dosing times until they fall at the same intervals as at home. But the most stressful aspect of travelling with medication is when you are entering countries whose laws prohibit entry to positive people or where being positive is looked upon less than favourably.

Catch 22

The United States is a popular destination for Australian tourists and business travellers, both HIV positive and negative.

Unfortunately the US imposes an outright ban on the entry of HIV positive visitors, although they sometimes offer a waiver for special circumstances such as attending a conference. The Catch 22 is that applying for a waiver identifies you as a positive person to the US authorities, whether you are approved for the waiver or not. Even if you get the waiver, you must reapply for another waiver whenever you want to travel there again.

The art of postage

Positive people have taken various precautions to avoid the consequences of such grossly unfair legislation. If you are going to be away for more than a few weeks, one idea is to post most of it ahead of you and only pack as much medication as you need for the journey. Be aware that you will need to make a customs declaration when posting medication. Posting prescribed medication for personal use is perfectly legal, but Australian customs authorities are attempting to intercept the illegal smuggling from Australia of subsidised medications for resale overseas. The Australian Health Insurance Commission recommends enclosing a letter from your doctor explaining the medication is for your personal use. The letter need not state the nature of your condition.

Some people address their parcel to a contact in the destination country, while others post it to themselves at the address they will be staying at. The receiving country's postal people will need to see the customs declaration stating that the parcel contains prescription medication of no commercial value. When posting, allow four to six weeks on top of the usual postal time in case of customs investigations at either end.

Some people have repackaged the medications they carry into vitamin bottles and other containers. However, some medications such as indinavir are sensitive to moisture; repackaging may jeopardise their stability. Also, the Australian Health Insurance Commission may consider this proof of smuggling.

Pick up the phone

Some countries ask on their immigration form if you have an infectious disease. Diseases such as tuberculosis are much more infectious than HIV and some positive people have felt quite comfortable saying no to questions like this. More information about overseas countries' restrictions on HIV positive visitors can be found in International Travel for Positive People, a factsheet published this month by PLWHA (NSW) (see the sidebar on page 16). In the rare event of an emergency, it's a good idea to know where to find HIV community organisations in the country you are visiting. Contact ACON's Treatments Information Officers, who can give you the addresses of AIDS organisations worldwide. They can also discuss any other difficulties that may arise when travelling with medication.

Positive people here know that they do not pose a threat or health burden to countries like the US. If you are still worried that such discriminatory legislation will interfere with your travel plans, remember that creative thinking and careful planning have allowed many other Australian PLWHA to fulfil all their travel expectations. ■

John Cummings is an ACON Treatments Information Officer and Graham Norton is an ACON HIV Health Promotion Officer. For more information about treatments and travelling call ACON on 02 9206 2000 and PLWHA (NSW) on 02 9361 6011.

Adherence Often shorthand for 'strict adherence to therapy', meaning pills are taken exactly as prescribed – on time, every time, and observing any specific dietary requirements. Also referred to as 'compliance'; less frequently, as 'concordance'

AIDS 'acquired immunodeficiency syndrome'

Antiviral A simplified term for antiretroviral drugs. Both terms refers to any drugs which are designed to inhibit the process by which HIV replicates. The more technical term antiretroviral refers to the fact that HIV is a retrovirus.

Antiretroviral a scientific term for antiviral drugs.

CD4 cells (also called T cells or T helper cells) A type of blood cell involved in protecting the body against viral, fungal and protozoan infections. CD4 cells are part of the human immune response. The CD4+ test is a measure of how your immune system is coping.

Cholesterol A pearly, fat-like substance produced by the body through the liver. Also found in external dietary sources like animal fats. High levels of cholesterol are associated with hardening of the arteries and heart disease.

Clinical trial Studies which test experimental medicines in humans, in order to establish that they are safe and effective. Clinical trials are staged in 'phases', beginning with small numbers of people, then tested more widely as data on safety and efficacy is established.

Combination therapy Treating HIV with a combination of two or more antiviral drugs at once to suppress viral replication and minimise the opportunities for the virus to become drug resistant.

Compliance see *adherence*

Cross-resistance Virus that is resistant to several or all of the drugs within a particular class of drugs (eg. to several or all protease inhibitors)

Drugs that directly treat HIV (antiviral drugs)

There are three different classes of drugs currently in use, which block HIV replication at different points in the life cycle of the virus.

Nucleoside reverse transcriptase inhibitors

Abacavir (Ziagen) also known as 1592
AZT (Retrovir) – also known as zidovudine
AZT/3TC (Combivir) – combined pill
ddC (HIVID) – also known as zalcitabine
ddI (Videx) – also known as didanosine
d4T (Zerit) – also known as stavudine
3TC (EpiVir) – also known as lamivudine

Non-nucleoside reverse transcriptase inhibitors

nevirapine (Viramune)
delavirdine (Rescriptor)
efavirenz (Sustiva or Stocrin)

Protease Inhibitors

Amprenavir (formerly known as GW 141): still in development
indinavir (Brand name: Crixivan)
lopinavir (known as ABT-378): still in development
nelfinavir (Viracept)
ritonavir (Norvir)
saquinavir hard gel capsule (Invirase)
saquinavir soft gel capsule (Fortavase)

Talkabout May/June 2000 ♦ Page 28

Experimental drug A drug which is not yet licensed but which is being evaluated for safety and efficacy

HIV Stands for 'human immunodeficiency virus', the virus that causes AIDS.

Immune system The body's natural defence system that seeks out and destroys invading organisms.

Lipodystrophy A clinical condition involving body fat redistribution and high levels of glucose, cholesterol and triglyceride levels. Men commonly experience increased fat around the stomach and upper back and women can experience a narrowing of the hips and breast enlargement. Thought by many to be associated with the use of protease inhibitors.

Metabolism The sum of all the physical and chemical processes occurring in body tissue. Includes those reactions that convert small molecules into large (anabolism) and those reactions that convert large molecules into small (catabolism).

Nucleoside analogue drugs see *Reverse Transcriptase inhibitor*

Prostate cancer Cancer of the prostate gland that surrounds the urethra of males at the base of the bladder.

Protease Inhibitors Protease is a substance that breaks down proteins. When first made into a cell, a number of HIV proteins are joined together. HIV protease breaks them into functional proteins. Protease inhibitors interfere with this stage in the HIV cycle, slowing the progression of viral infection.

Resistance The ability of a micro-organism like HIV to escape the control of the drugs used to fight it. In terms of HIV, this happens when the virus mutates during the replication process. Viruses like HIV, which have their genetic material encoded in DNA, lack critical genetic 'proofreading' mechanisms. So when new copies of HIV are created, often, minute errors in the genetic translation will occur. Over time, HIV may develop small changes to its structure which means that anti-HIV drugs, which are designed to interfere with the virus in quite specific ways, will not be able to control it.

Resistance test A test which looks at the genetic structure of HIV to determine if any mutations in the virus would make it likely to be resistant to particular antiretroviral drugs. Sometimes referred to as resistance assays.

Reverse transcriptase inhibitor A kind of drug which works to inhibit HIV by interfering with the enzyme which allows HIV cells to replicate. There are two kinds of HIV reverse transcriptase inhibitor: the nucleosides (sometimes called nucleoside analogues), and the non-nucleosides.

Glossary

\$100 drugs licensed under section 100 of the National Health Act, and mainly, but not exclusively, antiretroviral drugs.

Salvage therapy A combination of drugs, often more than three, and which may or may not include the re-use of some drugs used in past regimens, which is intended to drive down viral load and push up CD4 cells as quickly as possible, if a person is not responding to their current treatments and in danger of becoming ill.

Steroids (anabolic) Any of a group of synthetic derivatives of testosterone, which are clinically to promote growth and repair of body tissues in senility, debilitating illness and convalescence. Also used by body builders to build muscle.

T cells See *CD4 cells*

Treatment holiday 'Breaks' from antiviral therapy. Should be distinguished from structured interruptions to therapy under medical conditions.

Undetectable viral load Tests currently licensed in Australia cannot reliably detect and quantify virus particles if there are less than 400 or 500 per millilitre of blood. An undetectable viral load result does not mean that there is not virus present, or that replication is not occurring. It means HIV is there in levels too low to accurately measure. An ultra-sensitive viral load test that will be able to measure down to as few as 50 copies per ml of blood is expected to become commercially available soon.

Vaccine (therapeutic) An agent introduced into the body that is designed to stimulate an immune response to a virus or infection that is already in the body.

Viral load The quantity of virus measurable in blood serum or other fluid or tissue. This test is used to show how active the virus is at any particular time. The test is also used to show whether the treatments you are on are having any effect.

- ACON AIDS Council of NSW
- AFAO Australian Federation of AIDS Organisations
- NAPWA National Association of People with AIDS
- PSB Positive Speakers' Bureau
- PLWHA People living with HIV/AIDS

Sources
Terms taken from, but not exclusive to, the following:
Dorland's Medical Dictionary, 28th edition, 1994
Taking Care of Yourself, AFAO NAPWA, July 1999
HIV Drug Book, AFAO, 1998
Living With HIV/AIDS, Peter de Ruiter, Allen & Unwin, 1996
Positive Living, various, AFAO 1999/2000

ACON

AIDS Council of New South Wales Inc.

ACON is delighted to host the NSW launch of **TREAT YOURSELF RIGHT** *a new resource for positive women*

This launch is for positive women, friends and service providers

12.30 to 2.30pm | Thursday May 4, 2000

The Sanctuary, 6 Mary St, Newtown

TREAT YOURSELF! Come and be pampered!

Try a foot massage or laughter therapy, beauty make-overs, and more!

Delicious finger food and beverages provided.

Child-care is also available.

Treat Yourself Right is produced by the AFAO/NAPWA Education Team, in collaboration with HIV organisations and in consultation with positive women



napwa

a project for positive men run by positive men

HIV living

Information

Support

Empowerment

Self Esteem

'Genesis' Workshops a free weekend for those recently diagnosed (in the last two years). Helping you to make sense of a range of issues such as treatments, support, sexuality and disclosure. The next workshop is at the end of May 2000

Peer Support Groups 8 to 10 week groups, run by trained facilitators who are HIV positive. Groups are starting all the time
One-to-One Peer Support offering support, advice and information. Face to face or over the phone

Planet Positive a bi-monthly social night for positive people and their friends

Newsletter regular and informing

Office Space for positive people offering access to a computer and the Internet

For more information about any or all of the above contact the HIVliving team at ACON on 9206 2037 or 9206 2050 or Freecall 1800 063 060 or email hivliving@acon.org.au

ACON

AIDS Council of New South Wales Inc.

address PO Box 350 Darlinghurst NSW 1300 Australia phone (02) 9206 2000 fax (02) 9206 2092 TTY (02) 9283 2088 website www.acon.org.au email acon@acon.org.au

work out your blood tests

ACON offers two new ways to help you understand what your blood tests really mean.

A **brochure** explaining how to read your blood test results.

A **workshop** answering your questions on treatments and test results.

Workshop starts June 2000

Phone John & Barrie on 9206 2000 to register.

healthy + life

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- ◆ Support groups
- ◆ individual support, information and advocacy
- ◆ Family Support
- ◆ newsletters
- ◆ resources – Women and HIV factsheets, *The Informer, My Sex*
- ◆ treatments information and resources
- ◆ counselling
- ◆ vitamins services
- ◆ community forums
- ◆ website: <http://www.acon.org.au>
- ◆ TTY: (02) 9283 2088

Facilitator training for positive women

NEW!

If you would like to become a facilitator for one of the women's Peer Support Groups, please phone (02) 9206 2083 or (02) 9206 2012 for more information

ACON's Women and HIV Speakers Series

NEW!

Starting in June, this bi-monthly series is open to positive women service providers and community organisations who want to keep up-to-date with the issues. Speakers Program available, call Suzie on (02) 9206 2084.



Luxford Road Clinic

take control of your sexual health

complete investigation and treatment for all sexually transmissible infections | testing for hepatitis and HIV | all women's health services
| Pap smears and breast checks | contraception | counselling

Clinic staff provide a professional, caring non-judgemental, free and confidential service which enables people to take control of their own sexual health.

The Clinic is open

- ◆ Monday, Wednesday, Thursday and Friday
- ◆ Thursday for Aboriginal and non-Aboriginal women

**You can drop in or ring for an appointment.
No medicare card is required**

For further information or to make an appointment ring 9881 1733
or simply come to the Luxford Road Clinic, off Luxford Road,
in the grounds of Mt Druitt Hospital.

everyone is welcome

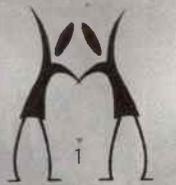
Western Sydney's 1st Annual one-day conference for HIV+ heterosexual people and their partners is on soon!

Family Matters

Saturday May 27 10.00am - 4.30pm • Blacktown

Want reasons to come along? Try lots to do, fun and laughter, panel games, quizzes, good food, make friends ... and it's all free! **Activities include:** Around the family table the other side of family life *There's something I need to say* telling the family *Change those attitudes!* making up with the family *Okay, so what's safe?* improving family confidence

Book now! (02) 9671 4100
1-5 Marion Street, Blacktown



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Top speakers comfortable venue a few minutes from the railway station free car parking

go on ... do it!

Diary



Events

Outings Outings are free events for positive people, carers and friends coordinated by South Eastern Sydney Area Health Service. Coming up on the May 5 is a bus trip to the Blue Mountains; June 2 a bus trip to Captain Cook's Landing; June 30 a taste of complementary therapies. Contact Jane on (02) 9319 4439 or Carolyn on (02) 9382 8374.

Positive Heterosexuals Positive Heterosexuals is a peer support and education project. Saturday and Sunday May 6 and 7. Pozhet-by-the sea at Shellharbour beach weekend for HIV+ heterosexuals men, women their partners and families. Details: Freecall 1800 812 404.

Support

Family Matters in the West Conference May 27 HIV+ heterosexuals coming together to develop positive ways to stay health and live well. The theme of the conference is 'Family Matters'. The program looks at: Strategies to deal with pressures faced by HIV Families; Disclosure and HIV; Changing attitudes; What's safe in the family. Family Matters will be held on Saturday May 27, 9.30am to 5pm, at 1-5 Marion Street, Blacktown. Contact Marie Lavis (02) 9671 4100 or David Barton Freecall 1800 812 404 or (02) 9515 3095.

Telephone support group for mothers The Ankali Project is currently planning a telephone support group specifically for mothers living outside the Sydney metropolitan area who have adult children living with HIV/AIDS. The group will start in June and run for eight weeks. For further information please ring Mary Bayldon on (02) 332 9742.

Pozhetwest Western Sydney peer support and education for men and women living heterosexually with HIV/AIDS. Contact (02) 9671 4100.

Grief support for young people and Youth Suicide Project The Project provides individual counselling, support for schools after a suicide, community education and a schools program promoting mental health. This is a free service available for young people aged 15-25 living in the Eastern Suburbs. Telephone (02) 9360 3232

Support group for significant others of people with HIV/AIDS related dementia The group offers respite care, company and support. Meets last Wednesday of every month at the Tree of Hope, cnr Riley and Devonshire Sts, Surry Hills. Contact Angela Kelly (02) 9829 4242 and Carole Knox (02) 9580 5718, the AIDS Dementia Outreach Team 02 9339 2078 or David at The Bridge (02) 9552 6438.

Shopping spree The Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt.

They'll pick you up from home, give you two hours to shop, then drop you off again. \$4.00. Available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville and Darlington. Call Diana on (02) 9516 4755.

Living with loss Evening groups (six weeks) for people who have had someone close to them die within the last two years. If you are interested phone the Sacred Heart Hospice on (02) 9380 7674.

HIV living peer support groups Joining a support group can be a great way to meet other positive guys and to share experiences of what it means to be HIV positive. For more information about when the next support group is starting, contact the HIV living project at ACON on 9026 2037.

Learn

Free Courses Wesley Mission is conducting free courses in film and video, plants and gardens, hospitality, and sales and marketing. Call Vicki or Anna on (02) 9261 4855.

Your Community Gym - Fit X Gym Fit X Gym is at the Community Pride Centre, Hutchinson St, Surry Hills. "Positive Access Project" offers qualified instructors, free assessments, free nutritional advice, free individual programs and free session to try out gym. \$2 a session or \$18 for a 10 visit pass. Contact Ingrid on (02) 9517 9118 leave a message and your call will be returned. Fit X Gym (02) 9361 3311 4pm-7pm Mon to Friday.

Home and Away Wanted: Gay men (HIV positive and negative) to talk about travel experiences overseas or interstate for a national research and education project. Interviews will take approximately one hour. Confidentiality assured. Call Dean on (02) 9281 1999.

Yoga for People with HIV/AIDS Special weekly classes at Acharya's Yoga Centre. Call (02) 9264 3765 for more information.

For Sale

Computer "Beyond" Pentium 166 Staright Monitor - Internal Speaker System, Keyboard, Canon Bubble Jet Printer Microsoft Windows Office Professional 95: Microsoft Word 7, Excel, Access, PowerPoint, Binder, Schedule. \$600.00 (ono) Contact Michael on 9300 6078 (home) or 0414 288 816 (mobile)

Talkabout Diary is a free listing for community and non-profit events. Listings in the Talkabout Diary are welcomed and encouraged. Please keep your listings below 40 words. Deadline is the 10th of each month. Please send your listing to Talkabout Diary, PO Box 831 Darlinghurst 1300, email: feonas@pluhx.org.au or fax: 02 9360 3504.

Olga's

Personals

ally nice male 30s, HIV+ Maintaining food physical and emotional health (never been <). 6ft, 83 kg. Is caring, affectionate and reliable. Lives in Melbourne. Is seeking genuine, ing female. Also would like penfriends interstate. **Reply 030500**

ring, sincere 34 yo. HIV+ heterosexual male looking for a HIV+ female to enjoy life's finer things together. I have many interests such as swimming; reading, music, bushwalking, nics, and dining out just to name a few. If you're interested - age open, kids OK - please **ply 020500**

yo, heterosexual guy HIV+, good in health 6ft, 66kg, Asian background lives in Sydney. honest, non-smoker, DTE and caring, easy going and likes quiet times. Would like to et heterosexual female with positive attitude 20-30, kind, honest, caring, with GSOH, friendship/relationship. Nationality no bars. **Reply 030500**

+hetero guy, 36. Lives Coffs Harbour Area, self employed carpenter. Enjoys fitness and athly lifestyle. Likes socialising, cooking, swimming, walking and quiet times. Seeking ing sharing female for life of fun and companionship. **Reply 010400**

ndsone, happy, professional gay man, 34, HIV positive and in excellent health, seeks male partner to jointly conceive and raise a child. GSOH, love of children and optimistic ure required. Practical details negotiable. **Reply 020400**

rene caring sincere passionate 39 yo HIV+ female, seeking friendship with sincere loving passionate gent, for quiet memorable times together, view to relationship if npatible. All replies answered. Please, no baggage. **Reply 010300**

Poz het male 24, single dad of 1, seeks poz het female, Northern Rivers area, to correspond with a view to meet. I am fairly quiet type, honest and caring. Discretion assured. Enjoy nights in, eating out and movies. **Reply 030300**

Guy 51 Lives Ryde area, HIV+ and healthy. Good shape 6'1" 85kg businessman. Enjoys entertainment, music, movies, videos, and a quiet drink. Would like to meet male or female for friendship, outings, companionship and home relationship. Please include phone number. **Reply 020200**

Gay guy, 50s, lives in NSW country, seeks any other HIV+ person to share my house and quiet times. All I ask is for someone honest, reliable. Please include phone number. **Reply 011199**

30 yrs old, positive, little bear cub. Try anything once. Looking for gym and swim partner as well as a mate to have some close times with from 18 to 30 yrs. I work heaps and love life. I hope you love life too. **Reply 031199**

36 hetero male, American, new to Sydney, healthy, very good shape, successful professional, discreet about status, living totally "normal life", never been sick, no baggage, seeks female who likes to laugh for friendship/relationship. **Reply 021199**

Hetero guy 38 HIV+, employed, easy going, positive attitude with GSOH needs a mate, HIV+ or - to share life with. Eventually would like to have HIV- children. Nobody knows I'm HIV+ so discretion a must. **Reply 021099**

Abbreviations: GSOH good sense of humour DTE down to earth

ow to respond to an advertisement Write your response letter and seal it in an envelope with a 45c stamp on it • Write the reply number in pencil on the outside • Place this evelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst 2010.

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

hyp



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Aidsmap

<http://www.aidsmap.com>

Rating Interesting, interactive British site full of little gizmos that put it a spot above the average.

I love the scrolling bulletin board, and a search engine to the left of the index page. Underneath this is an advert for the latest booklet called 'Glossary', the sixth in a series. It, and the others, can be read online. In the centre of the page is a selection of treatment links, news from the BHIVA (British HIV Association) conferences, Aidsmap News, and the Elton John AIDS Foundation links. The right of the page has buttons linking to the BHIVA site, and NAM (National AIDS Manual), another scrolling window with AIDS Updates, and news headlines for this week (yes, up-to-date). At the top of the page, links lead to News; Treatments – everything from the basics to clinical trials. This page also contains a search engine; Services links to UNAIDS, the Elton John AIDS Foundation, and AIDS Organisations Worldwide Online, which is available in German, English, Spanish, French, Italian and Portuguese; Books links again to the bookshop, and there is a Links page and a Site Map.

Reflexology – A Better Way To Health

<http://www.ozemail.com.au/~sharonc/practice.htm>

Rating One of a number of alternative therapy sites that I would like to cover in future columns. A simple site that gets the message across.

'More About Reflexology' opens to an explanation on what reflexology is, and the

benefits that can be derived from its use. 'See a Foot Chart' gives you examples of three different styles of foot charts and explains how they are used. 'Success Stories' links to two stories on the effectiveness of reflexology. I could add my personal experience (positive), but I won't bore you. 'Having a Reflexology Treatment' gives you details of what is involved in a treatment. Unfortunately, the reflexologist who put up this site lives in Tasmania. I'm sure you can find good treatment closer to home.

Editor's note: contacts features a guide to local alternative therapy practitioners and websites and will be published by PLWHA (NSW) in July 2000

The Elton John AIDS Foundation

<http://www.ejaf.org/ejafuk.html>

Rating The website of ... you guessed it! Even as a HIV site, it's camp!

The index page gives a rundown on what the Foundation is about. 'Mission' link leads to their Mission Statement, and Vision; 'Education' has additional links to facts and statistics, a 'special millenium message from Elton', and several other projects. 'Events' takes you to the dates of overseas events to raise money; 'Merchandise' to goods that can be purchased, (including a watch, candles (Elton Series 1 and 2, and a Millenium series), a book entitled 'Dockers Khaki – Cut from original cloth' – could this be an Elton fetish?, a Sir Elton Claus ornament for the Chrissie tree, a VISA Platinum Plus Credit Card (which you probably need to buy this stuff), and limited Edition Spectacles 111. 'Donations' tells you how to do just that starting at \$25; 'Press

Release' tells you how you could have got a kiss from Elton back in February; 'Resources' informs you how to contact the Foundation and apply for a grant; 'Accomplishments' is about the grant program and what it has achieved; and 'EJAF-UK' takes you back to the objectives page.

HIV Straight

<http://www.hivstraight.com>

Rating I have been after positive heterosexual sites for some time. This is a start.

The index page has links leading to Chat Room; Personal Ads; Help Spread the Word About Us; Find Other HIV+ Heterosexuals in your state (NOTE This is an American site); National HIV Heterosexual Events; Message Boards; Chatter Profiles; Marylands HIV+ Heterosexuals Support Group; Live AIDS Radio Broadcast; Great Medical Information Links; FDA Approved HIV Medicines; HIV Women; Contact Your Politician; National HIV Magazines; Pictures from Heterosexual Events; Email Support Group Links; Heterosexual Support Groups From All Over; Medical Escrow Society; Purchase Your AIDS Ribbons; HIV Heterosexual Links. You can also add a link, and review submitted links, there are Elton John Pictures, Personal Interest Pages, POZ Friends Home Pages, HIV Related Jobs, HIV Owned Businesses, Certification, and Prayers For People. The 'Special Interest' section towards the bottom of the page links to Face to Face of Northern Virginia, and information about the site owner.

quickclicks Family and Community Services <http://www.facs.gov.au> Want all the ins and outs on Senator Newman and her welfare reform report? Well, this is the site for you. Also links to tax reform. **HIV Dentistry** <http://hivdent.org>
A great site for people like me who have ongoing HIV related dental problems.

Subscribe now

VHA Membership Yes! I want to apply for membership of PLWHA (NSW) Inc.

\$ 2 Full member (NSW resident with HIV/AIDS receiving benefits) \$15 Full member (NSW resident with HIV/AIDS in employment)

\$15 Associate member (NSW residents affected by HIV/AIDS)

possession of HIV status entitles you to full membership of PLWHA, with the right to vote for all management committee positions.

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