

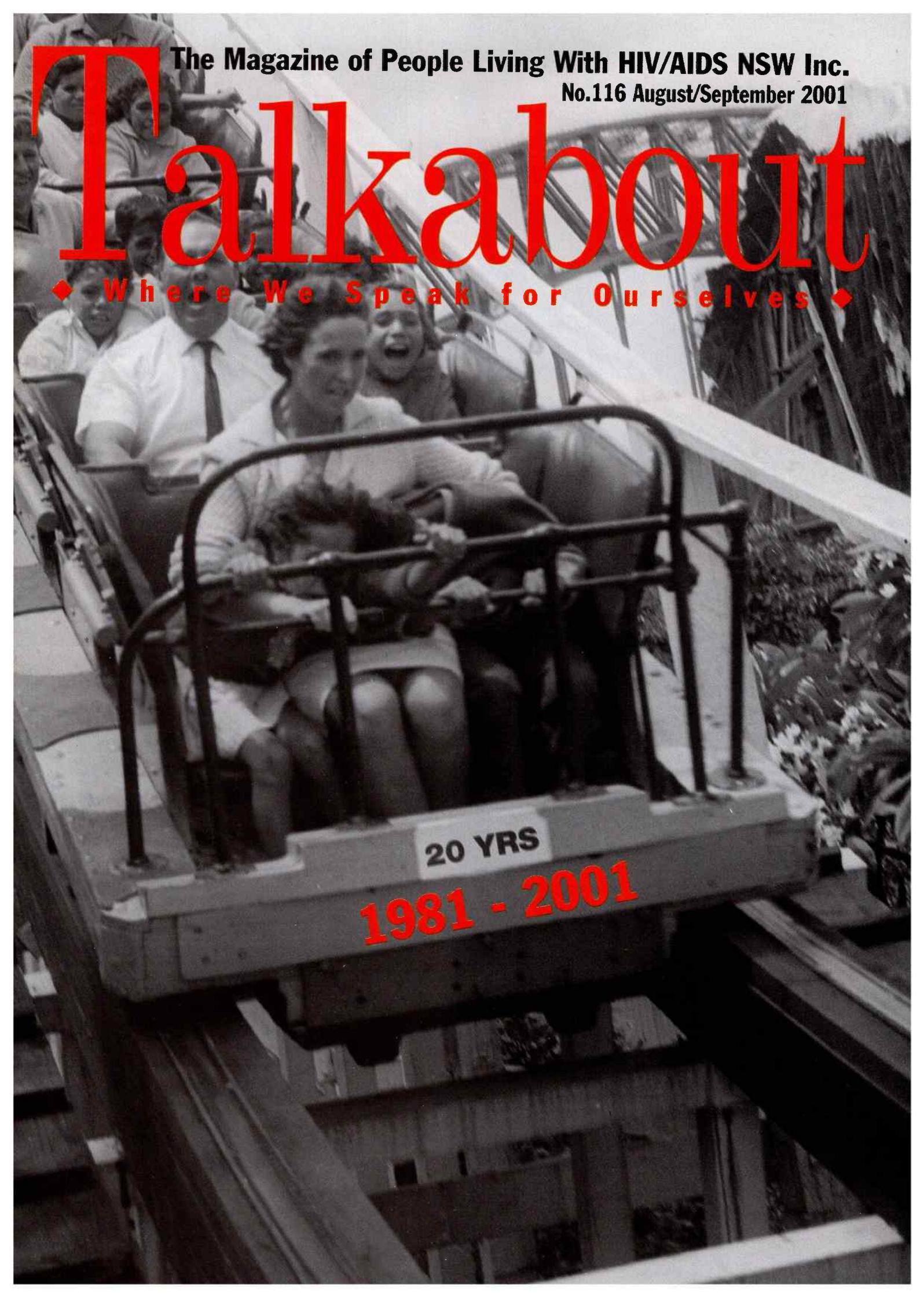
The Magazine of People Living With HIV/AIDS NSW Inc.
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Talkabout

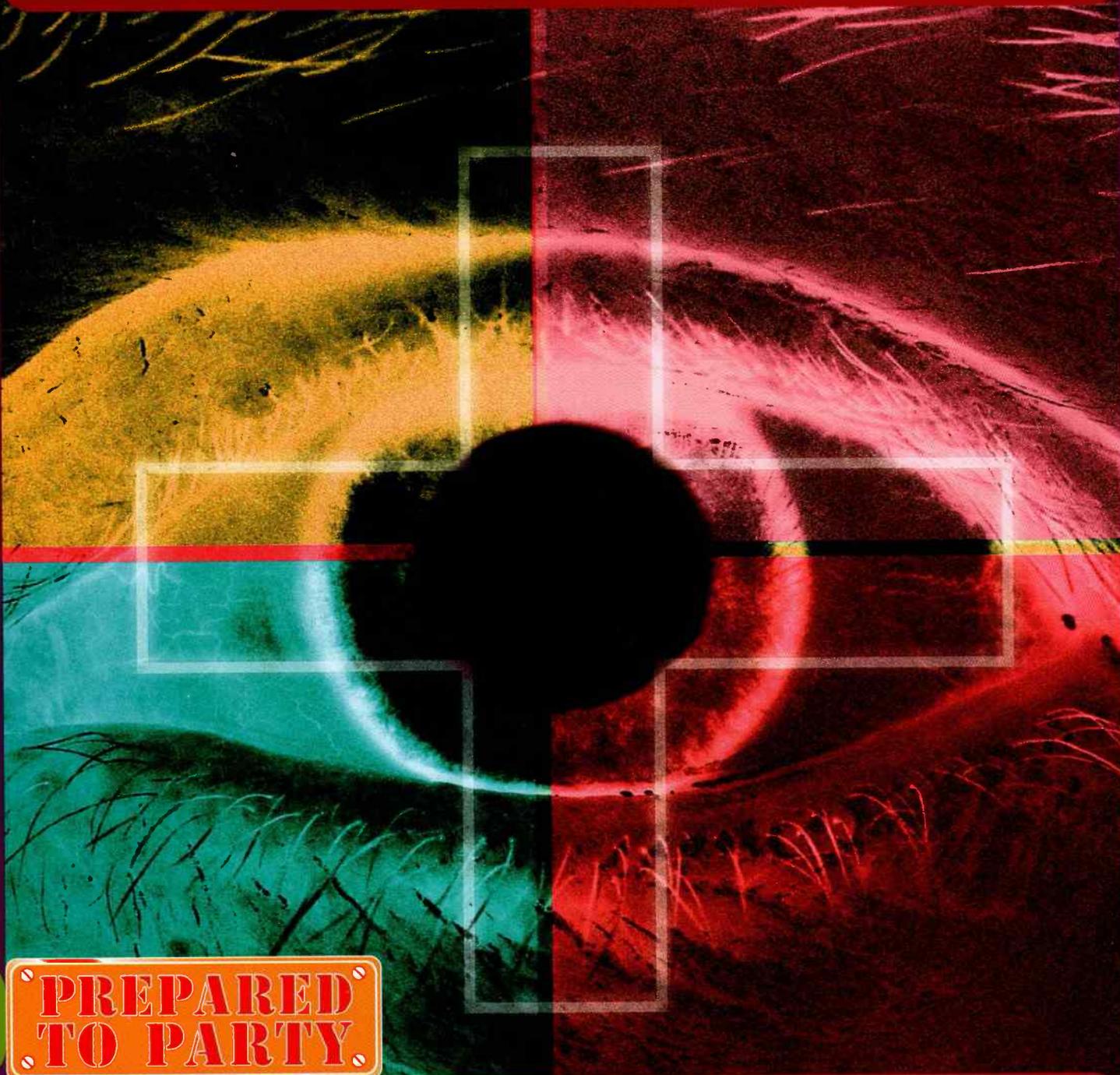
◆ Where We Speak for Ourselves ◆

20 YRS

1981 - 2001



TAKING YOUR DRUGS TO THE PARTY?



PREPARED TO PARTY.

If you're on HIV treatments and planning to party...

There are some extra things to prepare for. Plan to take your HIV treatments – pack extra doses in case you don't get home for a while.

It's best to keep taking your treatments through party time, but if you do decide to take a break, then it's best to stop taking all the drugs in your combination and start again when you've recovered.

Work out any planned treatment breaks with your GP or AIDS council treatments officer.

If you expect to take party drugs, get advice about any risky interactions. Combining some HIV treatments (especially Ritonavir) with ecstasy, other amphetamines or Viagra can be dangerous.

If you do take HIV and party drugs together, it's safest to take half your usual dose of the party drugs and leave a couple of hours between taking your treatments and the other drugs. Find out where the medical room is when you arrive at the party and, if you feel unwell or worried, get some help.

For more information call the AIDS Council of NSW on 9206 2000
or go to: www.afao.org.au/parties

If you plan to inject drugs, use a new fit for every hit.

ACON

napwa

HERO

ANONYMOUS

F E A T U R E S



The search for an appropriate image for the cover of our 20 years of HIV issue was fascinating – how to encapsulate such a milestone with a single image. We would firstly like to thank those PLWH/A (NSW) committee members and supporters who offered an enormous range of excellent suggestions. In the end, we went with the rollercoaster. The range of experience represented in life with HIV is impossible to define with a single snapshot from anyone's life, but the interpretations of this particular image are vast. The image is courtesy of the Mitchell Library, State Library of New South Wales, and we would like to thank Margo Riley at the State Library for her support, and our designer – Slade at FuelTank

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DISCLAIMER

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

from the publications working group

This issue of *Talkabout* has been put together through the efforts of the acting publications staff – David Urquhart and Geoffrey Williams. Both have been caretakers of the Publications Unit in varying capacities during this sometimes challenging period of staff transition. On behalf of the Publications Working Group I want to thank David and Geoffrey for their wonderful care and attention to *Talkabout*, and for the upcoming issue of the indispensable resource directory **Contacts**, due out just as we go to print.

One of the things I am constantly grateful for in working around PLWHA community-owned organisations is the capacity which people have to 'pull together' as a deadline looms or a space becomes vacant. I'd also like to thank those people who have taken the time to complete and return the Readership Survey from the June/July issue of *Talkabout*. Your valuable feedback is vital to the decision making processes at the Publications Unit, so if you haven't completed a survey, please do so and return it to us as soon as you can. Evaluation is also a common thing in the organisation of conferences. The recent NAPWA conference was a wonderful example of this generosity. The upcoming Sixth International Congress on AIDS in Asia and the Pacific

(ICAAP), being held in Melbourne in October, will no doubt see PLWHA, both locally and from communities overseas, rally together with the same sort of energy and enthusiasm.

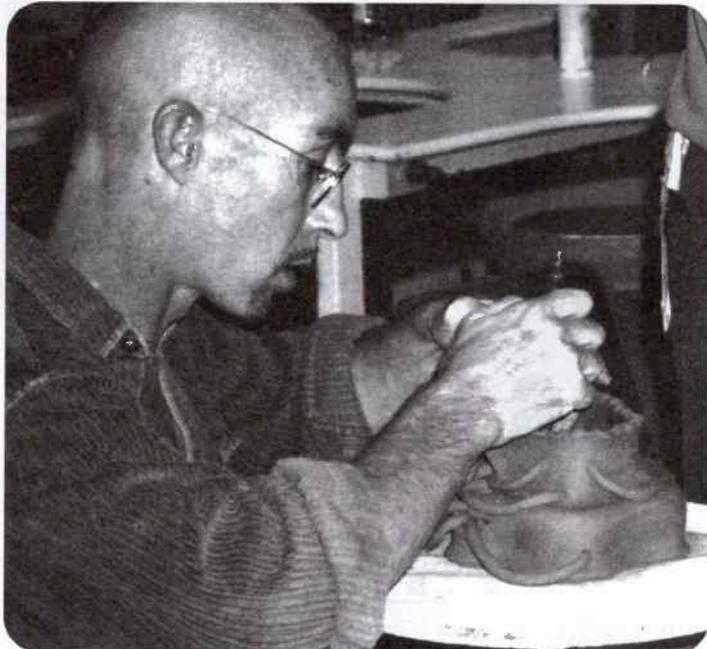
There are a range of ways that Australian PLWHA can be involved in this important regional conference, which has the resonant theme of Breaking down Barriers. For more information about the ICAAP program and the many associated events, check out the website www.icaap.conf.au.

The first Regional HIV+ Forum, specifically for PLWHA, will be held just prior to ICAAP, on October 4. This is being organised in a joint effort by PLWH/A (Victoria), NAPWA, and the Asia Pacific Network of PLWHA (APN+). The theme is to be welcoming, informative and sharing. Contact the NAPWA office – admin@napwa.org.au – to find out more, or for your group or organisation to become involved with the planned 'market place', showcasing Australian HIV organisations, which will take place on that day.

Whether it's across the region or across the street, PLWHA sharing experiences with each other can be a powerful encouragement, something with which *Talkabout* readers are already familiar.

Jo Watson

Creative pursuits can be the perfect partner during our annual winter hibernation – and when spring arrives, you'll have new vases, jewellery and artwork to show off! This issue, *Talkabout* features the range of options to explore your creativity. Glenn Flanagan introduces the classes in Talkshop on page 4; David Jobling's article on the team at Central Sydney Area Health is on page 9; and Winter blues busters are on page 29. Our photograph features one of the artists during the free classes held at the South Sydney Creative Arts Centre, 64 Pine Street Chippendale. See Talkshop for more information.





pos action

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

I remember, back in the early 80s after a '60 Minutes' expose on 'the gay plague', being asked and teased about having AIDS. In fact, I did not – but AIDS became synonymous with every gay man. I was a quiet, sensitive teenage boy in high school and that was the first time I heard about a subject that would affect the rest of my life. No one contemplated that in 20 years a vaccine would still be years off and a cure unavailable, let alone that over 35 million people would be living with HIV globally.

Apart from all the achievements around HIV in Australia (arguably with the most progressive and effective response to the epidemic in the world) some things have changed little.

Discrimination and misunderstanding are still just below the surface. The *Facts and*

Figures: 2000 Male Out Survey released by the National Centre in HIV Social Research, showed that over 80% of its respondents would avoid sex with those they think are HIV positive, yet also expected that HIV positive people would disclose. 'In such an environment it would appear there is very little motivation for HIV positive men to disclose their status. It is clear that these developments have to be taken onboard if future preventative education campaigns are to be effective.' said Peter Canavan, NAPWA President. I am stunned that among the most highly affected population in Australia – gay men – such judgments are still being made. Has *that* much changed? Is it just more subtle? ... or is it due to positive invisibility?

The United Nations Special Session on HIV/AIDS has completed a Declaration of Commitment, however blatant bigotry which prevents men who have sex with men, sex workers and IDU from being listed as vulnerable groups still exists – the reasons

being, primarily, to appease extreme political and religious will. The long term effect of the UN's decision will be less effective prevention, increased isolation and discrimination and less coordinated treatments, plus globally *millions* more people living and dying with HIV.

Had this occurred in Australia twenty years ago, the health outcomes would have been very different. Through the mobilisation of the politically astute gay and gay-attached community a willingness and bipartisan support from government, and such *forced invisibility* of vulnerable groups was prevented.

Despite all we have achieved, marking twenty years is not a celebration – nor is it time to relax. It is a time to reflect and contemplate all those that fought before us and are no longer here. We still have much to fight for and, in a time of increasing invisibility of HIV positive people, the positive voice must speak louder than ever.

Right: The winter season of fundraising galas has kept us busy and helped keep the icy and damp winter chills at bay – at least for a night or two! ACON's Miss Western Sydney was celebrated as 'the biggest fundraiser for ACON West, ever!' Maria Venuti and Bernard King were guest judges, and the night was hosted by Ms Chelsea Brown. Pictured (left to right) on the big night are Stuart, Noreen, Sonny and Adam. Photo Kent Gryphon.



Far Right: 'They came from far and near, didn't want to leave and begged for more!' was the word from Blue Mountains PLWHA Inc following their terrific 'Going Bananas' night at the Gearin Hotel, Katoomba. Leather, lace and fruit was the theme, and performances included The Gearin's Girls, Sugar Kane, Miss Western Sydney - Kimberley Clarke, Yvette and local performance artists Nadia Jellymonstar and Martin. The night was hosted by Victoria Falls. Blue Mountains PLWHA are holding their next fundraiser, a 'Spring Circus Carnival' night, on Saturday September 1 at the Gearin Hotel. Cost is \$7.00, which includes the party and the show! For more information, phone/fax 02 4782 2119 or email bmplwaha@iisp.com.au



agony aunt q&a

Maree Crosbie

Q: I have two credit cards and an old AGC loan. I was making payments but haven't paid for months, and now they are ringing me up and asking me to make payments for the whole amount. I try not to answer the phone and there are always letters in the mail talking about legal action. I just don't know what to do.

A: It seems that you are in a very stressful situation, but the good news is that there are things you can do and there are several options available to you, depending on your overall financial situation. If possible, it would be good to make an appointment with a financial counsellor to talk about your situation. If you wished, they could contact the creditor on your behalf and ask for a few weeks' grace to give you time to decide what to do. The financial counsellor can tell you about the options that are available for dealing with the debt.

Q: My phone was cut off because I owed money to Telstra. I said I would pay \$20 a fortnight and then I forgot to pay a few times and they cut off the phone. I really need the phone. What can I do?

A: Telstra has a service called *In Contact* which allows incoming calls only but it is possible to dial 000 in an emergency. There is also a new product which is a prepaid home phone, making things a bit easier to manage as you can't get into debt. Remember that if you make an arrangement to pay off the debt and then find that you can't make the payment, it is important to let the creditor know. If there is communication between you, things will usually be much easier for you. You would still have to make an arrangement to pay Telstra the money you owe. If you feel that you can't deal with Telstra yourself, you could ask a social worker or a financial counsellor to help you.

Maree Crosbie is a Financial Counsellor with the Bobby Goldsmith Foundation.

talkshop

PLWH/A (NSW) Community
Development Project Worker

Glenn Flanagan profiles

what's happening in NSW.



Help for when the HIV living gets tough

Sometimes we feel like everything is out of control – that there's not enough food, or the unpaid bills are stacking up. Possibly we're behind with the rent ... and everything's looking grim. The Bobby Goldsmith Foundation (BGF) has recently published 'Help' – a very useful little guide with lots of tips and a list of people and organisations to contact for guidance, advice and support. You'll find 'Help' at venues and community centres.

Managing the Blues

People living with HIV may not necessarily be 'severely depressed' or have 'mental health issues'. They may be just feeling down in the dumps or experiencing a form of social anxiety – isolation, nervousness and a loss of self-esteem. Blues Busters is a series of six free workshops offering participants access to information, skills and ideas to guide them through ways of dealing with moderate depression and anxiety. Blues Busters will be held in Sydney during August. For more information, and to find out whether these workshops are an appropriate strategy for you, ring 9361 6011.

Become a writer

Want to be a writer but not sure how to start? The Positive Writing Course – a six week series of workshops for people living with or affected by HIV – will take place at The Sanctuary (6 Mary Street, Newtown). Come along and get some ideas on how to start writing and meet people with similar interests. I'll be facilitating them on August 15 and 16, so if you would like to join us, give me a ring on 9361 6011.

Complementary Therapies at The Sanctuary

The Complementary Therapies Information Service at The Sanctuary is now one year old. PLWH/A (NSW) Complementary Therapies Treatments Officer Mac McMahon continues to offer guidance for

clients in prevention of, and dealing with, side effects resulting from combination therapies. HIV positive for about 18 years and having an AIDS diagnosis since 1994, Mac has experienced the gamut of treatments and side effects, and dealing with each one in turn, he can guide you through complementary treatment strategies. Mac is also able to offer general advice regarding health and lifestyle options. Drop in for a chat with Mac at The Sanctuary, phone 9519 6830 from 2pm to 6pm Mondays to Fridays or email him on complementarytherapies@hotmail.com

Yoga is a good way to manage stress

Yoga and meditation can become an important part of managing stress in our lives and The Positive Living Centre (703 Bourke Street, Surry Hills) is encouraging positive people to join in meditation and yoga with Daniel on Wednesdays between 11am and 12 noon. Telephone 9699 8756 for more information.

Unleash your creativity

The benefits of participating in creative activities can be considerable, and the 'Unleash your Creativity' art project – developed by the Sydney HIV/AIDS Team in the Central Sydney Area Health Service – is a good place to start. This project was very successful last year and the ceramic workshops earlier this year were fully booked! Printmaking is taking place now, with silver jewellery-making scheduled to begin late in August. Priority is given to people living with HIV who are socially isolated or have limited financial resources. The classes free of charge are led by qualified and experienced artists and are held at the South Sydney Creative Arts Centre, 64 Pine Street Chippendale. Contact Lisa or Carlos on 9690 1222 for any enquiries.

doctor q&a

Q1 My friend has just been diagnosed with HIV. Her CD4 count is 400 and her doctor told her she doesn't have to start treatment. Three years ago when I was diagnosed, I started treatment when my CD4 count was 450. I am confused because we both go to the same doctor.

A1 It all comes down to the cost versus benefit of treatment. While the benefits of treatment speak for themselves, we are all becoming aware of the potential costs in terms of side effects, compliance and quality of life. The pendulum has swung back a bit towards less aggressive commencement of treatment, with many doctors now believing that starting treatments a little bit later will deliver the same benefits but at a lesser cost. In fact, the official USA guidelines have been recently changed. They now recommend starting HIV therapy only when the CD4 count falls below 350. It is important to remember that there are no hard and fast rules. Most importantly, decisions regarding commencement of treatment should be made considering all factors relating to the individual patient. These guidelines are based on collected learned opinion. As with all things, treatment guidelines change with experience and greater knowledge of the risks and benefits involved.

Q2 My friends have all started drinking milk because they have heard that HIV patients have weak bones. I have HIV disease and have been on treatments for five years. Am I going to break my hip because of weak bones?

A2 While I am glad to hear your friends are supporting the dairy

industry, I am not recommending my patients to drink more milk just yet. There are very early reports to suggest that patients with HIV disease may have weaker bones than those without HIV disease. There is a lot of interest in this topic at present. Indeed, osteopenia (weak bones) is the 'toxicity du jour'. As usual, there is a lot of hype and not much data. Currently doctors around the world are collecting information about this condition. We are not at the point to be able to say if this is a real problem or if treatment is needed at all. For the time being, I am not recommending patients do anything about this problem. Increased calcium intake and increased exercise won't hurt though.

Q3 I have participated in a number of clinical trials. I don't mind all the extra visits which can be a bit of a nuisance sometimes. I know doctors have to do research. However I never hear about the results of the trials. How do I find out?

A3 Thank you very much for all of your hard work. It is only because of people like you that we have had the advances in HIV medicine that can assist patients today. In general, we (doctors/researchers) are not very good at saying thank you. The final results of the trial are very important for you, and you are entitled to know the outcome. You can always obtain the results of any trial from your current doctor, local treatment officer or other organisations such as National Association of People Living With HIV/AIDS (NAPWA) and AIDS Treatment Project Australia (ATPA).

treatment briefs

Testosterone helps prevent bone loss in males

Osteopenia – a condition which involves the loss of bone mineral density – occurs more frequently in people living with HIV/AIDS than in HIV-negative people. At this stage there is no clear indication as to the causes of osteopenia in people living with HIV/AIDS, however, it is thought that it may be related to HIV infection itself, side effects of antiretroviral therapy and/or as a result of low testosterone levels. A recent study, investigating the effect of testosterone supplementation in men with AIDS wasting syndrome, has found that weekly injections of testosterone over a period of three months significantly increased the bone mineral density of the lower spine column. A control group that did not receive testosterone but undertook resistance training did not show any similar increases in bone mineral density. *Journal of Clinical Endocrinology and Metabolism*, May 2001

New ddI formulation available in Australia

An easier-to-swallow formulation of VIDEX (ddI), called VIDEX EC, will become available in Australia from August 1. The new formulation does not require an antacid buffer to ensure absorption into the bloodstream. It is the buffer in the present formulation that is commonly associated with gastric side effects including flatulence, bloating and diarrhoea.

The dosing requirements of VIDEX EC are slightly different from the current formulation of VIDEX. It has to be taken on an empty stomach, at least one hour before food or two hours after food. VIDEX EC does not have to be dissolved in water beforehand and does not leave a chalky aftertaste. VIDEX EC is packaged into a single 400mg capsule, taken once daily. *Bristol Myers Squibb*

What kind of treatment information do you want?

ACON is currently conducting a major review of its 'Treatments' website. This review is surveying opinions of people living with HIV/AIDS to determine what issues and information are important. Anyone who would like to contribute to this survey can do so either using an online version (<http://www.acon.org.au>) or obtain a hardcopy together with a reply paid envelope from ACON by phoning 9206 2000.

Treatment Briefs are written by ACON's Treatment Information Officers. Telephone 9206 2036/2013, Freecall 1800 816 518, email treatmts@acon.org.au



welfare reform and mutual obligation

Fair and just welfare reform must be based on recognition of the needs of the vulnerable, argues **Douglas Barry**

Comprehensive restructuring of the welfare system has taken place in the UK and the USA with the intention of getting as many people as possible off welfare and back into the workforce. Throughout the 1990s, there have been attempts by Australian governments to reduce welfare dependency by a variety of methods, including employment programs, tightening eligibility criteria, compulsion and financial penalties.

The Final Report of the Reference Group on Welfare Reform, *Welfare Reform: A Stronger, Fairer Australia* (The McClure Report) was considered by Amanda Vanstone – Minister for Family and Community Services – last year. People anticipating a proposal in the May Budget, with dollars attached, were disappointed. Perusal of the Government's Welfare Reform Internet page reveals only that 'Over the next few years, the Federal Government will improve arrangements for people with disabilities'. It's difficult to know what that might mean.

It has been argued by the Minister that the high rate of dependence is due not only to the inherently reactive nature of the system, but also its complexity and a lack of incentive for participation. The Minister proposes that there be improved financial incentives to return to work, increased obligations on job seekers and expanded services to assist job seekers – a proposal criticised for its lack of policy detail and firm funding commitments.

How does this affect PLWHA? From the *HIV Futures II Survey*, it can be argued that about one-half of positive people in NSW identify their main source of income as a government benefit or pension. Hence the restructuring of the welfare system is of immediate and vital interest to positive people in NSW.

A joint research paper by the National Welfare Rights Network and ACOSS –

Doling Out Punishment – the Rise and Rise of Social Security Penalties (November 2000) contains a number of case studies illustrating the hardship caused by the imposition of inflexible administrative requirements by Centrelink. Included among these are instances of people with disabilities incurring penalties, where failure to perform required tasks arose from their disabilities. These were overturned only after sustained interventions on their behalf. They were far from being 'welfare cheats'.

A growing number of positive people are experiencing complex mental health problems. AIDS Dementia Complex and diverse psychiatric conditions are demanding increasing attention from service providers. It is not unlikely that such people will increasingly fall foul of Centrelink if the administrative obligations continue to be applied as ruthlessly as the research reveals. This will result in unnecessary hardship and suffering for many whose lives are already diminished by living with HIV.

Much of the Government's current approach is based on the concept of 'mutual obligation'. The Opposition, for political reasons, voices few objections to this concept and its implementation. Curiously, no one has seriously challenged this idea and whether it is appropriate in the welfare system of Australia in the twenty-first century. It does suggest that if a person who is unable to make provision for their livelihood performs certain tasks for the benefit of the community, only then is that person entitled to support from the public purse. This has echoes of the Victorian era and its moral distinctions between the 'deserving' and 'the undeserving poor'. Is this where 'mutual obligation' is taking us?

Participation in voluntary community work has been of inestimable value for many people with disabilities. Engagement with 'return to work' schemes, sensitively and appropriately designed and facilitated,

has been the springboard for many who have gone on to secure paid work. This brings with it a multitude of benefits for both the individual and the community. But these are for people who have the necessary emotional, physical and mental capacities to be so involved. For those who don't, compulsion must benefit no one – the individual or society.

PLWH/A (NSW) Inc. has long supported and promoted such involvement for and on behalf of its constituents but laments the lack of available resources to pursue and develop these projects. But now there is a growing fear that the support of the vulnerable and cruelly disadvantaged will be made dependent on whether they fall within the ranks of 'the deserving' – as determined by the harsh and unrealistic standards imposed by Centrelink and trumpeted by Government rhetoric, typified by Tony Abbott, the Minister for Employment.

In these circumstances, it is essential that those affected by and involved with HIV/AIDS in our community make their voices heard. We must convince Government that fair and just welfare reform should not be based on the glib and inappropriate misuse of concepts such as 'mutual obligation', but on the caring recognition of the needs of the vulnerable among us. Determined action is required to demonstrate to Government that harsh and punitive methods, directed at enforcing some vague duty to society, by those for whom the term 'quality of life' is meaningless, can only bring great injustice and suffering.

By all means, reform the welfare system; but reform it in such a way that a caring and just society would be proud of it.

Douglas Barry is a member of the PLWH/A (NSW) Management Committee and convenor of the PLWH/A (NSW) Legal Working Group.

positive in prison

Glenn Flanagan found that by working slowly and carefully, potentially life-changing rewards can be yours



It was a strange feeling visiting a prison for the first time. There were so many gates to get through and so many locked doors. I wondered about the prisoners: Would they want to see me? Did I have anything to offer them? And what was I doing there?

It all started with Sonny Williams. Sonny, who works for ACON Western Sydney, had been invited by the inmates into a prison to form a positive support group. Hearing about Sonny's excellent program of information and support, the prison's self-contained Lifestyles Unit coordinator – Janet – invited Sonny to continue his work within the Unit.

The goals of the Lifestyle Unit include developing a sense of responsibility for one's health, as well as increasing participants' knowledge of health issues. The Unit also provides the opportunity for prisoners to address self esteem and practical living issues, to prevent relapsing into the re-offence cycle.

Sonny was the only peer worker who had the necessary clearance to access the prison system and he would often invite people to his support group who might be able to provide information to the inmates. Peter Williamson from Positive Employment Support (PES) spoke about education and training and ACON Treatments Officer John Cumming spoke about treatment options and side effects.

Sonny then invited me, as the Community Development and Advocacy Worker with PLWH/A (NSW), to talk to the prisoners. By finding out about PLWH/A (NSW), ACON and PES, prisoners could be connected to services when their time for release arrives. Access to appropriate community owned services is a vital feature of building a support network.

Sonny then invited me to take over the support group for five weeks while he undertook other management responsibilities. I felt apprehensive and not at all sure

HIV positive prisoners ... share common concerns with other positive people: whether to take up treatments, how to manage any side effects and how to get the right health information.

what good I would do. Sonny admitted that he had started the programs wondering the same thing – but found that by working slowly and carefully with inmates, building trust, support and a sense of consistency in service provision, there was definitely a flow on effect.

The support group was part of a structured and intensive program and attendance was compulsory. The program included workshops on life skills, nutrition and cooking, as well as psychosocial support. There were classes in fitness, communication, life management, alcohol and other drug issues and art and a nutritionist/naturopath attended for three hours every week.

HIV positive prisoners (an extremely marginalised group of people within the correctional services system) share common concerns with other positive people: whether to take up treatments, how to manage any side effects, and how to get the right health information. By talking to peer support workers about their concerns, HIV positive prisoners can gain the skills and knowledge to improve their situation.

Confidentiality and disclosure are important issues for positive prisoners and most would not want to disclose their status in the mainstream prison

environment. If they wish to access the Lifestyles Unit, however, they need to disclose – and once they are in the Unit, they can explore valuable avenues of support. The 12 week program offers inmates priority of entry if they are due for release. It is completely voluntary and inmates can refer themselves for the program. They can come from anywhere in the State, but they need to be well enough, physically and emotionally, to be able to take part in all aspects of the program.

Meeting the participants in the Lifestyles Unit's program was a very personal and valuable experience – and one from which I learned a great deal. The prisoners appreciated getting news about what happens in the outside community so I continued Sonny's practice of providing copies of gay newspapers and magazines (for those who requested them) as well as copies of *Talkabout*. Several inmates spoke about getting involved in volunteer work when they are released. By the way, many prisoners would also like to have penpals. If you would like to write to a prisoner, contact Sonny Williams at ACON Western Sydney on 9206 2073 and let him know.

Glenn Flanagan is Community Development and Advocacy Worker at PLWH/A (NSW).

private practice

It is particularly important that privacy rules provide adequate protection for PLWH/A, writes **Derek Walker**

Under new privacy laws (due to come into effect in December 2001), PLWHA will be able to access their complete medical records. GPs can currently deny patients access to their records, if they choose to, because they are considered the property of the doctor.

The new privacy legislation actually applies across the private sector, not just the private health sector, however it is the implications for health information that are of most concern to PLWHA groups.

Shaun McCausland, President of PLWH/A (SA), has been following developments in 'e-health' over the last few years. 'Many European countries are acutely aware of the risks that supposedly 'de-identified' information could be easily 're-linked' by agencies with access to other databases and repositories of personal information. This possibility does not seem to be part of the debate in Australia, a debate that has largely occurred away from the public eye', explains McCausland.

It is particularly important for PLWHA that the privacy rules provide adequate protection. Discrimination against people living with HIV/AIDS is well documented and widespread. Failure to maintain privacy protection by health service providers may discourage some PLWHA from accessing information and support services.

The Australian Medical Association (AMA) does not believe the legislation offers sufficient privacy protection. The AMA is concerned that the issue of patient's access has overshadowed the issue of what happens with electronic records. In May, AMA President Dr Kerryn Phelps said 'It's not just about patients accessing their own records, it's about who else can access your records. These are the sort of issues that we think the privacy rules do not cover anywhere near adequately.'

The AMA is also seeking changes to the legislation regarding patients accessing their records. The AMA agrees that there are

advantages to patients seeing their records, but believes that in some cases, part of the health records should not be made available. The AMA believes, for instance, that a doctor's private thoughts about the possible diagnosis and the possible treatment plan, which may not end up becoming the diagnosis or the treatment plan, should remain with the doctor.

Malcolm Crompton, Federal Privacy Commissioner, disagrees, saying 'It is important that doctors' written opinions ... form part of the record. Providing this access to patients will build trust in the relationship between the health provider and their patient.'

Failure to maintain privacy protection by health service providers may discourage some PLWHA from accessing information and support services.

The privacy rules will give individuals new privacy rights, including the right to have access to the information an organisation holds about them. Individuals will also have the right to complain if they think their rights have been breached and to seek redress if the breach is proven.

The legislation covers private sector health service providers, such as general practitioners, private hospitals, private pharmacists and other health professionals in private practice including psychologists, physiotherapists, dentists and optometrists. Separate legislation applies to public sector health providers.

Much of the legislation is already current practice in the health sector because of the obligations health providers

have under professional and ethical codes of practice. However, under the new laws, this practice will be legally enforceable and will apply to all private sector health providers, not just those who belong to a professional body or association.

The new rules cover a wider range of information handling practices than the traditional confidentiality framework – for example:

- obtaining consent for the disclosure of health information;
- what to tell individuals when information is collected;
- securing and storing information;
- providing individuals with access to their health records; and
- restrictions on the use of government identifiers such as a Medicare number, etc.

Both electronic and paper health records are covered by the legislation. Health records are stored, increasingly, in electronic formats and transferred electronically, which can result in increased risk to breaches of privacy. One wrong click on a mouse could send the information to an unauthorised person or confidential information might mistakenly remain displayed on a computer screen. A glitch at the University of Michigan Medical Centre, for example, reportedly left thousands of consumers' personal health records on public internet sites for two months. The situation was not rectified until a reporter alerted the medical centre. It is intended that the new privacy rules will prevent any similar occurrence here in Australia.

PLWH/A (NSW) Inc. would be interested to hear of any breaches in privacy experienced by PLWHA that have occurred in the health sector, particularly if they relate to the use of new technology. We would like to include these experiences in the current consultation process with the Federal Privacy Commissioner. Please contact Derek Walker on 9361 6011 or email research@plwaha.org.au

keeping it together

The Central Sydney Area Health Community HIV/AIDS team are more than up to the challenge, writes **David Jobling**

Over the past few years the Central Sydney Area Health Service (CSAHS) Community HIV/AIDS Team has adapted its services to keep up with the changing needs of PLWHA, their carers, partners and family members. It's a fantastic achievement considering that at any one time the team provides services to as many as 400 individuals from a potential client base of 2,500 PLWHA living in Central Sydney.

The team provides localised and statewide services – not an easy call when you start adding up the numbers. From Tempe to Concord West, Riverwood to Birchgrove and all the areas between, there are nearly fifty suburbs. Coordinator Richard Riley and the team have considerable experience in identifying the needs of clients and providing a carefully considered response. 'We aim to assist people to optimise control of their health, maintain their health and control over the management of their health and wellness', Richard says.

Richard has worked in community care for many years, focusing on, for example, brain injury, aged care and rehabilitation. I first met him when I was in my teens and he coordinated a local community Drop In Centre for young people. Now he coordinates the CSAHS team response – and that's a long way to have come in twenty years. The thirteen member team at CSAHS offer specialised services including occupational therapy, physiotherapy, social work and dietetics, while managing projects such as the statewide Positive Heterosexuals and the Healthy Living Project at The Sanctuary in Newtown, in addition to involvement with other wellness projects. The HIV Clinical Nurse Consultant and HIV Mental Health Nurse also work closely with the team.

The Sanctuary is probably best known for offering free holistic therapies by qualified volunteers, including massage, foot reflexology, acupuncture and social gatherings such as free film nights in conjunction with

ACON's HIV Living Team. The support groups and classes available are designed to match the needs of PLWHA. 'We identify current needs and meet them in a multidisciplinary way', explains Richard, meaning that there's more than one way to help people take control of their lives. I regularly have Foot Reflexology (where the soles of the feet are massaged, stimulating the blood supply and nerves and consequently relieving tension). I find it extremely relaxing and it's not even particularly ticklish. I highly recommend it!

Long term use of medications and living in poverty impact on self-esteem, quality of life, diet and self expression among other things, so it is appropriate that the free classes offered by other service providers at The Sanctuary include Cooking for One, Cooking on a Budget and Asian Gourmet.

Positive Heterosexuals offers annual retreats, exercise programs, workshops and therapies as well as a freecall phone line, mail out service and social gatherings for positive men and women and their partners and families. The programs, classes, groups and events provided by the team via Positive Heterosexuals and The Sanctuary are the public face of the service. Less public, but equally vital, are the personal responses in one on one situations.

The term 'people with complex needs' comes up more and more when you absorb information about PLWHA. To dissect the term and expose its meaning is almost impossible because it encompasses so much. It is, however, an efficient way of saying human beings with all sorts of problems who need sensitive, compassionate and confidential solutions to their individual problems to enable them to feel well. It is this area, particularly, where the CSAHS Community HIV/AIDS Team really does the hard yards. The support offered by the CSAHS team is friendly, sensitive and confidential. If you feel isolated or tangled up inside, the social workers can help – by listening and making constructive, supportive suggestions or by linking you to services that are designed to help resolve specific problems.

No health service can fix every problem you may have, but the team at CSAHS will focus on your specific needs while helping you find some answers for yourself. The immediate future includes some great free classes. Whether it's art, cooking or a social outing, it all contributes to your wellbeing day by day.

David Jobling is Publishing Editor of Qstage, a community based information provider, and a community activist.

Community Health Centres offer a range of services to PLWHA, and in case you've never been entirely sure, here are just some of the services available for you at CSAHS.

Dietitian

- assessment and management of nutritional problems including: symptoms and side effects of drugs and infection; lipodystrophy; food and drug interaction; subsidised nutritional supplement service; and programs for skill development and health promotion

Physiotherapist

- provides access to hydrotherapy and gym; explores ways of managing pain; and introduces and encourages exercise

Social Workers

- counselling; referrals and linkages to additional support services; advocating and supporting people in gaining fair and equitable access to services and entitlements; and group work – social, educational and therapeutic

Occupational Therapy

- Stress management – individual and group programs; group work – therapeutic and social skills; exploration of work options – paid and unpaid; fatigue management; and strategies to manage memory and other cognitive problems

For more information contact Richard Riley at CSAHS on 9690 1222.

20 years of HIV

A Brief (Personal) Memoir of HIV/AIDS by **Tim Alderman**

talkabout's 20 years of HIV

An introduction by Acting Editor,
Geoffrey Williams

I can't remember who it was, but someone once said 'Sentimentality is the enemy of truth'. I don't know exactly why this piece of borrowed observation suddenly seems relevant, but as we observe the milestone which is 20 years of HIV, there are certain things we have been forced to consider ... and it is possibly 'the enemy of truth' part that I find so potent. No – it is, in fact, 'the enemy' part.

War, as metaphor, has been a consistent visitor to our lives since the dissemination of information about HIV began in 1981. There has been drug 'resistance', treatment access and funding 'battles', hundreds and thousands of 'lives lost' – 5,946 in Australia and 450,000 in America alone. There have been 'casualties', 'survivors', 'strategies' and 'battlegrounds' ... 'fatigue', 'rehabilitation', 'marches', 'parades' and 'memorials' ... and 'ribbons' – but in the case of life with HIV – one little ribbon in particular.

'20 years of HIV' is not a time to celebrate. Nor is it a time to sentimentalise or beat our chests and feel good about how much we have achieved. It is, instead, time to take a breath. In a fight as fast and furious as this one, maybe we need to take some time out in our respective corners to quickly take stock, before facing our opponents again. Maybe we could think of it as Round 2001?

As Robert writes on page 13 of this issue of *Talkabout*, 'It is hard to see this period of time in an objective historical context when it seems so recent'. And as Tim Alderman writes on page 10, 'I could say that compared to the bad, bad old days of 1981, life is a bed of roses today. But then I am aware that quite

a lot of people would still not share that sentiment, so out of respect to them, I will avoid such romanticism.' For those of us who live every day with HIV, it is exactly this mess of contradictions that defines our lives.

So if I may offer a suggestion? As it is our ever changing, intimate and personal needs within the broader context of a community's or a society's or a government's response to HIV that we need to consider, let's revisit ritual. For me, it was the ritual of pinning a red ribbon to my chest that served to separate the metaphor of war from the actuality. In actual war, the more ribbons you wear, the more celebrated your achievements. In the war against HIV, it is only one ribbon. It was only ever one ribbon. It will only ever be one ribbon. Why? Because even though our experiences of HIV differ supremely, we are all still fighting the same fight, for the same reason – to win it. So perhaps, at the 20 year mark, it's time to pin on the ribbon again, and prepare – as loudly, clearly, forcefully and cleverly as you can – for Round 2002?



I can't believe it has been twenty years since we first started hearing about HIV/AIDS. I find it even harder to believe that I have been infected for only a few months less than that twenty years. Almost half my life has been lived with this virus! In personal retrospection, I could say that compared to the bad, bad old days of 1981, life is a bed of roses today. But then I am aware that quite a lot of people would still not share that sentiment, so out of respect to them, I will avoid such romanticism.

I was living in Melbourne at that time, and I believe that HIV/AIDS got its first mention in the gay press a little earlier than 1981, though I could be wrong. There were only snippets of a strange STD that seemed to be selectively attacking the San Francisco gay community, or more specifically, those members of that community who frequented the city's baths and back rooms. No one here was particularly concerned. We thought it was just another of 'those American things', or just a mutated form of the clap. Nothing that a pill wouldn't fix! By the time I returned to Sydney in 1982, we had started to think quite differently. Some of us were getting very scared.

The media began drowning us in information, mainly from the United States. There was the dramatic scenario of 'Patient 0', from whom it was assumed the whole epidemic had spread like an out of control monster. The USA and France argued over who had discovered the virus and made the link between HIV infection and AIDS. A debate raged as scientists tried to decide what to call it and which acronym to use. We had GRID (Gay Related Immune Disease) and HTLV 1 and 2 (Human Transmitted Lymphoma Virus - if memory serves me well). They eventually settled on HIV for initial infection and AIDS for any subsequent illnesses that resulted from HIV infection. The original Center for Disease

S of HIV

Control (CDC) classification of the various stages of HIV and AIDS progression was so complicated that you really needed a university degree to be able to decipher them. Then came ARCs (AIDS Related Conditions) but, considering that politically incorrect, we settled on OIs (Opportunistic Infections).

The argument over names and classifications wasn't half as frightening as the reality of the disease itself, which started to hit home in 1985. Official testing began in that year, and is still the earliest date that medicos will accept as a point of diagnosis with HIV. Like many others, I assumed I was HIV positive long before testing started. 'Virgin' and 'chaste' were not words to be found in my life resume. Sydney's Albion Street Centre first began testing here – very discreetly and anonymously. We all used an assumed first name, and were issued with a number to identify who we were. (In 1996, when I needed to tap into my first HIV test results done at Albion Street, they were still there.) Counselling was atrocious. You were given your HIV positive or HIV negative, if you were lucky, status very bluntly, then quickly shunted over to a counsellor before the shock had a chance to set in. You were also told, almost apologetically, that you probably had about two years to live. That was HIV diagnosis circa 1985.

A number of our conservative politicians, and some of our outraged Christian clergy, started to say that they wanted us placed in quarantine. According to them, it was specifically 'a gay disease', and they truly believed that fencing off the gay areas of Sydney and leaving it to run its course could contain it. These people wondered why we got tested anonymously!

By 1985 people were starting to die. There were no dedicated HIV wards in any of our hospitals and patients were shuttled between temporary beds in wards and the emergency department. Reports started to filter through of hospital staff wearing contagion suits around patients with HIV.

Worse still, meals were being left outside the doors of rooms and would often be cold by the time the patient managed to get them. Cleaners refused to clean the rooms. There were scares of infection by contact with everything from a toothbrush, to a glass, to cutlery, so patients were offered very disposable forms of hygiene. Even mosquitoes copped some of the blame. Then, of course, we had the living daylights frightened out of all of us with the 'Grim Reaper' television ads. From 1985 to 1995, death lived with us on a daily basis. If you weren't visiting sick friends, lovers or partners in hospital, you were visiting them at home or attending their funerals and wakes. Most of us lost the majority of our friends and for most of us those friendships have never been replaced.

Around that time, the gay community took charge of what was quickly becoming an out-of-control situation. Tired of seeing friends dying in emergency wards, and getting only the minimum of care at home and in hospitals, we established our own care, support and advocacy groups. Out of the pub culture grew groups as diverse as BGE, CSN, ANKALI, ACON and PLWHA. Maitraya, the first drop in centre for PLWHA, was founded, and we raised the first quarter of a million dollars through an auction at The Oxford Hotel to improve ward conditions at St Vincent's Hospital. The gay community can forever take great pride in itself for bringing about great changes, not only in the care of PLWHA, but in the way the disease was handled, both politically and socially.

The Department of Social Security streamlined people with HIV/AIDS through the system and onto Disability Support Pensions. The Department of Housing introduced a Special Rental Subsidy so that those on a pension, and unable to wait interminable amounts of time for housing, were able to live in places of their own choice, at greatly subsidised rent. Home care became available through CSN. By

1992, considering the high incidence of candida, a need for improved dental services for HIV patients was perceived. The United Dental Hospital led the way with a HIV Periodontal Study, which at last provided reasonable dental care to PLWHA. The first vaccine, p24VLP, was trialed with absolute zero results. There were quite a number of scares with HIV contaminated blood and screening of blood donors was tightened. Discrimination reared its ugly head in the Eve van Grafhorst case, which forced this little girl to not only leave her school because of the hysterical reaction to her HIV infection, but to flee the country with her family.

In 1987, the first therapy for AIDS – azidothymidine (AZT) – was released in the USA, and its use in patients with HIV/AIDS was fast-tracked through the approval process here. In France a huge trial called 'The Concorde Trial' was conducted unethically and its findings were found to be inaccurate. The resulting announcement that AZT was ineffective in the control of HIV, and that the drug was nothing more than 'human Rat Sak', caused a universal outcry. The damage was done. Many had no faith in the new drug at all and local activists and proponents of alternative therapies tried to encourage people not to use the drug. Many of us chose otherwise. True, the effects of AZT were short-term only – maybe six to twelve months – but many saw it as a way to keep the wolf from the door long enough for some other drugs to come along. And come along they did. AZT was quickly followed by what are referred to as the 'D' drugs – d4T, ddI, ddC, and the outsider 3TC. However, these were all drugs from one class called nucleoside analogues and all had short effectiveness. Some doctors tried giving them in double combinations but the effectiveness wasn't much better. Despite their short life span, these drugs were being prescribed in enormous doses, resulting in problems such as haematological toxicity, anemia and peripheral neuropathy. We needed a miracle!

20 years

Those of us who had managed to survive to 1996 were starting to give up hope. Most of us were on a pension, had cashed in and spent our superannuation and disability insurance, had a declining health status and didn't hold out much hope for a longer survival time. Prophylaxis for illnesses such as PCP, CMV, MAC and candida had helped improve most people's lives, but they didn't halt the progress of the virus. The first of the protease inhibitors, Saquinavir, was introduced that year, and evidence started to emerge of the effectiveness of combining the two classes of drugs into what came to be known initially as 'combination therapy' and later as HAART (Highly Active Antiretroviral Therapy). The results were astounding; those close to dying suddenly found their CD4 counts rising, accompanied by a return to reasonable health. Viral Load testing was introduced and people were finding not just a raising of their CD4 counts, but a drastic lowering of their viral load, often to the point of its being undetectable. This became known amongst doctors as 'the gold standard'. Ganciclovir Implants to assist with the control of CMV retinitis were trialled the same year, and Albion Street Clinic started a trial using decadurabolan, a steroid to assist in controlling Wasting Syndrome. The new drug combinations (NNRTIs - non-nucleoside reverse transcriptase inhibitors) - a third class of drugs, introduced shortly after, were not without their complications and problems. Most combinations still required huge quantities of pills to be taken daily, not just of the HAART drugs, but also prophylaxis and drugs to help control side effects such as nausea and diarrhoea. Their use required time and dietary compliance. Other problems such as lipodystrophy and renal problems appeared, but we were, despite any drawbacks, a lot better off than we had been, hell, even two years earlier.

People's health changed drastically and suddenly, new services started to take prominence. Some people required lots of

counselling to help them reconnect with the life they thought had been taken from them. Others went to peer support groups or turned to treatment management groups, and some to the larger range of support services being provided by, among others, The Luncheon Club, The Positive Living Centre and NorthAIDS. There was recognition that there was a need for services to assist people with an improved health status, as some of them were contemplating returning to work. Despair had, to a large extent, been replaced by hope. Organisations concerned with people's changing needs reassessed and changed their services to meet the demand. Those that changed have survived and are still prominent in our community.

The war is far from over. New generations require new strategies, and while everyone seems happy that infection rates for HIV have remained steady in Australia (despite rampaging out of control in Third World countries), many feel it is still not good enough. Twenty years into HIV/AIDS, countries like Australia with high levels of education and accessibility to media and information should be seeing a decline in infections. Remembering my own youth, I find it difficult to comment on the attitudes of young people. I grew up through the very worst that HIV/AIDS had to throw at us, and the lessons it taught are not easy to forget. I have to ask myself, had I not had that experience, how would I be viewing it? It is no longer just the responsibility of the gay community to guard against new infections. Responsibility also rests with the straight community and the IDU community, as infection rates remain at their current level. Some scaremongers have ventured forth theories of a 'third wave' of infection, but I trust we are too wise and too educated to allow that sort of irresponsibility to happen.

Many of us (certainly not all) are going on to lead relatively normal lives. Many have returned to work either as volunteers, or in casual, part-time or full-time employment.

Many, like myself, have returned to tertiary education, determined not to leave this world without at least fulfilling some gnawing ambition. However, we are not living in a 'post-AIDS' world, and to think so would be foolish. We still need new drugs, and we still need people to trial both the emerging antiviral and opportunistic infection drugs and the immune-based therapies. We now have a fourth class of drugs in the form of nucleotide analogues. Many medical practices have adopted a holistic approach to medicine, and this can be judged to be a direct spin-off from the HIV/AIDS wars. Hopefully, soon please, a new vaccine will appear.

I really don't know how much longer I will live now. Certainly with the standard of health care I get, and the close monitoring, I may live out whatever my allotted time was to be. HIV/AIDS has been a two-edged sword. It has taken good health from me, I have permanent disabilities from AIDS, and I have seen far too many friends, lovers and partners die from this hideous disease. At the same time, it has presented me with opportunities I would never have grasped if it had not come along. I am re-educating myself, taking myself off along strange paths. It has given me a whole new understanding not just of HIV, but of disabilities in general and a great respect for those who overcome difficulties and recreate their lives.

At a university tutorial last semester, a young woman asked me if I thought about having HIV every day. I don't. It may have taken twenty years, but it is now so integrated into my life I have trouble remembering the time when I didn't have it. The pills are just pills now, and most of my current medical problems have more to do with ageing than with HIV. I can tell you, that really gives me something to think about!

Tim Alderman is a member of the PLWH/A (NSW) Publications Working Group.

rural community

From Alice Springs to Launceston, **David, Glen, Michael** and **Robert** share their experiences of 20 years of HIV – away from the 'big smoke'

The place we call 'home' plays a significant role in the way we define ourselves, as do the discoveries – about others and ourselves – we make in those places. And whether you can't live more than five minutes away from a 24 hour convenience store, or an hour and 25 minutes away from your nearest neighbour, location is everything!

The decision about where we live is a vast, complex and, at times, fraught one. For some, the liberating feeling of hitting the open highway enroute to the fresh, clean air, might be replaced by the urgent need to return to the mess of a big city – a kind of separation anxiety if you like. For others, a weekend away in the fresh air and incomparable peace and serenity might be enough – offering a new perspective on the crowded, loud and increasingly confused grid that defines life in a big city. But for some, the illicit love affair city dwellers have with the countryside sometimes evolves into a meaningful, lifelong relationship.

David, Glen, Michael and Robert share the experience of one such relationship. Their stories capture the essence of the affair: that until the final destination is realised (and that might well be where they are now) the journey through peace and tranquility, relaxation and time alone in relative isolation serves to highlight those places on 'the map' where some of us chose to explore and live our lives.



David

I was most surprised that the dirt wasn't red. Something must be quite wrong, as this landscape below was covered in trees, green fields bordered by thin yellow strips of the beaches and a gentle mountain skyline to the west. My new partner and I landed in Port Macquarie, and found it very different from Alice Springs where I had lived many years ago. I had buried a partner the year before, and was embarking on a, hopefully, quieter life away from New Orleans, to start my antiretroviral therapy. Rather a ways to come.

The overall nature of the daily routine in a rural community in New South Wales is, I think, clearly beneficial to the demands of HIV therapy.

I have found living rurally on the Mid North Coast to be quite wonderful – such a delicious year-round climate, friendly villagers and fresh bread daily. There is nothing to compete with the three-times-a-day, two-dozen pill regimen, and no temptations between my therapy and my life. In any big city there would be the stress of work, the din of society, the necessarily tight scheduling, the bars, fast food, alcohol, drugs, traffic, late hours and at-risk behaviours – all leading to non-compliance, the hobgoblin of triple therapy.

Living rurally, not once have I missed a dose, had more than a couple of glasses of wine with dinner or compromised my wellbeing by being under pressure. We see

our flying Royal North Shore doctors as needed in Port Macquarie and feel our care is excellent.

The overall nature of the daily routine in a rural community in NSW is, I think, clearly beneficial to the demands of HIV therapy. We love it and it loves us!

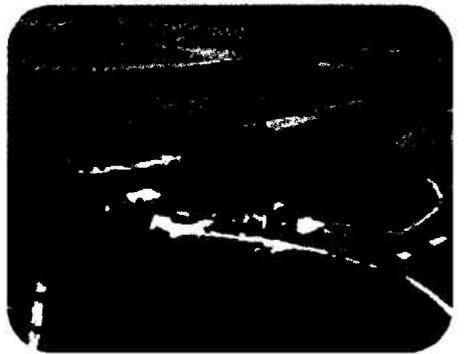
David is the website administrator for the PLWH/A LivingRural website at www.siteware.com.au/LivingRural. The website serves PLWHAs, NGOs and agencies in rural NSW.

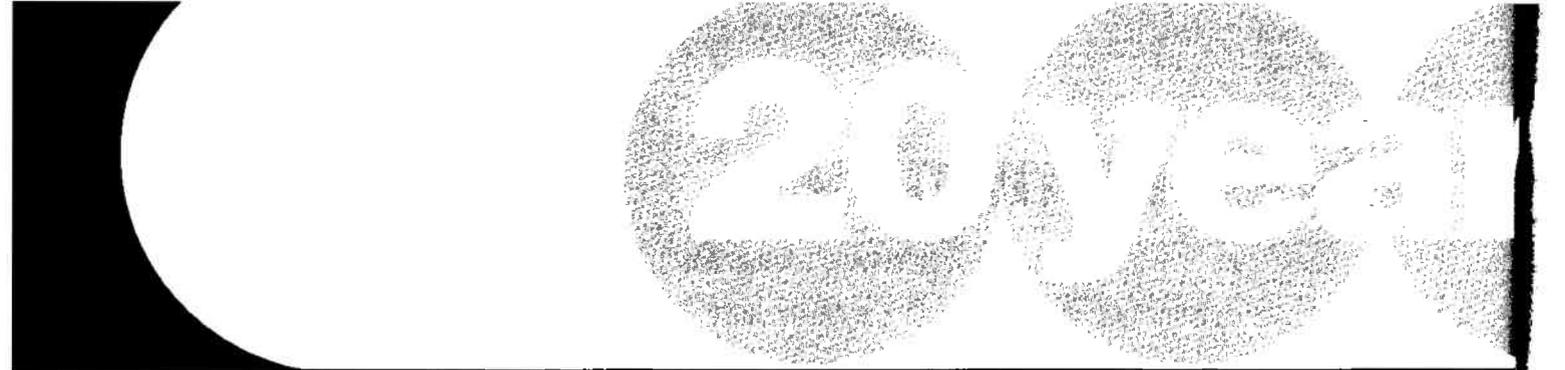
Glen

The Utility was loaded to the gills with everything including the kitchen sink. We were heading north from Sydney to camp for a fortnight in a place out the back of Kempsey before finding a place to call home, away from Sydney.

We had made a great start and the mood was convivial – though the Pacific Highway

... the locals thought we would be better off waiting for daylight. We didn't – and became lost. And so began our time on the Mid North Coast.





was not as good as it is now. As we were getting final directions in Kempsey just before dark, the locals thought we would be better off waiting for daylight. We didn't – and became lost. And so began our time on the Mid North Coast.

We had trips back to Sydney for many reasons – treatments for my partner and myself, discussions with the Public Hospital Pharmacy about the new wonder drug AZT, dealing with IPTAS to get refunds for flights to Sydney and finding a general practitioner who could prescribe s100 drugs.

The days became years, and of the three of us who were in the car travelling north from Sydney, I'm the only one left. Peers disappeared at an alarming rate, and all we could do was attend funerals and memorials.

Having a new partner to share the trials and tribulations of living with HIV has been a bonus, and I am, after twelve years, still here on the Mid North Coast.

The final destination is still unknown, however the trip to get to this point has been well worth it.

Michael

I'm a city guy who dithers between the Great Divide (excuse the pun) of a city and a country existence. This dithering has produced quite a few sojourns away from Sydney. Sometimes they have been for a few weeks or months and on a couple of occasions, for over a year. But I've always returned to the 'Big Smoke'.

I wonder if, in fact, I have some sort of major masochistic relationship with the Pacific Highway. That relaxed sensation of yet another oncoming truck claiming my side of the road ... or that soft, nurturing sound of a marsupial beneath my tyres!

On a different note, the country has always been a great attraction for me. Experiencing, for extended periods of time, a more peaceful and relaxing environment and having the space and a slower, less expensive existence are, at times, important to me. There is, of course, the other reality of accepting a certain amount of geographical

Experiencing, for extended periods of time, a more peaceful and relaxing environment and having the space and a slower, less expensive existence are, at times, important to me.

isolation and of being physically distanced from my support network which can at times be challenging.

Over the years, I have built up many relationships with other HIV positive people throughout NSW. This has given me an interesting perspective on the similarities and differences experienced between the 'city slicker' and the 'country bumpkin' and I believe that experience both advantages and disadvantages. The pros and cons can only be weighed up after some good hard thinking.

Robert

I sometimes feel like a fraud in the true rural sense, because although I have lived in several country towns such as Dubbo, Port Macquarie and Launceston, I was brought up in the inner west of Sydney and still

regularly spend time in Sydney and other large cities. However, I choose to live in the country – largely for those classic reasons of a less hectic lifestyle with a greater emphasis on the natural environment and my own self-reliance.

I was living in northern Tasmania in the 80s when HIV really hit, so my views were clouded by distance and some local extremist views, such as 'lock 'em up on Flinders Island'. I then spent some time in equally conservative Queensland before landing, once more, in the thick of it in Sydney in the early 90s, when the incidence of AIDS was at its highest in Australia. I began working in

I choose to live in the country – largely for those classic reasons of a less hectic lifestyle with a greater emphasis on the natural environment and my own self-reliance.

areas associated with HIV and doing volunteer work with Community Support Network (CSN). At this time, several friends, including a lover, died. It is hard to see this period of time in an objective historical context when it seems so recent.

My view of HIV now is one of living and working with it. I'm not sure how long my work and volunteer involvement with HIV will continue, but while it feels right and I feel that my contribution is helping others as well as myself, then I will battle on – ever the Catholic martyr! Life is good at the moment and I believe that part of this is due to my choice to live and work in the country.



particular ... and personal

The battles fought by brave, tenacious and angry volunteers were, and still are, personal writes **Tess Ziems**

Community Support Network (CSN) has spent seventeen of the twenty years of HIV supporting and caring for PLWHA. We all share, or have heard, stories from the early to mid 80s - stories of uncertainty, fear, discrimination, poor medical care, illness and death. I like to remember the bravery, tenacity, anger and sheer bloody-mindedness of the people who fought so hard for their own lives and for other people's lives.

It is also timely to remember the legion of CSN volunteer carers who have cared about, and for, people fighting their particular and personal battles. Those volunteers made a significant difference in the lives of many HIV positive people. They still do today. Originally, the volunteers came to CSN primarily from the gay and lesbian community, or as people attached to that community through friends or family. Many of them were HIV positive. Some also came, with a strong sense of social justice, from the wider community.

Those men and women provided short-term intensive support and care when required by bed-bound clients who were unable to fully care for themselves and who had decided to die at home. Many of these clients had no family or friends around or able to help. CSN carers became their primary support people, a link to the world outside the bedroom. CSN carers worked with kindness and dedication to make their clients' lives more bearable. They listened, they made beds, they laughed, they made lunch, they cried. All for, and with, their clients.

Things started to change slowly from about 1997. More effective treatments started to hold back the physical devastation of HIV, allowing many people a better quality of life, and the hope that death was not inevitable.

These changes for positive people meant that the type of support and care that CSN volunteers provided also changed. CSN

moved from a crisis, palliative care model to one of chronic illness management. The ups and downs of treatment side effects meant that clients experienced periods of wellness followed by periods of ill health, resulting in an inability to maintain their independence to a suitable level. Consequently, CSN has a much more fluid model of care.

We all share, or have heard, stories from the early to mid 80s - stories of uncertainty, fear, discrimination, poor medical care, illness and death. I like to remember the bravery, tenacity, anger and sheer bloody-mindedness of the people who fought so hard for their lives and for other people's lives.

Volunteers are fewer on the ground and generally do not come from the traditional communities. Before joining CSN, many new carers had never knowingly come into contact with an HIV positive person. Many are suburban mums, young students or retired men. More than ever before, many are heterosexual. This reflects the broadening of knowledge and the decrease in the stigma historically

associated with HIV. Even though some carers may now come from different backgrounds, their commitment and dedication is as strong as ever.

Ten years ago a CSN carer would expect to see just one client during their time with the organisation. Now they are more likely to see a number of clients, sometimes for as short a time as one month. This, in turn, demands that as carers, we change our training to reflect a new set of skills and mechanisms for coping. As always, it is the responsibility of CSN workers and management to constantly evaluate our volunteer support mechanisms - enabling them, to the best of their ability, to provide a consistent, quality service.

In the last two years, CSN has been actively promoting effective links with mainstream service providers, primarily Home and Community Care (HACC) funded services like Home Care Association of NSW, Food Services, Carer Respite, etc. With the HACC services, CSN is keen to offer PLWHA a range of care and support options. Because volunteers are harder to find, we want to be able to confidently refer our clients to other services if we are unable to meet their needs. We have been instrumental in tightening HACC confidentiality guidelines and in creating increased understanding of the issues and problems faced by PLWHA.

CSN workers and volunteers celebrate with those for whom treatments have meant a return to better health with renewed hopes and goals, while at the same time continuing to support those people who choose not to treat or for whom treatments fail. We'll be here as long as we can make a difference in the lives of HIV positive people.

We haven't always got it right, and now we struggle with how best to maximise the independence of our clients in a climate of fiscal rectitude. Like our clients, though, we will fight on to find the right path.

Tess Ziems is Care Liaison Officer at CSN.

ankali - then and now

A great deal has changed in twenty years, but the commitment to providing emotional support remains 'astounding', writes **Michael Buggy**

Twenty years of HIV worldwide; eighteen since the first diagnosis in Sydney; sixteen years of Ankali. A lot has changed since May 1985, when twenty volunteers became the first to complete the Ankali training. Change that has affected Ankali clients, volunteers and staff alike. So what have the changes been?

Kevin relates how hard it was for him in the early days of the epidemic: 'There really wasn't a support network to rely on - I wasn't coping and had no one to turn to. Ankali filled that gap, and they have continued to be a big part of my life ever since.' Other clients discuss how things have changed, and that the change itself is difficult to cope with.

Many clients came to Ankali for support when there was an enormous amount of ignorance and fear around HIV and AIDS; people were very sick and dying, and positive people didn't know who to turn to. Ankali provided unconditional emotional support and provided the much-needed 'safety net'. This aspect hasn't changed, although the needs may be different: treatments aren't easy for many people; living with HIV for many years can have a profound effect upon some people's mental and emotional wellbeing; and, sadly, people are still becoming sick and dying.

It's changed for volunteers too. Bill volunteered in the late 80s: 'There was so much fear and loathing out there, and we really needed to rally and mobilise in order to do something worthwhile. People were dying and it was a frightening time. I guess that's why I joined Ankali - to be there for someone in that situation. That has changed, but there are other things going on for my clients like loneliness, isolation and what is lost as a result of an HIV positive diagnosis. There has been a constant throughout all of this change, and that's the support I've got from Ankali. I wouldn't have been able to do the work without my volunteer support group. It really is a dynamic of the project that keeps

you going, and has kept me with the project for so long'.

Lou McCallum was one of the founding members of Ankali. Lou, Jim Dykes and Terry Goulden began offering volunteer emotional support at the beginning of the crisis to gay men who were sick in St Vincent's. 'The professional support people like the Social Work Department just didn't know what to do for these sick and dying guys', Lou says. 'Ward staff contacted the Gay and Lesbian Counselling Service, hoping they could help, and that's how Jim, Terry and I became involved. It wasn't long until it became clear that we couldn't cope on our own, and the idea of Ankali was born. Jim went to San Francisco to study what they were doing, and came back with the Shanti model, which we developed into Ankali. Our first volunteer training consisted of some positive people, together with a number of partners and carers. These people were already doing the caring and support, but were looking for ways to be able to cope emotionally'.

As a relatively new staff member on the Ankali team (I've been here about two years), I consider this history in relation to what I encounter today. There is still a need for volunteer support for PLWHA, their partners, carers and families, however it is harder to recruit volunteers. Despite this, the calibre of our volunteers never ceases to amaze me, and the dedication they show their clients and Ankali is astounding. We need more people like this to continue the fight.

I feel proud to be a part of an organisation that has such a rich and respected background built on the foundations laid down by all of the people involved in Ankali over the years. There have been a lot of changes and there remains a lot that hasn't changed, and the need continues.

Michael Buggy is a Social Worker and Coordinator at the Ankali Project. If you need the support of an Ankali volunteer or would like to become a volunteer, contact the Ankali Project on 9332 9742.

VOLUNTEERS NEEDED

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characteristic uncertainty

After seventeen years of service provision for PLWHA, it's 'bloody hard work and it's getting harder', writes **Georgina Harman**

What about getting back to work? How about a drug holiday? You're ill but you're well too. Life with HIV can be a confusing thing in the twentieth year of the epidemic. Change and uncertainty have always characterised life for PLWHA, no more so than in 2001 and no more so than for BGF. It comes as no surprise to many of us that it takes a milestone like twenty years for AIDS to become part of the public and media consciousness once again.

The Bobby Goldsmith Foundation (BGF) has been around for nearly seventeen of those 20 years, making it Australia's oldest AIDS charity. The founding members of BGF were also instrumental in the setting up of Community Support Network (CSN) and the AIDS Council of New South Wales (ACON). During those 17 years, BGF has evolved from a group of friends organising fundraising events to an organisation employing 30 people and running seven client services that assist over 15 percent of PLWHA in NSW. And I'm sure you'll be glad to know that we've reduced our administration and fundraising costs at the same time – confirming our commitment to spend the money we raise helping the people for whom BGF exists to serve.

Bobby Goldsmith House opened in 1996, our Financial Counselling Service was launched in 1998 and the Floating Care Initiative was launched in 1999. In the last year we have added Positive Employment Support, Reconstruction and the Ratten Fund to the range of services we can offer positive people. We have also focused on making sure that people who live outside of Sydney know about and use BGF's services.

The fact that the Foundation is still here today is testament to the skills, dedication and strength of countless individuals, most of which have given up their time and donated their skills and money to ensure that

BGF has survived. In 1984, BGF's founders raised a few thousand dollars to help Bobby die in dignity at home. In the last 12 months, 7,885 cheques totalling over \$650,000 have helped over 15 percent of PLWHA, hopefully to live in comfort and with dignity. In the last year, 39 of our clients have died – that we know of. We get an average of 40 calls a day for help and each week we send out an average of 150 cheques and six pieces of equipment. It's bloody hard work and it's getting harder.

There could be nothing better than reaching a point at which we could close the doors of BGF because you didn't need us any more. But in the year to date, the number of new clients coming to BGF is similar to pre-1995 days. A client who last used BGF's services seven years ago has been forced to turn to BGF again.

Quality of life (or lack of it) is a new crisis of a kind and it can be just as fatal as the pre-treatments era. Poverty, financial stress, hopelessness and poor health compromise your being well: they disrupt the magical flow of 're-engagement with life', and mean that basic things like eating properly are never a certainty. Because we have this information, we hear your stories and understand your needs and wants. We will continue to work closely with organisations who are the voice of positive people, like PLWH/A (NSW) and ACON, so that they can relay your experiences to the decision makers.

We all have the right to live in dignity, to have somewhere safe and warm to live and to have access to the medications and advice we need. Sometimes BGF can't give everyone what they have asked for but if we can't, there's always a reason and we try to explain why.

So, it's business as usual for BGF as we enter the third decade of AIDS. After all, BGF is here 17 years on because PLWHA need us more than ever.

Georgina Harman is the Bobby Goldsmith Foundation's Executive Director.

Proceeding with caution

Making the choice to re-commence treatments this time was totally different to when they first became available, writes **Mark Tietjin**

Being asked to give my account of twenty years of HIV initially seemed a daunting task, but I figured the easiest way is to tell my story.

In the very early 80s when I was living in New Zealand, news filtered through of a new disease in the USA which seemed to be affecting the gay community. David, my best friend and flatmate, was a GP and I clearly remember him coming home with the latest theories, such as amyl being a possible cause of the disease.

By the mid 80s I was ready to make some major changes in my life, including fleeing NZ for a while. When testing for HIV became available in 1985, the thinking was, why do it? – nothing could be done if you knew you were positive so to save a lot of angst it was better not to know. In 1986, when I told Dr David that I was off travelling the world again, he suggested I consider an HIV test and wrote the appropriate referral, telling me that the decision was mine. So, I had the test and the results came in as positive. Being a well travelled, sexually active gay man, I wasn't surprised. Dr David told me that I was brave to have been tested and that he wouldn't have done it. One of the first people I told was another close friend, a lawyer, who

suggested that the result of my test was not something I should share with anyone. This mystified me somewhat because, as far as I was concerned, the result was not unexpected and I felt it was something I should be able to share with my friends.

My world travels brought me to Sydney where I fell in love, and have remained. After a variety of occupations, I found myself doing a number of different casual jobs at the AIDS Council of New South Wales (ACON). One of them, in 1989, involved visiting doctors and clinics throughout Sydney, advising them to be prepared for a radical new ACON campaign encouraging people at risk (read: gay men) to have an HIV test and to consider regular monitoring of T-cell counts.

At the end of 1990 I was employed, temporarily, by the Bobby Goldsmith Foundation (BGF), where I have been ever since. Not long after I started at BGF, Dr David died from AIDS complications.

I have always had an interest in science and the logic for me was always that the only way to have any chance with this disease was to follow the scientific community, which meant advocating for treatments. Back then if your T-cell count was less than 500, you could access the treatment of the day – AZT. I had one dubious T-cell count of less than 500 and was straight off to my doctor to start the treatment. At this time, there was still a belief that AZT killed. It had been prescribed to very sick people at very high doses which they simply could not handle. I started on a low dose and had the comfort of knowing that I was still relatively healthy.

In the next couple of years, ACON set up a buyers' club and imported new drugs from the USA, such as DDC which wasn't available in Australia. Then came talk that a combination of drugs was beneficial. As this approach was not sanctioned by the Australian Government, my doctor would write me two separate scripts and I would collect one drug from St Vincent's and one from Sydney Hospital.

I had always felt that trials would be the best way to access the latest treatments but was reluctant to enter a trial where I might take a placebo. In 1995, a trial was advertised including a new protease inhibitor, indinivir plus d4T and 3TC, with a guarantee to get at least one drug. I rushed to enrol. The trial nurses told me I was probably the first in Australia to have access to indinivir. When I collected the drugs, I immediately contacted a number of laboratories to see if they would be able to analyse the drugs to tell me if I had the real thing or not. Because the drugs were so new, they had

no idea as they had no benchmark. Blood results showed I was definitely getting something that worked. I found out that I was indeed getting all three drugs. I was on the trial for three years.

Next came viral load testing – another whole new concept. The test was free to me through the clinical trials, but others had to pay \$125. Mysteriously, the viral load results on my blood coming back from America for the trial differed significantly from the local results.

It wasn't long before the availability of combination therapies was filtering through to anyone who was interested. There were still people who were resistant to drugs and still spoke of the AZT experience, but it soon became obvious that a lot of those taking the combination treatments were experiencing significant improvements in their health. Sadly, for a number of reasons, the treatments didn't work for everyone.

I have recently recommenced treatments after a ten month break. Making the choice this time around was totally different in that my approach was to proceed with caution rather than to agree to any of the available drugs, and to ask how the drugs will affect my lifestyle.

the view from here

Mark Tietjen describes the changes he has witnessed from behind his desk at BGF

In the early 90s the prognosis for most people with an advanced HIV diagnosis was not good. It was common for people to suffer long periods of debilitating illness before they died. Assistance provided by BGF and a range of other services was built on a model of a very high level of support to try to help people be reasonably comfortable for the period that was to be the end of their lives. This is the era when we used to regularly see two pages or more of the *Sydney Star Observer* taken up with death notices.

Then in the mid-90s, when the effects of combination therapies were starting to

kick in, there was a dramatic turn around. Suddenly, lots of people who thought they had only limited lives were experiencing renewed health. A whole lot of new issues started to surface, such as people having used up all their resources and more; running up huge credit card debts; burning all their bridges with friends and acquaintances; and discovering that they now had a future again. Boredom and lack of occupation became an even bigger issue. Things such as relationship breakdowns, substance abuse, mental health and dementia became issues we had to learn more about. People became absolutely fed up with the entrenched poverty resulting from living on benefits for a long period of time. To quote a client, 'It's like having been on death row and then being unexpectedly released'.

Both the mainstream media and the gay press implied that the crisis was over, however for many people, while their physical health may have improved, they were now having to face a range of complexities in their lives which they had never had to consider before. For many people, the issue of having HIV became less important as other issues took over. Services such as BGF had to start to think about how to sustain the levels of assistance being provided to their clients. This still continues today, when in fact BGF is experiencing higher levels of demand than ever before. Today, many people have a feeling of total despondency not knowing what the future will bring and having had their levels of self-esteem and pride eroded by long-term poverty and its associated social problems.

To complicate this even further, we are now seeing complacency in sustaining safe sex and infection rates are increasing, especially amongst younger gay men. In addition, many people have experienced treatment failure. The most recent medical development has been resistance testing and many of us are discovering that we are now resistant to all the current classes of available treatments, which again eats away at future plans.

We have come a long way in twenty years and lost far too many friends, but there is still a long, long way to go.

Mark Tietjen is a Client Liaison Officer at the Bobby Goldsmith Foundation (BGF).

the burden of silence

From crisis intervention to discovering hope for the future, **Stephanie Moore** examines the issues for HIV positive women



The advent of feminism and access to the Pill changed women's lives dramatically. Women had new choices, particularly reproductive choices. Women's Health programs worldwide became models of good practice, with good resources and funding. However, the picture for HIV positive women in Australia was, and is, different.

When the AIDS epidemic first appeared, the response was to support those already infected. In Australia, this was primarily gay men, and this is where community mobilisation began. It was successful for a number of reasons.

Gay men were already a marginalised group. They had experience of political action to draw on to make the Government respond to the AIDS epidemic. Whilst HIV positive women supported the protests voiced by gay men, they were busy with more immediate problems of caring for partners and children – leaving little if any room for practical commitment to political action. And unlike their gay male counterparts, all positive women had in common was that they were HIV positive. They had no existing community.

Positive Women (Victoria) was formed in the mid 80s in direct response to the lack of women specific services and to specifically address the needs of HIV positive women, which are very different from men's.

Some facts:

- there are approximately 170 positive women in Victoria;
- they are scattered throughout the State, and are often isolated in rural townships, where secrecy about their serostatus is vital. Sometimes this has resulted in late diagnosis, as the local medical practice has not thought to test for HIV. Why should they? She isn't a drug addict or a sex worker.

She doesn't, unlike the gay man, fit the stereotype;

- over 75% of women were infected by their male partner;
- over half of women with HIV have children. They are often the sole carer of children. Many live below the poverty level;
- additionally, women's treatment needs are different from men's. Most of the antiretroviral drugs have been tested on men, who don't have hormonal changes each month, don't bear children and who have a heavier body weight. In any case, women prefer complementary therapies where there is less risk of toxic side effects;
- women have still to fight to have their voices heard in society at large, but also, sadly, within the positive community.

Positive Women (Victoria) today is a different organisation from when it was formed. Then it was about crisis intervention. People were dying weekly, daily. Now with the advent of new treatments, there is hope for a future. We can develop long term plans.

Positive Women (Victoria) was set up as an independent statewide organisation. Today with access to the internet and the World Wide Web, we are having to respond to requests from all over the world. Although set up as a local agency, Positive Women (Victoria) now has a global audience, although we are not funded to meet those demands.

And yet, despite hope, some of the reasons Positive Women was formed over 14 years ago unfortunately still need to be addressed:

- we need to ensure that equity of funding and resources is achieved for positive women with special reference to childcare needs;
- we need to ensure that positive women are represented fairly in the media, and that the myths and stereotyping of positive women are challenged by

the HIV positive community and its supporters;

- we need to ensure that people know the epidemic is not over; HIV resides globally within the heterosexual community. Though the majority of HIV/AIDS literature concentrates on positive men, the reality is that globally, women represent over 47% of the positive population;
- we need to ensure that treatment choices are explored, particularly in the field of complementary therapies, so the medical profession does not marginalise those women who choose complementary therapies, but rather seeks to learn about this approach;
- we need to ensure that community education highlights the vulnerable situation women are in.

These issues were the ones that the group was formed around in the mid 80s. Unfortunately they are still relevant today and we continue to work on them. They are not the same issues that the positive male population has to grapple with.

However, due to success of treatments, we need to address additional concerns. As people aren't dying at the same rate, the general population could be lulled into thinking that HIV is no longer a danger. Whilst it may have been re-labelled in the public's mind as a 'chronic manageable illness', it remains an illness with toxic side effects.

AIDS related psychiatric problems, weight loss, lack of income, depression, the inability to have children or for those who have them, the knowing that they may never see them grow up, has made some of our members wish for the 'old' days of no treatments when death came more easily.

And to those who say 'Well, there are many long term chronic manageable illnesses around', I say throw in a good pinch of discrimination, isolation, stigma, fear of disclosure, the burden of secrecy for yourself and your family, and the knowledge that you were the

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unknowing recipient of the virus, transmitted by your loving partner, issues of betrayal and grief and it all makes the response needed larger than purely medical.

Support groups for women and community organisations have begun questioning behavioural traditions which have become deadly with the advent of AIDS, including tolerance of child abuse, rape and sexual coercion.

Positive women are not an invisible, unknown and unrecognised face of the AIDS epidemic. We need to ensure that positive women throughout Australia are heard - that they do not have to bear the burden of silence alone.

This is an edited version of a speech delivered by Stephanie Moore. Stephanie is Director of Positive Women (Victoria).

maxine's story

Maxine found out she was positive in 1994 - at the same time as her partner and daughter.

I guess at the mere age of 11 or 12 years - 20 years ago - the last thing I would be writing about was HIV, let alone what I've been through since contracting HIV.

Although I spent a few years in Sydney about this time, HIV was something that, as a het woman - even at this early stage - I didn't have to think about. After all, it was only the 'poofters' (as I heard them called) that it concerned. I remember some of the horrible jokes that were going around the school. The only one that ever stuck was: 'What does AIDS stand for backwards? Slip Dick In Arse.'

From there I left Sydney and moved back to the semi-rural town where I was born, even further away from the city. It was only the television news that carried info. Enough info though for our end of Year 12 item presented to the school to include the Grim Reaper. It makes me sit and realise how sheltered and naive I may have been back then.

It was only weeks after this - on New Years Eve 87/88 - that I harmlessly kissed a male friend and from there a relationship bloomed. Although he had been living in

Sydney for a year doing his apprenticeship, he was a local lad and still HIV never seemed to enter into the equation. I thought I was doing great strokes going on the Pill.

A year later, still together and madly in love, I made the move back to Sydney and found work. We lived in Sydney for a couple of years until the birth of our first child, a girl (JM) in 92. (I even passed an HIV test during routine tests in early 92.)

Shortly after JM was born we moved back home. Then along came a second girl (NE) in 94. Ironically during this time we would often hear stuff on TV and comment that you could only get it - HIV - once and we were OK.

The phone rang on 1 August 1994 and I started answering a series of questions to the lady on the phone. She requested I come down to a place called Byrne House. I got there to find out that they were calling in a group of women who had contact with a doctor who had HIV. They wanted me to have a test, which I thought nothing of, as I had been tested previously.

I was in for a big shock a week later when indeed I did have HIV, and my partner and children had to be tested as well. I guess it was at this time that my life was turned upside down and probably inside out as well. Not only did my partner have AIDS, but so did my eldest daughter. I guess this answered a lot of unanswered questions as my daughter had been sickly for about 12 months before this and nobody could tell us why.

So for her it was a godsend. Unfortunately for my partner, the guilt was too much and he passed away within months of finding out.

Although I haven't started treatments yet I've had plenty of experience where my daughter is concerned. JM has been on medication from the age of not quite two and on combo therapy since 97. She has done well on these when she will take them. It has reached the point in the past when I had to tell her bluntly that she needed to take the medication or she would DIE.

For me in the past it has been a question of: Will I see my children grow? How do I love a child that is going to die? Why did JM have to be infected when she was an innocent baby? And I guess the list goes on. But thankfully, due to the medications and what the doctors do know now (although there's more still to find out), I'm now at the stage of asking questions like: How do I explain safe sex issues to my daughter? Can I have a negative baby? What is the percentage of mother to baby contraction? How can I stop my baby from being infected?

learning to crawl

For curiosity's sake, Ben* obtained a summary from his doctor of his 14 year history of HIV treatments. He shared his history with ACON's Treatments Officer – **John Cumming**



In 1985 Ben, then aged 31, had two HIV tests six months apart. The first test was negative but the second test, prompted by a broken condom, was positive for HIV. 'I was given the results over the phone, the day before I was due to fly to Europe for a working holiday,' Ben said. He flew to Europe as planned and returned to Sydney in early 1987.

In February 1987, access to the first-ever HIV treatment became available through the first Australian clinical trial of AZT. (In 1993 the Concorde Study was to show that taking AZT alone early in the disease has no benefits.) Ben enrolled in the trial. 'I remember lots of mornings sitting in a waiting room at St Vincents filled with other people on the trial, many of whom were very sick. There was always an incredibly tense atmosphere,' Ben said. 'Nuns used to come round trying to make us feel warm and fuzzy. If you wanted last rites administered, I'm sure that could have been arranged!'

Six months after joining the AZT trial, he was told that he had been taking a placebo and was given the real drug. 'The dose was 1000mg over a 24 hour period, divided up into a dose every 6 hours, which meant waking up in the wee small hours of the morning to take one of the doses,' Ben recalled. He remembers this as a time when people with HIV were experimenting with some rather off-the-wall therapies for HIV. 'One that sticks in my mind, not that I actually tried it, was an enema of bitter melon. The longer you could retain it in your bowels, the better it was supposed to be. The only alternative therapy I tried was the Candida diet, which aimed to eliminate fungal infections, which were supposedly running rampant in your body. You had to eliminate fruit, most bread and carbohydrates from your diet. It was a fad that caused more harm than good. Lots of people lost lots of weight on this diet and probably got sicker as a result. But at least these alternative therapies gave us some sense of control.'

In December 1990 Ben started importing the nucleoside drug ddC through a buyer's club launched by ACON. 'I had been going to ACON support groups and was influenced by the mood of the times, which was 'do whatever it takes, get your hands on those drugs,' he recalled. 'I forget how much it cost to import, but it was a sizeable amount that I had to budget for. Viral loads hadn't been invented yet so I had no idea what effect ddC was having. What's really amazing to me now is that I was on ddC for nearly two years and never got peripheral neuropathy. Nowadays doctors don't prescribe it because it is the most toxic of the nucleoside drugs.'

Ben remained on AZT and ddC until 1994 when he replaced ddC with ddI. 'I forget why. At that time one of my coping mechanisms was not to question my doctor. I'm completely the opposite now,' he said. Up until 1994, his T-cells had remained at 350 but now they began to drop steadily. By April 1995 Ben had only 60 T-cells and was on prophylaxis for PCP and fungal infections. 'Just when I needed them, d4T and the first protease inhibitor, saquinavir, became available, so I went on those, plus ddI. My T-cells stopped going down but remained at 60.'¹

Viral loads became available in Australia in March 1996. Ben's first viral load was 62,000, proof that saquinavir had failed him. It was later acknowledged by the scientific community that saquinavir was poorly absorbed, leading to eventual drug failure in everyone who used it. The manufacturers eventually produced a new formulation of the drug that overcame this problem. 'Around the middle of 1996 I had to retire from work and go on the pension,' said Ben. 'I did not expect to live for very long at all, so I disclosed my illness to my family, who were devastated.'

Ritonavir, another protease inhibitor, became available through compassionate access in August 1996 and Ben's doctor added it to his combination. A month later his viral load has dropped from 94,000 to

4,600. In December 1996, Ben reported extreme nausea and abdominal pain to his doctor. A blood test showed that his amylase levels were abnormal and that he was on the verge of an attack of ddI-induced pancreatitis. Things returned to normal after he stopped the ddI. By January 1997 Ben had achieved his first undetectable viral load result. 'It was literally a load off my back, because my energy went up at the same time.' Ben remembers. His T-cells had climbed to 240.

Ben became aware in December 1998 of the advantages of combining indinavir with zidovudine (smaller doses of both drugs, less side effects, no food restrictions, twice daily dosing). He switched to indinavir/zidovudine/3TC/d4T and the persistent nausea and diarrhea caused by zidovudine disappeared. 'I've been on this combination ever since, with no side effects, 350 T-cells and an undetectable viral load,' he now says.

Reviewing his medical history has reminded Ben how different HIV treatment was in 1987. 'It seems to me that 14 years ago we were all, including the doctors, like babies leaning to crawl before they can walk. Now we know so much more about HIV but along the way we have had to learn from our mistakes. I still can't quite believe that I took high dose AZT and ddC for so long, but now I have the benefit of hindsight.'

'So many people I know died from AIDS', Ben continues. 'I didn't because, through pure luck, or by being in the right place at the right time, I got access to a new drug that turned my results around. I have no idea why, unlike so many people I know, I haven't developed high cholesterol, lipodystrophy, peripheral neuropathy or liver damage from combination therapy. All I've had to complain about is a recent drop in my testosterone levels, but that's possibly age-related and it's treatable. When I look at the odds I was up against 14 years ago, and my current good health, words fail me.'

¹ Healthy people have between 600 and 1200 T-cells

* not his real name



trials and tribulations

Bridget Haire introduces the preventive HIV vaccine trial

The first human trial of a new experimental vaccine intended to prevent HIV will take place in Sydney next year. The experimental vaccine uses the principle of 'double whammy' – or prime and boost – to stimulate an immune response that it is hoped might prevent HIV infection.

The Sydney trial will show whether the vaccine is safe in people and whether it produces the kinds of immune response that are believed to be important in preventing HIV. This phase I/IIa trial will involve between forty and fifty people. If it goes well – if there are no significant side effects and participants show promising immune responses – the experimental vaccine will then go into much larger clinical trials designed to prove whether or not it works (called phase III or 'efficacy' trials).

Some history

From the early 80s, vaccine researchers concentrated on trying to stimulate the arm of the immune system known as 'humoral' immunity, which produces antibodies to neutralise specific diseases. It is when a person produces antibodies to HIV that they are 'HIV positive'.

By the late 90s, vaccine scientists became more interested in stimulating another part of the immune system – the 'killer T-cell' or 'cell mediated' arm of the immune system. This part of the immune response relies on T-cells being primed to kill other cells recognised as being infected (with HIV, for instance). This response had been shown to be a key in reducing viral load in people with HIV from the sky-high replication rate at seroconversion to the 'viral set point' or much lower steady state of viral replication in the asymptomatic period. It is the 'killer T-cell' arm of the immune system that the Sydney vaccine trial aims to stimulate.

More on the science

The Sydney trial will use a vaccine made up of two separate genetically-engineered

The Sydney trial will show whether the vaccine is safe in people and whether it produces the kinds of immune response that are believed to be important in preventing HIV

vaccines: a DNA vaccine made from HIV genes; and a genetically engineered fowlpox vaccine which operates as a 'carrier' to transport several HIV genes into the body. The fragments of HIV used in both the prime and the boost vaccine are not sufficient, separately or together, to make up a complete HIV particle. It is not possible to become infected with HIV through being exposed to this dual vaccine.

There is a chance, however, that some trial participants may experience problems with HIV testing, in particular with the ELISA test. This is because standard HIV tests are looking for antibodies – an immune by product of HIV infection – rather than the virus itself. This phenomenon has been dubbed 'vaccine positivity' or 'false positives' and it will be possible to show by other tests that a participant does not actually have HIV.

While the experimental vaccine aims to prevent HIV, a recent study of a similar experimental vaccine showed in monkeys that it did not prevent infection. However vaccinated monkeys who were infected had very low viral loads and did not become sick, unlike unvaccinated monkeys in that study. It

is possible that the vaccine being trialled in Sydney might work similarly to prevent HIV disease progression rather than infection, but this will not be known until much later when and if efficacy trials occur.

The vaccine being trialled in Sydney is made to match the subtype of HIV prevalent in Australia. The vaccine will then be re-made using a subtype that is prevalent in Thailand and phase I/IIa trials will be held there in 2003.

Trial participation

People interested in the pros and cons of trial participation can contact Kent Gryphon at ACON or Bridget Haire at AFAO for more information. It is anticipated that researchers will be seeking both male and female participants aged between 18 and 55 who are HIV negative, in good health and at no significant personal risk of being exposed to HIV. It is important, however, that women on the trial do not become pregnant.

Bridget Haire is AFAO's Vaccines Policy Analyst and editor of the National AIDS Bulletin.

HIV

you decide!

HIV

information
and advice
to help you

...ance
...side effects
...in the pipeline
...and more.

This booklet is for anyone with HIV who may be considering starting, stopping or changing treatment.

Available free from your AIDS council, PLWHA group, user group, GP and online at:

www.afao.org.au

To get a copy or for more information call:

ACON switch: (02) 9206 2000

ACON Treatments Information: 1800 816 518

PLWHA (NSW): (02) 9361 6011



napwa



ACON





You don't have to make HIV Treatment decisions alone.

ACON's Treatment Information Officers provide objective and confidential information, support and referrals.

Get the facts on your treatment options: available by phone or make an appointment to talk face to face.

- * Blood tests and what they mean
- * Starting treatment
- * Changing treatment-future treatment options
- * Side effects
- * Post-exposure prophylaxis
- * Taking medication on time
- * Treatments and pregnancy
- * Clinical trials

A C O N

AIDS Council of New South Wales Inc.

phone 02 9206 2013 or 02 9206 2036
freecall 1800 816 518 fax 02 9206 2092
email treatmts@acon.org.au treatinf@acon.org.au
internet www.acon.org.au

healthier living

It's time to consider getting back on the bike, suggests **Graham Norton**

'...and in just seven days I can make you a man', or so said Frankenfurter in the Rocky Horror Picture Show. Some gyms and other organisations offer prizes of a million dollars to people who can change their body in 12 weeks. As a gay man with lipodystrophy, the prize is improved self-image and healthier living – but it may take a little longer.

Here in Sydney, we have been lucky that Gold's Gym believes enough in the beneficial effects of working out to offer 12 positive guys the opportunity to participate in their own healthy life program. Called healthyLIFE+, it has been a chance to try and offset some of the effects of fat stripping and weight loss and also to gain some good eating and working out habits – for health's sake – in a gay friendly environment.

Anyone who feels they have lost weight as did (or those who have gained weight) and who don't like what they see in the mirror, can start their own body transformation. We used Gold's Gym because they generously sponsored the free memberships during the program and the commercial gym has opening hours that allow any positive guy, whether working or not, the chance to participate. Gold's Gym is in Darlinghurst and there are significant benefits from being welcomed back into our community choice.

You can use a gym or work out at home through other physical activities. The main thing is to start doing something! healthyLIFE+ was a great program because nutritionists and physiotherapists specialising in HIV were involved in the program. We also had seminars on related topics that allowed us to think about lifestyle changes that will help us maintain the new attitudes (and bodies) we have been developing. We were particularly fortunate to have assistance from Simon Sadler (Barrington Street Nutritionist) and Andrew Rusman (RPA Physiotherapist).

These experts in health are accessible to

most positive people through the hospital system and some hospitals and local communities offer cheap or free gyms for PLWHA – which might be worth considering as well as the commercial alternatives. It is always important to talk to your doctor before starting an exercise program and always remember it takes much longer than seven days to change your body – in fact some changes simply cannot be made. That is why it's always good to consult a physiotherapist who specialises in HIV and someone who knows of your condition and what exercises will, might and won't help you.

None of the participants in the program have turned into Arnie – and I don't think any expected to – but most have seen good improvements in just twelve weeks. Many have lost abdominal fat and girth and seen muscle growth expand the size of their arms and legs. Personally, what started out as a self consciousness about how I looked and the fear of being tagged as positive through my weight loss, has resulted in feeling better about my body and feeling like I have more energy. I am also eating better and know a lot more about how to deal with stress and goal setting to keep my life moving ahead.

It is likely that healthyLIFE+ will run again – but you don't need to wait for ACON or live in Darlinghurst. Just talk to your doctor – think about what you want to change, be realistic and then talk to someone with knowledge about what aspects of a physical workout or exercise regime will work for you. If you want to contact us, we will pose your questions to our experts and help you connect with people and services in your area that will see you on your way to a new and improved health, life and body.

It is important to remember that working out can be taxing and make you feel worse not better. That is why you should also look at stress and other factors that impact on your health.

Graham Norton is a Project Officer at HIV Living and can be contacted on 9206 2011.

Personalising your fitness regime

Fit X Gym, Sydney's gay and lesbian community gym, offers Positive Access Program (PAP) – a fitness program for PLWHA. Structured and designed for the complex and specific exercise needs of HIV positive people, the aim of the program is to improve the overall quality of life for PLWHA by providing individually structured cardiovascular, weight resistance and dietary programs.

While there are many options available to PLWHA considering gym-based fitness programs, it is important to consider your body's individual needs when exercising. You need to take into account your body's ability to recover from exercise and to workout within your body's recovery limits.

Ingrid Cullen, Fit X Gym's licensed (and award winning) instructor, has the knowledge and experience to develop a personalised exercise program for you. Ingrid understands issues relating to lipodystrophy, wasting and energy levels and can direct you towards a productive and less stressful exercise program. One of the keys to getting the best results from a fitness program is discovering the appropriate ratio of rest, work and nutrition for your body.

PAP is on Monday, Wednesday and Friday from 9.30am – 12.30pm with aerobics and weights on Monday to Friday from 4.30pm to 7.30pm. Fit X Gym is located in the rear of the Pride Centre, 26 Hutchinson Street, Surry Hills. The cost is \$2.50 per visit or ten visits for \$20.

To support the Positive Access Program, Fit X Gym are planning a fundraiser on Sunday August 26. The event will kick off with an early evening cabaret and refreshments will be available over two levels of the Pride Centre in Surry Hills. For more information about the fundraiser or PAP, call Fit X Gym on 9361 3311.

Medicinal Cannabis Information Service

The NSW Government is in the process of investigating the introduction of the use of cannabis for medical purposes, for certified patients.

If you suffer from one of the following conditions, the Government's decision may affect you.

- HIV – related wasting and cancer – related wasting
- Pain unrelieved by conventional treatments
- Neurological disorders including Multiple Sclerosis
- Nausea and vomiting in cancer patients undergoing chemotherapy

If you use cannabis for medical purposes or want information on the use of cannabis for medical conditions which do not respond to conventional treatments, we may be able to help you with advice and information.

Ph 02 6689 1968 or write to
MCIS
PO Box 500 Nimbin 2480

HIV – Integrative Treatments Forum

Call for Papers/Workshops

In May 2002 the *Integrative Therapies Working Group* of People Living With HIV/AIDS (NSW) Inc will convene a forum entitled HIV-Integrative Treatments.

Integrative treatments combine standard medical therapies with a broad range of natural and holistically orientated therapeutic outcomes. It is anticipated that the forum will involve medical practitioners, naturopaths, acupuncturists, meditation and other related disciplines.

The aim is to provide information to educate plwh/as and their physicians on how to integrate complementary and standard medical therapies in the treatment of HIV. The forum will take place over two days in Sydney. Medical practitioners are invited to participate on the first day of the forum followed by a second day open to plwh/as, their carers and supporters and other interested parties.

Medical and complementary practitioners are invited to submit an abstract. Abstracts should be no longer than 250 words and include a title for the paper/workshop, name(s) of presenter(s) with full contact details (including e-mail if available) and a brief biography.

The deadline for receipt of abstracts is Friday, 21 September 2001

Submissions can be sent to ktriffit@mail.newcastle.edu.au or the *Integrative Treatments Working Group*, PLWH/A (NSW) Inc, PO Box 831, Darlinghurst, NSW 1300



mother helen's miscellany epistle-ette #8

Mother **Helen Highwater** OPI (ret*)

Blessings and a Perpetual Indulgence all youse gentle readers. I'll bet you never thought I'd inflict myself on you again, and now look! – lucky number 8. Well, it's the time of the year when I bestow another OPIA (Order of Perpetual Indulgence Award) upon an unsuspecting and much deserved recipient.

After a hideous experience channeling his 'talents' in our Western capital, Perth, this poor little mite trudged the Nullabor to inflict, nay, grace Sydney with his presence and goodness. Not being able to realise his true ambition of saving the planet from ecological devastation, he put himself through the rigours of the NSW Department of Education – teaching science at a glitteringly suburban high school whilst flinging himself with gay ab-abandon into the midst of HIV/AIDS politicking in the form of caring with CSN and being a CSN committee member.

Casting off his role as my Chief Executive Carer to assume the mantle of Community Development Officer at PLWH/A in 1998, he was responsible for the much loved 'Time-Out Room' at Mardi Gras as well as allowing us access to the PLWH/A office for work-related experience. His rise to glittering stardom was thus assured – and it gives me the greatest pleasure to recognise Antony Nicholas as the beneficiary of this soon-to-be prestigious award.

'Now, now Mother', I hear you all mutter, 'Surely he's paid to do this. So why honour him with this stunning accolade?' Well, gentle readers, for a number of very valid reasons. Antony doesn't just put in a 9 to 5 effort. He's also a spunk, and a pretty snappy dresser. I don't think I've ever seen him in a pair of fluffy Jiffies ... or a chenille dressing gown. You see now, as do many others, just how high the criteria are to even be considered for this recognition. But there's only one OPIA a year and with my having no intention of departing this mortal coil in the foreseeable future, there

are a number of worthy recipients yet to come. His mediation and advocacy on our behalf deserves recognition. If only we had a dozen more like him in positions of authority, we wouldn't have anything to grumble about.

Hmmm! That's just given me the idea for my next missive; a detailed account of how to complain effectively and actually get some response. We all know what it can be like dealing with service providers who either do or don't provide service. Oh boy, have I got stories to tell! I look forward to getting back to my usual self-effacing style in the coming editions of this much loved journal 'Where We Speak for Ourselves'. Please remember that I warned you ages ago about the imminent arrival of the GST, so if you see any nuns with less than satisfactorily Fabulonned wimples, don't say I didn't tell you!

A reminder that we await our invitations to the next CSN Client Forum on Wednesday August 15 at 1pm. Our contribution to the smooth running of this vital service is obviously needed and appreciated by ACON, so I urge as many as possible to attend. Give them a call now to arrange transport at 9206 2040 and speak to the delightful Evert.

In closing may I, in all humility, offer free electronic confessions (I'm a very modern nun) by simply putting pen to paper and addressing it to me c/o this glittering publication ... or if you are an absolute genius and know about these things to mthrhell@zip.com.au

A final word of warning gentle readers; please don't take your little kiddies to Fraser Island. Our sacred Dingo is having a bit of a rough trot up there at the moment, but being the sacred icon it is, it should have no difficulty in re-establishing its rightful place in the not too distant future. A tourism ban – similar to the Tassie boycott – may be one way of sending a very clear message to Queensland about the pagan slaughter of this much loved indigenous Australiana.

Dingoo Vobiscum.

*retired/retarded

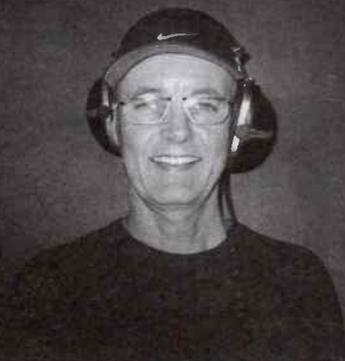
Espresso Yourself!

A twice monthly coffee night for HIV positive gay men. The night provides a space for networking and support. Alternates between Newtown and Surry Hills, some nights have a special guest



We're HIV Living too. As a team of positive people we have networks and skills to help you get the most out of life.

Positive Fun & Esteem. Fun and helpful groups and activities for young HIV positive gay and bisexual men helping you best manage your own life. We like to have a strong social content for the guys involved.



Planet Positive.

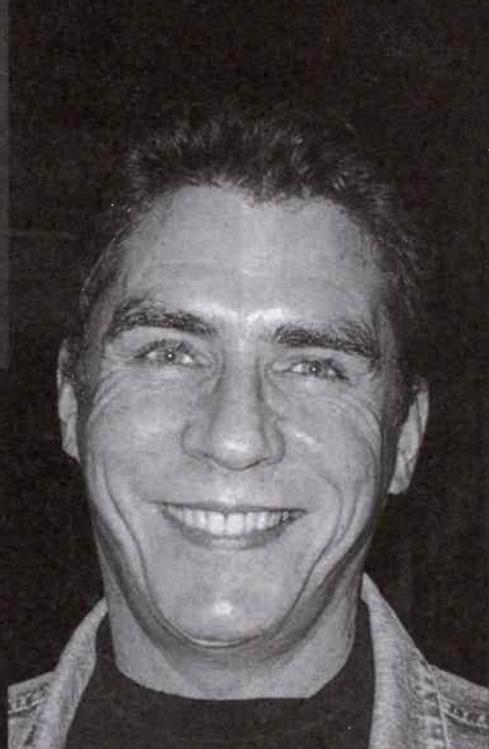
Winter starts to defrost and we celebrate the end of the cold weather with other positive people and our friends by turning up the heat. Happening mid August (check with us for details).

HIV living

The Positive Men's Project

Any images of people in this advertisement were taken at the June 2001 Planet Positive party and do not ipso facto imply anything about the actual conduct, health status or personality of those people.

Groups of all kinds. Do you need ongoing support or a chance to catch up with your own kind? Phone the HIV Living team for more information on groups that may suit you.



Free workshops, training, support groups, event nights, information, advocacy and support.



stay in touch with our newsletter.

join our mailing list (ph 9206 2000)

or view it at www.acon.org.au



POSITIVE SPEAKERS BUREAU

A Project of PLWH/A (NSW) Inc.

The Positive Speakers Bureau (PSB) is looking to increase its services to schools later this year. We are seeking applications for HIV positive people who would like to join this personally rewarding scheme. Full training is provided. We are especially interested in hearing from persons who are heterosexual (male & female) and people of non-English speaking backgrounds.

For further information please give Tony a call on 9361 6011.
Email psb@plwha.org.au

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, wills, power of attorney and more.

To make an appointment please call us on

02 9206 2060

All information is kept strictly confidential.

HALC

HIV/AIDS Legal Centre Incorporated
9 Commonwealth Street, Surry Hills NSW 2010
PO Box 350 Darlinghurst NSW 1300
Telephone **(02) 9206 2060** Fax **(02) 9206 2053**
email halc@halc.net
Freecall **1800 063 060**

WRITING WORKSHOPS

**A SIX WEEK SERIES OF WORKSHOPS
WILL BE HELD AT THE SANCTUARY
6 MARY STREET NEWTOWN**

FROM AUGUST 15TH 2001

**WOULD YOU LIKE TO WRITE ? DOES THE
THOUGHT OF WRITING APPEAL TO YOU ?**

**A POSITIVE WRITING COURSE FOR PEOPLE
WITH OR THOSE AFFECTED BY HIV. GET SOME
IDEAS ON HOW TO START WRITING AND MEET
SOME PEOPLE WITH SIMILAR INTERESTS**

**TO MAKE ENQUIRIES CONTACT GLENN
AT PLWHA TELEPHONE 9361 6011**

Give me SHELTER



ACON has produced a new booklet titled *Give Me Shelter: Housing assistance options for people living with HIV/AIDS*. The pocket-sized booklet has been developed to provide information on housing options, eligibility criteria and where to go for assistance.

Give Me Shelter is available free to people living with HIV/AIDS and to HIV support services by contacting the Information Project at ACON on (02) 9206 2024.

The booklet refers to a number of support services, and encourages PLWHAs to seek out assistance on issues such as the housing application process, financial management, tenancy issues, supported accommodation and other support needs.

ACON
AIDS SERVICE OF NEW SOUTH WALES

a mixed bag

Talkabout offers some suggestions for busting the winter blues

reflexology

As David Jobling states in 'Keeping it together' (see page 9): 'I find [foot reflexology] extremely relaxing and it's not particularly ticklish. I highly recommend. So what exactly is reflexology?

While the precise origins of reflexology are obscure, the practice appears to have begun over 5,000 years ago in ancient Egypt as well as China and is founded in the belief that our bodies are made up of 'energy highways' and 'zones'.

Reflexologists divide the body into a series of ten vertical 'zones' (five on each side of the body and five down each arm and leg) and believe that the left foot is connected to the organs within the left side of the body and the right foot is connected to the organs within the right side of the body. Reflexologists believe that distinct zones of the feet correspond to particular organs or body systems, for example the tips of our big toes are connected to the top of our head, or more specifically, our brain. Reflexologists further subdivide the zones of our feet into specific 'reflex areas' which relate to particular organs such as the heart and kidneys, and are able to recognise roughly 30 areas of the sole of each foot.

Reflexology involves the manipulation of these specific areas of the feet (and sometimes the hands or limbs) with the all goal being to balance the body's energies – in turn improving blood flow, unblocking nerve impulses and relieving stress. Reflexologists will apply pressure to your feet by holding your foot with one hand and pressing selected points with the thumb of the other. Using thumb and finger techniques to work on a 'reflex area', the aim is to remove tension within each 'reflex area' – tension interpreted as being a sign of 'blockages' or 'stagnation' in the relevant part of the body connected to the particular reflex point. Reflexologists believe that their therapy is described as 'preventive maintenance',

and that a person who pursues balance in their body's energies will relax stress and tension, thereby enhancing their general wellbeing.

This information is included for reference and interest purposes only and is not intended to be used as a substitute for advice or treatment by your doctor. It is important that no action of a medical nature be taken without first consulting your doctor for their opinion of how you might benefit.

Sources: Encyclopaedia of family health, Marshall Cavendish, 1991 and The Alternative Advisor, Time Life Inc., 1997. Thanks to Jill Snowden, Melbourne.



The winter blues

Talkabout has discovered some options for tackling the 'winter blues'

Blues Busters are a series of free workshops for HIV positive gay men who are dealing with depression and social anxiety. Facilitator Greg Millan is a sexual health counsellor, group worker and reflexologist who has worked in the area of sexual health and men's health promotion for over fifteen years. Blues Busters provides participants with information, new thoughts, skills, ideas and approaches to help in the management of our lives in a safe space where concerns can be shared and discussed. The Blues Busters

workshops will cover:

- What causes depression and anxiety and what can be done about it;
- How to relax more, have fun and visualise wellness in your life;
- How to deal with irrational thoughts and emotions;
- How to maintain a healthy sex life; and
- Some helpful hints on how to stick to difficult treatment regimes.

Blues Busters will be held on six Monday mornings from 10.00am – 1.00pm. For further information, telephone Holdsworth House General Practice on 9331 7228 or contact Greg directly on 0417 772 390 or email gmillan@netspace.net.au

The search for balance, peace and serenity in our lives can often be clouded with fear and trepidation about what might work and what might just leave us feeling worse. Meditation and yoga have long been considered valuable aspects of our search for ways to enhance our wellbeing. For PLWHA, Daniel is offering free meditation and yoga sessions on Wednesdays from 11.00am – 12.00noon. The sessions are held at The Positive Living Centre (PLC), 703 Bourke Street (between Devonshire and Cleveland Streets) in Surry Hills. Telephone 9699 8756 for more information.

Pozhet are promising a relaxed afternoon at their forthcoming 'Absolutely Fabulous Pozhet Clinic' where positive heterosexual men and women, their partners and families are invited to be treated to new lifestyle therapies – free of charge! Further details can be obtained by telephoning David and Jan on freecall (NSW) 1800 812 404.

Sydney's Museum of Contemporary Art (MCA) is hosting a marvellous exhibition (until August 19) called 'When Elephants Paint'. The exhibition features paintings created by elephants who were taught, in collaboration with their trainers, to 'hold brushes and, using non toxic paint, to paint paper and canvas and create colourful, abstract artworks'. For a sneak preview, visit www.elephantart.com



Olga's personals

r, romantic, sincere hard working 41yr old HIV+ divorcee seeks ship with HIV+ 42yr old gent. Must possess a wicked sense of ur and good intentions. All replies answered include telephone nrs/recent photo. **Reply 050801**

romantic Greek gay guy, HIV+, seeking 30-40 year old newly sed positive male for relationship. I enjoy bushwalking, going for ives and computers. **Reply 040801**

ore, Funky yuppie would like to hear from guys, transgenders and i, any age, looking for friendship and fun times. Background HIV+, talk about it. Treatments, still interested gay lifestyle. Future Confidentially assured, all mail answered. **Reply 030801**

tive HIV+ guy. 40 looks younger and Musician, is caring, mate and a romantic. I live a 'normal life' and in excellent Enjoys a healthy lifestyle and appreciates the finer things in es in Sydney would like to meet a HIV+ female to share my life at me serenade you. GSOH, and discretion a must. My first **Reply 020801**

4yrs, male, very good looking and humorous. I have many ful hobbies and friends, and I am completely together. Looking sone to share life with and to hopefully love and spoil. NO LOONS . **Reply 010801**

etero HIV+ 40yrs looks younger, in good health, Caucasian fun share activities of the body, mind and soul with a loving female. ust & reliability are recognised as the guiding values for giving er support & to being in love. I live in Melbourne and can travel, you need to write a reply first. **Reply 040601**

gay guy HIV+ 40yrs, 70kg, medium muscular build, blue eyes, head, very DTE/GSOH. Enjoy movies, playing pool, going to and bushwalking. Not into beats or drugs. Photo please. **30601**

good-looking 5'11" 70kg, genuine & honest with a good sense /+ & live in the Eastern Suburbs. Seeks friendship/relationship /s 25-40 who are sincere, genuine, fit & healthy. Interest cycling, swimming, meditation, music, movies, gym, and afes & weekends away. **Reply 020601**

'30's seeking non-scene, non smoking down to earth mature uy to 40 with strong body and will to live life to fullest. Casual rith, but seeking long term, I have a warm hairy chest for the nter nights. **Reply 010601**

de area 54 HIV+ 6ft, 80 kg healthy likes movies, live shows, d watching tv at home. Seeks female similar with gsoh for or relo, I have no ties, once married with 2 adult children. **0401**

years old, HIV+ gay man, Australian born, fair skin with brown s. Well proportioned body 6'1", 88 kgs. Cultural interests, motivated and live in Sydney. Love good food and sex. Seek ong term... (Please include phone number). **Reply 011101**

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

place your advertisement Write an ad of up ords • Claims of HIV negativity cannot be made. l claims of HIV positivity are welcomed and ed • Any letter that refers to illegal activity or is racist ill not be published • Send the ad to Olga, including e and address for replies. Personal details strictly al.

diary

social and events

Art Gallery of NSW has a number of excellent exhibits coming up in the next few months, the gallery has well priced concession rates for some and others are free. For more details call the info desk on 9225 1744 or visit the gallery's website www.artgallery.nsw.gov.au

'Outings' from South Sydney Community Transport is always offering day trips, and excursions. If you need more information and wish to book call Jane or Robbie on 9319 4439.

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

support

South Sydney Carers Support Group is a support group for carers of PLWHA. They meet every third Tuesday of the month at Sutherland Hospital. They have guest speakers and information. Contact Terry or Emma for more details on 9350 2955.

If you live in Southern Sydney **Friends of Waratah** is a support group for PLWHA who meet on the first Monday each month in Kogarah. They offer emotional support, information and social activities. For more details, call Emma or Terry on 9350 2955.

Pozhetwest Western Sydney peer support and education for men and women living heterosexually with HIV/AIDS. Telephone 9671 4100 for more information.

Grief Support and Youth Suicide Project for Youth

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 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 9829 4242 and Carole Knox 9580 5718, the AIDS Dementia Outreach Team 9339 2078 or David at The Bridge 9552 6438.

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. Price is \$4.00

and available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville and Darlington. Call Diana on 9516 4755.

health, fitness & learning

Your Community Gym Fit X Gym

Fit X Gym is at the Community Pride Centre, Hutchinson St, Surry Hills. 'Positive Access Project' offer qualified instructors, free assessments, free nutritional advice, free individual programs and a free session to try out the gym. \$2.50 a session or 10 visits for \$20. Contact Fit X Gym on 9361 3311 between 4pm and 7pm Monday to Friday.

Yoga for PLWHA

Special weekly classes at Acharya's Yoga Centre Mon - Fri 12.30pm to 1.30pm, call 9264 3765 for more information.

The Sanctuary offers free massage, acupuncture, therapy information, social work and shiatsu services. Call Robert for details and bookings on 9690 1222.

The Sanctuary will be including a series of new cooking programs including cooking for one, nutritious juices/smoothies and asian gourmet. To find out more contact Sidney Leung (dietitian) on 9395 044 for course dates and details.

Complementary Therapy Advice

Advice and referrals for PLWHA interested in exploring complementary therapies is available on Monday and Friday at The Sanctuary. Call Mac on 9519 6830 or email complementarytherapies@hotmail.com

Community Garden learn how to grow your own vegies! Call Carolyn at Waterloo on 9382 8374, or call Robert in Newtown 9690 1222 and if you're in and around Woolloomooloo contact Michael on 9206 1222. Remember spring and summer is a great time to be had in the fields.

Newtown Neighbourhood Centre has a number of groups ranging from Ninja Warrior Arts, Women's Kickboxing, Exotic dance classes and Shaja Yoga Meditation. Call Charlotte on 9516 4755 for more details.

Diary is designed to promote volunteer-based and/or unfunded projects that benefit PLWHA. We especially encourage items from rural and regional NSW. Items of 30 words or less are welcome. Send your diary item to Will Klassen at *Talkabout Diary* PO Box 831 Darlinghurst 1300 Fax 02 9360 3504 Email willk@plwha.org.au Ph 02 9361 6750

For a comprehensive site about the arts, including free entertainment listings see *Qstage Digest* <http://www1.loom.net.au/home/dpj>



hyperactive 19

compiled by **Will Klaasen**

<http://www.healingpeople.com>

PLWHA continue to consider complementary therapies as a feature of available treatment options – and the benefits of Eastern and alternative medicine have been the constant focus of much research, information and discussion. You can only benefit from increasing your knowledge of the complementary therapies available, and www.healingpeople.com is a comprehensive, if not always a serious, reference point.

The information contained here is both honestly and professionally discussed – especially regarding what can actually be achieved for PLWHA.

www.healingpeople.com also features an e-commerce function, through which you can purchase books, publications, journals, vitamins and supplements etc., however, being a US-based site, all the prices are in \$US.

Most noticeable on the site is that throughout the health arena and within each discipline, the advice is the same: work with your doctor, nutritionist and practitioner and really ask those questions. You can register as a member and go into their chatrooms to seek advice or share your thoughts with others.

www.healingpeople.com is a lifestyle site and, as with any information you seek, only consider taking out what you need for that moment in time – after all, it is going to be there for you again when you need other questions answered.

<http://www.poetry.com>

To budding poets out there, this is your opportunity to enter a truly international competition for non-professional writers. The International Library of Poetry is offering weekly prizes of US\$1,000 (and monthly \$10,000) for the best work submitted from around the world.

You have to be an amateur writer (meaning that you have not been paid to write) and it cannot be your full time occupation. All you have to do is submit twenty (20) lines or less, and there are no restrictions on how you present your contribution. Your poem can be on any subject matter that you desire.

The site is easy to get around, and boasts 3.1 million poets on record. If you want to read the work of other poets, you need to enter first names and surnames and see what turns up. Poetry.com also promises return (within seven weeks) a critique of your piece, which is all about encouragement.

So with all luck, *Talkabout* may assist in the discovery of a budding poet! Give it a go! All the best!

<http://www.nih.gov>

The USA's National Institutes of Health (NIH) is another of those large databanks of research information. You can spend an entire week getting lost with the amount of research papers and reports from clinical trials plus factsheets. As with all government monoliths surrounding health and social issues, the information is hard to grasp, but if you have lived with the virus so far you are already versed in the lingo. It's always good to know what the hell our doctors are saying at times.

<http://www.cochraneconsumer.com>

Cochrane Consumer Group (CCG) is a UK-based not-for-profit group and is supported in Australia by Medibank. CCG is the UK's version of *Choice* – offering regular updates on information about treatment trials, health-specific media releases and other relevant information regarding health issues. You will need to search specifically for HIV/AIDS as one of the many subjects offered.

Quick click

<http://www.cleansheets.com> is where you can buy adult stories and read personal opinions on the issues of the day. Please note this site is for adults only.

<http://www.hivolutions.com> offers an alternative method in complementary therapy; the procedures are being conducted on Indigenous American sovereign reservations and not through standard processes and protocols.

A word of warning

Some websites offer an e-commerce function whereby you are able to purchase products, resources and other often desirable bits and pieces. Before you consider a purchase, make sure that the site operates under a strict code of security in relation to financial transactions and that your privacy will be protected.



Check Me Out!



Living with your Liver

Your liver is the largest organ inside your body. It is your body's chemical refinery and without it you can't get rid of a whole range of toxins, including alcohol, and the drugs you take orally or through the skin. If you are taking HIV combination therapy, your liver will be working hard to process and get rid of the large doses of drugs you swallow as well as doing its usual work.

A severely over-worked liver may mean more severe side effects or failure of the combination therapy because your body can't absorb the right amount of the drugs. So it's important to look after it as best possible.

How to avoid stressing your liver:

- Eat well
- Avoid binge drinking
- Protect yourself from hepatitis

Checking for Hepatitis

This involves a quick blood test (just add it to your list). Ask your doctor for a Hepatitis test. With the result you'll know whether you've been exposed to Hep A, B or C and whether you need a vaccination for Hep A and B or a booster vaccination.

Coping with Co-infection

Most HIV medications are metabolised by your liver. If you don't look after your liver, acute Hep A or B, and chronic B and C infection can all make HIV therapy more difficult.

HIV and Hep C may affect each other if you have both of them. They may cause each other to get worse, so it is very important to discuss treatment options for both thoroughly with your doctor. There are several treatments available for Hep C (and B), some of which are similar to HIV therapy.

What to talk to your doctor about

Sometimes liver problems may be a side effect of an anti-HIV treatment, which is why doctors will monitor your Liver Function Tests (LFTs).

If you have both HIV and Hepatitis your doctor will closely monitor your LFTs. This could help balance the combination of drugs for HIV so as to minimise damage to your liver. Your doctor may also perform extra viral load tests for Hepatitis C and may want to perform a liver biopsy at some stage.

"I never thought what I did in my youth would have a long-term effect on my liver"

Hepatitis, HIV, Baby and Me

Monitoring your health throughout pregnancy is very important. Being protected from Hep A prior to pregnancy is important because acute Hep A during pregnancy can lead to miscarriage.

Hep B does not usually affect pregnancy. Transmission of Hep B may occur at or soon after delivery (rarely before), so it is recommended that you be vaccinated either before you get pregnant or during pregnancy. If you have Hep B, your baby's chances of getting it can be reduced from 90% to about 5% by giving it immunoglobulin and one dose of vaccine as close to delivery as possible. Your baby will also need 3 follow-up vaccinations (at two, and twelve months) after the birth dose. Breastfeeding is not recommended if you have HIV, regardless of hepatitis status.

Hep C does not usually affect pregnancy. Your doctor can check for the Hep C virus by a test, called PCR. If this test shows that you have the Hep C virus there is a 5% risk of your baby getting it from you. Otherwise there is no risk. It is not known whether this risk is affected by the way your baby is born (vaginal or caesarian). If a test shows that you have Hep C, and if you have cracked nipples, breastfeeding is not recommended.

Your baby will be born with antibodies to Hep B and C, just like with HIV antibodies, and they will be present for about 18 months. This does not mean they have been infected. This can be tested earlier than 18 months by a test looking for the virus itself called PCR.

REMEMBER ME

When we're negotiating sex, a lot of us have HIV on our minds and this often helps us to decide with whom, and how, we will have sex. It is important to consider other STDs, including Hep A, B and C, as well as HIV, when negotiating sex with your partner.

For hepatitis testing and vaccinations for hepatitis A and B call 9560 3057 in Inner Western Sydney.

In Sydney's City, South and East phone Sydney Sexual Health Centre on 9382 7440 or St George Sexual Health on 9350 2742 or Kirkeaton Rd Centre on 9360 2766.

Produced by Central Sydney Area Health Service and South Eastern Area Health Service in collaboration with PLWH/A (NSW), ACON and FPA Health.

**NEXT PAGE
FOR WHAT**





Check Me Out!

the A, B and C of Hepatitis and HIV

WHAT IS HEPATITIS?

Hepatitis is a condition where your liver is inflamed and often causes swelling and tenderness. It can be caused by things like alcohol, chemicals and viruses. Sometimes viral hepatitis can lead to serious liver disease (cirrhosis and cancer) and can be life-threatening. Hepatitis (hep) A, B and C are three different viruses that cause hepatitis.

Hepatitis A

The most common way to get Hep A (HAV) is by eating or drinking food/water contaminated with faeces of an infected person. Handling a condom after anal sex can also spread it. Hep A can be prevented by carefully washing your hands before and after going to the toilet, eating, drinking and smoking. People who are HIV positive can be vaccinated against Hep A and this is recommended.

The common symptoms of Hep A are fatigue, fever, nausea and turning yellow (eyes and skin) and usually last 1-3 weeks, but don't become chronic (long-term). If you think you might have been exposed to Hep A and have not been vaccinated or had Hep A before, you should see your doctor within 2 weeks who can give you immunoglobulin to prevent or reduce illness. There is no treatment for Hep A, however eating well, resting and avoiding alcohol may help you recover from the symptoms.

Hepatitis B

The most common way to get Hep B (HBV) is through sexual contact, and by blood-to-blood contact. Vaccination is the best form of prevention, and current guidelines recommend that plwha be vaccinated. Free hepatitis B vaccinations are available for plwha at sexual health services. Condoms will greatly help in preventing you from getting Hep B. Sharing any injecting equipment and personal items like toothbrushes and razors should be also avoided as hepatitis B can live outside the body, and be passed from one person to another by saliva.

Hep B can lead to chronic infection and symptoms. If you think you might have been exposed to Hep B and have not been vaccinated, you should see your doctor within 2 weeks as you can be given immunoglobulin or rapid vaccination to prevent it from taking hold.

Hepatitis C

The most common way to get Hep C (HCV) is by blood-to-blood contact. You can get Hep C through sexual contact though this is not so likely, and the risk is thought to be quite low where there is no blood present. However, there does appear to be a greater risk of getting Hep C through sexual contact if both partners are HIV positive. You can reduce this risk by using condoms where contact with blood is likely eg, during menstruation or when there are genital ulcers or sores.

You can avoid Hep C by not sharing any injecting equipment, or personal items such as toothbrushes and razors, and by using a condom where contact with blood is anticipated. There is no vaccine for Hep C.

Hep C can be a serious long-term infection and can take many years to show up. Without early detection and treatment, cirrhosis of the liver or liver failure could occur. Some people develop a liver cancer known as Hepatocellular Carcinoma.

THE QUICKIE !

- ✓ If you look after your liver, it'll look after you.
- ✓ Treatment is available for chronic Hep B and C.
- ✓ Hep A during pregnancy may lead to miscarriage.
- ✓ You can have Hep B and C and have a baby safely.
- ✓ Hep C is rarely sexually transmitted, but does happen.
- ✓ Think about hepatitis as well as HIV before negotiating sex.
- ✓ Having Hep C does not increase your risk of transmitting HIV.
- ✓ It is important for PLWHA to be checked for Hep A, B and C.
- ✓ Having Hep B or C may affect your treatment choices for HIV.
- ✓ Vaccinations for Hep A & B are available and they are safe and effective.

**NEXT PAGE
FOR HOW**



"We only worried about each others' HIV status before we had sex, we didn't think about hepatitis"