

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

No.105 February 2000

Talkabout

◆ Where We Speak for Ourselves ◆

DSP
END FREEWA

VOLUNTEER
NEXT EXIT

DEFENCE FORCE
WRONG WAY
GO BACK

POZTALK
ENTER HERE

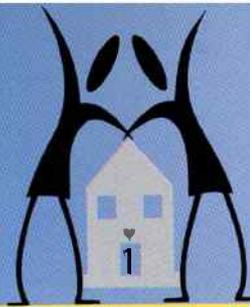
Reconstruction
... work in progress

PLUS interleukin trials, welfare reform, the luncheon club and an arts update

Details phone (02) 9671 4100

pozhetwest

2000 CALENDAR



FEBRUARY

Thursday 10

Open House *What can you tell your Doctor?*

Guest *Dr Barry Bland*
HIV General Practitioner
Seven Hills

MARCH

Thursday 9

Open House *Simply Talking*
Guest *Jan Gall, HIV Educator*
Wentworth Area Health

Thursday 30

Positive Business
There's more to me than HIV

APRIL

Thursday 13

Open House *Telling ain't easy*
Guest *Claire Black,*
HIV Counsellor
Nepean Hospital

MAY

Saturday 27

Family Matters
1st Annual Pozhetwest
Conference, Blacktown

JUNE

Thursday 8

Open House
Expand Your Horizons

Guest
Nadine Binstead
Options Employment Services

JULY

Thursday 13

Open House
At home with The Haven

Guest
Pat Kennedy
The Western Suburbs Haven
Blacktown

Thursday 27

Positive Business
You've got okay medical results
on paper and still feel dreadful

AUGUST

Thursday 10

Open House
You in the movies, on TV
and in books?

Guest
Marita Murline
on HIV/AIDS in literature

SEPTEMBER

Pozhetwest closes during the
Olympic Games

OCTOBER

Saturday 14

Pozhetwest-in-the-mountains
Pozhetwest and Pozhet (NSW)
coach trip

Thursday 26

Positive Business
Olympic fever.
What's captured you?

NOVEMBER

Sunday – Wednesday

Pozhetwest-by-the-sea
Bilgola Beach Holiday
Dates to be announced

Saturday 25

Body Talk
Looking good, feeling better!
5th Annual Living Heterosexually
with HIV/AIDS Workshop,
Surry Hills, Sydney

DECEMBER

Thursday 14

Out on the town!
Pozhetwest Xmas Party

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putting it all together

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david menadue considers the pros and cons of leaving the workforce

work me right 15

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work, HIV ... and us 16

returning to work often means facing your own fears and sometimes the ignorance and fear of other people. maxine, arthur and peter share their stories

putting it all together 18

pene manolas reports on the reconstruction project and frank and craig reflect on their experience

opening doors 20

sometimes thinking about a return to work can lead to doors never contemplated. sarah yallop reports on the positive employment service and michael riches reflects on his experience

the power of volunteers 22

they were rebellious, vocal, dutiful, dedicated and every so often totally outrageous. antony nicholas asks 'where to from here for our volunteers?'

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there are so many things to say about our lives, real or imagined. Now is your chance. One month to go ... and we introduce our fabulous judges and our fabulous prizes from our fabulous sponsors.

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positive heterosexuals **back cover**

editorial

The 2nd HIV Futures Study due to be released in May is expected to show that over half of Australia's PLWHA are on some type of government pension. The AIDS sector of NSW has begun to gear its services to those who wish to 're-engage'. This suggests that many of us had disengaged in the first place. In a highly competitive job market PLWHA are often out of the workforce for several years and need to retrain. What is it that provides the motivation to leave the security of discounted medical treatment, housing and transport? Why pull the plug on the hand that feeds us, particularly when we are surrounded by the uncertainty of treatment resistance or failure and a loss of potency in our new generation Cd4s.

Many of us live for our work. In a workshop in Thailand women were asked what got them out of bed in the morning – of the 50 or so present, the answer was unequivocally their family and children, or work. (Their work being mostly unpaid in care, advocacy or positive education.)

'Work' can mean different things to each of us and perhaps this is why there is resistance to the discourse of 'return to work' or 'life re-engagement'. Volunteering is one way to contribute and gain a sense of self-esteem or status. Volunteering often leads to future training or paid work, but it still requires consistent effort to be recognised financially by Centrelink.

Our work too often establishes our status in society. Being positive threatens that status. The current discourse runs the risk of categorising positive lives into the compartments of those who can't maintain their status and those who can.

The issues affecting PLWHA in the post-Vancouver era are more complex and individualised as the personal stories in this issue describe. Stepping back into the workforce may have been a logical conclusion for some of us who expected to die and didn't. It has also posed new difficulties to overcome, like the unexplained illness and absences, adhering to treatment regimes, coming up with explanations for weight loss or change in body shape, and a fear of disclosure. Unwilling to take the risk of disclosing – and nor should we have to – PLWHA have the added burden of secrets and lies. While many PLWHA have returned to work many have not. Instead of 'return to work' or 're-engaging', perhaps we should be talking about 'keeping going' or 'continuing on' because treatments are keeping us alive longer.

Vivienne Munro

No funds and no lunch

The Luncheon Club – run by volunteers – which has provided free lunch for PLWHA once a week for several years is to close due to lack of funds.

The Luncheon Club AIDS Support Group suspended the popular Monday lunch service in January to enable the committee to seek funding to ensure the long-term operation of the club's services.

President, Carol Ann King, said in a statement that, "the Luncheon Club can no longer continue to operate with the uncertainty of survival without permanent funding".

Ms King told Talkabout that the group's other well-known service the Larder, which provides eight items of food to PLWHA in need a week, will continue but is also facing financial trouble.

"We desperately need a secure home for the larder with adequate storage, client access, administration facilities and space for future growth of the service."

Until the Luncheon Club finds adequate funding, Monday lunches will be available at the PLC, King said.

Pictured are some of the volunteers and clients who are hoping that the Luncheon Club will secure the funding it needs to continue providing its invaluable service to the HIV/AIDS community.

Photograph Teano studdert



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Talkabout

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Parades, parties ... and permanence

Before The Parade passes by ...

'Remembering the Past - Forging the Future' is the theme for our 2000 Sydney Gay and Lesbian Mardi Gras Parade float. Thanks to AE Sharpe Chemist of Darlinghurst who have sponsored this year's float. Sam Rey, who gave many volunteer hours last year to the construction of the fabulous "Hot Positive Sex" float, will design and build our Y2K float. Sam will need help from volunteers to build and ride the float at the Mardi Gras Workshop. Sam's experience is an example of the enjoyment and reward that volunteering can bring.

Fundraising update

The first quarter of the year is always our busiest time for fundraising. Our Summer Raffle will be drawn on the eve of the Parade with fabulous prizes including a return airfare for one to Europe, donated by KLM Airlines. Our raffle coordinator, Charlotte

Long is looking for people to sell ticket books to friends and at various events. The Sydney Gay and Lesbian Mardi Gras for the fifth consecutive year has supported us by sponsoring the sale of stickers at the festival launch. This has become our major fundraising event. If you have never volunteered or been to this event it is recommended, as the crowd is generous and the atmosphere is full of community spirit. Let's just hope the sky shines over the Sydney Opera House on the evening of Friday 11 February. Other activities we're involved with during the festival include the Mardi Gras Party Time Out Room, the Bobby Goldsmith Foundation Raised Seating during the parade and our information stall at Fair Day - Happy Mardi Gras!! We also need energetic, skilled and creative people for our Fundraising Working Group (FWG). The FWG meets monthly and oversees our fundraising plan.

Give us a call if you're interested in any of these fundraising activities.

Ready ... set ... 2000

Major activities that are currently in development are a 4th Positive Speakers Training Course; a travel brochure for members; a positive traineeship program; and an Advocacy Project for members. *Talkabout* will keep you informed of these developments.

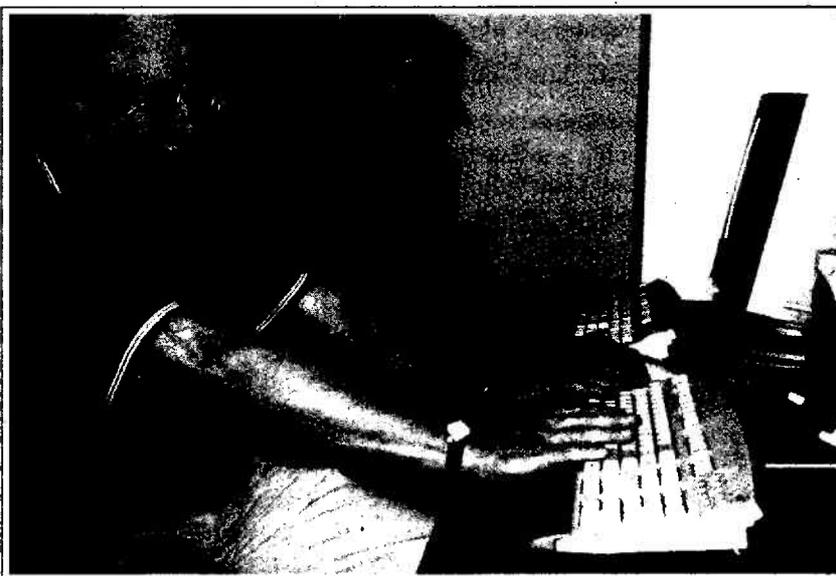
A permanent AIDS Memorial

PLWHA (NSW) and ACON have set up a working group to look at the feasibility of a permanent AIDS Memorial. If you have any comments about this plan you can ring me on (02) 9361 6011 or write to PO Box 831, Darlinghurst, 1300.

... and a Happy New Year

As I was on leave during the last *Talkabout* edition, I take this opportunity to wish all our readers peace, prosperity and fun with the turn of the new century. ■

Photo Dennis Tilney



What's happening at NorthAIDS @ Myrtle Place?

There are three PCs all with Internet access purely for the use of clients at Crows Nest. As part of NorthAIDS response to the changing needs of the epidemic, basic computing and internet classes are now being conducted by Sarah Yallop of the Positive Employment Service and Dennis Tilney, coordinator of Myrtle Place. The classes are aimed particularly at those persons who are doing well on current combination therapies who are looking at updating their skills and broadening their horizons. Dennis hopes to be introducing the first in a series of web page design courses this year.

3 Drugs in One Tablet

In December last year Glaxo Wellcome applied overseas to market Trizivir, a pill combining three nucleoside analogues – 3TC, AZT and abacavir – in one tablet. Trizivir's dosage regime would be just one pill twice daily, with or without food; however the abacavir content may cause a hypersensitivity reaction. Abacavir causes nausea, rash, fever and fatigue in about three to five per cent of people.

CATIE

Amprenavir Rejected in Europe, Delayed Here

European authorities have refused to license amprenavir, a new protease inhibitor, based on its poor performance when compared with another protease inhibitor, indinavir, and because of lack of information about its effectiveness in people who've tried all available therapies. In Australia the Therapeutic Goods Administration has asked for more information on amprenavir's long-term effectiveness. Amprenavir remains available in Australia for people whose therapies are failing and who need another drug option. It contains sulfa, which can cause an allergic reaction in some people. The manufacturers advise that anyone considering treatment with amprenavir should inform their doctor if they have a sulfa allergy.

<http://www.aidsmap.com> and Positive Living

IL-2 Trial

By the time this issue of *Talkabout* appears, a trial of Interleukin 2 (IL-2), a therapy that aims to improve immune function, is expected to have commenced. NSW hospitals involved in the trial, known as SILCAAT, are St Vincents, Westmead, Prince of Wales, John Hunter, and Royal Prince Alfred. Participating clinics in the trial are Holdsworth House General Practice and Taylor Square Clinic, both in Darlinghurst. For information about the trial criteria, see this month's Treatments Update (page 25).

National Centre in HIV Epidemiology and Clinical Research

A Community Pharmacy: Progress At Last!

For years, ACON and PLWHA (NSW) representatives have been campaigning for antiretroviral medications to be available at community pharmacies as well as hospital pharmacies. Now the NSW Ministerial Council on AIDS Services (CAS) has provided in principle agreement to a limited trial in a number of community pharmacies whose clients include positive people. Further details will be provided as they come to hand.



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

Q I am worried that over the New Year break I missed a few doses and now have developed resistance. What should I do?

A *New Year can be a chaotic time when routines are disturbed but temporary increases in viral load are not uncommon even in patients with perfect compliance. There are many causes for these 'blips'. Sometimes it can be as simple as a vaccination or intercurrent illness. Alternatively, levels of antiretroviral drugs can*

addressing these questions at the moment. Congratulations on taking this issue seriously.

Q I was diagnosed six years ago and remain well with an undetectable viral load on triple combination drug therapy. My partner and I have always wanted to have children. Is this a good idea or should I forget about it?

A *More and more women who are HIV positive are now considering pregnancy. Fortunately*

and also the paediatric team. You may have lots of questions, like how to get pregnant if your partner doesn't have HIV. Your health care provider can address these and the Women's HIV Support team at ACON is a valuable resource.

Q My viral load has been undetectable now for two years on triple combination anti-retroviral therapy and my CD4 count is stable. I have severe pain in my knee and my doctor is talking about a condition called avascular necrosis. Should I be worried?

A *Avascular necrosis is a painful condition affecting large joints like knees, hips or shoulders where changes in the blood supply produces weakened bone. It is also recognised as a complication of drugs like steroids. Treatment usually involves a surgical procedure, which is effective.*

There is limited information on avascular necrosis in HIV, however it was recognised as a complication of HIV infection in 1990. Only a small number of cases had been reported. More cases were reported at two recent conferences and it was suggested that this condition may be a complication of anti-retroviral therapy, particularly protease inhibitors. It may also be associated with raised lipids in the blood. It would appear that avascular necrosis of the bone, like other complications such as peripheral neuropathy, can arise from either HIV infection or from its treatment. ■

More and more women who are HIV positive are now considering pregnancy. Fortunately in countries like France, USA and Australia the chance of the baby becoming infected with HIV is now considerably reduced.

The risk to the baby is down to about 2%.

You should consider all the health issues from the point of view of both yourself, and your baby.

fall in your blood and allow HIV to multiply. The reasons for this include imperfect drug compliance; drug interactions (have you started any new drugs recently?) and reduced absorption from diarrhoea. Once these factors, if present, have been corrected you should repeat your viral load test. If your elevated viral load is confirmed discuss your options with your doctor. These include waiting and watching (particularly if your viral load is stable), intensifying your drug therapy by adding new drugs, or changing your current regimen completely. There are trials

in countries like France, USA and Australia the chance of the baby becoming infected with HIV is now considerably reduced. The risk to the baby is down to about 2%. You should consider all the health issues from the point of view of both yourself, and your baby.

Get up-to-date information from your doctor about the risks to the baby and about the best prevention strategies. Your doctor has information about the best antiviral therapy for you, and the baby during pregnancy, and the potential concerns about side effects. Discuss your concerns with the obstetrician

Answers provided by Dr Virginia Furner and Dr Mark Kelly of the Albion St Clinic. Decisions about treatments should be made in conjunction with your GP.

Expanded Options Inc.

Options Employment Agency will expand their Job Network Service for PLWHA in Sydney and Melbourne later this month.

Options Community Enterprises, a member of Job Futures Ltd, was among the successful tenders to provide Job Network services announced by the Federal Government.

The success means Options will establish agencies that can provide intensive assistance to PLWHA seeking work at Chatswood, Parramatta and in the Melbourne inner city suburb of Prahran.

Over the last 21 months, Options Darlinghurst has assisted over 300 PLWHA to find employment. The Darlinghurst office will continue to provide intensive assistance for Sydney's inner city PLWHA communities.

The General Manager of Options Employment and Support Services, Peter Garven, said in a statement that the expansion is a major breakthrough for all PLWHA.

Female condom arrives in Australia

FPA Health have announced the arrival of the female condom in Australia. Director of Research, Edith Weisberg, said in a statement that the female condom is the only device that is effective against the prevention of STD transmission, including HIV and unwanted pregnancy. "The female condom is a new option for women. It is the only contraceptive and safer sex device that is woman-controlled", the statement said. The United Nations AIDS Agency estimates that eight in ten HIV positive women contract the virus through unprotected sex with a male partner. Globally, heterosexual sex is the main mode of transmission of HIV. From this year, women will comprise the majority of positive people. The female condom has been available in the US, the UK and parts of Europe for over four years. It is not available in Africa or the Asia Pacific region - both HIV hot spots. The female condom will be launched in Sydney on International Women's Day - 8 March, and is available from FPA Health centres, sexual health centres and women's health centres at \$1.50 each.

Townsville Bombers Convicted

Gay and lesbian lobbyists say the sentence imposed on two men who bombed a Queensland AIDS Council office is insufficient to deter attacks on minority groups.

Wayne Jang and Nick Bower were jailed for nine months each for their part in the bombing of the Townsville office in June last year.

Co-convenors of the Australian Council for Lesbian and Gay Rights Rodney Croome said the sentence demonstrated the need for the judiciary to have training on sexuality issues.

National AIDS Bulletin

Talkshop



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

Mardi Gras Fundraising

Sydney's party season is here again and PLWHA (NSW) needs volunteers to assist us during February for various Mardi Gras and fundraising activities. If you are interested please call Antony during business hours on (02) 9361 6011. The work requires only a couple of hours of your time, it's fun and a great way of meet people. We need volunteers for our major raffle, the Mardi Gras launch and to work and ride on our fabulous futuristic float.

PLC Home Again

The Positive Living Centre has returned to its old home at 703 Bourke Street. I am sure everyone will be very pleased with the results (see our photos below).

The refurbishment has created an open and airy new venue far better suited to clients. The Centre will open 10am till 3pm, Monday to Friday while the Luncheon Club is not operating. Once the Luncheon Club re-opens the Monday service will cease. Well done to everyone on an excellent result and a great service for positive people.

Blackout

Indigenous people, irrespective of sexuality and gender, remain one of the leading at-risk groups to contract HIV. A community organisation, known as Blackout, plans to set up an Indigenous HIV Positive Support Network in association with state and national HIV/AIDS organisations. All information

received will be confidential. Further information from Blackout at PO Box 57, Darlinghurst, 1300 or email on: blackout_99@hotmail.com

Changing Needs Ongoing

The committee formed to guide a sector response to the changing needs of the HIV/AIDS community will hold its next forum on the evening of 29 February in the lecture theatre at the Australian Museum. Service providers and a diverse group of positive individuals will present a discussion on how the needs of positive people and the response from services have changed. Although being a serious discussion, some humour and entertainment is expected during the evening. ■



ready to serve at the new plc

Photography: Antony Nicholas

Are you getting it monthly?



PLWHA (NSW)
People Living With HIV/AIDS

Subscribe to *Talkabout* and support your monthly magazine. If you are a PLWHA on a pension and living in NSW, you can get your copy of *Talkabout* delivered **FREE OF CHARGE**. To subscribe, please fill out the form on page 29. Subscription renewals are due by 30 June, 2000. Thank you for your support

fresh and feisty @ y2queer

feona studdert's sneak preview of the 2000 Mardi Gras Film Festival – Y2QUEER

Anyone who, like me, is bored rigid by the turgid 80s and 90s style of documenting HIV/AIDS issues on film, will be refreshed by the diverse offerings of the Y2Queer Mardi Gras Film Festival set to kick off on 16 February.

My favourite is *All About My Mother*, the acclaimed Spanish director Pedro Almodovar's latest offering of queer and colourful characters including pregnant nuns, positive transgender fathers, and feisty chicks with dicks. It's a film about what is fake and what is real. It's also a tribute to women of every variety. Woven into this typical Almodovar craziness, honesty and humour are men and women who are living their lives with HIV/AIDS. To paraphrase Elmore Leonard, just because it's a serious topic, doesn't mean you have to be severe and Almodovar weaves positive and negative stories alike into a seamless whole that is ultimately about living.

If you prefer to be dumbfounded and aghast at the casual tragedies of life then

two intimate documentaries will leave you utterly speechless. Many *Talkabout* readers may have seen or be familiar with the story of *Chrissy* (*Talkabout*, November 1999), whose final year was recorded by her best friend, the director, Jacqui North. *Chrissy* reveals the strengths and triumphs of families pulling together and overcoming prejudice and ignorance to find honest love.

For *The Most Unknowable Thing*, Director Mary Patierno started filming when her gay brother David announced he was HIV positive, documenting significant moments in David's life over the next five years including his surprise marriage to a woman, the illness of his lover Carlos and his personal struggle with AIDS. Patierno's work won the Grand Jury Award for Outstanding Documentary at Los Angeles' Gay and Lesbian Film Festival – Outfest 99.

South Africa's black queer community is an explosion of talent, tragedy and triumph over bigotry and racism, and the history and present of this remarkable movement are just starting to be told.

One such doco-drama is *Sando* to *Samantha*, directed by Jack Lewis and Thulanie Punghula. Sando Willemse is a black drag queen turned soldier in the South African Defence Force who is dismissed after being diagnosed HIV positive. Films like this remind me that the term post-AIDS is bounded by class, race and geography.

An offering that may interest the educators and sex doomsayers is *The O Boys: Parties, Porn and Politics* – an historic look at the way American gay men in the safe-sex obsessed early 90s adapted their desires (and prejudice) to the reality of HIV/AIDS. If you don't go for the controversy, go for the bodies.

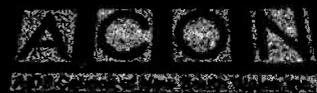
And for those who like horror schlock with a subtext of something evil there's always the German spoof, *Killer Condoms*. Of the 122 films from 17 countries in this year's festival, I'm sure you'll find something to enjoy. ■

Y2Queer is showing at the Academy Twin, Darlinghurst and The Ritz in Parramatta. Programs are available at all good outlets. feona studdert is the editor of Talkabout and a Y2Queer Board Member.



ACON is informing

ACON is discussing



Telephone 9206 2011

Reinfection and multi drug resistance

A forum for positive people and their friends on the likelihood of re-infection with a different strain of HIV, or a strain of HIV that is resistant to some medications.

You've heard the myths, you've heard the rumours; come along and hear for yourself. Medical people, lay people and activists discuss the issues.

Tuesday 15 February
Albion Street Centre Lecture Theatre
Cnr. Crown & Albion Streets
From 7.00pm

Shared or Shirked? A hypothetical

Just who is responsible for practising safe sex? Is it a right or a responsibility to disclose your status? A range of community members line up to discuss the issues.

This timely dialogue between panellists will bring new perspectives to this topic.

Wednesday 1 March
Albion Street Centre Lecture Theatre
Cnr. Crown & Albion Streets
From 7.00pm

ACON is here

2000

2000
FESTIVAL
EVENT

After the party is over, 24 hour free counselling line will be there for you! Look out for the number



Write to **HotBox** at
 PO Box 831 Darlinghurst NSW
 1300 or **Fax** 02 9360 3504 or
Email feonas@plwha.org.au

What's your New Year dream?

For positive people a cure (or at least effective, non side effect medications) and for the sector to work very closely together for the greater good, even if that means some organisations should merge and others should go altogether. We know there is no more money in the AIDS budget so to get new services or improve others, irrelevant services should be abolished. Harsh I know but a reality check is needed.

HIV sector worker

For PLWHA some level of certainty about security to make decisions about their long-term future. I think it is a shame that some people are in a quandary about their desire to return to work having discovered that a not-working lifestyle has some benefits in itself (certainly not economic). As for the HIV sector I have no idea, but then do they?

HIV positive woman

For PLWHA I wish there were easier regimes, with less side effects and more research into the long-term effects of medication, or ultimately a cure. We have achieved probably as much as we can expect from the HIV/AIDS sector. HIV is always going to have some stigma attached to it because it is an infectious disease and the ignorance and scepticism of the general community is not going to change.

HIV positive man

For PLWHA - the first thing that comes to mind is medications with no side effects; a cure is too unrealistic for the next couple of years. The sector needs to have more cooperative and less competitive relationships, more community based ideals and less hard core business. A more human approach rather than an economic rationalist approach

HIV positive man

Letters

To the Editor,

Mark Tietjen's letter (*December/January Talkabout*) attacks the self-defining by some people living with HIV/AIDS, as being long-term survivors. It is vital that we have models for how it is to live, well or unwell, as the case may be with this virus. It is just as vital now to have positive role models who are not dead, as it was back in 1985 when I tested positive. I will not deny my past or my present reality. If Mark believes that others should get naming rights over us try these phrases on for size: 'AIDS victim', 'AIDS carrier' or 'AIDS riddled poofter'. Should I kill myself now to prevent the possibility of growing older with this virus? Should I go back into the closet about my HIV status? I think not! I remain a longterm survivor.

*Matthew Cox
 Randwick*

Dear Editor

I read with great interest the 'Community Report' presented (*December/January Talkabout*) by Vivienne Munro of the Positive Women's Retreat held in October. As Coordinator of the Western Sydney Positive Women's Committee I found the report for the most part accurate and captured a wonderful weekend that as shared by the women who attended. There are some misconceptions that I would like to correct, namely:

We are not the Western Sydney Open Day Committee, we are in fact an established Committee of Health Care and

allied HIV Service representatives who plan and facilitate education and support for positive women in the Greater West. In 1998 we invited the HIV Women's Project to share with us some of their ideas.

The heading on the article could lead some to conclude that the Women's Retreat was an ACON Women's HIV Support Project when in fact it was one of the Western Sydney Positive Women's Committee Projects. We are funded by the Mercy Foundation, a Catholic Funding Body.

The houses we stayed at are owned and run by the Sisters of the Good Samaritan and all sorts of groups, including religious sisters, hire them for their use at a reasonable cost.

If the women reading this letter from the Greater West would like to contact me re happenings in the year 2000 or would like some information on support please don't hesitate to phone me on (02) 9671 4100 Mon - Fri. bus hrs.

*Marie Lavis,
 Blacktown*

Letters to the editor are welcomed and encouraged. Please include your full name and address (name and suburb will be published, unless a request to withhold this information is included). Letters should be addressed to The Editor, Talkabout PO Box 831 Darlinghurst 1300, fax: 02 9360 3504 or email: feonas@plwha.org.au. Letters should generally be up to 300 words and may be edited.

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welfare reform – a waiting

The 2nd HIV Futures Survey (HFS) – to be released in March this year – is expected to show that changed little from the 52% recorded in the first HFS in 1999. **Lindsay Varcoc** reports that

The *HIV Futures Regional Report* for NSW released in May 1999 found that 52% of respondents reported their main source of income as being a government pension, benefit or social security payment.

29% of respondents in the same survey reported incomes below the poverty line.

The DSP is different in many ways from other forms of welfare assistance. In simple terms it's paid to those who have an injury, illness or disability that prevents them from working at least 30 hours a week for at least two years. It's paid at a higher rate than the Newstart unemployment payment and the assets and income tests applying to DSP recipients are more generous than for some other payments. DSP recipients also get a Pensioner Concession Card and other free or low-cost benefits. Unlike a number of other welfare recipients, including the unemployed, those on the DSP don't have to provide the Government with reports on what they do with their time and the benefit they receive is not taxable.

The link between HIV and poverty is real, powerful and is evident the world over. In Australia PLWHA are protected from severe poverty to some extent by a welfare system that is relatively robust and wide-ranging by international standards (see 'i' left).

But all this could change in 2000 as the Howard Government sets its sights on cutting the size and cost of Australia's welfare safety net. Included in the Government's welfare reform agenda is a review of the all-important Disability Support Pension (DSP) – the major form of financial assistance available to those unable to work due to HIV/AIDS (see 'ii' left).

Last year Family and Community Services Minister, Senator Jocelyn Newman, set alarm bells ringing in welfare and community circles with the release of her discussion paper *The Challenge of Welfare Dependency in the 21st Century*. The paper followed a political storm in which the Federal Opposition alleged the Prime Minister had ordered Senator Newman to "tone down" her plans for massive cuts to welfare spending, prompting a Senate Inquiry into the matter.

Reading between the lines

The paper that did see the light of day set out plans for a wide-ranging review of the Australian welfare system, driven by the perceived need to cut spending and the Government's desire to weave the thread of mutual obligation into every rope of the welfare safety net. Where it touches on the DSP, the paper is vague and general – but the language is worrying.

It says the current DSP eligibility criteria are "essentially based on a medical model of disability and a test of whether people are able to work full-time at award

wages". It calls for a "new approach to identifying capacity for work", including "vocational assessments that focus on how people's capacities could be enhanced" which would form part of the test when determining eligibility for payment.

"This could also involve giving more explicit encouragement to people with capacity to undertake a range of activities such as job search, voluntary work, caring, part-time and full-time employment or further education," it says.

Reform or cuts?

The Government has set up a Welfare Review Reference Group to investigate ways of reducing welfare dependency. The group held public hearings in November and December to hear from a range of stakeholders, but the controversy and criticism did not die down.

Among the first to attack the review was Shadow Family and Community Services Minister Wayne Swan.

"Under the cloak of 'mutual obligation' Senator Newman will be trying to achieve deeper cuts to the pension in a desperate attempt to halt the growth in the numbers of pensioners, particularly disability support pensioners," he said.

The length of the review – organisations had two months to provide submissions – has also been widely criticised.

'Catch 22'

An AFAO/NAPWA joint submission to the Reference Group voiced concerns over the narrow time frame, which it states was "unlikely to be able to make the review comprehensive".

The submission said the current welfare system must be maintained, but it also highlighted a number of fundamental problems.

game

Members of PLWHA who receive a government pension, benefit or social security payment have a waiting game to see exactly what impact the reforms will have.

"The unpredictable nature of HIV illness means that people are periodically disabled. They can have periods of acute ill health, as well as periods in which they might actively participate in work," it said.

"HIV can manifest as a significant disability associated with the progress of the illness and the side effects of the treatments. Still many PLWHA find it difficult to access the Disability Support Pension."

"The unpredictable nature of HIV illness means that people are periodically disabled. They can have periods of acute ill health, as well as periods in which they might actively participate in work"

The submission highlighted the welfare 'catch-22' facing many PLWHA.

"People find it difficult to leave welfare to re-enter the workforce due to a real or perceived difficulty in re-acquiring benefits, particularly the DSP, should their efforts at remaining in the workforce be unsuccessful," it said.

Cutting through red tape

NAPWA Care and Support spokesperson David Menadue, believes the Reference Group will focus on other welfare recipients and that those on the DSP with chronic illnesses may be spared the harshest cuts.

But even if the committee do not recommend changing the DSP rules, Menadue argues there's plenty that can be done to make the current system work better.

"One of our main concerns is the red-tape and endless forms people and their doctors must fill out just to get even the most simple government benefits," Menadue said.

"Anecdotal evidence is strong that the process of qualifying for the DSP is already getting more difficult and complicated, and this is at a time when employment opportunities for positive people are very few indeed."

Whatever the outcome, one thing is certain – the Howard Government needs no encouragement to cut spending. However Senator Newman's "welfare reform" agenda goes way beyond the traditional clampdown on spending that follows the election of a Liberal government.

Many believe the DSP has, to some extent, been immune from previous welfare cuts for political reasons. A clamp-down on 'dole bludgers' may be seen as a potential vote winner but even the best spin doctor faces an uphill battle in trying to justify taking money out of the pockets of the sick and disabled, particularly when the economy is booming.

A hard target

However over the last 10 years the number of people on disability income support has gone from 300,000 to more than 600,000 and estimates suggest three quarters of a million Australians may be on the DSP by 2006. Less than one third of all working age people on income support are unemployed job seekers while 21% are on the DSP. The growth in the number of DSP recipients is clearly worrying the government, not only because of this year's or next year's budget, but because a majority of those on DSP remain on benefits for life. Clearly Senator Newman has decided

the cost is too great, and she is determined to do something about it regardless of the substantial political ramifications.

Disability coalition

In November last year, 26 disability organisations met in Canberra to consider Senator Newman's discussion paper. From that meeting has come the National Coalition on Disability and Income Support (Welfare) Reform. Sue Egan is the Convenor of the Coalition. She has called on Senator Newman to research the reasons for the increase in DSP recipients over the last 10 years before embarking on major structural reform.

"We support genuine reform that addresses the cost of disability and offers real assistance and support for people on disabilities to go back to work" she told *Talkabout*.

Egan argues that whatever reforms are put in place are likely to be broad.

"It would be political suicide for Senator Newman to target any group or sector – particularly PLWHA. The most likely change is a reduction in the pension, an increase in assistance to those who want to return to work, or tightening the eligibility criteria. The Disability Coalition will look at any changes very closely."

For PLWHA on the DSP, the only answer that counts will come after the welfare review reference committee hands down its recommendations. Only then is the Minister likely to detail exactly what changes she would make to the welfare system in general, and the DSP in particular. ■

Editor's note: Senator Newman has extended the date for the preliminary report to mid-March because of a delay in receiving some submissions. The group has received 362 submissions. The final report is still due by June 30. Although NAPWA was not able to attend the Canberra meeting, it is a member of the Disability Coalition. Readers interested in this topic could log on to the Disability Information and Communication Exchange website: www.dice.org.au

a sense of value

Steve and Blue share their thoughts about life on the Disability Support Pension.



I'm 42, I've been HIV positive since 1987, I worked as a supervisor of a Call Centre until 1998 and have been on the Disability Support Pension (DSP) since then. I find that there are other issues to confront about living on the DSP apart from just the money.

There's the social issue of friendships that have gone by the wayside. There's the issue of affordable housing there's the issue of not working and maintaining a sense of value. There's the struggle to maintain health and there's the sense that being on the DSP has squeezed out the joy.

There's the struggle to maintain health and there's the sense that being on the DSP has squeezed out the joy.

There are costs involved in maintaining friendships that I never realised before. You are in a situation where if your friends want to go for coffee, well its just not possible. I've had to give up cigarettes, I've had to give up alcohol, I've had to give up what most people take for granted, to simply try and make the money last. I wouldn't want

a lot of those people to know of my situation because I regard it as a private matter. I don't want to burden them with my condition so they are left just wondering. To me that is the best, well not the best option, but its what happens.

I try and go to the Pride Center Gym Mondays, Wednesdays, Fridays and go to the PLC for lunch. I like to read non-fiction at the library – health, art and gardening. That's my pleasure and then just watch television. ■



This article is about my thoughts as a positive dyke, mother and volunteer within the community. There's a lot of talk about PLWHA going back to work. I think, "hmmm, if I could arrange for my illnesses to strike on certain days it would make it a lot easier to hold down a job." I see doctors on a fortnightly basis due to what is called treatment failure and anaemia.

I do volunteer work, three hours a week. Unfortunately it's not enough to be eligible for the Department of Family and Community Services Mobility Allowance but the firm does reimburse my petrol expenses. Getting up and going somewhere is a great boost to my self-esteem, I look forward to it.

Hopefully I'll be able to do some more work. I'm not unskilled: I've studied for several years at TAFE and University and I see myself alive and doing my best for years to come. I see others who are an inspiration to me. As we all know holding down a job can be hard when your T-cells are below 20 and your treatments make you debilitated. I struggle to always have dignity and respect for myself. (So can't you tell that I have AIDS?) Yes, my denial is strong but so am I. I want to be there for my boy, and do all those responsible things you do as a Mum. There are times when I just can't get it together: I leave the housework and cooking (thank god for frozen dinners and laundromats) because the companionship I share with my son is more important.

Living on the pension is almost impossible, especially when your medication hits around \$35+ per week. I cut down on luxury items such as cigarettes. Lunch money for my son is also expensive, but at least he doesn't have to throw away soggy smelly sandwiches. I find that buying bulk washing powder is a good saving and not eating out more than once a week.

... if I could arrange for my illnesses to strike on certain days it would make it a lot easier to hold down a job.

I look forward to scheduling my time, and dementia, a little more constructively so as to lead a more fulfilling life. I'm lucky I have the will to live. One day my son and I will enjoy the fruits of my labours. ■

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Talkabout welcomes stories and letters from PLWHA.

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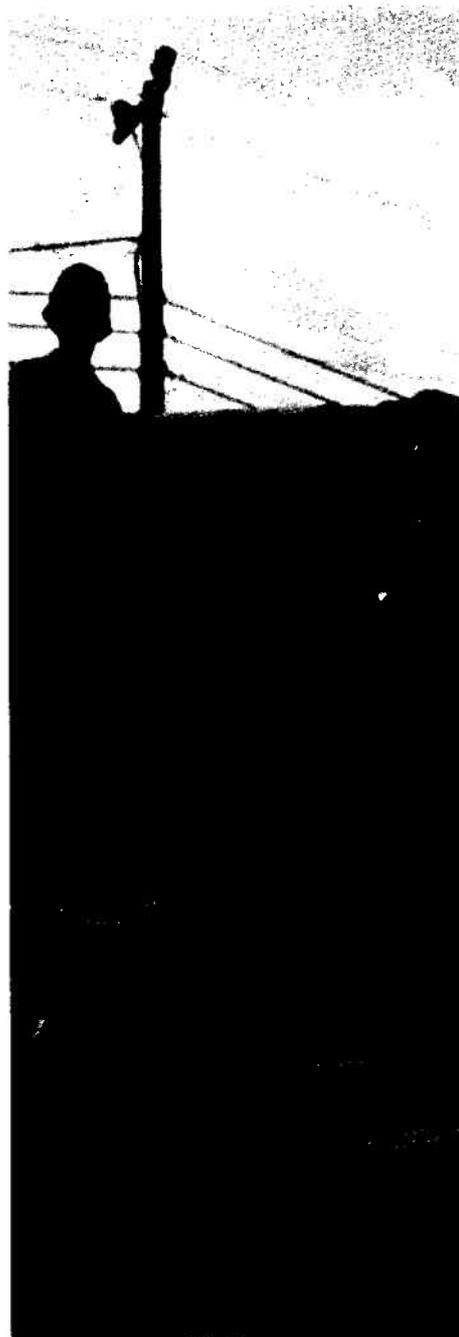
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from the defence forces to factory floor ... will discrimination win?

In a recent decision of the High Court, the rights of positive people to be protected against workplace discrimination received a setback. **Douglas Barry**, reports



In 1993, a man, known only as "X", enlisted in the Australian Regular Army. Previously, he had been a member of the Army Reserve, engaged in the Signals Unit. By signing the enlistment application, X acknowledged that he would undergo a medical test, which would include testing for HIV, and Hepatitis B and C. If any of these tests proved positive, in accordance with Australian Defence Force (ADF) policy, he would be immediately discharged.

After five weeks, his tests were returned, showing he was HIV positive and he was discharged.

X lodged a complaint with the Human Rights and Equal Opportunity Commission (HREOC), claiming that this dismissal, on the grounds of his disability, was unlawful under the *Commonwealth Disability Discrimination Act*. As the employer, the Commonwealth Government admitted it had discriminated against X. However, it said that an exception in the Act made the discrimination lawful.

The Commonwealth argued that an "inherent requirement" of being a soldier was being able "to bleed safely", either in training or in combat, which, they argued, X could not do. So their discrimination was legal.

The Commissioner disagreed with the Commonwealth. The essential tasks or skills of being a soldier did not include the requirement "to bleed safely" – this was a condition imposed externally by the ADF. It had nothing to do with X and his HIV status and his ability to do the work of a soldier, but was included in ADF policy to prevent the spread of HIV infection.

The Commonwealth had this decision tossed out in the Federal Court and X appealed to the High Court. There, regrettably, he lost by a margin of five to one, Justice Kirby the only judge disagreeing.

At one stage, Justice Kirby lamented that "... as past cases indicate, and this one again demonstrates, the field of anti-discrimination law is littered with the wounded" – those who obtain the justice the anti-discrimination laws are designed to provide, but who later lose that redress, when their cases are subjected to "closer judicial analysis of the legislation."

"... the field of anti-discrimination law is littered with the wounded" – those who obtain the justice the anti-discrimination laws are designed to provide, but who later lose that redress, when their cases are subjected to "closer judicial analysis of the legislation."

'To bleed safely'

Under this exception (section 15(4)(a)) of the Act, an employer can sack an employee, if, because of the disability, the employee is unable to carry out the "inherent requirements" of the particular employment.

The majority of the judges all agreed that the case turned on the true meaning of the words of the exception in sec15(4)(a): "the inherent requirements of the particular employment" – that is, what was really involved in being a soldier. These judges

argued that it was essential to consider the safety, not only of X, but of his fellow soldiers.

This was a vital and obvious part of the contract of employment between the Commonwealth and X. Whether X could "bleed safely" could require a great deal of evidence about the degree of risk involved. The Commissioner had not been considered and so the case was sent back to HREOC to decide the legality of the dismissal, in accordance with the correct interpretation of the law.

were all sorts of terms and conditions of the employment which made the employee unable to carry out the work.

The example given by the Commissioner is a positive worker in a factory where the risk of industrial accidents is a real one. The factory owner could dismiss the positive employee on the grounds of his or her serostatus, and claim that such discrimination was lawful, because of a risk to other workers.

... the struggle to hold onto the benefits initially offered by the anti-discrimination laws – the basic recognition of the human rights of not just positive people, but all disabled people, will be long and hard.

Stereotyped assumptions

Justice Kirby refused to follow his colleagues "legalistic and conservative approach". He argued strongly that the purpose of Anti-Discrimination legislation was to educate employers, including the ADF, into getting away from stereotypes about disabilities. It was contrary, he said, to that purpose to interpret these laws in a way that frustrated "its high social objectives."

The exception in sec15(4)(a) clearly focused on the individual, on his particular disability and on his particular employment. The policy of the ADF was a universal one, based on "stereotyped assumptions" about HIV/AIDS. The Commissioner had been correct in holding that the policy was externally imposed and had nothing to do with X and his ability to carry out his duties as a soldier.

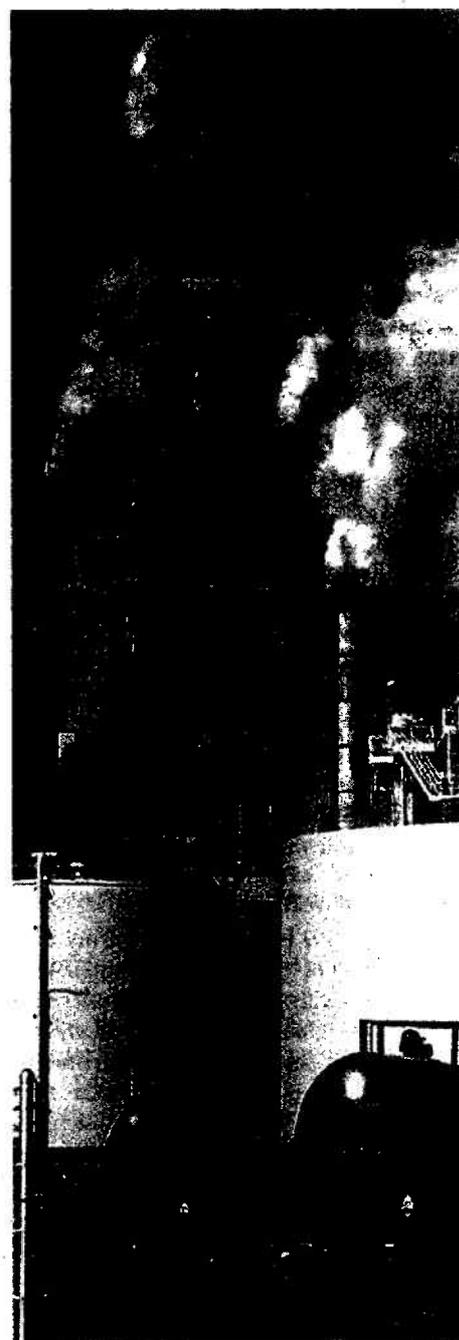
Where to from here?

A probable consequence of this decision is that employers will now be able to sack a positive employee and then claim that there

If X wants to keep going against the ADF and the Commonwealth, he will now have to go back to HREOC. He will have to present the kind of evidence that the Victorian footballer, Matthew Hall, did about the degree of the risk of transmission involved in all the activities of a member of the Army. Remember though, that he first complained in 1994; he is going to need a lot of courage and support to pursue his quest for justice against the Army to a conclusion.

It is clear that the struggle to hold onto the benefits initially offered by the anti-discrimination laws – the basic recognition of the human rights of not just positive people, but all disabled people, will be long and hard. The timing of this judgement is unfortunate, given the current Government's reduction of resources and restructuring of HREOC. It does nothing to assist the fight to change the "stereotyped assumptions" still alive in our community. ■

Douglas Barry is a member of the Legal Working Group of PLWHA (NSW)



reflections of a retiree

It may seem incongruous to be writing an article about retirement when the buzz is largely about returning to work. **David Menadue** considers the pros and cons of leaving the workforce.

When I decided to leave work in 1991, I had just experienced my second opportunistic infection, my T-cells were ten and the doctors said I had maybe two years to live. My doctor had no hesitation in signing the certificate recommending my retirement. My superannuation scheme doctor saw the word 'AIDS' on my referral form and didn't even bother with a medical examination; APPROVED was stamped on my file immediately.

But I was in two minds. I loved my work and my colleagues. I had spent fourteen years in a rewarding, creative job writing magazines for school children. I loved getting up and going to work in a way that few of my friends seemed to share. The going though was starting to get tough. I was in a middle-management position and yet another public service restructure was on its way, threatening to destabilise the work environment. My health was poor and my energy levels would see me rushing to the sick bay to have a rest at lunchtime. When I fell asleep during yet another important management meeting my boss agreed that it was time for me to go.

Mind over workplace

Retired at 39. How would I fill my days after years of productive output? What would I do without the social contact of the workplace? One counsellor friend warned that he had seen many PLWHA retire too early; with little to do but contemplate their situation; they would often get sick, he believed, because they thought that this was the path expected of them.

I have never found boredom or a preoccupation with my illness to be an issue. I took up volunteer work with PLWHA organisations and the Victorian AIDS Council, writing, travelling and so on.

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The absolute advantage of my new commitments was that I could curtail them at a moment's notice. I did not have to struggle through a day's work at the office. I could do absolutely nothing when I was feeling below par. I could take time for medical appointments without the guilt I had felt as an employee.

Pills and the job

When combination therapies arrived in the mid-nineties and a lot of us felt the benefit, I still found my illness a time-consuming business. I spend an inordinate amount of time each month trotting between doctors and chemists just to keep my drug cabinet full, thanks to our rather absurd drug dispensing system. Taking the tablets can be a full-time occupation as well – at one stage

Taking the tablets can be a full-time occupation as well – at one stage I was taking tablets at five different times of the day including some on an empty stomach, some with food and some several hours after eating!

How people in full-time employment manage on these gruelling regimes, I just don't know.

I was taking tablets at five different times of the day including some on an empty stomach, some with food and some several hours after eating! How people in full-time employment manage on these gruelling regimes, I just don't know.



Worthwhile still

There is a strong societal 'guilt trip' which says that if you are not in paid employment you are not a worthwhile person. I have countered this notion in my own head by PLWHA activism to improve things for positive people. I have also kept in mind how precarious living with HIV can still be. In recent months friends have been well one day and seriously ill the next: lymphomas or other formerly rare AIDS conditions have suddenly led to their deaths.

If people with HIV make a decision to retire to avoid the stresses of the workforce then we should respect their decision. DSP is a difficult existence at the best of times. I doubt whether I would have survived as long with AIDS had I not had the advantage of a slightly better superannuation pension to help me with my financial woes.

Apart from the medical commitment required by this illness, I needed to slow down, acknowledge that the virus had taken a considerable physical toll over the years and adjust accordingly. For those who have the confidence to rejoin the workforce, I wish you well. I'm waiting for something resembling a cure that gives me more energy than I know what to do with. ■

David Menadue is Care and Support spokesperson for NAPWA and an associate editor of Positive Living.

work me right

Tim Alderman argues that Australia is still about two years behind the United States in developing a full range of services and advocacy for PLWHA who, with combination therapy, are able to contemplate some form of work.



The 'return to work' of PLWHA is a complex issue that has been discussed in detail over the last couple of years. In that time we have seen some innovative government funded projects such as the Reconstruction Project, the Positively Working Project, and the Positive Employment Service. We've also seen the development of Options Enterprises - a community-based employment agency that, as a member of the Federal Government's Job Network, is able to provide Intensive Assistance to PLWHA who wish to return to the workforce.

I do not like 'classifying' people, but in regard to return to work issues, PLWHA fall into about three groups: those that are newly diagnosed, have started treating early, have had no AIDS related illnesses, and probably never will. They have good health, and will probably always be able to work if they look after themselves. At the other end of the scale are many long-term survivors who have had chronic illnesses that have permanently disabled them. They do not enjoy ongoing good health, will probably continue on the pension, and continue to use established services. Between these two groups sit those who have benefited from new treatments, are fit,

and experience relatively few side effects. Many of this centre group are currently on pensions, but are rapidly getting bored with their quality of life. They are talking about returning to work and are the ones future planning must be aimed at.

The new 'work'

The Positively Working Project Report (released in December 1999) pointed out that the way the word 'work' is interpreted has changed a lot over the years, particularly for people who have been ill, and find themselves restricted: People no longer see work as something that most be

The HIV/AIDS sector has established successful employment policies and workplace standards that protect and facilitate the employment of PLWHA.

endured just for the sake of having a job, and earning money. Work must be enjoyable, in an environment that is friendly and supportive. It is essential that employers of PLWHA are aware of the special

circumstances. Take my own experience of returning to full-time work as a Cash Office Supervisor with a large reputable retailer. At the end of the four months I was physically and mentally exhausted. My health had deteriorated due to a lack of time and the extra energy needed to attend appointments, obtain medications etc. It was only a short time after leaving that I got ill again.

Employers must also be made aware of the limiting factors of treatment side effects. Amongst these, diarrhoea and nausea are quite common place. Employees need to be in situations where toilets are readily accessible, and that sudden 'departures' from the workplace are understood.

Rights for all

The HIV/AIDS sector has established successful employment policies and workplace standards that protect and facilitate the employment of PLWHA. What would be useful at this stage of the epidemic is a national agency that can educate employers in universal workplace standards and practices suitable for all people with disabilities. This would overcome the necessity of positive people having to disclose their disability to their employer.

If people are to retain their current motivation to make themselves more productive, we must have the organisations in place to assist them. The four most common services that are going to be required in the coming years are counselling, peer support, treatment management, and an agency that caters to current employment needs and strategies. It is only through a combination of all these that people are going to make a successful transition back to the work place. ■

Tim Alderman is a member of the Editorial Working Group at PLWHA (NSW)

work, HIV ... and us

Returning to work often means facing your own fears, and sometimes the ignorance and fear of other people.

Maxine, Arthur and Peter have all come through ... stronger and wiser.



When I found out I had HIV I was working as an assistant nurse in a nursing home. The day I found out I never returned to the job. I told them I'd had bad news. I couldn't face them and keep it a secret.

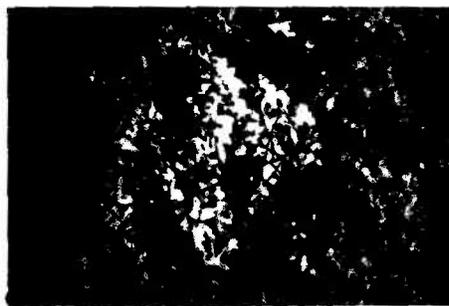
I was living with my parents at the time and they were supportive. I took some time out to re evaluate my life. In a couple of months I had planned to begin a Bachelor of Nursing degree and become a registered nurse. I knew that I couldn't be a nurse. Looking after sick people as a career seemed too confronting. I didn't work for two months. I was depressed, confused and frightened. I looked at my own mortality.

I decided that this challenge would be the making of me. I enrolled in a part-time Welfare course at TAFE. I got a job as a check out chick at the local supermarket. Working kept my head above water. I had to present a public face and I wanted to look good. I was earning better money than I had as a waitress in a 5 star hotel. Sometimes the depression and fear would hit me as I was serving a customer. I would battle to get through it. Sometimes, if a customer was rude to me, I felt crushed and my anger and pain would rush up. In that first year working and studying helped me stay sane. I was promoted to Head Cashier and there was talk of career opportunities.

But I wanted more heart in my work, and I hated carrying what seemed then like a huge secret. Sometimes I would look around at my work mates and imagine their reaction. I was sure the lunchroom would clear instantly. It scared me. I couldn't deal with that. One day I remembered that a job at ACON had been advertised.

I've been at ACON, in the reception team, for exactly one year now. The best thing is that I no longer have to hide my HIV status. In fact it's a bonus here. It's a big weight off my shoulders to know that I won't experience discrimination and rejection in the workplace. I can be myself and talk to other positive people. The positive people I have met at ACON have given me inspiration, hope and encouragement. I have a place here. ■

Maxine, is 30 years old and a positive person.



After school I became a butcher. I never stopped working and somewhere along the line I made a resolve that this virus would not kill me. Mentally I grew stronger and stronger. I meditated. I made a resolve to myself that if I was out of work I would not go on the dole or sickness benefits but keep looking for another job. Working has kept me alive.

I worked in the meat industry for about seven years. I was sacked on the spot once when my boss found out I had HIV.

A couple of years later I was at the Medical Centre to get my finger stitched up from a bad cut. Nobody knew I had HIV. They were going to stitch me up without gloves on and I freaked a bit and felt guilty. So I told the nurse in confidence I had HIV. She knew me - she bought her meat from the butcher shop where I worked. It was like a bomb hit the Medical Centre. The doctor and nurses all scrubbed up, the gowns went on, the gloves went on, the masks were up. They put one stitch in my finger, bandaged it up and sent me back to work. I had a bad feeling. The nurse no longer bought her meat at the shop. A couple of days later I resigned. The day after I finished up she told my boss and workmates I had HIV. I got the most abusive and nasty phone calls and vowed not to work as a butcher again. It was the last straw.

I didn't work for about three months, always looking for a job. I became a cab driver. That didn't work out. A few months later I was desperate for a job. I asked God for help. A tree lopper worked at our place one day. I gave him and his crew a hand. At the end of the day he gave me a job. I have been a tree worker now for eight years. I have never given up working hard.

Its been 14-18 years now living with HIV in my body. I will try to never give up. My pastor the other day told me to write out a 50-year plan. I followed his advice. Talking to my friends from CLASH and Positive Heterosexuals has helped me immensely over the past five years. I've got a serious 10-year plan to follow work wise. My boss supports me. The start of a new millennium came through the other night. I'm straight, positive, and hope to never give in to the virus with God's help. ■

Arthur is 32 and a positive person.



Suddenly, I had cut my finger. A long knife landed evenly upon the floor.

I stepped backwards and stared as my blood quickly began to spill. I am HIV positive.

Jennifer, my co-worker stood behind the shop counter, serving. I left the back room and crouched at her side, searching with my good hand for a Bandaid and antiseptic.

"Have you cut yourself?"

"Yeah."

"Oh, I was cutting a bloody pumpkin and it slipped."

I found the Bandaid box, which was empty. There was no antiseptic. I lifted my arm so the blood would flow down upon my wrist and not onto the floor. For a moment, my mind became unfocussed and lost.

Using my good hand again, I ripped some toilet paper off its holder (using my chin to hold the roll still). The tissue adhered to the wound.

In the café next door, people sat drinking lattes, eating and conversing. The morning sun shone deep inside. A waiter smiled hello and then promptly helped me.

"You'll need two Band aids, luvvy. Are you sure you don't want me to put it on?"

It felt good to receive this sympathy. I also acted a little aloof, aware that they did not know that I was HIV positive.

I found Jennifer outside in the back lane smoking a cigarette. She said nothing. She hadn't even locked the shop cash register.

Two months later ...

"Listen to me! I just asked you a question. Now tell me, have you got AIDS?"

I would not answer him. Jennifer stood to my left. Joe, our employer stood to my right. Opposite me stood Rodney, Jennifer's lover, impatiently waiting for a reply to his question.

Judging by the emblem upon the jacket that he wore, Rodney was also a member of a large motorcycle club. Rodney smelt like alcohol. His eyes were red. He kept stepping towards me before backing away.

A group of onlookers hovered in the shop entrance. Joe stepped in between Rodney and myself.

"C'mon people, no-one needs to get upset okay. I'm sure this has just been a big misunderstanding."

Joe had been my close friend since schooldays. He had often asked me if I had wanted a job. It was not until the recent advances in HIV treatments, when people previously more ill than myself had re-entered employment, that I became inspired to leave the DSP. My thoughts were that there was a two-year period during which I retained my concession card and could go back onto benefits immediately if I wished.

I remember my first weeks in the shop had been quite difficult. Having not worked for so long, I think my confidence was down and I tried too hard initially to impress. It took months before I learnt to slow down.

I later learnt that it was Joe who had informed Jennifer that I was HIV positive. He'd told her one work night over a friendly couple of beers. She had known this the day when I hurt myself slicing pumpkin.

Recently, Joe had sacked Jennifer for repeatedly turning up late to work.

"Yeah, that's right, Joe, 'a big misunderstanding'," said Jennifer. "So go on then, Peter. Tell us all exactly what happened after you cut yourself. How you didn't even bother to clean up your blood! How you left the knife just lying on the floor for me to deal with!"

I decided to lie about the knife. Looking at Joe I told the three of them that I had cleaned the knife. The truth was that I could not remember. Jennifer shouted again. I noticed Joe shrug his shoulders.

"Tell us if you've got AIDS or I'll smash your bloody face in!" shouted Rodney.

No one spoke. I could not believe what was happening. Ten minutes previous, I had been quietly stacking oranges. Now, a complete stranger was demanding that I disclose my most private concern.

Even as Rodney raised his fist behind his shoulder, my will was still firmly not to speak. The silence acted like a slow pull on a trigger.

"No, I have not got AIDS," I said.

Rodney stepped back. Then he slowly turned to stare at Joe.

"I haven't got AIDS," I said. "I am HIV positive."

This completely confused Rodney. He turned towards Jennifer who surprisingly nodded her head as if she knew what I meant. She tried to explain the difference to Rodney but he just got angry. He made a very big point of knocking some apples off a shelf as they left.

We closed the shop early that day. Joe took me out for dinner. We discussed why I need my HIV confidentiality to be recognised. Joe then apologised. He has never broken my confidentiality again. Then we discussed our need to have hospital grade bleach, a first aid kit and first aid instructions in the fruit shop.

We had never really thought about these issues before the incident. At least now we feel more prepared. I am now in my sixth month of employment at the fruit shop. ■

Peter Davis is from Victoria. He was one of the founding presenters of Positively Primed, the first weekly radio program for PLWHA in Australia that went to air on Community Radio station 3CR in 1994. Peter is still working in the fruit shop and has returned to tertiary study.

Editors note: This is a dramatised account of Peter's story.

together

The strength of projects like Reconstruction is

Reconstruction explores the concerns of PLWHA around renewed health since the introduction of therapies. It aims to assist people around the issues of future re-engagement, by exploring the practical and emotional concerns in this transition period. It acknowledges the need to build skills and a sense of self-esteem/confidence and is not intended as a back-to-work program, but instead, a service that explores issues around the quality of life.

AID Atlanta USA originally created the Reconstruction Program in 1996, and in 1999, the Reconstruction Working Group brought the project to Sydney via a grant from the NSW Government.

The four-month pilot of the Reconstruction Program in Sydney commenced in mid October 1999. Twelve participants were recruited for the six educational/supportive forums and attendance and feedback is very positive.

The Monday evening forums explore:

- The Psychological Impact of the Introduction of Therapies
- The Work Dilemma
- Making the Most of Your Income - benefits, debts, housing
- Medical and Treatment Issues
- Motivation and Personal Goal Setting

Six, weekly forums, and a follow-up group one month after the sixth session, are offered. Each forum has a guest speaker from a key HIV service in Sydney.

Clearly, if there is ongoing demand for this service the Working Group will push to continue the service. However this will be dependent on the goodwill of those holding the purse strings.

A full report and adaptation of the American information kit for use in Australia will be completed. The Reconstruction Working Group will continue to oversee this project and welcomes your support or ideas for future funding of the project. Please call Pene Manolas, Coordinator, on 0411 255 32 by 18 February, or write to the Reconstruction Project, C/- PO Box 831, Darlinghurst, NSW 1500.



I'm 56 and Mr Average. I lived happily with my partner for 21 years and had worked 28 years as a secondary teacher. We lived on a hobby farm. It was meant to be for the rest of our life but my partner died four and a half years ago and the farm was too much on my own. I sero converted two and a half years ago. I'm just still sort of coming out of the haze I think. My life has been turned upside down and inside out. That was the purpose of the Reconstruction Course, to give me direction.

I would like to get back to work - I think. But just what to do. I don't want to go back to my past life - for me that's finished. One of the big plusses is coming together with 12 like-minded people, different in many ways but all with similar problems.

I went back casual teaching. That was great mentally but looking back, it was too stressful. You are classified as chronically ill, so you've got to pretend that it is not a death sentence - but you don't know where it's going to lead you and people respond differently to treatment. The whole purpose of working loses any sort of direction.

I have become socially isolated. For me it was health. The difficulty is being older, not

they support diversity of experience and choice. **Frank and Craig** tell their stories.

alcoholic, not drug affected, into the clean living. I'm an ex athlete and competed in the 50 km walk at the Mexico Olympics in 1968.

Step by step

Reconstruction was a stepping stone for me. You've got something to look forward to that day. Same as the Luncheon Club, might be a small thing, but you've got to get out and walk to the station. Now I've started to retrain over at NorthAIDS doing their basic computer course.

Both the computer training and the Reconstruction course make you realise that you are opening a new door to unlimited knowledge if you are prepared to look into it. That's going to be the same with work. I've made inquiries already in a TAFE college about doing an Information Technology course but I'm apprehensive about full time employment. I think I would like to try volunteer work first.

*I would like to get back to work -
I think. But just what to do.
I don't want to go back to my
past life - for me that's finished.*

I've stopped treatments. The side effects were never manageable. It's an experiment that I've initiated with my doctor's support and depending on what the virus is doing we'll decide whether I can stay off treatments for a while. Then I will feel comfortable about working and trying to have a normal life.

If I go to work or volunteer, I would like the boss to know that I am gay and positive. If I had a choice, I would prefer to work in a gay environment where you aren't under stress. The other thing about

teaching these days is if you are a gay person you are stuffed, if you are a gay positive person, there are too many people that put up barriers. That's sad but that's why for me it is my past. ■



I've had 20 years in the computer/accounting industry. I had my first illness about a year ago. That led to a strict regime of therapy but I got to a stage where I was too sick to work and my colleagues started noticing it so I had to come out as positive. There was a bad reaction and I was retrenched. I took it as being paid to leave. I did feel discriminated against. I was with the company six years in a senior management role. It was in tourism as well, where a lot of gay people work. But I didn't want the drama and stress of a fight. I happily took the money and ran.

Now I'm going to do something completely different. I wanted to earn an income, go out and mix with society, get out of the house and stop being sorry for

myself. I went to the interviews with an open mind told them about my status and my lifestyle. Coming out as gay in the previous job had been a big enough step because it was a very straight environment. When I started getting sick it was even more difficult and I didn't want that again. I wanted my employer to know what my circumstances are. I thought that would knock me out, but the offer was genuine and I start the training early in the new year.

Being flexible

A lot of people say (the job I'm going to do) is stressful and others say it's a great job. If it doesn't work out then I'll leave and try something else.

The Reconstruction Course helped me get through the whole process of finding a new job, or career path. The way I figured, if I wanted to go back into my previous career after a year out, I'd probably have to be retrained and explain why I had a year out of work. In the long run I thought the only other way is to do another degree or retrain in something different.

*I went to the interviews with an
open mind told them about my
status and my lifestyle.*

One of the things that did surprise me about the course was how well people understood the changes to your lifestyle that combination therapies can bring. You know people who were expecting to die are now expected to live so we have to deal with that. I sometimes think that some people I talk to have this morbid outlook with regard to HIV. A little bit of positiveness helps. ■

opening doors

Sometimes thinking about a return to work can lead to doors you never contemplated, as **Michael Riches** discovered.

By July 1999 I had been out of full time work and living on and off the Disability Support Pension for a few years. I was feeling a little forlorn about future work/career prospects and had no idea of what I wanted to do or what skills I had that could be readily transferred.

I heard of the Positive Employment Service (PES) and threw myself at their feet. I found the Service to be fantastic. Sarah Yallop – the sole staff at that time – was engaging and easy to talk to. Sarah is one of those people who have the ability to find that fine line between confidant, adviser, and counsellor.

We met weekly for several weeks and concentrated on getting a clear account of my past working history, and more importantly, what work I wanted to pursue. To do this we looked at my life interests, my values, and what it was that had been significant and challenging to me in the work I'd done up to then. Also, and importantly for me in my current situation, we discussed my dreams and aspirations.

Complex issues

To support these discussions we used tools such as the *Guide to Educational and Vocational Planning* by John Holland. This is a group of multiple choice questions that looks at numerous areas in your life ranging from one of my favourites, your occupational daydreams, to others like where you think your life competencies lie to activities that interest you in your general life.

Through my contact with the PES I gained insight into what my vocational strengths are, and the areas that required improvement and attention. I completed a Computer Course and a Bridging course at

a local TAFE Institute. Having completed these courses and with a clearer idea of my direction, I am commencing a University Degree this year.

I sometimes think that being positive brings all the 'life crisis' to you at a much earlier age. How 'normal' is it to retire in your thirties, or earlier? I had felt for a few years as if I was in a mid-life, mid-career crisis, mixed in with the 'post retirement – what do I do now syndrome!' The PES helped clarify some of these issues and gain a clearer, more objective view of my life's occupational options.

... being positive brings all the 'life crisis' to you at a much earlier age. How 'normal' is it to retire in your thirties, or earlier? I had felt for a few years as if I was in a mid-life, mid-career crisis, mixed in with the 'post retirement – what do I do now syndrome!'

The service is not just employment focused unless this is where you want to go. Far more importantly, among the current hype on 're engaging with life' – which for me is a shroud for the system saying: 'get back to work' – it's about discovering occupational options for you that will be fun, achievable and have meaning. ■

Michael Riches is Convenor of the Treatments Working Group at PLWHA (NSW)



“pressure that I'm supposed to be overjoyed that I am better, and part of me is. But a turnaround like this brings up multiple issues in the psyche. You can't just say 'Gee, all my problems have gone away'

PLWHA quoted in 'Tuller', November 24, 1996, *San Francisco Chronicle*.

Faced with the intimidating realities of the job market PLWHA wrestle with their honest desire to return to productive work and its rewards on the one hand and their fear that the experience could hurt them on the other. The situation has indeed become tricky and no road map is available to guide people through the maze.

Crockett, 1997 - HYPERLINK <http://www.thebody.com>, www.thebody.com”

you are (a lot more than) what you do

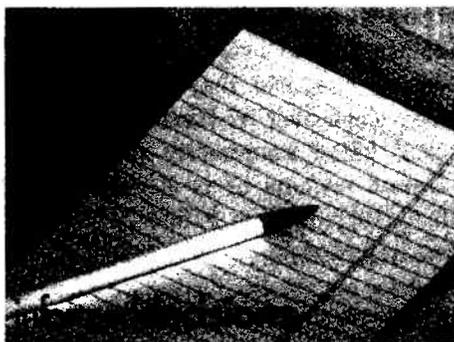
Sarah Yallop is a Project Officer at the Positive Employment Service (PES) - one of the emerging services specialising in assisting PLWHA to reconstruct a sense of their future

The last few years have brought many changes for PLWHA. Combination treatments and resulting improvements in health for many have made it possible to contemplate the idea of returning to work. Many PLWHA feel a sense of pressure to return to work from a society that dictates 'you are what you do'. Added to this is the discomfort when faced with questions about why you are not working and why you have been out of the work force.

The future can be complex

However, as the above quotes show, this can be a complex and confusing process and just one of many aspects of trying to reconstruct a sense of future. Returning to work raises many issues. You must adjust your focus to living rather than dying, and balance a range of financial issues like the loss of pension benefits and superannuation issues. Fluctuations in health must be managed with complex medication regimens to be taken during work time, disclosure and discrimination, and explaining periods out of the workforce all relevant to the process of returning to work. Many experience a loss of confidence and self esteem, uncertainty of the long term benefits of HIV medications and care, and a common desire to change career paths, often, because their values have changed through the process of living with HIV.

Positive Employment Support (PES) was developed early in 1997 to assist PLWHA in Sydney through this process. The aim of the service is to assist PLWHA to explore and contemplate future work options and make informed decisions about the directions that they want to take. PES recognises that



work takes different forms for different people - paid work, study, training, volunteer work, development of an interest - and the emphasis is on finding something personally meaningful and relevant. The service draws on occupational therapy in its belief that being involved in meaningful productive activity has benefits for health and quality of life.

The aim of the service is to assist PLWHA to explore and contemplate future work options and make informed decisions about the directions that they want to take.

PES is an initiative of Northern Sydney Health and has recently expanded to become a joint project between Northern Sydney Health, South Eastern Sydney Health and ACON Western Sydney. In 2000 there will be three project officers based in Northern Sydney (Sarah Yallop - 9926 6767), at Bobby Goldsmith Foundation (Rob Hardy - 9264 0037) and at ACON Parramatta (to be appointed early in 2000). ■

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Are you interested in meeting other Positive people on the coast? I am currently trying to get together Positive people from the Central coast to form a **Support/Social group**, focusing on the positive worker and or positive persons who cannot make the daytime. **This is a group for all positive people.**

If you are interested you can give Norman a call on 4396 2422 or 0410 640 416

the power of volunteers

It's common knowledge that there has been precipitous drop in volunteering over the last five years but, according to **Antony Nicholas**, no-one has yet answered the question of what to do about it.



They were rebellious, vocal, dutiful, dedicated and every so often totally outrageous. Did they die or decide they were over it? Have the 'wonder pills' killed community mobilisation around HIV/AIDS or is it natural that dinosaurs become extinct?

The government has acknowledged that for every dollar funded a community based organisation (CBO) contribute four times that value thanks to the work of its volunteers. Generally they can be anyone from barmen to barristers, (the HIV sector is awash with solicitors) but volunteers come from across the social and economic spectrum. Without them the community sector would grind to a halt.

The HIV sector demonstrates the power of volunteers. Dedicated volunteers, driven to see that something was done for their friends and lovers dying of AIDS, created many of our major organisations. The Australian gay and gay friendly community mobilisation around HIV in the early eighties is a case book example of community development.

A perceived decline in the urgency of the epidemic has left organisations desperate for volunteer support. Not surprising when coverage of HIV/AIDS in the mainstream media is limited to reports of possible medical 'breakthroughs', or sensational 'Iron Man steps on dirty needle' stories.

Is it apathy or shell-shock?

Ankali has 120 volunteers who offer one-on-one emotional support but there are many more clients waiting. Stewart Clarke, who spent nine years on the staff of Ankali, believes HIV has impacted on most people in affected communities and that they are reluctant to take on more.

"Volunteers would rather assist people in crisis. It is too confronting to deal with people as they rebuild their lives."

ACON is undertaking a Volunteer Improvement Program. Their Strategic Plan notes that "Staff and volunteers are our most important asset". CSN now has shorter shifts in response to different client needs. But over the last eighteen months, training sessions have been cancelled due to lack of interest.

New recruits

NorthAIDS Manager, Adrian Eisler, told *Talkabout* that both the Des Kilkerry Lodge and Myrtle Place Centre rely on volunteers. Both services have broadened their recruitment strategy to the wider community with some success but it is early days.

"We had a good response to an article in the local paper. The typical profile of our volunteers in supported housing is mature, retired women from Northern Sydney who have been affected by HIV/AIDS. At the drop-in centre we have had success recruiting professional health care workers for our free alternative medicine services. We currently spend 2% of our budget on recruitment and recognition programs but I may well have to devote more as volunteers are vital to the survival of our services."

*The HIV sector demonstrates the power
was done for their friends and lo*

The most likely scenario is that organisations will have to work harder to recruit from their traditional source: the gay and lesbian communities, their friends and families.

Amazing feats

Last year the Bobby Goldsmith Foundation volunteer program received a high commendation from the National Australia Bank Community Link Awards – an extraordinary effort considering that over 200 organisations were nominated for the

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NORTH SHORE HOSPITAL

awards. The Coordinator, John Brimer, recruits for the BGF office, specialist administrative work, and for the vital task of fundraising. John has overseen an increase in volunteers from 900 in 1998 to 1500 during the three peak fund raising weekends in February 1999. He argues it is not always necessary to dedicate a huge amount of resources to recruitment.

"We spend less than 3% of our annual budget on recruitment. I use an intensive, broad communication strategy that targets the gay and gay friendly communities from other social groups and large corporations."

Like most people that *Talkabout* spoke to for this article, Brimer agrees that recruiting is not getting any easier.

"I think it's easier to find people for a short rather than long commitment. It helps that we can offer a range of benefits in return. This year it is harder. It is especially difficult to recruit from within our client group. Life for the BGF client base is hard enough and many don't have the resources or the energy to volunteer."

Are we being used?

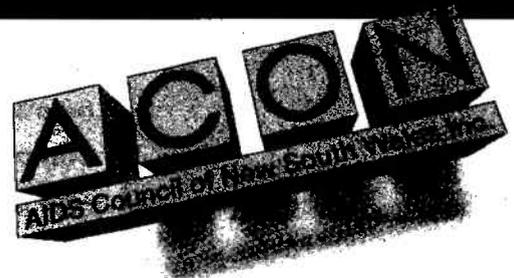
Norman is among those PLWHA who do regular volunteer work. He currently volunteers at PLWHA (NSW) three days a week, and says his main motivation is to give something back to those organisations who have supported him and his friends.

"I started because I wanted to face my situation head on. Then I began to enjoy it. Volunteering has made me stronger. I've been out of the workforce since 1992 and I definitely see volunteering as a stepping stone to paid employment. Not many of my friends volunteer. Sometimes they ask me why I let myself be used, but I don't think I am, I get a lot from volunteering."

volunteers. Dedicated volunteers, driven to see that something dying of AIDS, created many of our major organisations.

Perhaps Australia could learn from the the UK and Canadian HIV sector where considerable resources are devoted to recruitment, training and recognition of volunteers. I doubt the sector can perform at its current level if the community continues to disengage and as more PLWHA return to work. After all we often forget that just as busy staff rely on volunteers to stuff envelopes and rattle tins. Most HIV organisations revolve around their voluntary working groups, committees and boards. ■

Antony Nicholas is the Community Development and Volunteer Officer at PLWHA (NSW)



WHERE IS ACON/CSN HUNTER???

ACON and CSN Hunter have moved their offices from Newcastle to Islington. Our new premises are located at:

**129 Maitland Road
ISLINGTON NSW 2296**

Ph: 02 4927 6808

Fx: 02 4927 6485

email: hunter@acon.org.au

Rest assured we haven't changed our service or the things we provide.

Some of our services include:

- Community Support Network (CSN) provides physical, emotional and practical support to PLWHAS – including advocacy and referrals, volunteer carer program and a laundry co-op.
- Counselling
- Vitamin service
- Provision of condoms, lube, dams and fit packs
- Sexual Health testing (Hunter Area Outreach Service)
- Peer Education groups and workshops
- Sex Worker Outreach Project (SWOP)

With this move, ACON Hunter feels like it's come home – Islington was where the first Hunter office was established nearly 11 years ago!

There are so many things to say about our lives, real or imagined. Now is your chance.

PozTalk

C O M P E T I T I O N

Our Fabulous Judges

Robin Gorna is the Executive Officer of the Australian Federation of AIDS Organisations and author of the groundbreaking text on women and HIV - *Vamps, Virgins and Victims*.

Marcus O'Donnell is an artist, journalist and editor of the *Sydney Star Observer*.

Our Fabulous Prizes

Fiction

1st prize \$500 cash sponsored by South East Sydney Area Health Service
2nd prize Sydney Theatre Company tickets valued at \$300.

Non-Fiction

1st prize Accommodation for two at Sullivan's Hotel, \$100 book voucher from Darlinghurst Bookshop, Double pass to the Sydney Dance Company May Season.

\$75 voucher at Statements Homewares.

2nd prize \$300 cash sponsored by *Sydney Star Observer*

Children up to 16 years (words or pictures)

1st prize \$500 books from Random House Books

2nd prize it's a mystery!

Highly commended in any category

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8 commendation prizes will also be awarded

PozTalk is open to all people affected by HIV/AIDS.

▶ **One entry per person and category and your entry must be unpublished. Posthumous writings will be accepted.** ▶ **Categories are fiction; non-fiction; and there's a special kids section (to 16 years - words or pictures).** ▶ **Two prizes will be awarded for each category.** ▶ **The word limit for all categories is up to 1,000 words and an A4 page for pictures** ▶ **Deadline for entries is 1 March, 2000** ▶ **Winners will be announced in April 2000 and published in *Talkabout*.** ▶ **Attach the entry form below to each entry and check below for the conditions that apply.** ▶ **Send your entry to PozTalk Competition, PO Box 831, Darlinghurst, NSW 1300** ▶ **It's our culture - so let's define it!**

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PozTalk Competition Entry Form

If entering multiple categories, please attach one form per entry

Name _____

Age (only required if eligible for children's category) _____

Address _____

Daytime phone or e-mail _____

Category _____

Title of entry _____

Word count (limit 1,000 words) _____

Conditions of entry
Entry is open to all people affected by HIV/AIDS except PLWHA (NSW) Inc. staff, family members and members of the Publications Working Group. **Entries close March 1, 2000.** The judge's decision will be final and no correspondence will be entered into.

interleukin-2 is it for you?



We know that when combination therapy lowers someone's viral load, the damaged immune system usually begins to slowly improve itself, indicated by a climbing CD4 count. However many people find their CD4s refuse to climb past a certain point. These concerns have led to increased interest in therapies such as interleukin-2 that instead of controlling the virus, aim to strengthen the immune system.

Interleukin-2 (IL-2) is a chemical produced by the immune system, one function of which is to encourage the production of more CD4 cells. Current interest for IL-2 therapy stems from studies using the drug in intermittent doses, which has resulted in dramatic and sustained CD4 cell increases. In September 1999 the French Ministry of Health authorised the use of IL-2 for people who were not experiencing immune reconstitution despite being on effective anti-retroviral treatment. At the Australasian Society for HIV

Medicine's 11th annual conference in Perth in December 1999, Dr Sean Emery presented an analysis of the results of two US and one Australian trial. Two years after the end of the trials, those who had received IL-2 had higher CD4 counts and lower viral loads than those who received antiretroviral therapy alone. The fact that these people were able to maintain their IL-2 boosted CD4s two years after stopping IL-2 is impressive. The question with these CD4 cells is, do they provide increased immunity or are they duplicates of the CD4 cells that were present before IL-2 therapy began? Two large international studies including Australian patients are commencing soon to answer these questions more fully. At the time of writing, SILCAAT, the first IL-2 trial, was due to commence late January to early February.

Trial inclusion criteria

Because IL-2 stimulates replication of all CD4 cells, including HIV-infected CD4 cells, it can temporarily stimulate HIV replication, therefore trial participants must be on combination therapy to maintain viral suppression. The drug hydroxyurea cannot be part of the combination therapy because it suppresses the replication of CD4 cells. Trial participants must also have between 50 to 300 CD4 cells and a viral load of less than 10,000. Recruitment will take place over two years and participants will be monitored over a four-year period. This regular data monitoring will enable any potential benefits of IL-2 to be determined as early as possible. It also means that if a consistent increase in CD4 cells is noticed, IL-2 treatment will stop and will only be re-administered if CD4 cells start to decline.

Because the trial is designed to compare the benefits of combination therapy against

combination therapy with IL-2, participants will be allocated IL-2 on a random basis. The second IL-2 trial, known as ESPRIT, is due to commence in March-April 2000 and will recruit people on combination therapy with more than 300 CD4s.

Drawbacks

IL-2 has to be administered by subcutaneous (under the skin) injection every two months twice a day over a five-day period. Aches, pains, fever, shivering are commonly reported during the first few days of IL-2 injections and are more noticeable in higher doses. Pain at the site of the injection has been reported, as has a condition known as skin peeling and more rarely, swelling due to water retention. These symptoms usually clear up after two or three days. Although these side effects sound daunting, the trials allow for dosage reduction for people having problems with side effects. Also, if CD4s climb to healthy levels and remain there, further IL-2 injections are not required unless CD4s start to decline.

The jury is still out on the effectiveness of new CD4s in someone on combination therapy, but encouraging information is slowly emerging. In 1998 nearly 300 Swiss PLWHA on combination therapy stopped taking Bactrim when their CD4s climbed to over 200. None got PCP during 11 months of follow-up, suggesting that new CD4s over 200 protect against that particular infection. The SILCAAT and ESPRIT trials will contribute to similar knowledge on the effectiveness of CD4s boosted by IL-2. ■

John Cumming is one of ACON's Treatment Information Officers. Treatment Briefs (see page 4) has information about participating in the IL-2 trials. For more information, consult your HIV practitioner or an ACON Treatment Information Officer - telephone 02 9206 2013/2036 free call 1800 816 518.

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

AIDS 'acquired immunodeficiency syndrome'

Antiretroviral a scientific term for antiviral drugs.

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

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

Complementary therapies A term used to describe therapies that follow holistic, traditional, or culturally diverse philosophies and practices of healing, which can be used alongside medical treatment. The term 'alternative therapies' is related, but refers to practices and philosophies that are used instead of (not in addition to) medical treatment. Naturopathy, acupuncture, massage and herbalism are examples of complementary therapies that people with HIV have described as being useful.

compliance see *adherence*

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

Drugs that directly treat HIV (antiviral drugs)

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

Nucleoside reverse transcriptase inhibitors

Abacavir (Ziagen) also known as 1592

AZT (Retrovir) - also known as zidovudine

AZT/3TC (Combivir) - combined pill

ddC (HIVID) - also known as zalcitabine

ddI (Videx) - also known as didanosine

d4T (Zerit) - also known as stavudine

3TC (EpiVir) - also known as lamivudine

Non-nucleoside reverse transcriptase inhibitors

nevirapine (Viramune)

delavirdine (Rescriptor)

efavirenz (Sustiva or Stocrin)

Protease Inhibitors

Amprenavir (formerly known as GW 141):

still in development

indinavir (Brand name: Crixivan)

nelfinavir (Viracept)

ritonavir (Norvir)

saquinavir hard gel capsule (Invirase)

saquinavir soft gel capsule (Fortavase)

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HAART Highly active antiviral therapy. Usually means a combination of at least three HIV antivirals from at least two of the three classes of anti-HIV drugs available.

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

Immune-based therapies Anti-HIV treatment that aims to improve, maintain or extend the capacities of the body's immune system against HIV infection, or other diseases. This usually means maintaining a functional immune response in the presence of HIV, or repairing/improving immune response if HIV has already caused damage. Immune-based therapies include therapeutic vaccines and IL-2.

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

NNRTIs see *Drugs, Non-nucleoside Reverse Transcriptase Inhibitors*

Opportunistic infections (OI) HIV damages parts of the immune system. Once the damage reaches a certain level (roughly indicated by your CD4 count), some of the infections your body could normally deal with may establish themselves.

PBS Pharmaceutical Benefits Scheme which has a list of the different drugs listed by the Federal Government. These drugs are subsidised for people prescribed those drugs.

PCP (pneumocystis carinii pneumonia) is a potentially fatal lung infection caused by an organism that is common in our environment, but which only becomes destructive in people with weakened immune systems. One of a several common AIDS-related illnesses, known as opportunistic illnesses.

Peripheral Neuropathy (PN) Nerve damage, usually involving the hands, arms, fingers, legs and feet. It can cause numbness, tingling or burning sensations, pain and muscle weakness. It is a side effect associated with some HIV antivirals, particularly d4T, ddI and ddC.

PEP post-exposure prophylaxis. This term is used in HIV medicine to refer to individuals taking a course of anti-viral drugs after they have come into contact with HIV in such a fashion that infection may occur. The aim of the treatment is to make infection with HIV less likely.

Glossary

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

s100 drugs licensed under section 100 of the National Health Act and cannot be stored exclusively in a hospital or pharmacy.

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

Special Access Scheme A scheme that allows access to experimental drugs prior to being licensed in Australia.

Toxicity The capacity to cause a poisonous or unwanted reaction.

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

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

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

Acronyms used in this issue
ACON AIDS Council of NSW
AFAO Australian Federation of AIDS Organisations
NAPWA National Association of People with AIDS
PSB Positive Speakers' Bureau
PLWHA People living with HIV/AIDS

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

Go on... do it!

Diary

Events

Learn



Outings

Outings are free events for positive people, carers and friends coordinated by South Eastern Sydney Area Health Service. Coming up is a bus trip on 4 February and a ferry trip to Camellia Gardens and lunch on 11 February. Contact Carolyn Murray 9382 83 74 or Amanda Fossey on 9350 2955.

Planet Positive

A night for positive people and their friends. At Annie's Bar, cnr Bourke and Arthur St, Surry Hills, 16 February 7.30pm to Midnight. Free pool, food, and entertainment.

Positive in Penrith

Guest Speaker: Dr Tong Liang 'Drugs and HIV, including new treatments'. Wednesday 15 February from 6.30pm. Please bring a plate. For venue details call 4724 2507 or 4724 3984.

Central Coast Connections Day Walk

An easy 6km walk through the Red Gum forest in the Wyrrabalong National Park at Toukley on the Central Coast. All welcome. Contact David 02 4342 6270. Transport can be organised from Wyong Station.



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. Ph: 9360 3232

Shopping spree

The Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt. They'll pick you up from home, give you two hours to shop, then drop you off again. \$4.00. Available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville or Darlington. Call Diana on 9516 4755.

Living with loss

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

Significant Others of People with HIV/AIDS Dementia

We are a newly established support group formed and run by significant others for significant others who have a loved one with HIV/AIDS Dementia. We meet at 6.30pm on the last Wednesday of every month at the Tree of Hope, cnr Riley and Devonshire Sts, Surry Hills. For more information call Carole Knox (02) 9580 5718 or Angela Kelly (02) 9829 4242.

Counsellor/Therapist

Kim Gotlieb free service is available to PLWHA on Tuesday afternoons at the Positive Living Centre. Bookings are essential. Bookings 9699 8756. Call 9310 0931.



Free Courses

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

Homophobia on Air

ACON Fun and Esteem Project and South Sydney Youth Services are looking for young gay men to take part in radio production workshops for five weekends beginning 19 February in the inner city. The radio program will look at homophobia and other issues. To join call Shane 9318 0539 or Ashleigh 9206 2077.

Gym Fit X Gym

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

Women Learning Together

A free eight week Women's Health Course. Learning Together has information on how to keep well and healthy in Australia. Small, safe, and private classes with other women. Childcare is available on request. At the Women and Girls Health Centre, 6 Prince St Blacktown - a 10 minute walk from Blacktown railway station. If you have difficulty with travel arrangements please phone Marie 9515 3098, Violet 9827 8022 or Julie 9843 3124

Home and Away

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

Support

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

Olga's

Personals

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

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

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

Active sailor seeks HIV+ girl to 35ish for friendship and sailing comfortable 35' cruising yacht. No need for sailing experience, my aim is for friendship and maybe a relationship. Might even take the boat (and you!) to the Whitsundays. **Reply 041199**

How to respond to an advertisement

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

How to place your advertisement

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

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

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

Hetero female 35yr HIV+, employed, fit and healthy. Likes going out, swimming, relaxing, family, good sense of humour and honesty. Looking for male of similar disposition with positive attitude to correspond with a view to meeting. This is a first for me discretion a must. **Reply 010200**

Hyperactive



... anywhere in the world
with **tim alderman**

Inform Victoria

<http://www.inform.webcentral.com.au>

Rating Apart from the 'Interstate' link to mainly AIDS Councils, the site is Victorian orientated. However, it would be handy for PLWHA planning to travel to Victoria.

A site developed by SWAIDS (Social Workers in AIDS). This is a fast loading site, which you enter from the bottom of the page.

You can use links to various sites for information on Health; Counselling and Support; Financial; Housing; Travel and Transport; legal; Information and Education; Telephone Counselling; Rural Information; Interstate; and Interpreters.

Health World Online-Women's Health

<http://www.healthy.net/womenshealth>

Rating A comprehensive site on women's health issues, especially alternative approaches.

From the left-hand side of this page, links are provided to a QUICKN'Dex; Site Search; Medline; Forums; Calendar; Healthy News; Marketplace; Health Food Store; Bookstore; Diseases/Conditions; and much more. Main links on the page are to Medical Self-Care; Integrative Medicine and Women's Health; Naturopathic Medicine and Women's Health; Herbs and Women's Health; Homeopathy and Women's Health; Nutrition and Women's Health; and Acupuncture.

The Natural Pharmacist

<http://www.tnp.com/home.asp>

Rating Another comprehensive site on alternative medicine, which, I was pleased to see had been updated the day I visited.

There is a search engine on site for herbs, supplements, conditions and interactions. It has a 'News Flash' section, 'TNP Health Tools' which includes interactive tools for concise answers, 'Conditions In Depth' that covers everything from anxiety to rheumatoid arthritis. There are also 'What's New In Alternative Medicine', and 'Answers From the Experts'. There is a section for professionals, which gives detailed scientific information for physicians, pharmacists and other health professionals. Registration is free, and you must register to access the professional section.

NSW Health Study Grants Program

<http://www.nswhealthstudy.nsw.gov.au>

Rating A site principally for people wishing to do ongoing study in sexual healthcare.

This is a training program in HIV/AIDS, Sexually Transmitted Diseases and Hepatitis. The Index page has 'About the Program'; 'Application Form' which is an online form; 'Guidelines for Applicants'; 'Training Directory' with search engines to find courses by subject or area; 'Aboriginal Scholarship' which is funded by NSW Health AIDS/Infectious Diseases Branch; 'Seminar Series' which has sub-menus for Application Form; About the Series; and Upcoming Seminars; 'NSP (Needle and Syringe Program) meetings; 'What's Hot'; 'Links'; and 'Contact Us'. ■

Please note: In the November Talkabout we reviewed 'The Bungalow' - they now have a new URL: http://members.xoom.com/_XMCM/thebungalow/homepage4.html and note the underscore before XMCM

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

- \$ 2 Full member (NSW resident with HIV/AIDS receiving benefits) \$15 Full member (NSW resident with HIV/AIDS in employment)
 \$15 Associate member (NSW residents affected by HIV/AIDS)

Disclosure of HIV status entitles you to full membership of PLWHA, with the right to vote for all management committee positions. Membership status is strictly confidential. **Members of PLWHA automatically receive a subscription to Talkabout.**

Talkabout Annual Subscription Rates

Talkabout subscribers also receive *With Compliments* newsletter eight times a year **FREE!** NSW Talkabout subscribers also receive *Contacts* resource directory.

- Individuals** I am not a member of PLWHA (NSW) and/or I live outside NSW **\$30 per year**
 I am receiving benefits and living in New South Wales (enclose proof of concession) **FREE**
 I am an individual living overseas **AUS\$70 per year**

- Organisations** **Full** (business, government, universities, hospitals, schools etc.) **\$80 per year** Please specify number of extra copies @ \$30 each per year
 Concession (PLWHA organisations, non-funded community owned groups etc.) **\$40 per year** Please specify number of extra copies @ \$13 each per year
 Overseas AUS\$120 per year Please specify number of extra copies @ \$40 each per year

Donations Yes! I want to make a donation to PLWHA Talkabout

\$100 \$50 \$20 \$10 Other amount \$ Total amount forwarded \$ (include membership fee if applicable and fees for extra copies)

Method of payment Cash Cheque Money Order Mastercard Bankcard Diners Club AMEX Visa

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Please make cheques payable to PLWHA (NSW) Inc. A receipt will be sent upon request. **Donations \$2 and over are tax deductible.**
 Please note that the Membership and Subscriber database is totally confidential. **Publishers** — talk to us about exchanges with your publication.

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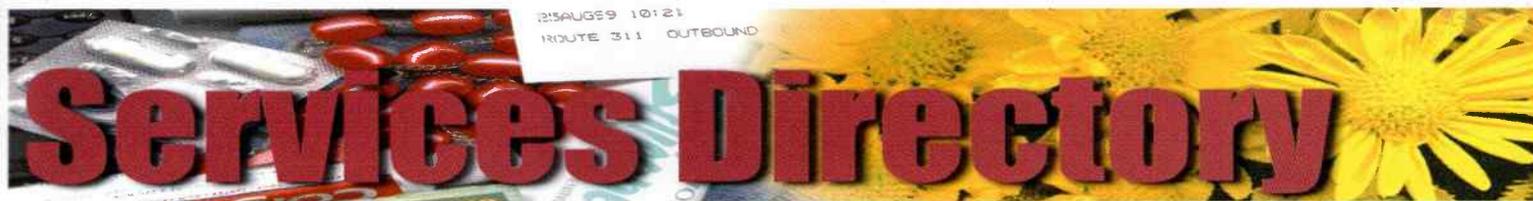
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Talkabout is published monthly by PLWHA (NSW) Inc and covers areas of interest to people living with HIV and AIDS including treatments, news, features and personal stories. 3,000 copies of *Talkabout* are distributed throughout the Sydney metropolitan area and regional New South Wales. *Talkabout* is also distributed to AIDS organisations and libraries nationally. **If you would like to advertise in Talkabout's Services Directory, please contact Rosi on (02) 9361 6750.**

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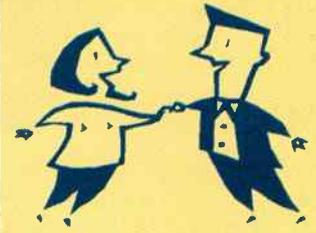
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positive heterosexuals 2000 CALENDAR



january

friday 28

Open House: Scottish Welcome
Guest: Betty Ramsay, Highland bagpiper

february

friday 25

Open House: Ain't Misbehavin'
Guest: John Richardson,
Animal Psychologist

march

friday 10

Positive Business:
Play your cards right

friday 31

Open House: Train again!
Guest: Jan Smallwood,
Vocational Counsellor, TAFE

april

friday 14

NEW

PozhetOutreach: Our Pathways
Open House for Woollongong Pozhets

friday 28

Open House: Nepalese welcome
Guest: Vicki Hannam-Cassella,
Prerama (Inspiration) Nepal Australia
AIDS Project

may

friday 5 to sunday 7

Pozhet-by-the-sea
Shellharbour weekend away

NEW

friday 12

Positive Business: The protease prison

friday 26

Open House: Our seventh birthday!
A jazz evening

saturday 27

Family Matters Pozhetwest
1st Annual Conference, Western Sydney

NEW

june

saturday 17

Pozhet Partners Forum:
Missing person

friday 30

Open House: Pills in the pipeline
Guest: Denise Cummins, RPA Clinical
Nurse Consultant

july

friday 14

NEW

Pozhet Outreach: Karumah
Open House for Newcastle Pozhets

saturday 29

NEW

**The Absolutely
Fabulous Pozhet Clinics**
One for men and one for women

august

friday 11

Positive Business: Hello soul mate

friday 25

Open House: Greek welcome
Guest: Maria Petrohilos,
Multicultural HIV/AIDS Service

september

15 - 30

**Pozhet closes during the
Olympic Games**

october

saturday 14

Pozhet-in-the-mountains
Pozhet and Pozhetwest coach trip

friday 27

Open House: Is aging a health risk?
Guest: Ruth Melville, Manager
Community Nurses CSAHS

november

friday 10

Positive Business: Piece of mind

saturday 25

Body Talk: Looking good,
feeling better!
5th Annual Living Heterosexually
with HIV/AIDS Workshop

december

friday 8

Open House: Irish welcome
Pozhet Xmas Party