

No. 75 April 1997

Talkabout

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

◆ Where We Speak for Ourselves ◆

back to work



back to the future

Convenor's Report



MARCH KICKED off with PLWH/A's presence at the Women's Festival in Sydney. Our stall there was, by all accounts, fairly busy. A 'guess the number

of pills' competition pulled in around \$100, a bonus for the day. Thanks to the Peasant's Feast, a Newtown restaurant, for donating the prize, a dinner for two, which was enjoyed by prize winner Delah Gomas-Zumavor and his mum Jo Perks. And how many pills were there? 5,386 — and yes, they *were* all counted.

During the past month the organisation has been working very closely with ACON on a number of issues. Shane Wells is our representative on ACON's Housing Working Group. The group's main focus at present is the issue of special rental subsidies, which as you know are under threat.

Vincent Dobbin is our official representative on ACON's Legal Working Group, and of course Ed Moreno, HALC Co-ordinator, is also a PLWH/A Committee member so we have good representation in

the legal area. This working group is currently most concerned with cuts to legal aid.

I've been working with ACON on the issue of proposed changes to Research Guidelines which would give researchers access to HIV medical records if passed. The deadline for submissions was April 1, keep an eye on *Talkabout* to find out what happens.

PLWH/A has joined the BGF Housing Project Management Committee as an affiliate member. The Housing Project expects people to move into the units in early April and four Housing Support workers have already been employed. These workers will be providing 24 hour support to residents, which includes assistance with daily living, emergencies and ensuring that they're supported by other relevant services.

Progress is being made with the Positively Working group (see page 16). This group has been looking at ways of re-training retired positive people so they are able to go back into the work force in the future. During April there will be community forums held to

ascertain what the positive community would like and where they feel training is needed.

Over the past two months the Committee has been preparing the annual business plan for the organisation which will determine the direction and prioritise the goals to be achieved by the next AGM. Our priorities will be treatments and clinical trials, complementary therapies (we're hoping to conduct some research into the use of complementary therapies) and expansion of the Care and Services portfolio.

The Mardi Gras period has been very intense for all staff and volunteers, and ill health among the staff has placed added pressures on the organisation. The commitment of volunteers and staff over this period has been exceptional and the committee deeply appreciates their work.

— Phillip Medcalf

The latest news.
Where we're at with HIV treatments.
How to get the most from your treatment.

HIV TREATMENT FORUM

Your chance to get a balanced report from expert speakers:
Colin Batrouney (National Treatments Information Officer)
Dr Cassy Workman (Albion St Centre)

TUESDAY APRIL 22

Start: 7pm

Albion St Centre Theatre
(enter from cnr Albion & Crown Street)
DARLINGHURST
free admission

Presented by PLWHA NSW

It's Your Time II



People Living With HIV/AIDS (NSW) Inc.
Current committee:
Philip Medcalf: **Convenor**
Claude Fabian: **Deputy Convenor**
Vincent Dobbin: **Secretary**
Erycka Fars: **Treasurer**
Chris Holland, Andrew Kirk, Bill Whittaker, Ed Moreno, Rolf Petherbridge, John Trigg, Shane Wells

Current staff:
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Luke Smith: **Finance/Admin Officer**
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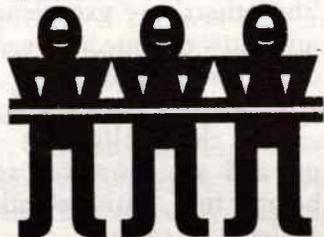
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back to work



back to the future

This month's cover

By **Alex Zinzi**. As the years of retirement roll on, with any luck you might be one of those whose viral load and T cells have reversed their directions. And suddenly, retirement is looking a tad boring and just a bit unrealistic. On page 12 we start an ongoing series of articles about returning to the workforce and other changes people are going through as a result of the changing treatments.

Talkabout

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Letters submitted to *Talkabout* or its editorial co-ordinator are assumed to be for publication in whole or in part unless specified otherwise.

If you would like to be involved with *Talkabout* call Jill on 9361 6750 for the date and time of the next Newsletter Working Group meeting.

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DTP: Alex Zinzi.

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Briefs



In February the US Centers for Disease Control and Prevention (CDC) reported that for the first time in the AIDS epidemic, there has been a marked decline in the number of deaths among people with AIDS in the US. Deaths among people with AIDS declined 12% during the first six months of 1996, compared to the first six months of 1995. The decline is probably due to recent improvements in treatments that delay the progression of HIV and prevent opportunistic infections, coupled with the success of prevention efforts in slowing the growth of the epidemic overall, the CDC said. The CDC also stated that while it is too soon to determine the impact of protease inhibitors, these therapies promise to further lengthen the lifespan of PLWHA. Trends in AIDS incidence and deaths varied by risk group, gender, and race, and both AIDS incidence and AIDS deaths continued to increase among women and among people infected through heterosexual contact. While deaths declined among all racial/ethnic groups, declines were much greater among whites (21%) than among blacks (2%) or Hispanics (10%). (CDC)

● Since 1987, a total of 284 AIDS cases have been reported in Nicaragua, the Health Ministry said in mid-March. The country's AIDS rate remains the lowest of any in Central America. Honduras has the highest rate, with between 6,000 and 8,000 patients in the late stages of the disease. (CDC Daily Summaries)

● The publisher of *POZ*, a magazine for PLWHA, is preparing a similar publication for Spanish-speaking people and another for women with breast, ovarian, or cervical cancer. *POZ en Espanol* is slated to appear in late April or early May, while *Mamm* is expected in late September or early October. *POZ en Espanol* will not be a Spanish translation of the original magazine, but will have editorial content especially for the Latino community. (CDC Daily Summaries)

● Antoinette Distilio, a Canadian woman who had to practically scrounge to pay for her AIDS drugs, won \$10 million in Canada's lottery jackpot on New Year's Day. The big winner, who quit her job as a clerk in 1991 when she was diagnosed with AIDS, plans to buy a fully loaded Toyota MR2, find a top AIDS doc in the US and share the remaining loot with friends, family and an AIDS foundation. The French Medical association is to issue a "very firm recommendation" that HIV+ doctors stop performing surgery, after in announcement in mid-Jan that a surgeon had infected a patient. (New York Times)

Magic yellow van

AFTER SEARCHING THE COUNTRYSIDE for over 12 months the Luncheon Club recently found a mobile food van in Tamworth and without hesitation, Fashion For AIDS donated the money to purchase it.

Under a shadow of secrecy and amid rumours the luncheon club had a new venue, luncheon club diners gathered outside the Exchange Hotel on Monday February 17. To their sheer amazement, the bright yellow mobile food van was escorted by police from Surry Hills and Kings Cross down Oxford Street, it was decorated for the occasion with a huge red ribbon and bow for Peter Chadwich Chairman of Fashion For AIDS to cut as he launched our new venture. Among the first to enter were Clover Moore, MP for Bligh and entertainer Maggie Kirkpatrick.

The following Saturday being BGF's Shop Yourself Stupid day, the van was used for the first time at Taylor Square and proved to be extremely successful, serving over 400 customers with hot chips, hot dogs, steak sandwiches, hamburgers and drinks. Our volunteers worked tirelessly in 38 degrees temperature.

The van is now going to be temporarily moved into the PRIDE Centre yard and on Thursday April 10, from 11.00am till 8.00pm, everyone is welcome to free food and entertainment as volunteers are put through their training program.

The van has tremendous potential not just for fund raising but for being able to provide free food to people living with HIV/AIDS. It also provides a job opportunity for plwha, who can be trained and then will be paid to work the van at various events. If you would like to become involved, please register by phoning the Luncheon Club on 9389 7477.

— Carol Ann King
President, Luncheon Club

Couples unite

AN EXPERIENTIAL THERAPY GROUP for gay, lesbian and heterosexual couples where one of both partners have HIV is due to start at ACON as soon as there are enough interested couples. But what's an experiential therapy group?

In an experiential therapy a group of people, (in this case around four to six couples) commit some time to being together in order to learn, grow, share thoughts, voice fears, acknowledge others - or none of the above, but perhaps sit, observe and listen. An experiential therapy group doesn't require active participation from everyone and yet allows the action or inaction of the participants to be noticed and ultimately accepted.

And whoever heard of a group which includes gays, lesbians and heterosexuals together? Some people have told me it's a great idea and others have said no way, too challenging, too threatening, too complex.

So what's the benefit of mixing? Well for a start, HIV quite obviously is not limited to specific groups of people and the wisdom, knowledge, doubts and fears within each affected group is not unique — or is it? As a mixed group has yet to happen, none of us know what 'the others' are experiencing. Up until now no-one has been curious enough to find out.

It's time to open the doors, and smash the walls that separate us, and see ourselves as human beings first with specific sexual preferences second.

I anticipate this group will start early May. I would love to hear from anyone willing to become pioneers, risk growing, become happier, and enjoy an overwhelming feeling of self satisfaction. Call me or Alex Sosnov on 9206 2018, or pick up an application form from ACON.

I believe it's time for a group like this. So much of our lives focus on the relationships we create and destroy. As both creation and destruction are vital elements of a relationship, by

creating a group like this we may be destroying the myths that have kept us separate for so long.

You know courage is a funny thing: It takes the same courage to run a group as it does to join one. None of us know how it will turn out until it happens. But I have a hunch it's going to be wonderful.

— Sharon Snir

Safe babies

UNPROTECTED SEX DURING pregnancy may increase HIV transmission to babies, reports *AIDS*, a US publication. A study of 175 HIV positive pregnant women found that heterosexual intercourse without a condom increased the transmission of the virus to infants.

Women reporting no incidences of unprotected sex had a transmission rate of 9.1% (four out of 44 women), while the five women who said they didn't have sex at all did not transmit the virus.

Women reporting "moderate" incidences of unprotected sex (inconsistent condom use & less than 80 acts of intercourse) had a transmission rate of 22.2% (20 out of 90 women).

Women reporting high frequency of unprotected sex had a transmission rate of 39% (16 out of 41 women).

Unprotected sex was a greater risk for transmission even after researchers adjusted for factors such as injecting drug use, CD4 counts, women who had an AIDS diagnosis at the time of giving birth and use of AZT. Although women who transmitted the virus reported a slightly greater number of acts of intercourse, this number was not statistically significant.

Researchers listed ways in which unprotected intercourse might increase the transmission rate increased viral load due to immune reaction to semen or infection with a new strain of HIV; increased direct contact between the embryo and the virus; greater inflammation of the cervix occurring from tiny abrasions or from contact with sexually transmitted diseases caused by



The PLWH/A Stall at the Sydney Women's festival attracted a lot of interest – especially our 'how many pills?' competition, which ended up being quite an educational exercise. Organiser Jo Watson said she was surprised how many people wanted to know which of the smartie look-alikes was 'the cure'. (Yes, they were all AIDS drugs in that jar!) A big thank you to volunteers Erycka, Sharon, Bridget, Bev, Jill and of course Jo.

PHOTO: JILL SERGEANT

frequent intercourse and greater inflammation of the placenta and the membrane surrounding the foetus, also cause by frequent intercourse.

(Positively Aware, a US PLWHA publication)

KM1 fights for gaol access

THE NSW DEPARTMENT OF Corrective Services institutional ethics committee has once more rejected the application from the KM1 herbal formula trial organisers for prisoners with HIV/AIDS to be allowed to join the trial - this time to our faces.

Following pressure on the Corrective Services Minister, Bob Debus, the Committee agreed to a meeting on March 12 with Trial Director, Jan Kneen-McDaid. But the conduct of both the meeting and of the 18 months since the original application have lead trial organisers to make a complaint to the NSW Ombudsman.

"Basically the meeting was a set-up", said Kneen-McDaid. "And they were making decisions without, amongst other serious

issues, any expert advice on HIV therapy or complementary therapy."

Trial organisers intend to publicly campaign on human rights grounds for prisoner access to the trial. Their campaign has the backing of prisoner rights group Justice Action and trial organisers expect to receive continuing support from leading HIV/AIDS and other agencies.

— Paul Canning

KS hope

THE KS CREAM BASED ON a vitamin A derivative that you've been seeing advertised in *Talkabout* really works! A recent article in the *Sydney Morning Herald* said that the cream was showing early promise in the trial, which is co-ordinated by Dr Neil Bodsworth at Taylor Square Private Clinic.

Dr Bodsworth told the *Herald* that an earlier small study showed the vitamin A derivative caused "complete or partial resolution of 30% of tumours", and that in the new study, the cream is looking even more promising.

The study is expected to involve 270 patients internationally; 42 Australians are already enrolled.



For the first time in nearly 20 years, Aboriginal & Torres Strait Islander health workers will be gathering at a conference on April 28 - 30. Uniting Our Voices will be looking at a range of indigenous health issues including HIV/AIDS. Kathy Kum-Sing, who has had a long involvement with HIV both personally and politically, will speak at a plenary and there will be number of other sessions. Participants will also be treated to a preview of a video about the life of Ross Smith, an Aboriginal man from the Far South Coast who died a few years ago. Produced by Wally Stewart, the video is to be used as an educational resource in Aboriginal communities. For more info call 9311 4051.

● The National Centre in HIV Social Research is recruiting people living with HIV/AIDS to participate in a study on treatment choices. They want to identify the ways in which PLWHA make decisions about the kind of health care strategies they use. Give your experience a voice. To participate in this one-off, confidential interview, call Rob or Phillipa on 9850 9436.

An HIV+ doctor has been brought before the Victorian Medical Practitioner's Board to face allegations that he had unprotected sex with two patients, one of whom he knew to be HIV+. The doctor is also facing other charges. (*HIV/AIDS Legal Link*)

● Are you caring for someone you love who is living with HIV/AIDS and want to know what training resources and support are available? Community Support Network at NorthAIDS invites you to an information forum on Tuesday, April 8 at Myrtle Place, 2/349 Pacific Hwy, Crows Nest. To register call Liz on 9206 2048 or Angelo on 9206 2031.

● The therapeutic use of cannabis by terminally ill patients is being considered by the South Australian Government. The issue is being investigated by the SA Drug and Alcohol Services Council, which will present a report to the Ministerial Council on Drug Strategy in June. The medical director of DASC, Dr Robert Ali said it would look at the methodologies of studies which offered evidence that smoking cannabis was therapeutic; at ethical questions on the use of the drug; and at guidelines on how the drug could be provided. (*Adelaide Advertiser*)

● Oops. In the last issue it was stated that CSN has branches at ACON Illawarra & Hunter. We forgot Western Sydney! Sorry.

Sex on the road

ON FRIDAY 28 FEBRUARY, (amazing how many people had to be in Sydney that week!), the Australasian College of Sexual Health Physicians held their Fourth Scientific meeting. I know it sounds particularly boring, but wait, the theme? *SEX and TRAVEL!*

Now I know some of you are interested in at least one of these things, so I went along for the day. Topics included sex and travellers, the HIV positive traveller, recent advances in travel medicine, and some panel discussions on the best travel advice. I'll try and walk you through the day with this brief overview.

In world travel health, those most at risk are infants, pregnant women, and those with existing health problems. But health risks increase when travelling through rural and non-tourist areas, taking a prolonged stay in particular spots, or participating in sexual contact with locals.

Diarrhoea is the biggest risk for serious illness out of all the travel related problems, followed by other gastro-intestinal illnesses. Obviously prevention of these is vital, so basic hygiene precautions such as following clean water and food guidelines will be top of the list. Other interventions include immunisations, and prophylaxis for preventative measures. These can include antibiotics such as Norfloxacin.

With vaccinations there were strong indications at the meeting that the HIV positive traveller needs to discuss their travel plans and vaccination options with their doctor carefully. Speakers generally agreed that you needed to weigh up risks and benefits of live vaccines, especially if your travel plans don't include going to high risk areas, a la Indiana Jones. Sipping cocktails and walking between the hotel room and the pool, is hardly the same as a trek through Nepal! Basically, there is not a lot of data in yet about how safe these vaccines are for HIV positive people, so get advice and go through your options.

The Travellers Medical and Vaccination Centre is a good port of call for more information.

Remember, minor health impairments will occur in most short-term travel experiences, but if you plan ahead, have strategies for returning home quickly if necessary, pack sensible amounts of all your medications, and think about everything that you are putting in your mouth, then travel life should be that much more enjoyable. Cheers!

— Jo Watson

OPI Update

SO, WHAT DOES A POSITIVE LIVING centre co-ordinator do when the service users disappear into work-oriented re-training? Promise caviar at lunch? No, he promises them the world - on the Internet! Watch this space!

Several of us donned the togas to join with ACON/CSN Illawarra in the Mardi Gras Parade, which was a hoot. Then, a week later, in dinner jacketed elegance, sold out the Gala Opening Night of 'The Importance Of Being Earnest' at Wollongong's Workshop Theatre and raised \$500. The next fundraising theatre night is 'Accidental Death Of An Anarchist' on May 24 and there are plans for a Queer Xmas in July Panto. We are also very keen to hear from performers interested in being part of our World AIDS Day Benefit Night at the Illawarra Performing Arts Centre on November 29. Or from artists, as there will also be a two week long exhibition at the IPAC leading up to the Benefit Night.

Considering the Fair Day success, we are also putting out a plea for jumble! You got it? We want it! Give us a call if you're cleaning out the cupboard/garage/etc. We have three Sundays at Berry Markets between now and December to supply with trash and treasure.

An excellent day was spent with Tony from PLWHA Western Sydney who came down to check out Our Pathways Inc. and get some ideas for their group.

Networking with PLWHA in Cooma and Newcastle has also proved rewarding. Don't forget the bus trip to socialise with our southern peers and chuckle the night away on Thursday, April 24 at Bomaderry Bowls. Only 12 seats so book soon!

The vegie garden's all set for a giant weed-out so if there are any idle green thumbs reading this and looking for a pleasant pastime — drop in. Hands On Massage has been busy and is planning a massage day in the Shoalhaven for April. The Carer's Support Group is being well attended and massage, reiki, acupuncture and naturopathy are available on request. April's video is 'A Beautiful Thing' and if you'd like more info or just a chat call Our Pathways Inc (042) 29 2944.

— Cameron Sharp

Hep C 1st

THE FIRST AUSTRALASIAN Conference on Hepatitis C was held in Sydney March 16-18. This was a significant conference for many reasons, but not least because it is thought to be the first multi-disciplined conference held in the world specifically covering Hepatitis C (HCV).

The presentations covered four streams: Basic Sciences, Clinical Sciences, Epidemiology and Social Research, and Public Health: Prevention and Community Support.

This was a jam packed program, and with sessions carried into the evenings, days lasted up to 12 hours. There was a sense of almost an urgency in getting definite agreements to issues and problems. I think the conference was successful in highlighting the impatience that many HCV people are feeling about getting education and support services improved and expanded.

As the Third National HIV/AIDS Strategy was broadened to include Hepatitis C and sexual health strategies, many of the presentations at this conference are relevant and important to the HIV/AIDS community. Not only because of the differences, but also



All HIV/AIDS floats travelled together in the Mardi Gras Parade, united by ribbons such as the one pictured, in the colours of the rainbow.

PHOTO: C. MOORE HARDY

because of the common causes and concerns.

Here are some brief highlights.

In the Basic Sciences stream, the problems identified to date are that HCV is difficult to study because they have no way of cultivating the virus in test tubes and it's hard to find appropriate test animals; that there still isn't accurate diagnostic and testing equipment; and very slow disease progression with no defined clinical endpoints.

In the Clinical stream it was pointed out that there are up to 200,000 HCV infected people in Australia at present. This number is increasing at a rate of 8 - 10,000 new cases every year and 85% of those infected will go on to carry the virus long-term.

After ten years, HCV is highly likely lead to chronic hepatitis. After 20 years, it can lead to cirrhosis of the liver and after 30 years, to carcinoma. But it's not clear how many people's HCV will progress in this way and it is not known what other factors can increase disease factors, — age, for example.

Currently, treatment is of limited clinical effectiveness and expensive. The drug Interferon gives a sustained response rate for only 20% of those using it. There is obviously a need to develop treatments which have better sustained responses, which are cost-effective. It was heartening to hear that natural therapists and doctors may find common ground in working with HCV and the presentations from natural therapists were well received during the conference.

In the Epidemiology and Social Research stream there was agreement that surveillance of this disease is difficult, because it has been a "clinically silent" disease for such a long time.

This also makes it hard to determine those groups which are most at risk. For example, while it is known that injecting drug users are the highest risk group for HCV, the groups within this population, such as youth, prisoners, and those with a long history of injecting drug use, all have different characteristics which increase their risk of disease transmission, and/or reinfection.

Briefs

X The 3rd International Conference on Biopsychosocial Aspects of HIV infection will be held in Melbourne June 22-25. Co-hosted by the Centre for the Study of Sexually Transmissible Diseases, La Trobe University, and the National Centre in HIV Social Research at Macquarie University, the conference will cover a number of themes. Major policy, cultural and social issues concerning HIV prevention and health promotion and issues confronting PLWHA and their carers will be addressed by world experts. Topics include community and care, mental health, indigenous communities, euthanasia, and social/ethical dimensions of drug and vaccine trials. For info contact: The Meeting Planners, 108 Church St, Hawthorn, 3122, Victoria. Phone: (03) 9819 3700, Fax: (03) 9819 5978.

● Merck Sharp and Dohme have been carrying out a community consultation across Sydney, Melbourne, Brisbane and Canberra over the past month. They want to know useful their product information is, and what can be done to improve it, especially for people using large numbers of drugs. Individuals have been surveyed and in phase two, will be 'testing' materials. Treatment Officers will be then piloting some of these with the wider positive community.

● French researchers have stated that the debilitating and common pain suffered by PLWHA is "gravely underestimated and undertreated". Their study in 34 HIV treatment centres included 315 patients at different stages of infection. Patients reported on presence and severity of pain, and rated quality of life. Doctors recorded disease status, estimated pain severity, and analgesic prescriptions. HIV associated pain was reported by 30% of outpatients and by 62% of inpatients, who also said that severe pain significantly reduced their quality of life. Doctors underestimated severity of pain in 52% of those patients who reported pain. The authors observed that the more severe the pain, the more often it was under-estimated by doctors, and that doctors were reluctant to prescribe potent analgesics. They recommended that improvements of the management of HIV related pain will require changes in clinicians' knowledge, attitudes, and practices.

● The National HIV Reference Laboratory (NRL) is to expand its role to monitor and oversee testing procedures for all blood borne disease. The NRL's role has been recognised as vital for maintaining the quality of HIV testing, as well as the increased testing needed for hepatitis C. The facility will be renamed the Australian National Reference Laboratory.

— Jo Watson, PLWH/A Research Officer

There was agreement that social research is of great importance if prevention and education strategies are going to be targeted appropriately. We need to know what motivates people, before you can develop campaigns to change behaviour and educate.

With several international speakers drawing attention to the size of the HCV epidemic in places such as India and Thailand, there was also acknowledgement of the urgency of prevention campaigns, as well as campaigns which target the ignorance and discrimination which is so prevalent here.

In the Public Health sessions it was clear that the epidemic is a significant public health challenge. At present there are limited strategies in prevention and HCV is more infectious than HIV. With 1% of the population infected, this will have significant costs in healthcare resources.

Many speakers referred to discrimination, ranging from that directed at stereotypes of IDUs, to systematic discrimination in services. Concern was also expressed at the need for more education of GPs and those working in prisons.

The difficulties of working with a group which is often stigmatised and therefore has little incentive to be involved in research or data

collections, also highlights some of the problems around 'hidden populations'. This conference was important because it showed how complex the Hepatitis C epidemic is. It is important to those with HIV/AIDS to understand the prevention and transmission issues of HCV, and for those who are co-infected with both HIV and HCV to know about services and information resources available through organisations like the Hepatitis C Council of NSW and the NSW Users and AIDS Association (NUAA).

It is important that we are aware of some of the common aims and objectives we will be sharing with HCV groups over the course of this Third National Strategy.

— Jo Watson

Stop Press

DUE TO A VARIETY OF PRESSURES, including the costs of staff ill health and leave, the May and June *Talkabouts* will be combined into one issue, due out in mid-May. The theme of this issue will be artistic and cultural responses to the epidemic. We hope to publish as many original artworks as we can fit! Get your contributions in now.

Treatment Information

You Name It,
We'll Help You Find It

New drugs and treatments, how to keep up with the latest advances and announcements

Information access can be tailored to your personal needs

Contact Jo Watson, the Research Officer at PLWH/A

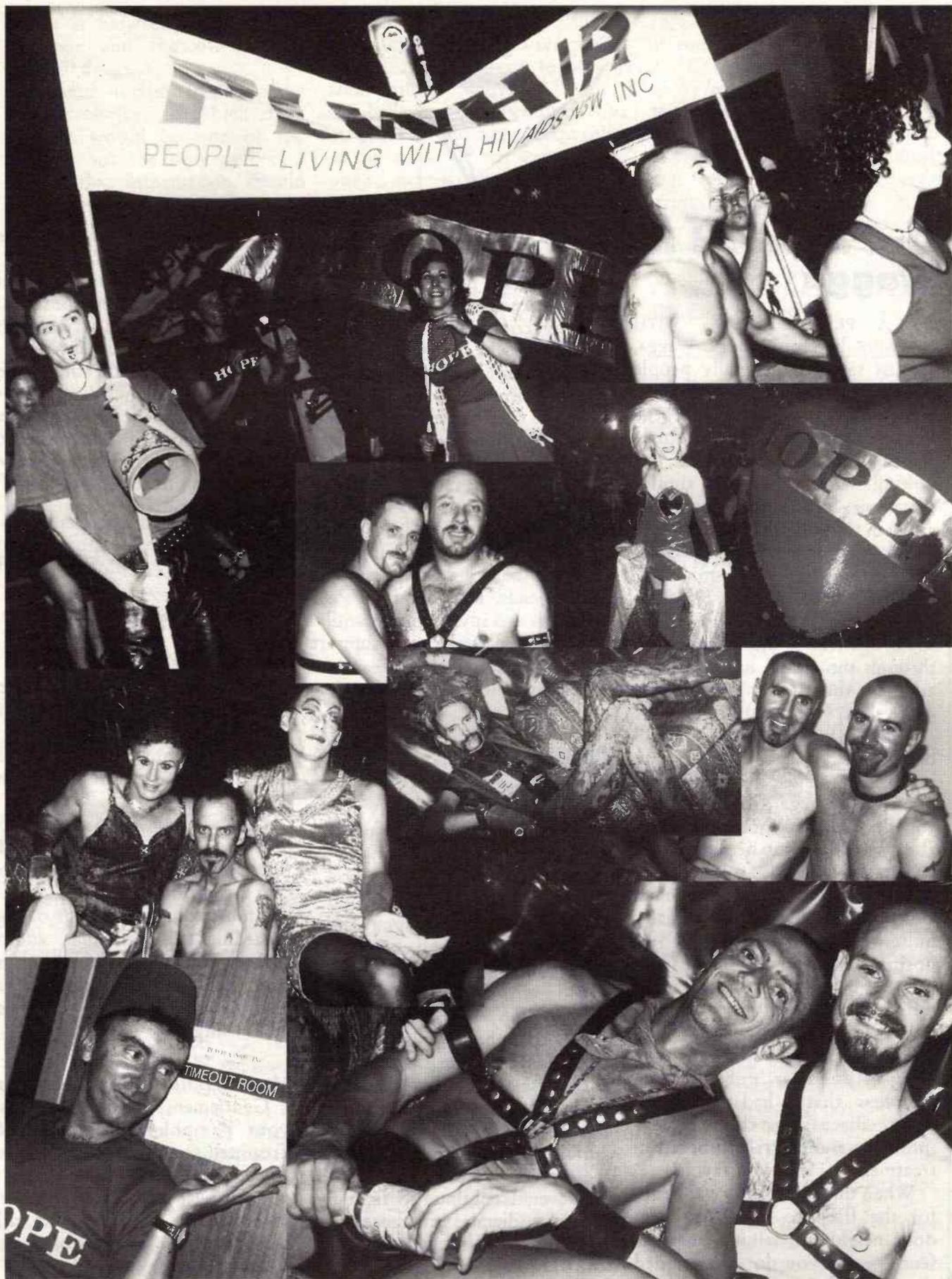
on (02) 9361 6011,

Freecall 1800 245 677

Fax (02) 9360 3504

Email on plwha@rainbow.net.au





PLWH/A DOES MARDI GRAS

PHOTOS: C. MOORE HARDY, MAZZ IMAGES, PAIGE SLAN

If you were photographed in the Timeout Room, drop by the office to pick up a copy of your photo.



Out & proud in Wagga

AS A PERSON LIVING WITH HIV/AIDS here in Wagga Wagga, I must say that generally people couldn't give a damn about us. This unfortunately includes the local gay and lesbian population.

I can only speak for myself, but talking with others in similar situations, I find that I am not alone in thinking this way.

When my partner Ricky and I decided to leave the big smoke the two major factors for us choosing Wagga were that I could get access to drug trials and medication through the sexual health service and that there was an active gay and lesbian social/support group.

So it amazes me that I am still being asked what I believe are insensitive and pretty stupid questions in regard to my health and that I am questioned on my ability to do my job because of my HIV status.

I am very proud to be a gay man and funnily enough, I am actually quite proud to be so openly HIV positive, as without being positive I do not believe that I would be so outspoken today for what I believe in.

This January the Wagga Wagga *Daily Advertiser* published an interview that I had done with them, discussing the protease inhibitors and tri-combination treatments. (Hope you saw it!)

When this came out I was ready for the flack to start. My next door neighbour, talking over the fence — as you do — mentioned that she had seen the article. *And?* ... To my surprise she told me that she had found the article very interesting and that she had told

her workmates that we are the nicest couple she knows.

The only negative reaction came, surprisingly, from within the gay community. Rick and I were asked why we would want to be so open about our HIV status. This made no sense to me whatsoever, as people need to be informed and if some small-minded people want us to go back to the dark ages and be ashamed of ourselves, then they can go and get stuffed.

So in future, when I am asked about support for PLWHA in Wagga I will tell them, yes, I have support from friends, Riverina HIV Peer Network and my partner's family. But I could not guarantee support from anywhere else.

Iain Campbell

No more quandary

IN ANTICIPATION OF RESPONSES TO my letter published in February's *Talkabout* I feel compelled to write the following:

My letter (originally a 1,000 word article) was written in October last year when I was in a quandary over treatments. You will be happy to know that after much thought, discussion with free-thinking human beings and the support of an excellent GP, I have started HIV treatments and I sing the praises of these individuals and the treatments themselves from the rooftops. However, I continue to fight the extremist dictates of those who would deny individuals the right to make their own decisions free from harassment.

I remain firmly of the view that uncompromising and fascist approaches to HIV treatments are

not the answer and if anything are disrespectful and dishonest.

Decisions about HIV treatments must be informed and consensual as anything else only serves to the detriment of all parties involved.

I should also add that, since my last letter was published I have experienced first hand discrimination in attempting to access a service from an employee and adamant treatments fascist of a community service organisation — clean up your act babe!

James Urban

Carbon copy

DEAR EDITOR,

enclosed is my letter addressed to the authors of "HIV Tests & Treatments". I would appreciate if this was published as I would like to hear responses from the community.

I am not opposed to any therapy that helps people. I am only opposed to misleading information that misinforms.

I must admit to feelings of rage regarding this pamphlet, adding fuel to the fire was that it's on the back of your magazine. What are the checks made on your advertising?

Messrs. Duffin, Gallagher, & Strum

Gentlemen, I have recently read your pamphlet "HIV Tests & Treatments — Now more choices than ever before" and I must say that I found it to be very objectionable. Firstly your title suggests plural tests & treatments. After reading your 14 pages I found one test and one treatment. My first question is: where are the choices? If the choices you suggest are there, then obviously the only

choice is between saquinavir or zidovudine and the other eight antiretroviral drugs.

My interpretation of your cover was of choices in which drug therapy would be one of the choices, not the only choice. I believe that information should be designed to empower people to make choices from the information given (which should be as comprehensive as possible), not to limit people in their chosen medium of healing.

I would be interested to know who funded this article. If Roche or some other company did not fund it, then it really is good for them. Even from the point of view of side effects, in relation to diarrhoea or nausea you suggest drug therapy and skip over complementary therapies. Not one natural alternative is given, not even a dietary guideline eg; if diarrhoea is present stop dairy products. Slippery elm may be good for nausea. These are two basic suggestions that you didn't even bother to intimate.

If drug companies did fund this, then what were the limitations placed on its content that you had to adhere to?

In your conclusion you state that antivirals are not a cure but represent a significant improvement over what we've had. *What have we had?* Over-prescribed toxic materials that I believe killed more than helped. This is one of the few certainties (my turn to generalise and make assumptions).

I am HIV positive and have been for four years. I am very fortunate that I have never been sick, have never taken drugs (AZT etc.), very rarely take recreational drugs, except pot and a few drinks. I eat well and look after myself. After a recent viral load test the doctor said that without the therapy you're advocating I will be dead in three years (another omnipotent Queen).

May everyone find out what they need to know from this virus and use that information for their healing. Your pamphlet doesn't offer much in the way of empowerment. Unfortunately it

offers limitations that will continue to categorise and disempower people if they choose to believe what you have written.

I believe what goes into your mouth is the most important thing in the world. If we want to live one's diet is the pinnacle of importance. Your relegation of this fact to almost an advocacy of bad diet is intolerable. I do hope you consider the implications of what you write in any future publications, even if it's not using plurals when all you are offering is a very singular therapy.

Gregory Kelly

Talkabout responds: Talkabout accepts advertising from a wide range of community organisations and businesses. We rely on advertising to supplement our income — it all goes towards making Talkabout a better publication. A copy of our advertising policy is available to readers on request.

According to this policy, advertisements which are accepted for publication include those promoting services, issues or events of direct value, interest or concern to PLWHA. Publication of an ad does not necessarily mean PLWH/A endorses the product, service or event being advertised, however we do place limitations on what advertising is accepted. Advertising for antivirals is not accepted at present. An advertisement will not be accepted if it is thought to be discriminatory, misleading, false, fraudulent or exploitative.

In the case of the HIV Tests and Treatments pamphlet which was published by ACON, the ad was accepted because the pamphlet is a new education resource for PLWHA and therefore "of direct value, interest or concern to PLWHA".

The booklet is specifically about recent developments in pharmaceutical drugs and the viral load test, and does not claim to be anything more general. This is important information for PLWHA, especially because if you choose to take the new drugs, there are things you need to be aware of —

such as resistance — which were not an issue with earlier drugs.

ACON confirmed at the launch of the booklet that it was produced with funding from several drug companies. However, ACON has a policy that sponsorship dollars will only be accepted if there are no strings attached — that is, there is an agreement that sponsors cannot influence content.

Jill Sergeant, Talkabout Co-ordinator, for the Newsletter Working Group

We welcome your letters. They should ideally be <300 words and may be edited for length. Please include your name and phone number or address and send them to:



Talkabout, PO Box 831

Darlinghurst 2010

Olga's Personals

Sydney Can we talk? Visit gay bars, clubs, sex venues! Happy-go-lucky guy, broadminded, healthy, mentally together, in control of status, professional, likes usual fun stuff, good company, good conversation. Seek guy(s) 18 yrs up to 39, enjoys casual sex, takes it seriously, view friendship based on communication, support, caring interest. Straight, bisexual, gay or transgender welcome. Discreet Ala 970405

How to respond to an advertisement:

- Write your response letter and seal it in an envelope with a 45c stamp on it.
- Write the box no in pencil on the outside.
- Place this envelope in a separate envelope and send it to: Olga's personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on. *To protect your confidentiality, make sure the envelope is clearly marked Olga's Personals.*

How to place your advertisement:

- Write an ad of up to 40 words and be totally honest about what you are after.
- Claims of HIV negativity cannot be made as it is not possible to verify such claims, however, claims of HIV positivity are welcomed and encouraged.
- It is OK to mention that you are straight, bisexual, gay or transgender.
- Any ad that refers to illegal activity or is racist or sexist will not be published.
- Send the ad to Olga, and be sure to include your name and address so that responses can be forwarded on to you. This information is not published and is kept confidentially by Olga.

A Darlinghurst miracle

Just over a year ago, Sherman thought his next destination would be the Botany crematorium. Now he's working, bonking, and saving for a trip to Europe. Sound familiar?

I UNPACKED SOME OF MY PHOTOS the other day, stuck them up on the wall. They had been in boxes for ten months. I hadn't wanted to unpack them and then have to repack them.

The last two years had been a process of whittling everything down. First the emotional stuff of getting all those unresolved 'you're going to die' issues sorted out, setting up support networks for the family, getting people prepared for my sudden departure. If I had to do it again, I wouldn't. So I unpacked the history and wondered why I hadn't done it earlier — too messy, not tidy enough.

I started the ritonavir the week before Easter '96. The turnaround was extraordinary, by Good Friday I felt I had staged my own resurrection. I had been very sick in the weeks before Mardi Gras. My sight was going, the fatigue was a constant source of joy to me and what I thought would finally kill me was the tedium of the whole process. I had kept going in the previous year through a combination of B12 shots, acupuncture and a large super pay-out, all of which had either run out or were failing me.

The first thing that returned was my sense of humour, which my friends — who had been humouring me for too long — rejoiced at. Still, it's hard to feel

too confident about miracles, so I returned to that great retirement village in the south, Adelaide, determined to consolidate my recovery in spite of my pessimism about the longevity of this turn of events.

Lots of gym, the company of old friends, good food and a lack of any night life saw me gain 12kg and an intense desire to return to Sydney. I started considering study, and even contemplated the idea of staying in Adelaide, but two days before I was due to come back I realised the stupidity of the

in my appearance. A little part of me understood, but I was annoyed at the lack of discretion or perhaps honesty about my former appearance. But hey, I had done exactly the same.

So, the big project to go OS. The 3TC and d4T had been added just before my return and the saquinavir on my arrival back. I started back at the gym and bumped into an old manager, who asked me to work for him in that pre-Christmas frenzy that characterises the hospitality industry.

Work was fun for I'd say four weeks, mixing with people other than health professionals or alternative therapists. Exciting yes, but a little perplexing, all these people who knew nothing of my recent life/death experience or throwing off of the shroud. The fitting in of the drug regimen and an expectation of unconditional devotion to employment. Well at least in the hospitality industry the last is a rarity.

Fortunately, the DSS were very helpful. An earning threshold before the pension was affected, a \$300 a week back to the workforce subsidy and a seeming complacency about how much money I was earning, even after I went out of my way to make it clear to them (I know it will end in tears or at least a tribunal).

The Department of Housing were similarly helpful, but I fear like any honeymoon period in a relationship, they will turn at any second or it will come undone at the end of the financial year.

It wasn't just working, it was like a crash course in life. After not wanting or having sex for at least a year, I wandered into the Phoenix, picked up a boy and well, actually he fell asleep on me. We arranged to meet a few days later.



GRAPHIC: JOHN DOUGLAS

idea. I'd changed too much and little had changed there. There was the trip OS that I had planned for too many years and had never pulled off. So what could I do? The super pay-out had evaporated, time to return to work. It appealed to me, the idea of being normal again (if that was a term you could use to describe living in the Eastern suburbs). Novel and exciting.

I returned September 9. Friends were bowled over by the change

Mindful of what I'd been through, I thought it would be a good idea to make him aware of my status. Not an issue. What can I say, after feeling like the storage compartment of a fridge, and a suspicion that I wouldn't be able to get it up - it was like that proverb about getting back on a bike.

Very curious - pick up a boy on the Thursday, get chatted up on Saturday, meet someone the following Wednesday - dizzying at the least, but I thought I'd just go along for the ride. Suddenly having to tell guys that I couldn't see them because I was seeing someone else.

I'd forgotten love, jealousy, uncertainty. Because if there was one thing I was certain of in those last months before I bit the bullet and started the drugs, it was my approaching death. Easy to tidy up when the future is not an issue. So it's now five months since I've arrived back. I've tried drugs again, got pissed, had sex, fallen in love and been heartbroken. All of which are fairly full on without the additional feature of a disease on hold.

I found setting my own limits hard but necessary. If you're juggling the pension and work, get some good advice. The Federal Government may change

aspects of legislation dealing with HIV/DSP issues. As of March 22, the \$300 work subsidy was no longer available. It is a good idea to keep abreast of these changes. There is a Disability Support Officer attached to each DSS office, who may be helpful when you have to deal with the whole range of issues related to returning to work (see box).

Well, I'm off to Europe - repackaging my drugs and seeing exotic places - take it easy and good luck.

Because these days it seems like all anyone can talk about is either their viral load or what they're going to do with those new T-cells, we plan to run a series of articles over the next few months on the changes that treatment successes have brought about in people's lives - such as returning to the workforce, feeling secure enough to have a baby, resuming your sex life etc. If the combination therapies are not working for you, we'd like to hear from you too. Send your story to Talkabout, PO Box 831 Darlinghurst 2010, or Email: plwhagen@rainbow.net.au. If you'd prefer to be interviewed, call Jill on 9361 6750 or 1 800 245 677 (non-Sydney calls only).

How your pension is affected

IF YOU RETURN TO THE workforce full time (over 30 hours a week), your Disability Support (DSP) payment is suspended for up to two years. You continue to qualify for concessions for 12 months. Within that two year period you can resume the pension if you leave work. All you need is a letter from your employer and you'll be paid on the first payday after you tell the DSS that you've quit.

If you are working on a part time or casual basis, you can earn up to \$98 a fortnight before your pension is affected. If you earn more than that, 50c is deducted from your pension for every dollar you earn. You still qualify for rental subsidy, but the cut off point is higher. You need to keep the DSS informed of changes in your situation. If you work irregular hours - like five hours one week and fifteen the next - you can notify the DSS with each change or average it out over a longer period.

The Disability Support Officer (DSO) is available at all DSS offices to give advice about medical and disability issues and help people return to work. The DSO can arrange access to a range of programs including work rehabilitation, further education, vocational training and specialised job search. The DSO will also make sure that you are fully informed about all your entitlements.

An opportunity to explore your relationship with your partner, HIV & a group of people with similarities & differences

*6 Weeks from
Thurs May 22 -
Thurs June 26
6.30pm - 8.30pm
Free!*



COUPLES

*An experimental group for
GAY, LESBIAN & HETEROSEXUAL
COUPLES*

*Where one or both partners are
HIV Positive.*

*Contact: Sharon on 9206 2000
or Alex on 9206 2018
Before May 15th*



*Can Gays, Lesbians
& Heterosexuals
really work
together in
a group?
I believe we can!*

*Facilitated by
Sharon Snir an
experienced counsellor
& psychotherapist
who has been in
relationship with her
partner for 16 years
and acknowledges
that relationships
are sometimes hard
work sometimes not
such hard work*

Back to work

So you left work due to HIV illness? But times have changed and you're thinking about getting back into the workforce. Where do you start? Guy Taylor offers some suggestions.

IF YOU'RE TAKING A NEW LOOK AT your employment prospects after several years of retirement, you're likely to find that your previous occupation is no longer relevant to you, or you might have been left behind by changes in the workplace. Like many others, you may be seeking part time, casual or project work rather than a full time job. Going back to the workforce means you'll have to juggle a number of obstacles such as disclosure, taking drugs in the work place and time management of your HIV life and work life.

Unfortunately the labour market generally is not interested in your problems. Employers need people to perform and produce the goods. Education and training are the keys to empowering individuals in preparation for the workplace of the 1997.

I'll be looking at some of these issues in future editions of *Talkabout*, but I'm starting with the most basic: getting the job.

Getting an interview

In a very competitive labour market you need to make it as easy as possible for the employers to identify you as a potential employee and match you with a specific vacancy.

A cover letter and chronological or skills-based resume addressing the vacancy is the best option when you don't wish to highlight your absence from the work force. This type of resume will help focus on your achievements rather than a gap in your resume. Your resume should attempt to present

you as an interesting and capable person, so you must impress the reader with your background by giving facts, not making general statements. I've given examples of a cover letter and a resume that you may find helpful.

You should prepare ahead of time in case the employer notices that you've been out of the workforce for a while and wants to know why. Have a chat to us at the HIV Living Project or speak to a counsellor about how you might handle awkward questions.



Handling the interview

As a former Employment Officer, the question I've been most asked by most clients is: "I have had interviews but haven't been successful in getting the job. Why is that?"

My answer to that question is to suggest you try looking at things from an employer's perspective, then ask yourself if you're meeting the employer's expectations. At

interviews, employers generally want the answers to five questions:

1. Does the potential candidate have the skills and experience to do the work?

2. Will I be able to manage this person?

3. Does this person possess the right attitude?

4. In terms of professionalism and personality, is this person a team member?

5. Does this person have the right image for our business/organisation?

Competence

Competence is fairly straightforward. Think about the skills and experience you possess and relate them to specific requirements of the job. Try to think of circumstances or anecdotes that will demonstrate your competence in particular areas. Try to think about your skills in the context of the industry in which you are to be employed. If you can demonstrate applied skill together with industry knowledge, then you will be further ahead than if you try to sell yourself on the basis of technical competence alone.

Management

Can you be managed? All managers can think of occasions when they have had people working for them who have refused to take direction or do what was asked of them. Given a choice, a manager prefers to have an employee who is prepared to take direction, even if it is not carefully and considerately given. If you give the impression that you can be 'difficult', then it may stop you proceeding to the next phase. If you are a team member and you get on well with others, and you are happy to do what ever is asked of you, make sure you demonstrate it during the interview.

Attitude

A good attitude is the characteristic of being willing and prepared to pitch in and do any task as long as it is good for you or the company. If you are asked during the interview whether you will be prepared to pitch in to a project so that that they can finalise it, don't ask if it is going to be part of the job description. A manager with temporary crisis to deal with doesn't want an argument but someone who is prepared to pitch in.

Questions such as this at interview are designed to establish whether you are the kind of person who is prepared to do what it takes to help the team. Are you prepared to do that little bit extra? Make sure you can relate such an experience from your career.

Fitting in

Do you fit in? At interviews, managers often look for candidates who are going to fit in with the rest of the team. If they perceive you as being less professional than the rest of the team, then it will obviously go against you. If a manager has an aggressive and competitive team and you are a little cranked back and easy going, the interviewer may focus on another person. It's ambiguous, because if a manager thinks you are 'too good' compared with the rest of the team, then that may go against you as well because you may be perceived as having an unsettling effect.

However, this is a very grey area. Your interview may be with someone who has a complacent team who wants a good operator to come in and shake them all up a bit. You have little control or influence in this area, all you can do is be yourself.

Image

Finally, dressing for success. Image is important to employers so make sure that your attire is the expected. In researching your prospective employers it's good to get a look at the location and what

Sample: Cover Letter

Your Address
(SUBURB AND STATE IN CAPITALS)

Your telephone number

Date

Name of person you are sending this letter to
(if you know) **their title** (usually you will just write to the Personnel Manager)

Company or business name

Their address (SUBURB AND STATE IN CAPITALS)
Dear Sir/Madam

FIRST PARAGRAPH: Introduce yourself and state why you are sending this letter (i.e. to seek a position with your company).

MIDDLE PARAGRAPH: Briefly explain your background (skills, experience, qualifications, training and personal characteristics relevant to the job) and what you are looking for. Promote yourself and convince the Personnel Manager that you are worth considering as an employee. Refer to your enclosed resume and references.

LAST PARAGRAPH: Request the opportunity to speak with the Personnel Manager at an interview at their convenience. (e.g. Should you require any further information please don't hesitate to contact me. I look forward to your careful consideration of this application and await your earliest reply.
Yours faithfully (or sincerely)

Your signature
YOUR NAME PRINTED

Sample: Resume

PERSONAL PROFILE

List personal particulars: Name, address, telephone number, date of birth (optional), current driver's licence if applicable.

PROFESSIONAL OBJECTIVE

Outline your career objective beneath your name. Many find this the hardest section to write. You may need to attempt it several times before you're satisfied.

E.g. My career objective is to obtain a challenging and responsible position which utilises my expertise in public relations. My particular skill would benefit ...

ADDITIONAL TRAINING

This section should be devoted to your accomplishments; eg: Train the Trainer - give training provider's name
Customer Service Training - give training provider's name

EMPLOYMENT HISTORY

Employer: Department of Public Relations

Position: Training Officer

Duties: Emphasise how well you perform your tasks. Avoid going into excessive detail if the duties don't relate to the position you are applying for.

Your resume should be divided into sections. Often applicants don't give these section headings much thought, yet they are a really good way of making your resume stand out from others. Use interesting headings, put the heading in capital letters, underline it, or centre it above the section to make it more interesting.

other people are wearing and what seems to be acceptable. Or drop in to a competitor's workplace for an overall industry image check. Remember, first impressions do count.

HIV Living and the Sydney PWA Living Centre has a computer which you can use to write and lay out your application and resume, or contact your local CES for assistance.

As returning to the workforce becomes increasingly relevant for plwha, regional plwha groups and ACON Branches are looking into ways to assist people. Give your local organisation a call to find out what they're up to. Good luck with the job hunting.

Guy Taylor is HIV Support Officer at ACON Sydney

Positively Working

You've combined those treatments, complemented all the right things and now you feel better than you have in years - but what now?

One of the most complex issues plwha are facing at the moment is how to return to the workforce. After any period of unemployment the why's, what's and how's are always tough to negotiate. For plwha, these issues may be further complicated by matters such as disclosure of status, fluctuating conditions and the need for a supportive working environment that is responsive to your unique needs.

The good news is, a working party to address this issue has been started in Sydney. Initiated by Alternative Networks (a community-based employment agency) and the PRIDE HIV/AIDS Community Development Project the working party includes representatives from PLWH/A (NSW), ACON, Redfern Skill, Epping Skill share, Sydney PWA Living Centre, Sydney Sexual Health Service and several Area Health Services.

One of the group's first major activity will be to hold a series of forums aimed at ensuring that the direction of the working party reflects the needs of the community. These will be held at a number of venues throughout April and will offer people the opportunity to contribute to the development of a useful and

much needed service which will be responsive to the particular requirements of PLWHA. The forums will also provide some basic information about successfully negotiating a return to the workforce. In tandem with this, efforts are underway to investigate training, funding and employment opportunities for PLWHA that will accommodate a variety of lifestyle choices, skill backgrounds and individual concerns.

Bronte Morris, Executive Officer of PRIDE, recently highlighted the significance of the endeavours of the working party. "The opportunity for PLWHA to participate in the workforce in a capacity they are comfortable with can only further develop their overall wellbeing and self esteem. the collaborative efforts of this working party indicate a strong commitment amongst a diversity of organisations to ensure that all plwha have the chance to improve their quality of life".

For more information call me on 9331 1333 and keep an eye open for dates of the upcoming forums.

- Julie Brown, PRIDE HIV/AIDS Community Development Worker, Steven Emerton, Alternative Networks, Senior Case Manager

Poetry (etc)



Still here!

Do you know the tune that Shirley MacLaine sang in 'Postcards from the Edge'? It's a song by Stephen Sondheim and David Jobling rewrote it to sing at the PRIDE treatments forums last year. It goes like this:

"Good times and bum times,
I've seen them all and my dear -
I'm still here!
Plush velvet sometimes,
Sometimes just Cheezels and beer
- but I'm here!
I stuffed myself with Chinese herbs,
Then wretched and heaved and
had to purge.
So much for herbal treatments.
Never fear,
I started chemical warfare - and
I'm here!

Now it's "take nine twice daily
after each meal"
Gee this is fun and a half.
Negotiate "take nine twice daily
after each meal"
(I rattle when I la,ugh),
ddI, nausea, AZT, headaches and
yet - I'm still here. d4T, 3TC,
Nizoral, Saquinavir - and I'm
here.

Wake up each day and take my
dose,
Then hit the street and adios!
I'm gonna chase those grey clouds
outta here.
I'm finding joy in living and I'm
here.
Look who's here
I'm still - here!

IT'S YOUR LIFE

"...how could anybody so handsome, so sweet, so sincere, so innocent, so sensitive, so gentle, so caring be positive... But I am."

No matter how good a judge you think you are, you can never tell a person's HIV status from their appearance, profession, age, or whether or not they own a condom.

TAKE CHARGE

**MEN
LIKE
US**

PHONE ACON on 9206 2000 or FREECALL 1 800 063 060 or TTY 283 2088

ACON
AIDS Council of New South Wales Inc.

Your future is back?

By Erycka Fars

FEAR OF SICKNESS IS A COMMON factor in our positive brains & hearts. We want to think 'safe future', to feel free from HIV. So when we hear "Here is a new drug combination, take it and your future is back", It's tempting to swallow. Mr. Media is such a sinful power (although power with no sin has never been seen).

Anyway, Media knows which string to pull. On the front page their ink spits out bright news "Hope at last, etc . . ."

My friends were so happy, they brought me a newspaper. We nearly 'champagne celebrate'.

Back home my partner wanted me to translate the miraculous article, (his English not being 100% yet). As I was reading the 'news', the light of a forgotten life appeared to me. Could it be possible? Tomorrow I can relearn to make love without feeling dirty. No more rubber reminder. My husband won't be a widower. Now fearless, I can have a baby, no more prospect of sad birth story. With all those new concepts waving at me I burst into tears more heavily than ever, almost as if I was letting go of all the pain I ever kept inside.

So I cried my 'guts out'. Felt good to be empty. Feels bitter cos it is just a lie. Not a complete lie, just a slice of the truth. In the drug field it's the big battle with Star Trek tools. Drug companies don't teletransport themselves yet, but some of their steps toward a cure are big jump for sure. (let's be Positive)

Yippee! PI*. Still, what do I do? PI are so recently born. OK, PI in combination therapy stop the virus replication. So affected cells die and get replaced by clean new

ones, and if you are really good at swallowing your drug regime at the right times, the virus can become undetectable (to make it simple). I have seen the results on sick friends who are full of life again. The choice for asymptomatic people is a difficult one. Taking early treatments makes sense because the less damage is done to the immune system, the easier it is for it to rebuild itself. Looks good on paper, but I feel so healthy with my herbs and positive mind!

I'm happy to see Professors, Doctors who get mad when PLWHA don't accept automatically the latest drug offer, because I'm glad they believe in what they do.

To me the dilemma is beyond trusting or not trusting the new drugs. Where is the mega-problem of an asymptomatic positive person? It's between the ears, in

the head. Sickness is a futuristic concept, not present, not real.

For me HIV is not just a virus it's also a different life philosophy.

As you know, to be declared positive really knocks you down, knocked me down. So on the way back up we develop a different way of taking the 'trip', of living the 'voyage'. Takes time to see life bright again.

The present drug revolution is troubling my mind. And nothing is more important than protecting my happiness, I worked hard on having it by my side. So forgive me if I need bigger proof that PI in CT are good for me.

Right now no-one has the right answer and after all it's my life, my gamble.

* PI: Protease Inhibitors
CT: Combination therapy



GRAPHIC: JOHN DOUGLAS

Why HIV has been good for me

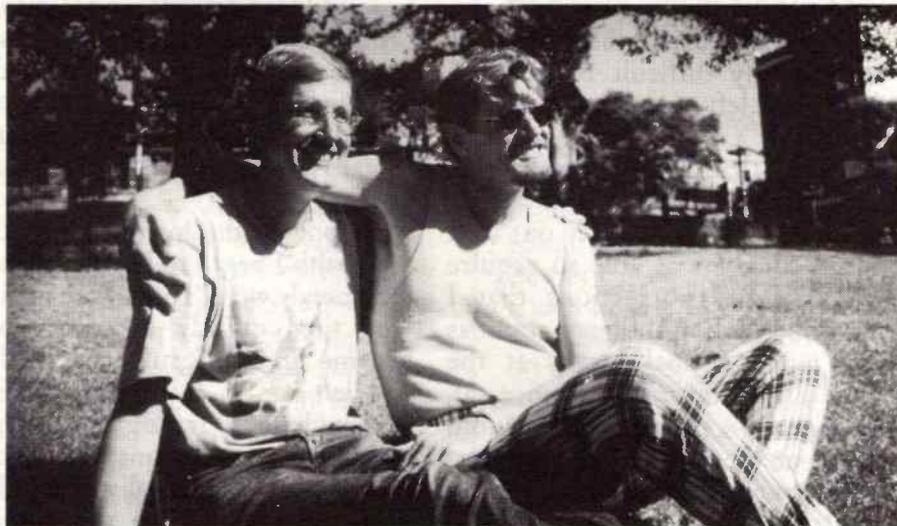
By Ian J Thompson

AS I ENTER MY TWELFTH YEAR OF living with HIV sharing my body and mind, I am overjoyed to see what might be the beginning of the end of this terrible and destructive nightmare. HIV has been the major focus of my psyche for over a quarter of my life and has caused a major change in my behaviour, reason for being and outlook on life.

After becoming seemingly immune to the disruption and grief of losing friends and other loved ones, I recently acknowledged to myself that a new perspective had begun to take hold – a perspective that has been hanging around since the first day of my diagnosis, but one which I have so far managed to keep in the background. I am talking of fear. *Fear!*

You see, although these new treatments are giving wonderful results to many, for me they are not working quite as well as I would like. Sure, I have decreased my viral load significantly and been given more time while the wonderful wizards develop further potions and pills, but most of the talk and action in the community seems to be about those who have achieved zero or negligible viral readings. Much of my fear is that those of us who are either taking time to respond, or not responding at all, will be left behind.

It is very difficult to be amongst a group of people who are celebrating growing health and planning for a return to work or other new and evolving opportunities, and know that one's own prognosis is perhaps not so bright. It seems to me that each time I pick up information or read the press, someone is



Ian (right) with hubby Tim

shouting the joys and happiness of regained health. Don't get me wrong – this is wonderful for those concerned, but I wonder how many people like myself are starting to feel afraid of reading these stories. Often they bring about a sense of 'what about me?', which can lead to serious bouts of depression.

My previous levels of fear as my health ebbed, with the prospect of imminent death, seemed to be a natural part of the course of events the universe had set for me and had never taken control of my mind. I had been a party boy for many years, was single, and didn't believe I had too much to lose anyway. A future was never further away than the next drink, party, or drug-feast and work was never more than a means to keep a roof over my head, some food in my stomach, and pay for my hedonism.

Survival was my main concern and fear was one thing I never allowed myself to dwell on. But then came the new therapies and when I began to compare all the wonderful stories of hope and improvement with my own

situation, I began to sense this creeping feeling of fear that although I had come a long way and pulled through many crises, begun to build a future that could be bright and successful, it could still be all taken away. I realised that fear was gaining the upperhand. I now have much to lose.

I had to delve into myself to understand this fear and put it back into a place where I believe it can do only the minimum of harm. I decided the best way to do this would be to accept what is and fight on with positive thoughts, embrace and enjoy my brothers' and sisters' happiness and relief, and continue to give thanks that against the odds I am still here at all.

I decided to embrace my virus with appreciation rather than contempt and foreboding and began to look for ways in which my HIV status had enhanced my life. I was astonished by how much I had to celebrate.

The first and most obvious is that I still awake each day to see a new dawn, something which I once took for granted. Now the miracle of life is sacred to me and rarely a day goes by when I do not

stop and give thoughts of thanks to whoever or whatever has spared me thus far in this long and black journey. I have evolved in a spiritual way that probably never would have happened otherwise.

I was able to withdraw my superannuation funds at a relatively young age as a lump sum. It seems that this is increasingly difficult to do. If I had been left to take the natural course of a worker it now seems unlikely that I would ever have received much pension at all, let alone be able to take it out as a lump sum. I was able to acquire the material possessions that I never needed or bothered about as the party animal I was at the time of my diagnosis. A nice car, furniture – things that would make me comfortable for the rest of what I believed would be a short life.

Having always been someone who never particularly enjoyed the routine of going off to work and having my time so strictly controlled by someone else, HIV retirement suddenly freed me from that grind. My time was my own and I have been able to explore creative interests and hobbies to my heart's content.

I had the option to travel and see the places and experience the cultures that had always interested me at a leisurely pace. Although

I never chose this option as my health did not allow it, knowing I had it added to my sense of freedom.

My involvement in AIDS organisations gave me a sense of helping not only myself but others also. I met people who have become dear friends and I have received an insight into those wonderful people, young and old, who give so much time and love to ease our conditions and help us towards continuing meaningful lives.

At one of the lowest points of my health I began to learn who my real friends were. There were many who tired quickly of seeing me become ill, thin, gaunt and needy and left me to my own devices. Although this hurt me greatly at the time, had my circumstances not changed so dramatically I would probably still believe that these people were friends who cared for and loved me.

New people came into my life – people who were concerned and did care for me, as well as people who were in a similar situation to myself, who I could identify with and discuss things with. Strong people like myself, who were not going to give in and who I could share the battle with.

Because of our need to maintain high calorie and fat levels in our diets I have been able to enjoy the

foods that most people must shun. I adore pastries and cream cakes and to regain my weight after I reached the low 60kg (my usual is 80kg), I was able to guiltlessly pig out.

If not for my HIV infection I doubt I would have met the wonderful man who has become my adored and adoring husband. It would be no exaggeration to say that without him I would have been dead by now. He rekindled my interest in life when I was very low, both mentally and physically, and in the two years we have been together my life has changed completely.

The new treatments, taking their time to work properly, have added strength and weight to me, and living in a secure and loving situation gives me optimism that there just may be a future after all.

If the virus was to take me tomorrow or next week I have learnt much and developed in a way that never would have happened without it. I believe I am a much richer and caring human being for the experience, I have grown spiritually and there is very little that I believe can frighten me. Should I survive, I will work to help this world become a much better and tolerant place. I know what I want and where I would like to go. Yes, I do believe AIDS has been good for me.

Help Us To Help You

The Complementary Therapies Working Group of PLWH/A (NSW) is setting up a directory of complementary therapies practitioners in NSW who have experience with HIV/AIDS.

We need your help to do this

If you are a complementary therapist, or want to recommend one, let us know. We need to know: the particular speciality of the therapist, their geographical location, contact number, and their experience and willingness to work with people with HIV.

Any area of complementary or natural health care for people with HIV/AIDS is appropriate for this directory.



Contact Jo Watson the Research Officer at PLWH/A NSW.
Phone: 9361 6011 Free call: 1800 245 677, Fax: 9360 3504
Email: plwha@rainbow.net.au

NO discrimination

Returning to the workforce may mean that you're exposing yourself to discrimination in a new area of your life. You don't have to take it. Mei Tan outlines what you can do about it.

What is discrimination?

In NSW, the Anti-Discrimination Act 1977 makes it unlawful for people to discriminate on the basis of race, sex, marital status, homosexuality and physical and intellectual impairment in the following areas: employment, education, accommodation, and the provision of goods and services.

People living with HIV/AIDS are covered by the disability provisions of the Act. You are also protected by the Act if someone thinks that you are homosexual and assumes you have HIV/AIDS. In this case, you would be protected by the Act even if you are HIV negative, so long as the basis of discrimination is that you are believed to have HIV/AIDS.

You are discriminated against if a person treats you differently and less favourably because they think you have HIV/AIDS. If a person treats people associated with you (such as relatives or your partner) less favourably, that is discrimination too.

Discrimination also arises if a person requires you (or your relative/friends) to comply with a requirement or condition which they don't impose on people who do not have HIV/AIDS (or their associates). The requirement or condition may be one that you are unable to comply with or one that is unreasonable under the circumstances.

The Act allows discrimination where it is necessary to comply with a requirement of another law, orders made by courts and

tribunals or under the terms of an industrial agreement.

Voluntary bodies, establishments that provide housing and ancillary services for the aged, and charities, are not bound by the Act. Religious bodies may also claim exemption from the Act.

A person accused of discriminating against you may argue that their act is lawful if they can show that they will suffer unjustifiable hardship if they do not discriminate. For example, an employer who sacks an HIV positive employee may try to argue that to keep employing the person would cause unjustifiable hardship to his/her business.



GRAPHIC: JIM CHAN

What you can do

If you feel you have been discriminated against, you can make a written complaint to the Anti-Discrimination Board (ADB) within six months of the date on which the act of discrimination took place. If you are late, you will have to show good reasons why before the Board will agree to look into the matter.

It is always advisable to seek legal advice before lodging a complaint under the Act as there may be other avenues and remedies available which are more appropriate to your situation and will get better results (e.g. the Health Care Complaints Commission, see page 30). You

Here are some examples of cases which HALC has handled for clients at the ADB.

● X went to a travel agent with a child to book a holiday. When arranging travel insurance, X was asked whether she had any ailment or pre-existing illness to disclose. X refused to answer the question and on this basis, X's child was refused travel insurance too. X obtained an apology from the insurance company who in turn claimed that their staff had not been trained properly and admitted mishandling the matter. They would change their policy and ensure that this did not happen again.

● P went to see the doctor at a health centre to get a blood test done to check the level of his T cells. P told the doctor he was HIV positive. The doctor refused to take blood samples for a pathology company to do the test and refused to see P again. P made a complaint to the ADB and the matter was settled to P's satisfaction before a hearing.

● Y took driving lessons. When Y's instructor found out from Y that she was HIV positive, the instructor refused to continue teaching Y. Y has filed a complaint with the ADB which settled at the conciliation stage.

● G was sacked when he told his employer that he was HIV positive. After a complaint to the ADB, G was awarded damages when the employer could not show that to continue to employ G would cause unjustifiable hardship to his business.

can ask for assistance from the HIV/AIDS Legal Centre (HALC) at ACON, or at a community legal centre [see *Contacts*]. HALC operates Monday night legal advice sessions for people who have legal problems due to their HIV status. Please call 9206 2060 to make an appointment.

If the matter can be resolved by mediation (discussion), a conciliation conference will be arranged. The people concerned sit down with an officer from the ADB and try to resolve the matter, usually without lawyers.

If this process is not successful the President of the ADB must refer the matter to the Equal Opportunity Tribunal, who may conduct a hearing. During hearings, the Tribunal has the power to summon witnesses to appear before the inquiry and to produce documents and give evidence, just like in court. Those involved in the inquiry and their lawyers may call witnesses, cross examine witness and make submissions.

The solution

The Tribunal may make orders for the discriminator to pay damages of up to \$40,000 to compensate you for loss or damage, including non-monetary losses such as stress, humiliation and loss of self esteem. It may also make an order to prevent the discriminator from acting unlawfully, or requiring them to redress any loss (e.g. by reinstating an employee).

The Tribunal may also decide to dismiss the complaint. It is an offence to fail to comply with an order by the Tribunal. The maximum fine for this is \$1,000. If you are not satisfied with the Tribunal's decision you may appeal to the Supreme Court, but on very limited grounds.

Mei Tan is a volunteer solicitor at the HIV/AIDS legal centre in Sydney

Art Works are being sought from HIV Positive People, their friends & carers for the exhibition

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The AIDS Council of NSW (ACON) is a community-based organisation providing a diverse range of services for people living with HIV/AIDS and affected by HIV/AIDS. ACON services include preventative education programs, support, legal and advocacy services. ACON is an equal opportunity employer and encourages people with HIV to apply for positions.

HIV Positive Community Development & Education Officer - Western Sydney Branch

We are seeking a suitably skilled HIV Community Development Worker to work as a member of the ACON Western Sydney Branch. This is a new project for ACON Western Sydney. The Officer will develop, implement, and evaluate relevant support & education services for HIV positive people in Western Sydney/Blue Mountains. This will be done through a needs analysis and on-going consultation with HIV affected people, to identify the issues of most concern to them. As a result of this consultation and liaison the Officer will develop appropriate strategies and deliver relevant programs. If appropriate the Officer will also be responsible for the initiation and development of peer support programs. The Officer will liaise closely with the Western Sydney Education Team & CSN Western Sydney/Blue Mountains. It is essential that you have experience in conducting community needs analysis or similar research/consultation; an understanding of current care & support issues for plwha; skills & knowledge of adult peer education; excellent oral & written communications skills; computer skills; a current NSW drivers license. Under ACON's HIV employment policy preference will be given to a person with HIV.

Salary Range \$33,548 - \$34,607 per annum
Closing date: 11 April 1997

Essential criteria for the above position includes a desire to work with and a sensitivity towards people living with HIV/AIDS. A duty statement, terms and conditions of employment and selection criteria must be obtained before applying. Please telephone reception on 9206 2000 after 1pm Monday-Friday. ACON is located at 9 Commonwealth Street Surry Hills. No agencies please. ACON has a policy of non-smoking in the workplace.

Partners of HIV Positive Men

New groups are running for HIV negative gay men who are in relationships with positive gay men. The groups provide a place to talk about your relationship as well as a range of other issues. Each group decides what they want to talk about. The groups normally run over 6-8 weeks

To find out more call:
Greg 9206 2076

OTHER CONTACT DETAILS

Switchboard: 9206 2000 • TTY (for deaf): 9283 2088
Free call: 1800-063-060
Hunter: 049 293 464 • Illawarra 042 261 163
Northern Rivers: 088 221 555



BMB470ACON7A

Haemophilia – The HIV connection

*What is Haemophilia?
What's it like to have HIV
and haemophilia? Luke
Chipperfield thought it was
time to answer the questions
that he's often been asked.*

I WAS BORN WITH HAEMOPHILIA, which is a rare blood disorder I was diagnosed as having at 13 months. I'm 19 years old and I have been HIV positive for around 14-15 years.

Last year I became a speaker with the Positive Speaker's Bureau (PSB). It only became apparent to me through being a speaker how little people know of the true impact of the HIV epidemic. Most I've spoken to still believe HIV is and has always been a disease you can only get if you're gay or participate in activities such as injecting drugs. I realised this at a very early stage and have set out to make people realise it is a disease that no-one is exempt from.

When I was finishing school I had people approaching me asking if I had AIDS, not because I looked sick or because they thought I was gay or a drug user, but because someone had started a ripple effect. It was no time till the biggest gossip-bags in the school had hold of it. They all knew I had haemophilia but never made the connection to AIDS. They were too ignorant to ask why.

The connection between HIV and haemophilia is as old as the epidemic itself. Haemophilia affects approximately 1 in 20,000 males. It is a disease that you are born with, inherited from the mother (who carries the genes). A rare haemophilia can affect females. The disease is not contagious. It causes serious, uncontrollable bleeding, usually within joints and muscles. The

bleeding episodes are quite painful, can go on for long periods of time, and can cause long term damage.

A person with haemophilia is missing a blood clotting agent called either factor 8 or 9, which would normally stop internal bleeding. The most common forms of Haemophilia are Haemophilia A – people like me who are missing factor 8; Haemophilia B (Christmas Disease) – people who are missing factor 9; and Von Villenbrands Disease which is a different factor again. The treatments for this disease have varied over the years but are all based on blood – that's the connection to HIV.



GRAPHIC: JOHN DOUGLAS

Initially there were no treatments for haemophilia so people would suffer and become crippled or even die. When treatments did come along the bleeding would still be painful but could be stopped more swiftly. Initially whole blood was given to patients, which was only mildly effective. Then came whole plasma, which was a little more helpful. In the 1970s a new product called cryoprecipitate came out, which

was a more concentrated plasma derivative. It was good but took hours to administer – by the time it took effect joint and muscle damage had already occurred.

It wasn't until the end of the '70s when a product called Anti-Haemophilia Factor (AHF) came out that people's sufferings were eased, but this was the product that would bring us down. AHF was a concentrate of the clotting factor haemophiliacs didn't have. It could be administered personally in less than 20 minutes and it meant that finally all haemophiliacs could live an almost normal life.

AHF was made from the blood of thousands of donors. When HIV hit, many haemophiliacs were infected Australia wide. The irony is that the blood bank and other government organisations said there was no risk of getting HIV from their products. This meant that instead of having us resort to an older, safer product, we were unknowingly injecting ourselves with HIV.

So it was as easy as that. Negligence was wide spread and as it happened, similar all over the world. Many haemophiliacs have died – husbands, fathers, sons and friends whom I had a lot of contact with and looked up to. It will always be hard for me to accept the unnecessary loss, but I just live day to day and try not to dwell on the past.

My parents informed me that I was HIV positive in 1986, four years after becoming positive and just months after my diagnosis. When I was told it pretty much rolled off my back, being a kid helped.

It was worrying to think what had happened to other haemophiliacs around the world. Many had been forced from

schools, towns and even countries. I think it was because of this that my parents told me to keep it a secret and I did for many years.

At primary school only the principal knew I was positive. there were no problems so it wasn't necessary to tell anybody else. At this stage haemophilia was more of a problem than it seemed HIV could ever be. At high school it was the same, only the principal knew until about year nine when I frequently began to miss school, mainly due to fatigue. My teachers were informed of my condition and were very supportive. Still, only close family and friends knew I was positive.

It wasn't until my final year that I disclosed to all my friends. I was 17 years old. I had frequently been missing school and my friends knew I had been receiving blood products for a long time but they never made the connection. they were all so cool about HIV, I

realised then how good my friends were – they are my best mates.

After that HIV wasn't a problem, I didn't really care who found out. Just a few weeks before the end of school I was approached by a girl asking if I had AIDS and I was going to die. I replied "yes I'm HIV positive and no, I'm not going to die".

I know of and have met many haemophiliacs with HIV from around the world who are all still kicking after all these years. Only recently through the Internet and a chance Email I met another haemophiliac with HIV who lives in the USA. His name is Shawn Decker and like me, he's been HIV positive for 14-15 years Shawn has had a very interesting life which only seemed to get better when he launched his web site called "My Pet Virus" early in 1996.

I've been contacting him since about September and have found him to be quite a cyber-pal. We're talking about meeting up some

day soon. [Shawn was also interviewed in *Poz*, December issue, which featured several articles by HIV positive haemophiliacs].

Shawn has recently received a grant to produce a CD compiling works by HIV positive musicians. He aims to have it played on as many radio stations as possible next World AIDS Day. Anyone interested should forward original works by May to : The Daniel Murphy Project, PO BOX 2094, Waynesboro, VA 22980, USA

Anyone interested in checking out Shawn's excellent web page or just wanting to get a taste of his humour contact him at: <http://www.cfw.com/~sdecker>.

If you are really into the cyber world check out my latest creation, Rebel Without a Cure:<http://www.geocities.com/hotsprings/4218>.

I hope that this article has answered some of your questions, but feel free to contact me anytime!

Vitamin A Cream for Kaposi's Sarcoma

- ◆ Taylor Square Private Clinic is studying an investigational vitamin A derivative (cisretinoic acid) as treatment for Kaposi's sarcoma (KS) skin lesions.
- ◆ Early published work has shown a response in 30% of people with KS, reducing the size and number of skin lesions without causing the side effects of chemotherapy or radiotherapy commonly used.
- ◆ Treatment is with active cream or a placebo for 12 weeks. Everyone then receives the active treatment (or earlier if the lesions enlarge).
- ◆ Clinic visits are every four weeks and payment is made to cover your incidental costs.
- ◆ For further information contact Margaret Slade RN or Neil Bodsworth at Taylor Square Private Clinic at Darlinghurst on 9331 6151.

Health care in crisis

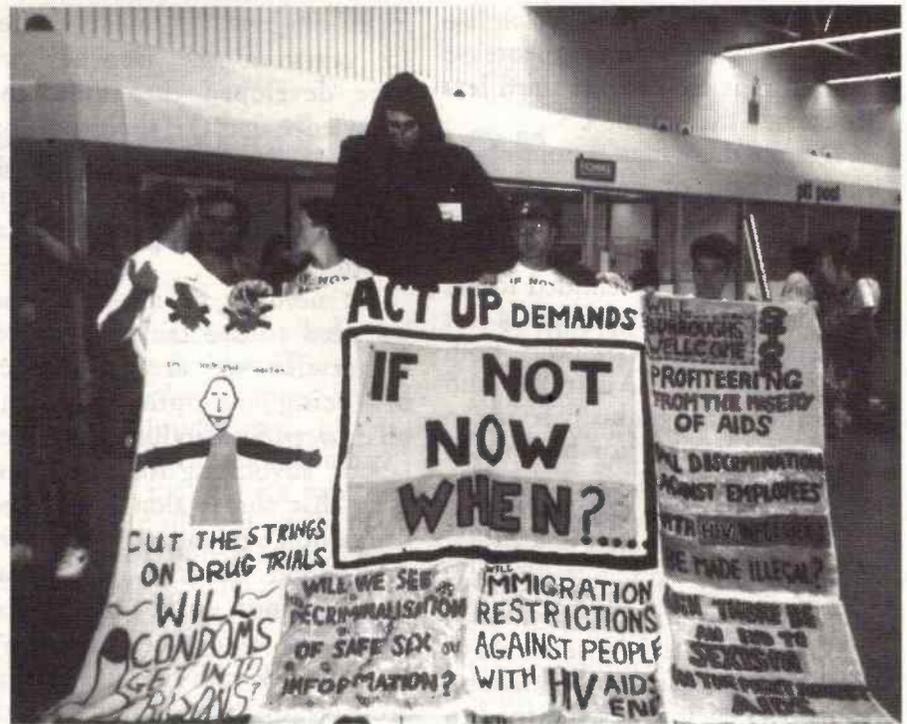
At the national conference for people living with HIV/AIDS last November, Craig McLure, Treatment Service Co-ordinator at Community AIDS Treatment Information Exchange in Toronto, Canada, issued a challenge to treatments activists in his keynote address. This is a slightly edited copy of his speech.

TO MY KNOWLEDGE, THERE HAS never before been a community movement so powerful that has been centred around a health care issue. In my opinion, the HIV/AIDS movement is at a cross roads. As newer and more sophisticated drugs become available to treat HIV disease, and people continue to live longer and live healthier, the HIV movement can settle into being a lobby group for access to treatments, or broaden its agenda and lead an emerging social movement centred on health care and social justice.

Health care is in crisis all over the world. In the developing world, it is virtually non-existent. In the developed world, health care is dominated by and dependent on pharmaceuticals and technology.

This dependency has put enormous financial pressure on governments who have traditionally provided universal health care, such as Canada and Australia, whilst at the same time enabled pharmaceutical companies to amass huge profits. Last year alone the pharmaceutical industry as a whole increased its profits by 50%. It is now the single largest legal industry in the world.

As HIV treatment activists we have often looked to the United States as a model for successful advocacy. The US now has an accelerated approval process for



Amsterdam, 1992. At the 8th International Conference on HIV/AIDS, ACT UP had a broad political agenda. Is this in danger of being forgotten, as activists in the developed world focus on their own immediate interests?

drug licensing and an extensive network of clinical trials and basic science research in HIV disease. But we often fail to look at the big picture.

In reality, the US is a particularly sad and demoralising place to be sick in. Drugs are more expensive than anywhere in the world. Health care ranges from superb for those with unlimited funds to virtually non-existent for the poorest and most vulnerable in society. The pharmaceutical industry increasingly owns and administers health care in the US through health maintenance organisations (or HMOs) and pharmacy management organisations. The bottom line for health care in the US is profit. That means that [those who] bring in the least profit . . . are allotted the cheapest and worst health care.

At the recent International conference on Antimicrobial and Chemotherapy Agent sin New Orleans, a paper was presented comparing people with HIV/AIDS

who received their health care through a fee-for-service system (the way we all receive health care in Canada and Australia, and some people in the US) versus a managed care system (the HMOs). 1,000 men with HIV/AIDS were followed for five years. Of the men who had AIDS at the time they entered the study or who developed AIDS while in the study, the average survival time under managed care was 17 months. The equivalent average for men in the traditional fee-for-service system was 30 months — an increase in survival time of 60%.

Other statistics are noteworthy — while the aim of managed care is to be cost effective, the cost per capita of health care in the US is one third higher than in Canada. Also, because we have universal health care systems, and therefore our governments are buying drugs and diagnostic tests in huge volume, they cost less. British

Columbia and Ontario, the two provinces in Canada that cover viral load testing for all HIV positive people, pay \$100 US for each viral load test. In the US the figure is over \$200. The wholesale cost of the three protease inhibitors is almost one third less in Canada than in the US.

Despite these figures pointing in the direction of saving universal health care – and I haven't really got into the political argument that everyone *should* be entitled to the same level of care, regardless of cost efficiency – our governments, both in Canada and Australia, and [elsewhere], are gradually trying to shift responsibility for health care to the market place, much the same as has happened in the US.

As AIDS activists, positive and negative alike, it is our responsibility to ensure that all people with HIV disease have quality health care, not to mention roofs over their heads and food to put into their mouths. No drug is as effective at preventing the

progression of HIV disease as good housing and nutrition.

I believe we need to focus our attention on the broader picture of health care, rather than a limited focus on new treatments. After 15 years in the trenches we have developed the skills, the knowledge and the sophistication to mount a calculated campaign with our governments and our communities to preserve universal health care.

We need to be informed and we need to see the big picture. Otherwise we are in danger of being co-opted by the pharmaceutical industry as free labour, advocating for every new drug that comes along. We need drugs, don't get me wrong, but we need good drugs – drugs that don't diminish quality of life, that don't cost a fortune, that don't make us sick with side effects, that are easy to take, and that work over the long haul. But above all we need quality health care that is

not dependent on how much money we have.

We might begin by campaigning for our governments to institute a tax on the pharmaceutical industry, the revenues from which would go towards health care. In exchange, companies could be guaranteed longer patents on their drugs and be ensured of a secure marketplace. We might even be more creative and campaign that a percentage of that tax go towards basic health care in the developing world.

I hope that with the advent of combination therapies and the even newer and better drugs coming down the pipeline in the next few years that our movement begins to address these issues. I also hope that as people live longer and healthier with this disease that HIV positive and HIV negative women and men begin to work more closely together, to build a renewed community that maintains and strengthens its political will to fight together for social justice.

**What is it with gay men and relationships?
How can we make them work?**

Performance Positive is a space where performers can provide some answers to these questions from their personal cutting edge. It's also a chance for you to be an instant critic and feedback your thoughts.

So come along to YOUR community center for some entertainment that'll make you and your friends think!!

Performance Positive IV

★ APRIL 25 + 26, 1997 ★

@ PRIDE Centre, 26 Hutchinson St, Surry Hills. 7.30pm-10.30pm

Watch the gay & Lesbian press for details of performers

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PRIDE gratefully acknowledges the assistance of the NSW Health Department

This event will be videoed for archival purposes

R E L A T I O N S H I P S

Gloria's Food



Healthy drinking

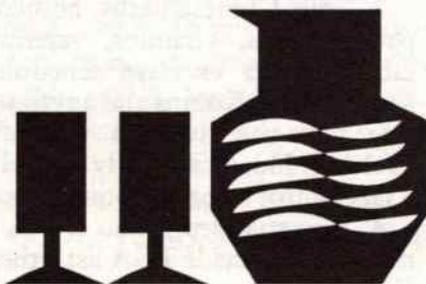
By Ian J Thompson

I DRINK A LOT OF THE REHYDRATION mixture that is recommended to us. This mixture contains a lot of salt and as I have also contracted Addison's disease because of my severely compromised immune system, I have to take high quantities of salt elsewhere in my diet. This leaves me very thirsty, and with a need to replace large quantities of fluid on a daily basis. I have tired of soft drinks and water so have developed a drink that is inexpensive, tasty and thirst-quenching during the hot summer days.

You will need one lemon, one orange, half a cup of pearl barley and a cup of sugar. The sugar can be adjusted to your taste but use a full cup the first time you make it, then either increase or decrease the amount according to how you like it.

Grate the rind of the lemon and orange and place in a two litre jug. Squeeze the juice of both fruits and add to the jug with the barley and the sugar. Fill the jug with boiling water and stir until the sugar is dissolved. Put this aside

overnight, or for at least eight hours and then strain off the rind and barley. I like to drink it chilled and it not only makes a good thirst quencher, but is a good tonic as well.



For those who are not aware of the rehydration mixture, here's a quick recipe. Get a script for Chlorvescent tablets from your doctor (cheaper than over the counter). These tablets contain potassium and chloride, both of which are needed to maintain electrolyte balance. Put three of these tablets into a two litre jug. Dissolve eight teaspoons of sugar and a teaspoon each of salt and baking soda with a little boiling water. Fill the jug with boiling

water or mineral water and watch it fizz. Let it cool, flavour it with cordial and try to drink a jug full a day.

If you are taking ritonavir and suffering diarrhoea, I have found that a tablespoon of slippery elm powder and a couple of teaspoons of pectin - available at health shops - sprinkled over or mixed into your breakfast food, will ease the problem considerably. If, like me, you find it hard to eat breakfast, make a banana milkshake and add this mixture to it. It seems that the milkshake is enough to aid the absorption of the drugs.

Make use of your increased energy to spend more time in the kitchen and look after your nutrition. The epidemic is not over yet and we all have a long way to go still - some further than others.

If changed circumstances and more effective treatments are raising fear and depression levels within you, rather than giving you cause to celebrate, I urge you to think about your situations, especially the long-term survivors. I am sure you will find there are positives to being positive - celebrate those instead. Keep fighting.



Updated & Revised February 1997 Edition OUT NOW!

Look for the GREEN COVER at a venue where you pick up your copy of Talkabout



Two hours in Green Park

The Darlinghurst Syndrome, a Mardi Gras event by Fletcher Jetspree & Kathy Triffitt. Reviewed by Paul de Koning.

THE NIGHT WAS BALMY, AND THE air full of promise as I strolled into Green Park at 7.00pm. Banners of butcher's paper were hung around the park, giving the space a more enclosed feel, on which were written the stories of various people and groups. The Kirketon Road Centre's Banner was particularly witty and moving. Even the flagstone I sat upon was inscribed freshly with a warning against the smack around town: "deadly, way deadly". All in all, the promise of a great night.

Seven rolled in 7.30. David Jobling orated a short piece, sending ripples of laughter through the crowd, then silence. 7.45pm. I asked when the show was starting – I was told it was a night time performance, the show would go on when the sun went down. Painfully, almost unwillingly, it finally became dark. Twenty minutes later the show began, 8.35pm by my watch.

After a short 'soundscape', the audience began to hear Jetspree's story. Different voices spoke from different speakers situated around the park – a soundscape in motion now it seemed. Switching from Jetspree's story, to a history of the area, to excerpts from some poor AIDS-ridden faggot's diary, and back to Jetspree again. All sound, no 'vision'. Interesting idea, I thought.

Unfortunately, Jetspree was performing, I had just missed it. Shuffling back and forth, head down, reading from cue cards, was Jetspree himself, dressed as Captain Moonlight the dandy bushranger, but with none of his flair. I'm not sure why I had missed him. Perhaps the voices speaking to me from around the park made me feel that there was no visual focus. There was a spotlight trained on Jetspree, which had failed to attract my attention. The speakers around the



FLETCHER JETSPREE. PHOTO: C. MOORE HARDY

park lighting up when they 'spoke' may have added to my confusion about where my focus was supposed to be.

The story of Moonlight's demise interested me, and the parallel drawn with the Holocaust excited my imagination. Jetspree's vision of Moonlight, in his smacked out haze, was particularly uninspiring. As the performance dragged on and on, the audience left in droves. I departed at 9.15pm, midway

through the piece I assume – I didn't hear the story of the positive sex worker. My bum was sore and two hours in Green Park was enough for me.

Jetspree was commissioned by the PRIDE Centre to create this piece, which was funded by PRIDE, Mardi Gras, and the NSW Department of Health. With such backing I was looking forward to what sounded like innovative and empowering theatre. What I saw and heard reminded me *very* much of the launch of ACON's Myths Campaign of January, 1995, for which Jetspree was the artist. The story of his viral meningitis? Heard it. The story of him being denied pain relief? Heard it before. And it wasn't very good the first time either.

This lead me to wonder what the brief for this piece entailed. Was it to be original? I wonder. We all know horror stories of bungling nurses, misdiagnosing doctors, and the indignity of AIDS.

There are stories that should be told. I have one too: once, when I was feeling AIDS-ridden but well, I went to see a play, a free one, my only Mardi Gras play in fact. I sat on the ground for an hour and a half waiting for it to begin.

What I heard was rehased, reworked, and had essentially been done before. It was amateurish, cold, and performed with a lack of care or feeling. While there were items of interest, the piece as a whole failed and the opportunity to create worthwhile community theatre was lost. It was video-taped for archival purposes. I suggest those responsible for *The Darlinghurst Syndrome* watch the tape and learn from it.

Service Update



Health Care Complaints Commission

IF YOU HAVE A PROBLEM WITH A dentist or a medical centre, the Health Care Complaints Commission is the place to call. The Commission is an independent body which acts as a watchdog on the standards of health care in this State. It also aims to promote people's rights in regard to health care.

The Commission investigates and prosecutes complaints against health care providers. It will handle complaints against anyone who claims to provide a health service, regardless of whether they are registered or unregistered. Complaints can be made about individual providers such as doctors, nurses, naturopaths, counsellors and dentists, or about services such as public or private hospitals, medical centres and nursing homes.

If you have a complaint about a health service, you can contact a Patient Support Officer (PSO), who can help you figure out the best action you can take to resolve the problem. In some cases the PSO will direct you to the Health Care Complaints Commission or another complaint handling body, e.g. the Private Health Insurance Commission. In other situations, when the problem is less extreme or could be resolved at a local level by talking to the provider or health service, the can help you plan your approach. The PSOs, like all Commission staff, are independent of the Health Department, Area Health Services and health care providers. There are seven PSOs serving the Sydney Metropolitan and Hunter regions.

When the Commission investigates your case, it gathers information from everyone involved, including

a peer reviewer who will provide an independent opinion regarding the standard and quality of the treatment you have received.

An investigation can have a number of outcomes. The most serious would be disciplinary action, causing a health care provider to be deregistered or have restrictions placed on her or his practice. Or the practitioner could be required to undergo counselling or further training.

In one case investigated by the Commission, a general practitioner had failed to tell a man that his CD4 count was 180. The man didn't learn what his CD4 count was for nine months. He also complained that the doctor had not given him a hepatitis B result and had treated shingles inappropriately. The Commission investigated the case and referred the doctor to the medical board for counselling. This means the doctor had to meet formally with doctors who were skilled in the area of HIV, and develop skills and strategies to overcome his lack knowledge which had caused the problem.

The Commission can also recommend policy changes, for example in a hospital's policy. This usually occurs when a problem has arisen not because of any individual's fault, but because of a breakdown in a system.

The Commission works in the public interest to maintain and improve health services and protect the public. At all times, its aim is it to improve service delivery, not just penalise individuals or services.

— **Levinia Crooks**
Policy Officer

The Commission can provide brochures about how to make a complaint in Arabic, Assyrian, Chinese, Croatian, Greek, Italian, Japanese, Khmer, Korean, Laotian, Macedonian, Portuguese, Russian, Serbian, Spanish, Turkish, Vietnamese and English. (Brochures in English are available at the PLWH/A office)

A two minute recorded message is available in these languages at a cost of 50 cents per minute:

Arabic	1902 260 639
Cantonese	1902 260 640
Khmer	1902 260 641
Laotian	1902 260 642
Macedonian	1902 260 643
Turkish	1902 260 644
Vietnamese	1902 260 645

Contact

The telephone enquiry officer
02 9219 7444
1 800 043 159 (for callers
outside Sydney)

Telephone service for the deaf
9219 7555

Patient Support Officers

Penrith	(047) 24 3870
Mt Druitt	9839 1506
Zetland	9382 8129
St. Leonards	9926 8184
Liverpool	9828 5710
Concord	9736 8300
Newcastle	(049) 21 4943

Calls from outside Sydney
1800 043 159

Talkabout

WERE WE SPEAK FOR OURSELVES Join PLWH/A in the fight against AIDS! Subscribe now!

PLWH/A (NSW) Inc. is part of a worldwide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice. Help yourself and others affected by HIV to create a positive, friendly and supportive environment in which we can all live with HIV & AIDS - join PLWH/A.

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Yes! I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year as a:

- Full member (NSW resident with HIV/AIDS)
- Associate member (NSW residents affected by HIV/AIDS)
Disclosure of HIV status entitles you to full membership of PLWH/A, with the right to vote for all management committee positions.
Membership status is strictly confidential.

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Thank you!



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SUNDAY MAY 4th

United in Remembrance, Hope and Action

for information and name leaving call the AIDS Hotline: 9332 4000