

Vol. III No. IV July 1992

# Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



## Into The Mainstream?

# ddC approved in the US

ON JUNE 23 THE FOOD AND DRUG Administration (FDA) in the USA approved ddC for use in combination with AZT in people with a CD4 count of less than 300. According to David Kessler, Commissioner of the FDA, ddC approval was a first step in a new FDA policy on accelerated approval for drugs to treat life-threatening illnesses.

FDA approval of ddC was granted on the basis of surrogate data; in the case of ddC the FDA waived the traditional requirement that a drug must demonstrate "hard" clinical benefits (because ddC was still at a comparatively early stage of testing, the trials which could demonstrate these benefits are not yet finished).

So instead of requiring that the drug must show that it helps a person with AIDS live longer and get fewer opportunistic illnesses, the FDA acknowledged that it was sufficient that persons on ddC showed improvements in their CD4 cell counts. Based on such data, the FDA decided to approve ddC for use together with AZT, but not for use by itself. However, the FDA also specified that further testing must continue post-approval, and that ddC's marketing licence could be removed in the future if comprehensive testing showed that ddC did not live up to its promise.

## But in Oz . . .

MEANWHILE IN AUSTRALIA, approval for ddC has still not been given by the Therapeutic Goods Administration (TGA).

On June 12, ACT UP held demonstrations in Sydney, Brisbane and Canberra to demand ddC's approval. Specifically, the demand was that the Therapeutic Goods Administration finish



Russell did something about AIDS today — Russell lay on dirty concrete at a Die-In staged by ACT UP outside the Sydney offices of the Therapeutic Goods Administration on June 12. PHOTO: JILL SERGEANT.

examining the data so that ddC could be approved at the June 18 drug evaluation meeting. But June 18 came and went, and ddC approval was not mentioned. The TGA said that ddC will instead be on the agenda for the next drug evaluation meeting in August.

Access to ddC, despite the TGA telling us otherwise, is still extremely limited in Australia.

A person can get ddC only through strict clinical trials, a limited expanded access program, or buy it from a buyers club. All of these methods come with inherent, immutable obstacles, and the only way to ensure acceptable access to ddC is for the TGA to approve it as soon as possible.

— Lyle Chan

# Contents

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confidentiality & the law **10**  
mainstreaming **11** raindrops & dentists **13**  
lew katoff **14** profile **16**

## regulars

news **4** letters **7** tribute: peter base **9**  
gabby talks **18** anguish in bohemia **19**  
service update **20** home front: ddc **21**  
fair treatment: holistic **33** gloria's food: bratt **23**  
doctor, doctor **25** what's goin' on **27** contact list **29**



### **This Month's Cover**

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by Paul Kearns. Mainstreaming: what is it? does it, matter? how will we be affected by it? Paul van Reyk takes up the issue in *Against the Current*, page 11.

## Passive hyperimmune therapy

PASSIVE HYPERIMMUNE THERAPY (PHT) is a method of treatment that has been developed in England. It is now in trial in a number of the specialist hospitals in London, and is thought to have some potential in slowing the progress of HIV disease.

The procedure involves the drawing of blood plasma from people who are HIV+ but who have not shown any symptoms. The plasma is purified against possible infection and then infused into a person with HIV/AIDS who has experienced severe damage to the immune system.

Evidence suggests that with regular infusions of plasma there is an improvement in that person's ability to fight off infections and thereby preserve their life quality and increase survival time.

In March the interim results of the first six months of a year long placebo controlled trial were released. The results indicated that in those on full dose of PHT, as compared to the placebo controlled group, there was a statistically significant improvement in CD4 (T-cell) counts and a lower level of opportunistic illnesses.

Interim findings also noted only a third the number of deaths in the treated group as in the placebo controls. Also, the reports of side effects in the treated group were minimal and no different to the control group.

The trial is continuing for a further six month period and results are expected to be released at the end of the year. A similar pilot study in London had used the technique with ten patients and observed similar responses, particularly in people in the 'pre-AIDS' group. However the report from this trial indicated that

they had great difficulty in obtaining 'donors' and the trial ended prematurely because of this problem.

In England a program has now been set up whereby the recipient of the plasma recruits his/her own 'partner' who acts as a sole donor for this person. In cases where the individual is unable to find such a partner, the hospital is also recruiting healthy HIV+ people who are willing to donate to the trial. However it is reported that there is a lengthy waiting list.

The next phase of the trial program is to introduce PHT to people at an earlier stage in the disease. That is, people who are healthy and who have a CD4 count greater than 450. The objective of this study is see if it is possible to delay the progression of HIV infection to AIDS. The triallists have indicated that they hope that this technique may delay progression by years rather than months. This trial will not be placebo controlled.

An interesting side line to this treatment is that 50% of the plasma taken from the donor is held and frozen. This plasma can then be reclaimed by the donor at a future date if they wish. This is not unlike the CD8 rescue protocol that is being run at Prince Henry Hospital in Sydney (*see March 92 HIV Herald*).

The triallists have also reported that the donors' condition seemed to improve after the plasma extraction and that when the plasma was returned to the donor at a later date they appeared to produce a greater number of antibodies than were there originally.

If the PHT process appears to be so beneficial why have we not heard more? The technique has been used since the late 80's, but with very limited reporting. The current trials have generated new interest in the press, but there is still the obstacle of providing

adequate numbers of donors to the program. PHT is not a cure, but it does appear to have some potential as an effective therapy in slowing progression and incidence of opportunistic illnesses. I hope that we may see some movement in the near future, to commence work with this technique in Australia.

— Ian McKnight

## PID & CDC

MANY AMERICAN SOURCES BELIEVE that the US Centre for Disease Control (CDC) should define Pelvic Inflammatory Disease (PID) as an AIDS-related opportunistic infection (OI), under certain circumstances.

PID is an infection of the uterus, fallopian tubes and ovaries that can result in chronic pain, infertility and even death. It is a common and debilitating condition faced by at least one million women every year in the US. Cases of PID in women with HIV tend to be more serious, resist treatment and take longer to resolve.

Women with HIV are stuck in a catch 22. There is no data on how many positive women have PID because it is not considered AIDS defining. The whole area is under-researched and under-funded. Any change of definition cannot take place without the results of research — but of course there is no money for research as PID is not AIDS defining.

If PID was defined as an AIDS related OI by the CDC, positive women with PID would be recognised and treated for AIDS; clinicians, physicians and women who have PID would be alerted to the possibility of HIV infection; and positive women with PID would be eligible for AIDS related social security benefits.

Source: *Body Positive*, May 1992.

## Positive young men

THE HIV SUPPORT AND FUN AND Esteem Projects are currently working together to establish a peer support group for young men who are HIV+.

After recent inquiries, the two projects decided to meet with several younger HIV+ guys to discuss and evaluate past Positive Young Men's Groups. As a result a starting date for the new group has been set for July 3.

Opinions are currently being gathered from a wider range of HIV+ young men who have had contact with both projects in the past, so we can successfully get a group happening that specifically meets their needs.

*For further information call Russell Westacott at the Support Project on 283 2453.*

## New ANCA announced

AUSTRALIA'S TOP AIDS POLICY body, the Australian National Council on AIDS (ANCA) has been radically reformed by the Health Minister, Brian Howe.

Membership has been slashed from 16 to 10 in the hope — according to Howe and his minders — that it will function more efficiently.

At the top of the new body is a four person executive, which is expected to have a major role in policy directions:

- The new chairperson is former senator Don Grimes, who was Social Security Minister for the first four years of the Hawke government. After leaving politics, Grimes became Australian Ambassador to the Hague and he is now a member of the Administrative Appeals Tribunal.

- Deputy chair is Professor Peter Baume, now head of Community Medicine at the University of



**Demonstrating for ddc. See story page 2.**

NSW, a former Liberal senator and a senior minister in the Fraser government. Baume, a strong supporter of gay rights and a humane approach to AIDS policy, ran a one person inquiry which radically speeded the approval of new drugs. More recently, he was member of the NSW Anti-Discrimination Board's inquiry into HIV discrimination. Lobbyists had strongly supported Baume as chair, but Howe appeared determined to appoint someone from his own party.

- Professor Peter McDonald, head of microbiology and infectious diseases at Flinders medical Centre in Adelaide. As head of the Commonwealth AIDS Grants Committee — a post he retains — he is a key figure in research. McDonald was deputy chair in the former ANCA.

- Bill Whittaker, who until May was National president of the Australian federation of AIDS Organisations. Whittaker is the only gay man on the new committee, and one of only two on the new ANCA. Whittaker

resigned from AFAO to concentrate on his work with ANCA and national policy.

Though not on the executive, the other gay man is Ross Duffin, who is openly positive and works in the National Treatments Information Project.

The number of members aligned with community organisations has been slashed from five to two; and the number of gay men has been halved from four to two. But the most frequent opponents of AFAO and community policies, Professor Ian Gust and Dr Graeme Stewart have not had their terms renewed.

As a result, it is likely that the level of consensus and, therefore, the ability to take decisive action on key matters, will improve.

Up to two days before the new membership was announced, it was still apparently not intended to appoint an executive. This would have meant ANCA would have been effectively run by the chair, and would have been a major blow to the influence of community organisations. It would also have weakened ANCA

as a source of informed, independent policy advice.

Though this would have pleased some powerful federal bureaucrats — who regard ANCA as a nuisance they could well do without — some community leaders have advocated withdrawing from ANCA altogether.

Finally, after intensive lobbying and an ultimatum, Howe changed his mind. The appointments are for two years.

— *Martyn Goddard*

## Media handbook

HELPING JOURNALISTS GET IT RIGHT is the role of the new HIV/AIDS Media Handbook, to be launched on July 2. The handbook was produced jointly by ANCA and AFAO, and written by Martyn Goddard.

It is designed to provide journalists with background information about HIV and AIDS, recommendations on appropriate language and a contact list of key people and organisations involved in dealing with the epidemic. It is hoped that the handbook will assist journalists in ensuring that reporting on HIV and AIDS is up to date, factually correct and well informed.

## TAT gene watch out

AT THE THIRD TRIENNIAL SYMPOSIUM on developments in antiviral chemotherapy, held recently in San Francisco, enzymes that suppress the 'TAT gene', (TAT gene inhibitors) were hailed as a "breakthrough" in the development of treatments against HIV activity.

TAT genes act as a 'lightswitch'. When the TAT gene is switched on the virus becomes active; when switched off, it appears to become dormant.

In the test tube data inhibitors prevent HIV reproduction. They also seem to protect uninfected cells from HIV infection.

Preliminary clinical work in humans, with Ro 5-3335, a TAT inhibitor from Roche, suggests that it can also suppress HIV replication in viral strains that are resistant to AZT.

The phase I study with 45 mildly symptomatic HIV+ patients is, as far as we know, still recruiting. We hope that some preliminary commentary on this study will be made at the International meeting in Amsterdam in July. We will report as soon as it comes to hand.

— *I.M.*

## TIBOs not totally dead

A STUDY IN THE US WITH THE Upjohn TIBO (Reverse Transcriptase Inhibitor) will test this new non-nucleoside anti viral in combination with AZT. TIBOs have developed resistance to HIV strains at an alarmingly rapid rate if used alone, but there is some evidence that they may be effective when used at slightly higher doses and in combination with nucleoside analogues (AZT/ddI etc.)

This new agent, a TIBO derivative called U87201E, will be trialled in patients who have CD4 counts lower than 500, but who have not used AZT before.

In Australia the National Centre conducted a trial with another TIBO drug called Nevirapine. As with other TIBOs, resistant strains developed. It is possible that lower dose levels may have enabled HIV to mutate and hence become resistant to the drug.

At 400 mg doses, however, there appears to be a better anti-viral effect and it is thought that this dose may be high enough to stop resistance developing. Therefore the six people who were in the

Australian study will be offered Nevirapine at this higher dose in combination with treatment with AZT. They will be monitored closely in case there is a resurgence of resistant virus.

TIBOs have not been discarded altogether as an anti-HIV treatment, but they may end up as a treatment that can only be used in combination with other drugs such as the nucleoside analogues.

— *I.M.*

## Video women

HEALTH MINISTER BRIAN HOWE launched a resource package for HIV+ women on June 22. The package includes a video and a book of women's stories and information on relevant issues and concerns. It was produced by Positive Women Victoria with Commonwealth funding. The package, which targets newly diagnosed positive women, will be distributed to health centres throughout Australia.

## Cherry trees

AN AVENUE OF CHERRY TREES WILL be planted in Medlow Bath on July 4 to remember loved ones who have died, many of them from AIDS. The trees will be planted in a park that is being regenerated by local people. All shrubs, trees and seedlings are being donated.

## STOP PRESS

Patients of Mark Bloch please note he has temporarily moved his practice to

**49 Grosvenor St**

**Bondi Junction**

(very close to the station).

Mark will be moving back to Oxford St in a couple of months.

Appointments can be made on 389 6022.

# Talkback



## A younger voice

Hi. I WRITE THIS LETTER BECAUSE I feel strongly that not enough is being done to help young positive people specifically. I feel there needs to be a forum and a discussion of issues directly facing young positive people. As a young positive person I feel there's a need for representation of youth. Too often people forget that young people have a voice and need proper representation on young people's issues.

In 1987 I tested positive for HIV. I was seventeen years old and very scared. I needed support and it is a very important part of my life today. When I meet young positive people I feel very close to them in my heart as a special friend. For me, meeting and talking to positive young people is a vital part of my life. Communicating and listening to other people, who are young and in a similar situation.

There's issues we can talk about and face, the best part is other people have, and are going through the same issues you will face as a young positive person. It feels good to be able to hear their similar circumstances and how they dealt with it. There are things in our lives that can be difficult. Talking to other young people in a safe, confidential place, it felt great knowing I wasn't on my own.

I've been quiet for five years, and it built up inside me till I exploded with my emotions to a group in 1991. Since then life has taken a turn for the better. Now, I feel I'm a person again. I have a respectable disease and rights to uphold as a young positive person.

I would like to revive the

positive young men's group, but change the name to 'Services of Positive Youth', SOPY for short.

I would be interested in hearing other young people's thoughts on this matter, especially young positive people under 26. We need a voice and a place for this to happen, so young positive people can help other young positive people with issues directly affecting us.

Services available to us and where we stand in the AIDS community.

A few suggestions are as follows:

1. A survey should be conducted into HIV and AIDS in relation to youth.

2. A survey into the needs of positive youth.

3. A public or private forum on young positive people, eg. information nights, especially for youths with AIDS and for families of youths with the virus. Info nights to help with better understanding of what we feel and how we can help.

4. Write a letter to stars who are activists who might be able to help.

5. Create a poster.

6. Sophie Lee might help.(?)

7. Find out every possible service angle to helping young people.

8. Set up a youth fund for positive youth.

9. Float for Mardi Gras.

10. Canned food fundraiser

12. SOPY (Services of Positive Youth): Let's undo the knots together.

12. Meet once a month.

13. Direct link to youth 24 hours phone link to emergency help services eg. legal counselling.

Glen.

## Beds case disputed

I FIND IT INCOMPREHENSIBLE HOW an article on page 11 of the May *Talkabout* [ACT UP on beds at St Vincent's] can be written when the facts are sometimes the exact opposite to the way you show it.

My nephew died of AIDS in January this year. He was a patient at the Sacred Heart Hospice at the time, he had been a patient in St Vincent's Hospital, a patient in Caritas, received care and attention in his home in the inner city, ambulance transfers to and from the hospital on a daily basis if he required it, medication constantly provided, loving care and attention from a medical team devoted to his — and others' — problems.

I am sure he was not an exception. At no time did this cost one single cent to his family.

I think your slogan 'bigots beware' may have another meaning.

Alison Hale.

## Attitude I

Never one to keep my mouth shut I felt compelled to reply to Michael Staiff's article 'Attitude' (*Talkabout*, June 92).

Thank you Michael for doing the dirty deed and saying it. I'm too fed up with the 'we have to have specialist support groups for everybody' attitude.

Why is *Talkabout* not published in every language known, including Braille, where is the support group for green-haired lesbians with wooden legs who play piano? It is just not feasible to anticipate and cater to every eventuality. Besides, I don't want

# Talkabout

ISSN 1034 0866

*Talkabout* is published every month by People Living With HIV/AIDS Inc. (NSW). All views expressed are the opinions of the respective authors and not necessarily those of PLWHA, its Management Committee or members.

*Talkabout* is produced by the Newsletter Working Group of PLWHA (NSW) Inc. and printed by Breakout Printing 389-391 Sussex St Sydney, NSW.

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*Talkabout* is made possible by subscriptions, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* is also grateful for the assistance of the AIDS Council of NSW.

## DEADLINE FOR THE NEXT ISSUE

July 20

Send contributions to PO Box 1359 Darlinghurst, NSW, 2010. Call Jill for the date and time of the next Newsletter Working Group meeting.

### How to Contact People Living With HIV/AIDS Inc (NSW)

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to end up in a series of groups where everybody is identical to me. I enjoy the diversity in humanity and want to experience as much as possible.

When I lived in Darwin there was only "Friends" (the equivalent to PLWA NSW). The group met once a week and catered to everybody alike. People with Haemophilia, women, men, children, gay, straight, Australian, ethnic, old and young. All I can say is that I greatly enjoyed and immensely benefited from this multi-talented mix.

As I said before it is ridiculous to expect PLWA NSW to provide specific services for every imaginable sub group, but what we can, and have to do is create an atmosphere in which all people feel welcome and free to ask to have their special needs met. This is a lot cheaper and certainly less patronising than pre-empting all possibilities. But most important of all can we please not forget we are all human. We make mistakes. I can't remember how often I have not considered all gender-challenged, hearing-impaired marine mammals living with lifelong manageable infections. All I can do is make an effort and try to do better next time until then I can only ask all manageable marine mammals and gender-impaired infections to bear with me.

*Matt Bradshaw*

## Attitude II

I would like to respond to a few points raised by Michael Staiff in his 'Attitude' in the June *Talkabout*.

The first is his over-riding assumption that the 'average' or 'landslide' majority of PLWHA are not catered for by most HIV/AIDS services. By this majority I assume he means men who identify as being gay/homosexual/faggot whatever and are between 26 to 45 years old.

As someone who fits into this category, (and was diagnosed at the early, unfashionable time of January 1985), I feel I am more than adequately catered for. There are many medical and emotional support services for us, such as the HIV support groups scattered throughout NSW. Also, many gay men in this group have excellent support through their friends (who are HIV affected or infected), colleagues and family. We have reached a stage in our lives (mostly) where we can access internal and external help and comfort fairly easily.

Secondly, experience has shown that people in the groups outside the landslide majority need more assistance to remain HIV negative or to deal with being HIV+. They often do not have the excellent information we have on prevention, treatment etc. (eg. beat users); or the peer acknowledgment and support (eg. women); or have not developed internal means of dealing effectively with HIV issues (eg. young men).

It is a measure of the success of many HIV/AIDS services that only a small number of PLWHA do not fit into the 'landslide majority'. Education/prevention for the 'minority' has dramatically slowed the infection levels of these marginalised groups unlike in most other countries.

Finally, some of your language and attitudes show how difficult it is for people who do not fit into the majority to access many services. To dismiss young gay men as a 'pretty young queen' or to fail to recognise the special difficulties and needs of the deaf shows, I feel an egocentric and narrow attitude.

*Stuart Pullen.*

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We welcome your letters.

Send them to:

**Talkabout, PO Box 1359  
Darlinghurst, NSW, 2010**

# Tribute



## Peter Base

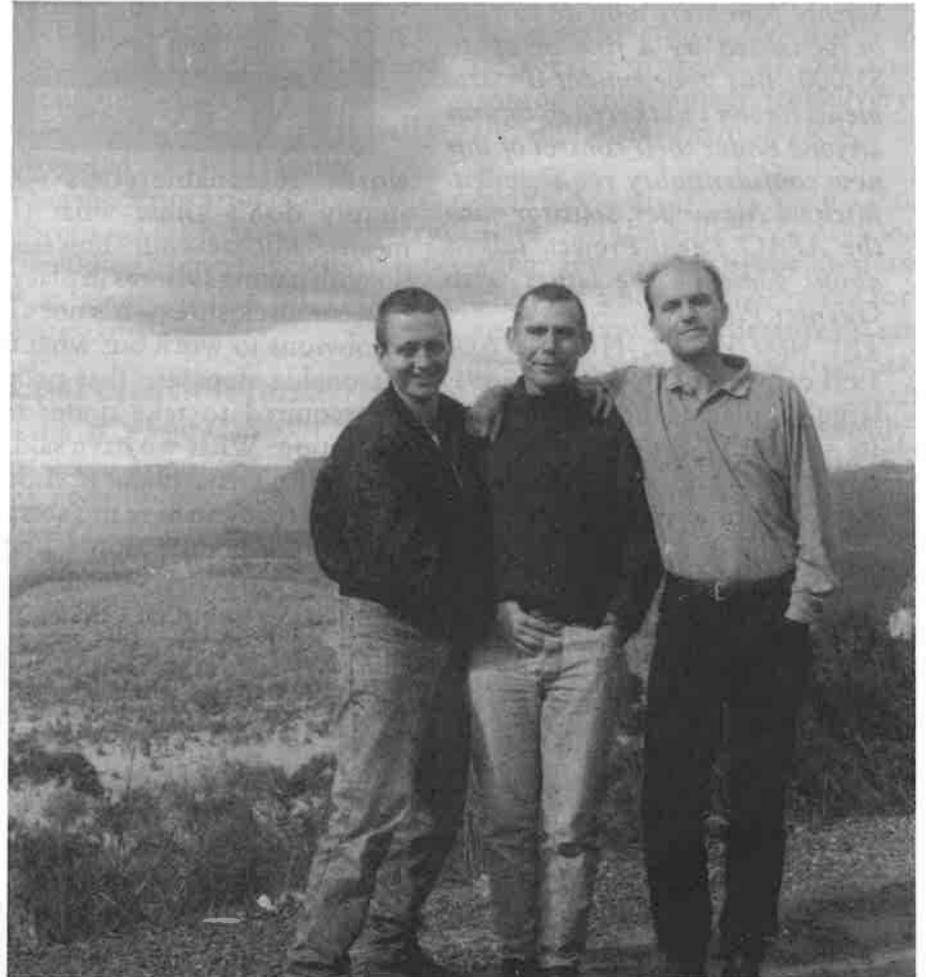
THANK YOU FOR THE NOTICE ABOUT the death of Peter Base in your last issue. However it contained two errors; you say he died in the hospice and you described me as Peter's primary carer.

Although I stopped work in October so I could go on the carer's pension and spend more time with Peter, the current terms 'carer' and 'care' were never used by either of us to describe our relationship. Peter called me slave, bootdog or boy and I addressed him as master, sir or boss.

Early in our loving friendship Peter secured a worn leather dog collar with long spikey studs firmly around my neck. We drank a toast, "like I am", Peter joked, a mispronunciation of 'Le chaim', which is translated as 'to life'. I fell in love again and became a bigamist, and thankfully my two husbands remained in harmony and friendship. Lucky me.

Soon after I was getting messages on my answerphone where Peter instructed his marxist leninist bootdog to get over and lick his bunny slippers. At the time Peter had had HIV for ten years, battled twice with cancer, had run out of T-cells and been told he had eight months to live.

Fourteen months and many good times later Peter put the dog collar on me again to go to the leather pride fair. Peter was getting around in a wheelchair and I pushed in the manner of a chauffeur. He wore leather and a wicked grin and carried a well worn whip which he used on every cute



From left to right: Jamie, Peter and Chris. PHOTO: JAMIE DUNBAR.

arse that took his fancy.

He died beautifully ten days later on may 21, cuddling with me and surrounded by love from friends in a bed on Seventeen South at St Vincent's hospital. The team who work there were part of that group of friends, they were wonderful and made us feel at home.

Peter was an AIDS worker, giving support, information and encouragement to anyone who asked. He was also an AIDS activist

and fought injustice wherever he saw it.

He dedicated himself to his brother Mikael Golan's comfort and well-being during Mikael's last weeks alive so that with CSN, Ankali and other friends Mikael could live well until his death in Peter's arms on October 17, 1991.

Peter also knew how to have a really good time. I share my only regret with Peter, that we didn't meet sooner.

*Love, Jamie Dunbar*

# LEGAL MATTERS

## No confidence tricks

*Disclosing a person's HIV status (under certain conditions), has become a criminal offence under the Public Health Act of 1991. Service providers who do so may be penalised by a fine of up to \$5,000. But government departments haven't bothered to inform anyone under their control of this new confidentiality requirement. Michael Alexander, solicitor with the AFAO Legal Project, talked about some of the issues with Guenter Plum.*

THE NEW PUBLIC HEALTH ACT 1991 came into effect in late 1991, largely replacing the previous Act. Its section 17 *Protection of identity* is new and very significant. ACON lobbied hard for its inclusion in the Act, and we're happy that it's there, despite reservations," says Michael Alexander. "The section is quite strong in requiring that a service provider who finds out that a person has been or will be tested for HIV, or is HIV positive, 'must take all reasonable steps to prevent disclosure of the information to another person'."

The section makes deliberate disclosure illegal other than "as a normal duty as a consequence of providing the service in the course of which the information was obtained". For example, if anyone involved in the provision of a medical service passed on a patient's HIV status to someone unconnected with the patient's medical treatment, he/she would certainly be guilty of the criminal offence created by the Act. However, since 'normal duty' is not defined, that particular exception to keeping such information confidential could turn out to be problematic.

"Our reservations concern the



words 'reasonable steps' — I simply don't know what that means," Michael said. "This has to do with having systems in place to prevent disclosure — it's not easy or obvious to work out what the reasonable steps are that people are required to take under this legislation. What we have said to the Health Department is, 'Look, it's great that you have this section there. But people don't know about it, even your own employees don't know about it. You need to be embarking on an education campaign about this, to tell service providers firstly that there is this important legal requirement, this criminal offence you have created; and secondly that they've got to take all reasonable steps to prevent disclosure, and help them work out what the reasonable steps are'. They haven't done a thing about it. But of course the Government will say that as always in criminal law, ignorance of the law is no defence."

This attitude clearly doesn't solve any of the problems since PLWHAs are more interested in service providers maintaining confidentiality than in a few of them being charged with a criminal offence, (other than in cases of deliberate and malicious disclosure).

Forexample, while most doctors will have some knowledge of confidentiality requirements, they may not know that these probably

extend to all involved in the provision of the service the doctor provides, and so this leads to the doctor not taking 'reasonable steps' to ensure that all involved are able to maintain confidentiality.

Furthermore, section 17 does not limit the confidentiality requirement to the providers of *medical* services; it applies equally to providers of other services. For example, if the Housing Department learns of someone's HIV status in the course of an application for emergency housing, any officer of that Department is equally obliged not to disclose this information.

And so the AFAO Legal Project is now trying to do the job for the government departments unwilling or incapable of doing it: "We have applied to the Commonwealth for a CAWISE grant to employ somebody to develop very specific confidentiality guidelines for different kinds of service providers. That person will work in conjunction with professional associations, consulting widely, and set out some specific practical steps for people to take. There are different issues for different kinds of service providers."

I wondered what had to happen for somebody to be found guilty of this criminal offence.

"Somebody will have to lay a charge. Now, who has the power or responsibility for doing that under this Act, I'm not sure. The police? The Health Department Legal Branch? I don't know. It would be interesting to see what happened if a patient went to the local police saying, "My doctor has breached my confidentiality. I want him charged." It would be interesting to try."

# MAINSTREAMING

## Against the current

*ACON Policy Writer Paul van Reyk argues a case for being wary of mainstreaming.\**

### What it is

THE CURRENT BUZZ WORD IN HIV/AIDS is 'mainstreaming'. There was a workshop about it in February organised by the Australian National Council on AIDS (ANCA — when are they going to up-date that to ANCHA for HIV/AIDS, I wonder?). It was also one of the closing sessions at the NSW HIV/AIDS Educators' Conference in June.

It's more than just a word, though. It's central to the implementation of the NSW State health plan for the development of HIV/AIDS services, and is occurring to varying degrees in other states. If we do have a new national HIV/AIDS strategy post 1992, you can be sure that mainstreaming will be in there somewhere.

What the term means depends a little on who's using it. Generally, it means gearing up a range of specialist and non-specialist health education, prevention, treatment and care services which don't have a specific HIV/AIDS focus to be able to effectively provide services for people affected by HIV/AIDS.

In the NSW State plan this means that over the next few years you should see more local services — hospitals, community health centres and nursing services and general practitioners — providing some level of service to people with HIV/AIDS.

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*\* This article is based on a paper I presented to the NSW Educator's Conference in June. That in turn was based on work done for AFAO by Margaret Duckett and I gratefully acknowledge her contribution.*

Most of the talk about mainstreaming has so far been limited to the areas of care and support. The NSW Educators' Conference is the first place it's been raised openly in relation to education, both preventative and for people with HIV/AIDS.

Mainstreaming is usually proposed for two reasons:

- as a mechanism for ensuring cost effective health service delivery (including health education);
- as a mechanism for ensuring equity of access.

### Cost effectiveness

THIS IS BASICALLY AN ADMINISTRATIVE argument that doesn't necessarily have a lot to do with better health for the client. Increasingly, there is a view that providing the one type of service through a range of different organisations or agencies is less efficient and therefore less desirable than if services were provided through one centre. In there somewhere is also an untested notion that the provision of specialist services is more expensive than the alternative of delivery via generalist services.

What we are basically being asked to do is to trade off health outcomes for the client against the economics of service provision.

Now, the cost of health care is certainly spiralling and some hard decisions on allocating funding have to be made. But who is making these decisions? Decision making about mainstreaming rarely involves consultation with those most directly affected by the decisions: people with HIV/AIDS. It is also often done without consulting the services currently providing specialist care and support, particularly the community-based services.

At a very minimum we should be demanding that those most affected are consulted on our view that mainstreaming may have an adverse and unacceptable impact on access to services, the adequacy of service provision, and the appropriateness of service delivery through mainstream services.

### Equity

THESE THREE ISSUES — ACCESS, adequacy and appropriateness (hey, it's a new kind of rating for services, how they measure up on the triple A scale!) come together in the concept of equity.

Equity in health care basically means that no-one should be disadvantaged in getting the best standard of care that can be provided. The need for a concept or principle of equity rests on the self-evident fact that our society is organised in such a way that some classes of people are structurally disadvantaged, for example women, Aborigines, people from non-English speaking background, people with disability.

Equity has also of course been a long term concern for people living with HIV/AIDS. This concern comes from our experience of service provision as gay men and lesbians, as intravenous drug users, and as sex workers. That experience is historically one of limited access to appropriate and sensitive mainstream service delivery.

Let's be blunt, it is a history of discrimination, intolerance, invasion of privacy, moralism, breaches of confidentiality and health agendas more concerned with curing 'deviant' behaviour than with providing health care on just terms.

It was because of this that the earliest responses to HIV/AIDS

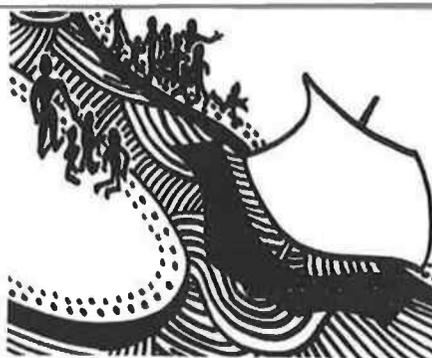
at the level of education, care and support were developed by the affected communities themselves. Gay men were central to the establishment of Ankali, Community Support Network, the Bobby Goldsmith Foundation and the AIDS Councils. Sex workers, organised as the Australian Prostitutes Collective, first began condom distribution and education with other sex workers. IVDU established ADIC and began the first needle exchanges.

Many of us fear that a total mainstreaming of HIV/AIDS services may mean that these initiatives will be eroded, if not lost altogether.

The equity argument when applied to mainstreaming usually goes that equity is assured through generalist or mainstream services rather than through a continuum of services which includes specialist services.

It is in effect the old argument that has surfaced in women's services, in disability services, in ethnic services and in Aboriginal and Islander services. It has been rejected there and should be rejected here. There is established merit in the argument that equity is best assured by having a plurality of services which allows many access points. If we accept the concept of multiculturalism, why not the concept of multihealthism? (Dreadful word but you know what I'm getting at.)

This isn't an argument against mainstreaming at any level. I firmly believe that all so-called mainstream services should be able to provide some level of service to people with HIV/AIDS. It's what we should expect of a public health system and we should demand nothing less. In isolated areas in particular, it's unlikely that a range of services could be funded. But this shouldn't lead to a simple argument that equity is best assured through mainstreaming all service provision.



Any move to mainstreaming has to be accompanied by guarantees of the maintenance of equitable access to services. I believe that's best assured by having a continuum of services which includes both generalist and specialist services so that people can exercise some choice.

## Empowerment

MAINSTREAMING THEN RAISES THE vital issue of the ethical allocation of health resources. It asks what the appropriate balance should be between need and equity and financial considerations.

I think it's important to recognise that the push for mainstreaming has not come from people with HIV/AIDS but from governments nervous about the expanding health budget.

But I have a more basic concern about mainstreaming. Again, this comes from looking at the role developed by women's services, or Aboriginal services or ethnic services. The best of these services operate through what can be described as peer-based and community-attachment models. That is, they are as much about the long-term development of the communities from which they spring as they are about addressing specific health issues for those communities. Community-based HIV/AIDS services now also work on these models.

This is a fundamentally different approach to health than is taken in the generalist services we have today. And I'm not sure that it isn't in the long run flatly contradictory to the notion of mainstreaming.

The central principle in both

models is that of empowerment of a particular community. Empowerment requires ownership of the program by the targeted community. And I doubt whether the mainstream can genuinely deliver on ownership.

I say that for two reasons. First, the range of clients/users of generalist services is by definition very broad. What consensus of interests can there be that would give any sense of ownership of generalist services?

More importantly, many of these generalist services are the very services which have till now been seen as disempowering. If mainstreaming health care is to be successful they will have to win back the confidence and trust of the affected communities. The bulk of the cases of discrimination identified in the NSW Anti Discrimination Board' Inquiry into HIV/AIDS Related Discrimination were in the area of health services delivery. That's no way to win back trust and confidence. Not ten years down the track it isn't!

## Where to, then?

I'M NOT, AS I SAID EARLIER, arguing for the abandonment of mainstreaming. I support it to the extent that it achieves a better service for people with HIV/AIDS through the public health system that should be there for all of us. But I don't support doing away with specialist HIV/AIDS focussed services entirely.

I think the best service for people with HIV/AIDS will be assured through the provision of a range of services from generalist to those with an HIV/AIDS specialisation. Which services can be main-streamed and how soon are matters for negotiation between the government, service providers and people with HIV/AIDS so that the triple A's of access, adequacy and appropriateness can be guaranteed.

# RAINDROPS FALLING ON MY HEAD

## or:

### what wonderful people dentists can be!

NO, I HAVEN'T GONE TOTALLY crazy (at least I hope not), but I'm sure in a good mood lately, despite ever increasing health problems. (No, no drugs either).

You know how everybody always complains about the bickering and fighting that goes on within the gay community and to a similar degree in the AIDS world. I suspect even the most reclusive gays have had some taste of it by now! Negativism any which way one looks! Right? Well, not quite!! Undoubtedly there is some bickering going on, in fact there is lots of it. I can't remember how often I have stormed out of meetings, feeling I just had a close encounter with the invasion of the body snatchers, wondering why I keep going and what is it all about.

Well, I found out, and it was about time for a reminder. What I'm talking about is the Candlelight Rally. Not only was I impressed by the expert planning and execution of the event (thanks Gerald), but also by the people present. It became abundantly clear to me what our community is all about and what we are able to achieve. After all is said and done we roll our sleeves up and we are there for each other.

In that park, mourning our dead, I had to think about how our community has risen to the challenge. All the services we provide, how we look after our sick and dying (financially and emotionally), how we have organised to fight for new and better treatments and managed all kinds of support for the needy. I can't think of any other community that has stood so well by its members in the face of

adversity. And it is not done by big organisations that choke to death on paperwork, but by lots of 'ordinary', little people.

Sitting in the drizzle in Hyde Park that night I got to think the mightiest floods start out with lots of very little raindrops. That reminded me of the Stonewall riot, the anniversary of which is coming up on June 27/28. This mini riot, now commonly held as the start of the gay movement, wasn't much to look at. A handful of drag queens aided by some trash cans and stones as ammunition menacing a handful of cops.

But those few raindrops were enough to cause a flood. Gays had learnt that night that we can fight back. And the news spread fast. Sure, the battle is far from over and we have our fair share of defeats, but we are steadily gaining ground. And as more and more of us learn that we have the right to be who we are and stand up and fight for that right, the chance of success increases.

While thinking about that my mind wanders to the next wonderful experience I had recently. It makes me feel good to see people fight for their rights and help each other, but every once in a while someone comes along who not only stands up for his own interests but for those of others, without any direct benefit for himself.

I recently met one of those silent heroes of the AIDS world.

I suspected that Peter Foltyn was no ordinary dentist when I first attended the dental clinic at St Vincent's. Sitting in the waiting room I could hear laughter coming from the dentist's room —

probably the last thing I'd expect in a dentist's surgery. And when I was called in, smiles all around. Despite the depressing reason for my visit I had a good time. Upon leaving, Peter asked me if I would like to come in that following Saturday as a life sample for some dentists to look at in connection with a seminar he was running. Naturally I went along; after complaining for years about uneducated health care providers I could hardly say no.

After 57 dentists had a look in my mouth that Saturday morning I was invited to stay for lunch and a session on 'the human face of AIDS' afterwards. Lunch was an enormously enjoyable affair. I never had so much fun with dentists. The afternoon session was equally fantastic. I learned a lot and had a great time and think the dentists got a lot out of it too. The amount of hugging and support at the end of the event leaves no doubt. This was certainly not your ordinary dentist convention.

This was actually the third of those workshops, all organised by Peter. He certainly impressed me with his spontaneity, enthusiasm and drive. I would like to take this opportunity to express my heartiest gratitude to Peter, his staff and all those like him, who make life for PLWHA that much easier to bear.

With all the justified attacks on the medical profession we should take time to acknowledge those doctors/dentists who do more than is required and go out of their way to help us in our struggle against this disease.

*Matt Bradshaw*

# *Working in AIDS: A question of balance*

*Gay Men's Health Crisis (GMHC) in New York is the largest community based AIDS service organisation in the world. Lew Katoff, who works at GMHC, visited ACON in February. While he was here, he spoke to Gerald Lawrence.*

**What's your involvement in GMHC, Lew?**

Initially I was the director of our Buddy program, then I became director of support services and did that for several years. For the last year I was directing a project to provide training to people from AIDS organisations around the US.

**What do you think you've learned from your work with people from these other organisations?**

One of the things I learnt is that some of the conflicts that we've had in GMHC happen everywhere. In most AIDS organisations people have come because of their rage and their sadness and their feeling of helplessness about the epidemic, and there's a lot of passion. But there's also, as numbers grow, and with funding coming mostly from government, a pressure to become more institutionalised and more formal and to have more structure. There's a conflict between the need for structure and that passion and feeling of urgency.

I think probably that feeling of

urgency is one of the things that most organisations have, and that sometimes leads to unrealistic expectations - that people work for 60 or 70 hours a week. If you do that for six months or a year you tend to feel angry and bitter and exhausted. Some organisations pay a reasonable amount of attention to support and morale issues; other organisations don't, and really do let people burn out. They don't pay as much attention to issues of grief, to making sure that people use their vacation time, or take mental health days.

**The balance of education and support is a contentious issue here, the government is perceived to spend much more on prevention education.**

I think it's very different in the States. The Federal government has funded educational projects, some media and poster campaigns. But they've never done a national campaign that's got posters on billboards or bus stops or any of those things. That's only been done locally. They spend some money on education, but the state and city governments that have provided funding are much more concerned about support services and projects like counselling, support groups, practical support volunteers, emotional support volunteers.

Probably about 50% of the money for GMHC comes from state and city government. The

rest comes from individual donations. GMHC has been successful in raising money through large special events. Every year in May we have what we call an AIDS Walk. Last year we did a dance. I think those kinds of events have accomplished a lot. It gets a lot of media attention. We still have very conservative forces in New York, the Roman Catholic church is still very powerful and very anti-gay. We need to have a very confident image of gay and lesbian people and of people with HIV.

**One of the things you're doing while you're out here is a workshop about HIV positive and negative people working together. It certainly seems to be an issue in all organisations in Sydney at the moment. What do you see as the issues, and how successful have you been in getting that balance to work?**

It's very striking to me that there isn't as much of a conflict in the States because there's not as many openly HIV+ people in organisations who feel a responsibility to making sure that the input is made. There certainly hasn't been as much tension in GMHC. The same circumstances have not produced the same anger. I think one of the differences is that some people who felt like GMHC wasn't doing enough activist work formed ACT UP, and ACT UP has been extraordinarily strong

and active in New York city. So people channelled their frustration and their anger and their desire to make change into ACT UP. It's really striking to me that there's so much more feeling of frustration here, and I think that probably there's as much or more support here as there is in other places.

One of the things I see a lot and have experienced myself is outbursts of anger. It seems to be something some people cope with and others don't.

AIDS is a plague, it's a horrible illness, it's horrible, the number of people that have died is horrible, the number of deaths of people connected to ACON in the last month is very hard. Of course people are going to feel frustrated and angry and urgent and helpless and when we feel helpless and angry at the same time we explode.

People do need to be able to get angry and express that more frequently and it's really positive if there are people who are able to do that. I think it's good to be angry, but I think that more can come of it if it's expressed without a message that other staff are doing something terrible and wrong rather than 'you can do something better'.

I think the other problem is that people perhaps don't actually ask for the kind of the support that they want, and everybody, positive and negative, needs a certain amount of support. Some people need somebody just to come in and chat, to distract them or take them out for a coffee, or bring food in for them while they're working. People have to be comfortable asking for that kind of support.

Something I've talked to people about is the transition from being a carer, worker, support person to being a client yourself. It's an issue that I find



difficult, and I think other people do. Have you any thoughts on that?

I think most of the GMHC employees recently who've become ill or died have not used the organisation's services. If they have, for example, problems with their health insurance, they've continued to use the personnel director, they didn't necessarily use the regular support services. I know a couple of people who use support groups. I think deciding to do it probably is very difficult.

It's incredibly difficult. I think the answer is for people to ask for help. I had a terrible reaction to ddI, I lost a lot of weight, I looked pretty awful, and people found it extraordinarily difficult — they didn't know what to do, they didn't know what to say.

I felt so frustrated... I continued to work through it. I think I pushed myself a little bit too much

for other people... even if I didn't want to stay home, I probably should have for their sake, because they were worried and concerned. I think it's very hard to ask for help. It's taken me a while.

Recently the HIV Support Project at ACON and PLWA put on 'the antibody party' for positive people and their friends. I think everyone that went had a fabulous time. Since then there've been some fears expressed as to how much do you provide almost exclusive space for positive people?

I think it's good that the negative people should come. Then they're also reminded that there's all this vitality... they need that emotion, that energy. that's why we're doing the work. I think it would be good if there were more social events. That's what some people really need, is an opportunity to connect.

# What am I doing?

Robert Ariss speaks with one of Talkabout's latest and most conscientious contributors, and finds Matt Bradshaw

## *Dancing with all parties*

I FIRST MET MATT BRADSHAW when he visited my house on his preliminary rounds as the National PLWA Coalition's needs assessor in mid 1991. My first reaction to this leather clad, stormtrooper-like figure was one of caution, particularly after an altercation quickly developed between us regarding a photograph hanging over my desk of a young Israeli soldier praying at Jerusalem's Wailing Wall. Irony and ideology clashed over tea on the balcony. A warm working relationship was quickly in the making, however, in spite of our apparent differences, and Matt and I currently share an appreciation of the view from Bondi Beach. On the eve of his departure for his native Cologne, Matt paused to recount his globe-hopping history as a gay man with HIV.

Like many who became involved in AIDS related work, Matt cut his teeth on the gay politics of the 1970s. In Matt's case, becoming involved in the many and varied activities of the Cologne gay community centre in 1979 both introduced him to gay political strategies and provided him with opportunities to explore ways in which he could make his own contribution.

"Gay politics was where my people were", he reflects. "That's where I could try and change things. It was the height of the time of political experimentation. We did anything, from setting up book stalls on the street, lobbying

or endorsing politicians, demonstrating on the street. It provided both political education and social opportunities. There were counselling services to be involved in, artistic groups, debating teams on Tuesday nights. I sat on committees for organisations". Some things never seem to change, he laughs, "I always seem to be on committees".

Cologne represented something of a stronghold for gay activity, says Matt. "The law changed in 1969, making gay sex legal, and from then on there was a steady increase in the gay community. And of course everyone was having sex everywhere. Good god, the things we did were unspeakable!" And adding his own sense of irony hastily assures me, "I have *no* regrets!".

But in the late 70s there was a falling out between the different gay organisations. Suddenly the socialists didn't want to talk to the mainstream for example. For 4 or 5 years no-one talked to anybody. Finally, just before I left in 1983, the groups seemed to have managed to pull it all together. They then opened the all-encompassing gay community centre".

When Matt returned briefly to Cologne in 1988 the AIDS epidemic had brought significant changes to his home community. "They'd established the AIDS Hilfe (AIDS Help) organisation. It was full of gay men but it was

entirely independent of the gay centre, which was still going strong. There was some overlap of personnel in the two areas - in gay politics and AIDS. The gay community seemed to be heading toward the mainstream. It was becoming something more palatable for television and mass media".

And Matt himself had changed. What was it like being an HIV positive gay man returning to Cologne?

"Most of the people I knew all turned out to be positive. But being positive and being gay are different kinds of shoes. There seemed to be a split developing between positive and negative people. Positive people seemed to be saying things like they weren't going out anymore".

On leaving Germany, Matt journeyed to the USA and then on to Australia. Time in the land of enterprise left Matt with an American lilt which disguises his European origins. He recalls life for a positive gay man in the USA in the early years of the epidemic as one of caution and secrecy. "I'd told only a few other people about my status. My boyfriend and a few other people knew. I worked in a gay book store and you had to be a bit careful. Rumours spread pretty quickly and if word gets out— sales drop".

Crossing the Pacific for a spell in Melbourne, Matt got his first taste of the Australian gay scene.

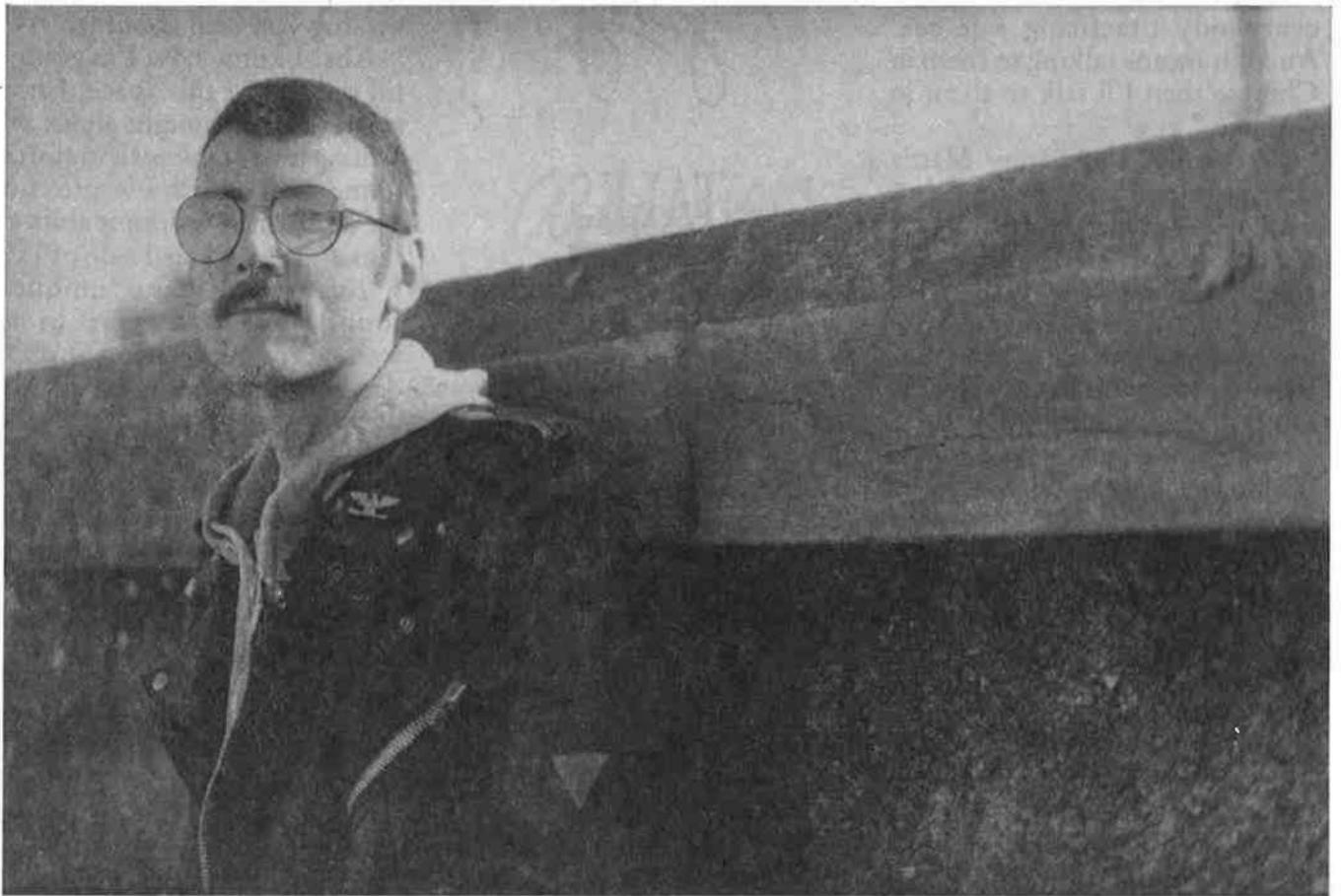


PHOTO: LEE TILMAN

"They seemed to be doing pretty well in AIDS, they had the AIDS Council and all that, so I got more involved in the gay community".

Moving to Darwin "for the weather" left Matt about as far from chilly, cosmopolitan Cologne as he was going to get. But it was in that unlikely European outpost that Matt found himself for the first time engaged in full time volunteer AIDS activities. When a friend asked him to help out at the local AIDS Council, "I ended up getting really involved. The Council was on the verge of collapse. It was a combination of ineptitude and the small town syndrome. If you went to the AIDS Council it meant you had AIDS". There were a lot of competing interests, between straights and gays, men and women, and Matt, formally in the position of Treasurer for the Council, "tried to speak for the gay community. I tried to keep

the communications going, using myself as a channel for correct information. It worked out quite nicely because I had quite a wide pool of information from the different areas I was involved in. From my work as a social worker I could access street kids, I could get AIDS information to the health department, and of course I was on lots of committees. It was beneficial to dance with all parties".

Securing the position of Needs Assessor for the National PLWA Coalition in 1991 brought another move, this time despite the weather, a move which led Matt to full time, professional AIDS work. "In Canberra I went from doing AIDS work as a hobby to being a professional. I worked in AIDS, I volunteered in AIDS. My life became enormously one-centred around that issue. It's something I can't recommend."

Under its copybook exterior, Canberra hides peculiar contra-

dictions for the AIDS worker. "The organised gay community is fairly clandestine, fairly white middle class and in the closet. If you come at them with pink banners and leather jackets that's probably going to be somewhat counter-productive. You have to work out some kind of language level that reaches them. The local gay club has been good that way. It offers its facilities for AIDS functions, they donate money, they provide AIDS information through their newsletter".

And where does Matt Bradshaw see himself fitting amongst this AIDS geography?

"I see myself in all camps. I can really empathise with the radical approach. I'm somewhere between ACT UP and the establishment. I can recognise the right of people to be conservative middle class if they so choose. We should allow people to have the life they want and not reject them as a lost cause.

For example, I want to see everybody practicing safe sex. And if it means talking to them in Chinese then I'll talk to them in Chinese."

Personally, I'm happy Matt's next stop was not Beijing, but Sydney. Overcoming a dislike for big cities, Matt settled on Bondi where you have the advantage of being able to turn your back on the smog. And the pace has changed once again. "I now do less organised kinds of work. I'm writing, I'm participating in a training program for dentists, I'm going to the Maitraya centre and making suggestions about how to improve things. I can't help it but I always end up getting involved and find myself trying to urge other people to get involved too." The move to the city presented some advantages. "Unlike somewhere like Darwin, where you just get thrown into the trenches, in Sydney you have the luxury of finding your own niche. I'm operating on the principle of "where do they need me? — that's where I'll jump in. In Sydney I can pick something that I personally like doing."

Moving to Sydney on the advice of doctors, Matt has taken advantage of the full range of services available to people with HIV/AIDS. "I'm fairly impressed with the AIDS services, they seem to be working well. So far I've got whatever I needed. I don't know if that's simply because I worked in the area and I know all the people involved. But even for me accepting help from somebody else is a bit of a gruelling experience. I wonder how many people out there are too scared to say 'I need help'".

Next stop? Moscow. Keep working on your Cyrillic, Matt, you may need those three little words to get you to that special bar just up from Red Square. And don't forget that goddam leather jacket!

Gabby

## TALKS

WRITING MY LAST COLUMN WAS very therapeutic, and very easy. I felt like I had come to grips with the challenge of writing a column and every month would be just as easy. The unfortunate result of my euphoria was that I nearly forgot I had to write a column again this month.

So of course I've only had a day to think about what I might say. And because I've felt a sense of urgency about getting this written my mind has been a complete blank. Jill has extended my deadline to the last possible moment but my mind is still blank.

I've spent most of this morning weighing up possible options. I thought about just not writing a column this month until Jill mentioned that she'd saved space for me. I thought about asking her to delay printing *Talkabout* for a week but I didn't like my chances much. In a very desperate moment I even tried to think of really good reasons why *Talkabout* shouldn't be published at all this month but I couldn't think of anything believable.

As the deadline has got closer I've had sudden urges for cups of tea or cigarettes. My mind has been full of ideas — all sorts of good reasons to put off the moment of truth.

Unfortunately the moment of truth came and found me in the garage (aka smoker's lounge) and chained me to my desk. In desperation I started with what you've just read but I'm wondering if I can keep this theme going for another half a page. I'd rather have a cigarette.

Why am I putting myself

through this agony? Why am I making you read about it?

Aha! I know how I'm going to fill the rest of this space. I had a cigarette and thought about why writing for *Talkabout* is important to me. Last month I wrote about PLWHA and it's unique ability to present the personal side of HIV.

*Talkabout* is also unique. I found my first issue in the waiting room at Albion St on the day I had my positive result. I had never realised how uninformed I was about HIV until then. The first few months were spent getting all the information I could find. It was really frustrating to read over and over how not to get HIV — it wasn't really relevant.

Once again it's the personal perspective that makes the difference. It's great to have a space where we can share our experiences and discuss the issues that we have about living with HIV.

I know that at first I didn't feel that I could contribute to *Talkabout*, I didn't feel that I knew enough about HIV. After a while, when I felt I did know enough, I started to contribute. But you don't have to know a lot about HIV to get involved. Everyone living with HIV knows how their lives have been affected, that's all the 'information' you need.

Everyone's experience of HIV is individual. The message in all of this is really to encourage you to contribute because that's why *Talkabout* exists — for you and me.

P.S.

The AIDS Council of NSW has recently undergone a restructuring process. This has implications for PLWHA as ACON administers our funding and manages our staff. Negotiations are underway to establish our new relationship under these changed conditions. We'll keep you informed.

## CHAPTER 11

by Ms Ada O.

*The story so far: Robbie fears he has seroconverted and fights with Nancy. What news does the doctor have in that envelope? Nigel finds his parents have disappeared and his hometown is armed against him. Hitch-hiking back to civilisation, he is threatened by a truckie with a sawn-off shot gun. Can he save himself from being ravished? Does he want to save himself? Nancy and Brad panic over Manhattan ingredients on the front steps of the Bohemia apartments. Will they be crushed by a plummeting piano?*

*Gentle reader, for answers to these questions, read on . . .*

### Get yer pants off kid

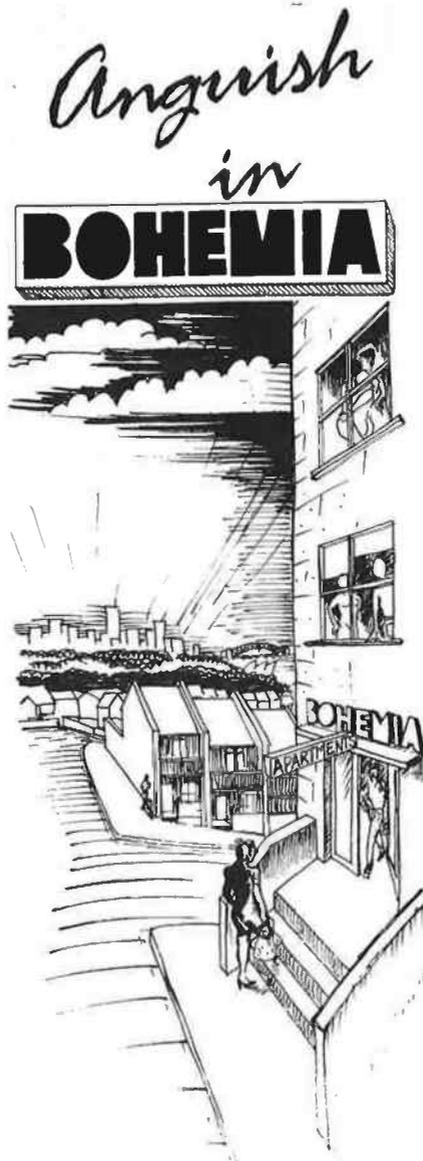
FEELING SOMETHING BETWEEN terror and excitement, Nigel did as he was told. Slowly removing his pants, his eyes alternated between the sawn-off shot gun Rod was holding and the not-so threatening one he was concealing. Rod stopped unbuttoning his own jeans and smiled.

"That's right, kid", he said. "Nice and slowly."

Nigel slid his pants down his shaking legs and struggled to manoeuvre them over his shoes.

"Carefully, mate", Rod breathed. Carefully? thought Nigel. This guy's a real weirdo. But he removed his shoes, then his pants and was about to lay them neatly on the floor of the truck's cabin when Rod stopped him.

"No. Hold your pants up by the open window."



Nigel, now thoroughly confused, obliged. He began to mutter something obvious like "why?" when Rod cocked his gun and aimed it directly at the fly of his jeans.

"Hold still, mate". Nigel cringed and looked at the spot he was aiming at, directly below his grasp. In the instant he saw it, Rod fired and blasted into kingdom come the biggest funnel-web spider he had ever seen.

### Falling debris

ROBBIE LEFT THE SURGERY FEELING strangely elated. The traffic cheered him along and he smiled at every pretty-young-thing he passed. "Syphilis!" he felt like singing to them. "I've got syphilis!"

Stopping in at the corner store he bought a bunch of glads for Nancy. "The poor thing", he thought. "God, I've been an asshole these last few days. Giving her such a hard time about my test results. She's the one who needs supporting."

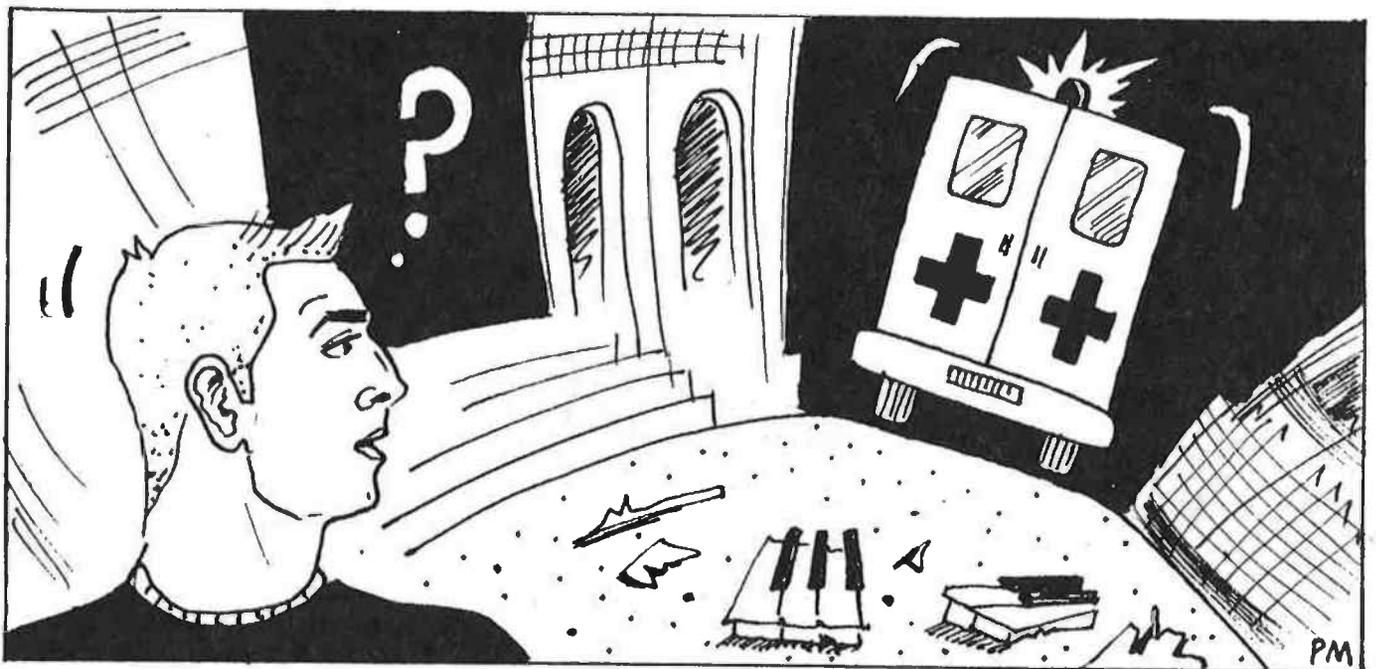
These thoughts came to an abrupt halt as he approached the block of his apartment building. There were more people about than usual and they were all facing in the direction of the Bohemia. He saw a police car, then another. He could see the top of an ambulance parked further up the road near the building. The crowd thickened as he got closer and he tried to push through. A burly policeman stopped him at the tape.

"Keep back, please, young man", the policeman told Robbie politely.

"What's going on?", Robbie asked.

"There's been a little accident. Nothing for you to worry about. A piano fell on a couple of people, that's all."

"What people?" Robbie pushed past the imbecile and ran towards the carnage. There were pieces of shattered wood and piano keys everywhere. A distraught young man wept pitifully on the steps of the building. He was being



comforted by a young woman in a brightly knitted jumper. He approached the woman. "Who was hurt?" Robbie asked her, tension rising in his voice. The woman looked up calmly and he read "Carin — Social Worker" on the name tag pinned to her jumper.

"A woman and a man are being

taken away right now", she said. Robbie looked over at the ambulance. The doors were closed and the siren began shrieking as it pulled out.

"What did they look like?" he spluttered, but was overshadowed by the young man on the steps who broke into a wail.

"You must have been very close", Carin said, comforting him.

"Close?", moaned the young man. "That piano and I haven't been separated for ten years."

TO BE CONTINUED

## SERVICE UPDATE

### Heffron Hallelujah

ONLY SIX MONTHS AFTER SETTING up a community centre in Darlinghurst's Heffron Hall, the Metropolitan Community Church (MCC) have got the place bustling with activity both day and night. The Hall, in Burton Street, has been made available for a diverse range of community activities including singing classes, aerobics, amateur theatre workshops and band practice sessions.

On Sunday mornings and nights MCC conducts Christian services with a special outreach to the gay and lesbian community. These services provide a much needed spiritual outlet for a

community dealing with an enormous amount of grief and pain as a result of the AIDS epidemic. The Hall is used for memorial services and wakes for families and friends of the bereaved.

Every Sunday at 12.30pm there is a luncheon for PLWAs, carers and friends. In a relaxed social environment, people living with AIDS and their supporters can get together to share stories and experiences away from the hospital wards and doctors' surgeries. This lunch is normally sponsored by the Heffron Community Centre, however, commencing Sunday July 5, the Boomerang Social Club will begin sponsoring this event one Sunday in every month. On these Sundays lunch

will be followed by Boomerang Bingo, a riotous experience for anyone who comes along and pays \$2.00 for lunch and bingo cards!

On the last Saturday of each month there is a community garage sale from 10.00 to 3pm. It's only \$10.00 to reserve a table, if you have something to sell.

The Gay and Lesbian Concert band also performs at the Hall. On Wednesday, July 22, the Band will give a concert with singer Andy Farmer. Tickets are available from the Centre for \$10.00.

*Heffron Community Centre, cnr Burton & Palmer Streets Darlinghurst.*

*For more information call the co-ordinator, Colin Wiseman, on 332 2457.*

# Home Front



## Me and ddC

DECEMBER 1991, AND MY CD4 count, ratio et al were not looking good after an alarming and unexpected (though graceful) plummet. A number of friends were on various anti-virals with mixed results. Articles I had read (and friends' anecdotal evidence) left me with the impression that ddC might be effective.

I was surprised at myself because for once in my life I was 'stuck' — I did not know what I wanted to do. Were the toxic drugs likely to be of use? . . . perhaps a new naturopath? . . . time to retire from my crazy job? . . . how about recreational drug therapies of my own design? In the interim, my CD4s were probably feeling rather lonely as they continued their graceful plunge to the low forties.

After changing my mind at least six times an hour for the previous few days I made a commitment to try ddC. I was not ready to stop working yet, I decided and I *certainly* was not ready to please the bureaucrats and drop dead. DDC seemed like a life affirmation.

Aside from some minor side effects in the initial days (chiefly a foul metallic taste in my mouth, which disappeared after about a week) I had no adverse side effects. My CD4 count began to soar (even more gracefully than it had plummeted). By May, after six months, I had a CD4 count of 251, was antigen negative and felt great.

One morning I woke with numb feet that progressed to pins and needles when I started moving around. "Just the cold", I told

myself. "After all, 40 is just around the corner."

The next day, my feet alternated between being totally numb or else feeling as though they were traversing white-hot coals with a sharp dagger poking through. This was not just the cold!! You guessed it, a case of peripheral neuropathy. Three weeks later it has completely resolved and I have feet again.

I certainly do not regret taking ddC — I now have a partially restored immune system in the bank for when I need it. I've learned more about me being the one who is in control of my life.

So — "to ddC (ddI, AZT), or not to ddC?" It's your question and you need to work out *your own* answer.

- Jacques Monroe

## Bruckner & ddC

*Lyle Chan's ruminations on ddC, brought on by toxic doses of Anton Bruckner on an empty stomach.*

I have often wondered why ddC is the poor third sister of the three nucleoside analogs we have today (AZT, ddI, ddC). In test-tube studies, ddC is actually the most potent inhibitor of HIV of the three. Unfortunately this is not reflected in clinical use. Why is this?

There is an enormous difference between the standard ddC dose and the standard doses of ddI or AZT. People tend to be able to tolerate about 400 mg of ddI and about 600 mg of AZT. But people can generally only tolerate doses of ddC of about 2 mg.

The key word here is *tolerate*. Yes, ddC is the most powerful anti-HIV drug of them all, but

only if you can tolerate high doses of it. In the initial trials of ddC, where researchers used the doses that were used with AZT and ddI, the side effects were devastating. For a while they thought they had a turkey on their hands, until some bright-eyed doctor decided to try very, very minute doses. Only then was it discovered that ddC was useful even at a tiny dose of between 1 and 2 mg per day.

And what's the deal with AZT in combination with ddC? It has been demonstrated that ddC is not that good a drug when used by itself as first line treatment. Then why, in people who have never used any anti-retroviral before, do we see these dramatic T-cell responses when ddC and AZT are used together? These increases are above what one could expect for either drug alone. And, to the best of my knowledge, we haven't yet seen that happen with the combination of AZT and ddI.

Why, why, why, especially if it's true that ddI is the better monotherapy drug compared to ddC? Maybe the AZT+ddI trials haven't run for long enough. Or, more romantically, maybe there's an as-yet-undiscovered interaction between ddC and AZT that isn't occurring between ddI and AZT. And we clearly don't know if these AZT+ddC results seen with so-called nucleoside-naive people are also seen with people who include ddC in their treatment regime after failing on AZT.

We clearly don't know a lot, and I wish someone would convince me that there are people out there looking for the answers.

# Fair Treatment



## A holistic approach

HOLISTIC TREATMENTS DEAL WITH the body as a whole, both at a spiritual and physical level, and without the use of chemical drugs to achieve healing. There are a number of disciplines under this banner and this article aims to create some awareness of some of the options that are available. We will publish more in depth reports in future issues of the *HIV Herald*.

### Massage

MASSAGE IS AN ART THAT DATES back to ancient times. It is said to have both physiological and psychological effects on the person receiving the treatment. It is an important aid in the maintenance and stimulation of the body's systems and functions. In particular massage can assist circulation and lymphatic drainage, the latter being an important mechanism for the removal of wastes and toxic materials from the body.

Massage also helps to relieve muscle tension, and of course psychologically it helps to rebalance the emotions, reduce stress by relaxation and bring about a feeling of well being. The full body massage takes about an hour and there are a number of specially trained people who are able to provide massage to people with HIV/AIDS.

### Aromatherapy

The essence (excuse the pun) of aromatherapy is the use of essential aromatic oils in a number of specific routines that are associated with massage. The oils used are said to

have specific therapeutic properties. After application they diffuse through the skin and hence affect the body over an extended period of time.

### Reflexology

THIS IS A FORM OF MASSAGE THAT focuses upon the application of pressure to areas of the hands and the feet. It is suggested that this balances the energy that flows through the body thereby balancing the body's functions. Reflexology works by establishing an environment in the body that permits self healing and/or the maintenance of a healthy status.

### Alexander technique

AN ASSESSMENT IS MADE OF THE individual's general posture and breathing. The practitioner then suggests ways that people can improve their bodily functions by correcting their posture. In particular the intake of oxygen into the body is considered of vital importance as through this the body's maximum work and energy function can be achieved. In reaching these levels, self healing mechanisms may also be stimulated.

### Relaxation therapy, meditation and yoga

These programs can effectively reduce and counteract the stress levels in a person's life. Stress has been proven to have a negative effect on the immune system. Significant drops in CD4 cell

counts can be directly correlated to the incidence of stress in the person's life.

Therefore, reduction or control of the stress can help to improve and maintain the general health quality of a person living with HIV/AIDS. A number of different stress management techniques have been developed and it is a matter of identifying which is most helpful to the individual.

### Energy healing

THE BODY CONSISTS OF MANY millions of cells which depend upon energy for their existence. The energy healing therapist directs it or balances this bodily energy, so that it can be focused upon the healing mechanisms associated with cells that are sick. The practitioner places his/her hands on strategic points on the body to redirect energy fields (aura) to sites where it is of greater need. Clothing is kept on during these treatments.

### Spiritual healing

IN A SIMILAR VEIN TO ENERGY HEALING, the therapist's laying on of hands is a source of energy. Reported effects are a feeling of relaxation and relief, in varying degrees, of the conditions that are being treated. This is not the same as faith healing, which has a religious component.

— Ian McKnight

*If you want any further information please contact us at the treatments office. (Call 283 3222).*

# Gloria's Food



## Nutritional solutions for diarrhoea

OCCASIONAL CHANGES IN BOWEL function are common to everyone. Diarrhoea can be brought on by changes in lifestyle, diet or anxiety. With HIV, diarrhoea may be caused by infection, medication or medical treatment and even the virus itself.

Diarrhoea comes in many shapes and forms. There are four main types of diarrhoea: non-specific, enteropathic, colitic, and cholerrheic.

**Non-specific diarrhoea** is the kind that is not caused by bugs. This kind of diarrhoea is characterised by loosely formed stools. It is not associated with pain or cramping. Your appetite usually remains OK and the diarrhoea is not related to the food you eat. In this kind of diarrhoea soluble fibre may be useful. Soluble fibre includes gums and pectin (the stuff that helps jams set). It is found in foods like apples, citrus fruits, oats, barley and rice.

**Enteropathic diarrhoea** is characterised by frequent (4 to 8 times a day) watery diarrhoea. Although it is often hard to find an offending bug it is still a good idea to have a stool test done. With this kind of diarrhoea, fat and lactose should be restricted as they often make the diarrhoea worse.

**Colitic diarrhoea** is associated with cramping and perianal discomfort. It is often worse in the

morning. Stool cultures often identify MAI (*Mycobacterium avium intracellulare*) or CMV (*Cytomegalovirus*) as the cause. This kind of diarrhoea is often referred to as 'the squirts' as you seem to be constantly running to the loo but never producing large volumes. Up to 30 trips a day is not unusual! It is very important to maintain your fluid intake with this kind of diarrhoea.

Dehydration can be life threatening. You should try to drink plenty of liquids to replace lost fluid and to provide energy. Try diluted fruit juices, diluted soft drinks, weak cordials and broths. *This will not make your diarrhoea worse.* Food on the other hand may. Avoid foods that contain lactose and fat. Fibre often makes this kind of diarrhoea worse. (See the hints below.)

**Cholerrhic diarrhoea** is very watery large volume diarrhoea. It is possible to lose 3 to 8 litres of fluid a day. Obviously, what was said before about keeping up a regular intake of liquids counts double here. This kind of diarrhoea is often caused by Cryptosporidiosis and sometimes Microsporidiosis. It is also associated with cramping and perianal discomfort. Elemental nutritional supplements can be very useful. These supplements have already been broken down and therefore give your gut a bit of

rest. Unfortunately they are expensive. It is very important to try to keep the fat in your diet low as it will make this diarrhoea worse. As with colitic diarrhoea, try to avoid lactose, fat and fibre.

### General hints for coping with diarrhoea

- Lactose is the sugar in milk. The lactose in cow's or goat's milk may make your diarrhoea worse. If so, try a reduced lactose milk instead. (Milk with Lactaid added, soy milk, Digestelact.) In small amounts yoghurt (1/2 a carton) and hard cheeses are usually okay. Try yoghurt that contains *lactobacillus acidophilus* or *bifidus*. This is especially useful if you have been taking antibiotics.
- Fibre may make your diarrhoea worse. To reduce the fibre in your diet:
  - Remove all skin, pips and seeds from fruit and vegetables. This may even include tomato seeds for some sensitive people.
  - Choose white bread, rice and pasta.
  - Avoid dried fruit, nuts, seeds, peanut butter and tahini.
  - Avoid dried beans, peas and legumes. E.g. baked beans, lentils, red kidney beans.
- When you have diarrhoea, fat may not be as easily absorbed. Avoid high fat foods and limit the

use of fats in cooking or food preparation. E.g. avoid pastries, pies, fried foods, cream sauces and sausages.

- Diarrhoea may result in loss of potassium. Potassium is found in bananas, mushrooms (cooked), tomatoes, oranges and fruit juices. Try to include some of these foods daily. Bananas may also help to reduce your diarrhoea.

- Avoid alcohol and limit caffeine as they can make your diarrhoea worse. Tea, however, may actually help.

- Follow a diet that is high in protein. Protein containing foods include lean meat, poultry, fish, eggs, soy products (e.g. tofu) and dairy products.

- Try to eat small, frequent meals and try to avoid very hot or very cold foods or drinks.

- See your dietitian about the use of special supplements if diarrhoea remains a problem. Some nutritional supplements contain lactose. Ensure Plus, Jevity, Polycose and Vital don't contain lactose. They are available at cost price from ACON. Ensure Plus may need to be watered down slightly.

- As the diarrhoea decreases, gradually return to a normal, well balanced diet. Over a week re-introduce wholemeal breads and cereals, then whole fruits and vegetables and lastly lactose containing foods.

The BRATT diet is a diet developed in America for short term relief from diarrhoea. It is high in potassium and soluble fibre. It is not a balanced diet and should not be followed for more than two or three days. Many of the above suggestions follow the same principles but are more nutritionally balanced.

B = bananas

R = rice (white)

A = apples (peeled and preferably cooked)

T = tea (black)

T = toast (white bread)



## Recipes

**Note:** use a low lactose milk or substitute instead of milk in these recipes.

### One Pot Meal

125g lean bacon chopped  
3 cups beef stock  
1 onion chopped  
1 apple peeled and chopped  
salt and pepper  
500g trimmed blade steak cubed  
1 cup white rice  
1 tblsp chopped parsley (optional).

Fry bacon and onion in large saucepan until onion is clear. Pour off any fat. Add meat and fry until browned. Again, pour off any fat. Add 1 cup stock, salt and pepper. Simmer until meat is cooked, about 1 hour. Add remaining 2 cup stock. Bring to boil. Add apple and rice and simmer further 15-20 minutes, until rice absorbs liquid. Add parsley and serve.

### Tuna Casserole

1 large can tuna (tinned in water or brine)  
1 tsp butter  
1 onion sliced  
1 apple peeled and diced  
1 tblsp flour, 1 tblsp sugar  
1-2 tsp curry powder

1 250g can button mushrooms  
salt and pepper  
2 cups stock or water  
2 tsp chutney.

Fry onions and apple in butter (or water) until onion is transparent. Stir in flour, sugar, curry powder, mushrooms, salt and pepper and cook 1 minute. Add stock or water and stir until mixture boils. Add tuna and chutney. Reheat, serve with boiled white rice and steamed peeled vegetables such as carrots.

### High Energy Jelly

1 cup jelly crystals  
500mls polycose syrup  
boiling water.

Dissolve jelly in boiling water, add polycose syrup, add extra boiling water to make up 1 litre.

### Tropical Shake

150ml milk  
3 tblsp pineapple juice  
half a ripe banana  
Liquidise and serve immediately.

### Apricot Dream

1 tsp honey  
3 tblsp yoghurt  
300ml apricot nectar.

Blend all ingredients until smooth and serve immediately.

### Baked Rice Custard

300 ml milk  
2 eggs  
2 tsp sugar  
pinch nutmeg  
25g raw white rice

Place rice in bottom of dish. Mix together the rest of the ingredients, except nutmeg, and pour over rice. Sprinkle with nutmeg. Place dish in a baking dish containing about 2 cm of water. Bake in moderate oven (190 C) for 1/2 - 3/4 hour until set.

*Information and recipes compiled by Hilda High, dietitian at the Albion Street Centre, in consultation with the Dietetic Association of Australia's HIV/Oncology Special Interest Group.*

# Doctor, Doctor



HI. WELLCOME'S RECENT ADVERTISEMENTS in the *Star Observer* promoting early intervention AZT treatment have raised a degree of comment in various circles.

Just a few comments. Firstly, AZT (aka Zidovudine or Retrovir), has been trialed and tested for quite a while so one can hardly accuse Wellcome of being either precipitous or erroneous in publicly advertising this drug.

Secondly, it is quite incredible that an ethical pharmaceutical (ie. available only on doctor's prescription) is being promoted and advertised to the general public.

This is not only possibly close to illegal, but it is certainly considered by a number of health care professionals to be very unethical. It is also an amazing break in the traditional link of drug company, doctor and patient, where the doctor mediates the process by prescribing the appropriate medication.

Thirdly, while undoubtedly Wellcome is determined to make money out of AZT, making money (even out of health care) is the incentive for lots of companies, organisations and people in this world. To criticise Wellcome on this ground alone is spurious.

Fourthly, and most important of all, the simple truth is that a number of US AIDS/HIV activist organisations, and in particular Project Inform in San Francisco, (none of whom have any love for Wellcome or any hidden agendas) have suggested that early intervention with antivirals such as AZT and other drugs may well be a very good way to go at this

stage of our knowledge of the progression of HIV.

In fact Project Inform's slogan is "It's never too early to take charge of your health"; by which they mean considering anti-viral treatment above 500 T-cells, or if T-cell counts are on a downward trend or below 500 using an anti-viral (ideally in combination).

Doctors are influenced to a greater or lesser degree, rightly or not so rightly by drug company advertising, among other sources of information. Now, we the consumers are also being targeted and the issue of the commercial motivation of drug companies does need to be kept in mind.

Wellcome's major failing in the advertisements is that it effectively dismisses ddI and ddC (from rival drug companies Bristol-Meyers and Hoffmann-La Roche respectively) as experimental, which is simply not true. Nor does the information given on the 0055 line tell the complete story about early intervention. However the virtue, as I see it, of the Wellcome advertisements is that they have set a number of people thinking about early treatment and that seems to be a good result.

All of which swings back to an idea a friend suggested to me about looking for a doctor. He suggested that the doctor one should be looking for should be neither too young nor too old. Neither too young because, although they may have up-to-date professional knowledge, they would tend to be inexperienced, nor too old because although they may be experienced they may not have the time or the concern to keep up to date with

the latest medical information, whether provided by drug companies' publicity or by their own independent reading.

Which brings me to the next instalment of Michelle Rowlands' article 'Managing Your Doctor', reprinted with permission from *AIDS Treatment News*.

## Finding the right doctor for you

IN ADDITION TO DETERMINING HOW active you want to be in your health care relationship, you need to decide the general philosophical approach you think you will want to take in terms of treatments.

Some people feel most comfortable following the standard of care in the medical community. At this time, that would include such suggestions as starting AZT when your T-helper cell count has fallen below 500 and prophylaxis for pneumocystis pneumonia if the count falls below 200. Most often, the standard of care includes approved drugs or treatments for which there is much data supporting their safety and effectiveness.

Other people want to try new treatment approaches which have not yet been proven to be effective. A recent example which falls into this category is oral alpha interferon. Some patients want to try new drugs in the context of a clinical trial, others prefer to use them with only their physician's monitoring and advice.

Finding a doctor who is already participating in clinical trials or who is willing to refer you to local trials will be important for patients

# Talking Drum

WELL HERE WE GO WITH THE second *Talking Drum*. As no-one wrote in with any queries about crabs or tinea, obviously either nobody gets them, or you all know how to get them under control. If you fit into the first category and are *not* the stay-at-home type, please write and tell us how you do it.

We did, however, get a response to the query about how to permanently get rid of warts on fingers:

IN ANSWER TO YOUR FRIEND'S WART problem, may I suggest Pigface, a plant commonly found near coastal regions. Some time ago, I managed to rid myself of two warts by using the juice found in the fleshy leaves. It is similar to aloe vera and so long as you apply it as often as you remember, the warts magically disappear. Needless to say, mine have not ever returned.

The few friends of mine who have tried this treatment have also found success. I'm not sure of the plant's true name, but it has long oval, dark green leaves and grows like a vine or ground cover. The leaves are firm but when broken contain lots of gel.

Best of all, it's a free treatment and there is plenty of it around.

*Melissa*

In closing, here's another question for someone to answer:

**Mouth ulcers** — excruciatingly painful, take all the pleasure out of any oral activities. What can we do to prevent them, or get rid of them fast?

---

If you have any questions about HIV/AIDS matters that you would like answered, drop us a line.  
**Talkabout, PO Box 1359  
Darlinghurst 2010,  
Phone 283 3220.**

*Continued from previous page*

who want to access potentially effective new treatments in this way.

Finding a doctor who is willing either to provide you with largely untested compounds, or to monitor you if you get them through another source, will be important if you want to try this approach. Not all doctors feel comfortable participating in the use of unproven drugs with their patients. It is a good idea to determine your doctor's willingness to monitor and support you in this area if you think you may want to try such a drug now or in the future.

Many people may want to add non-traditional (to the Western medical model) approaches like acupuncture, Chinese herbs, homoeopathy, relaxation/visualisation, vitamin therapy, etc. to their health care program. Finding a doctor who is supportive of your total health care approach is important in this case. If you want to use both unproven drugs and adjunctive therapies, you should find out how your doctor feels about each of these concepts.

Once you have determined the elements you are looking for in a doctor, you will have to talk about these issues with your current doctor or any new doctor you may be considering. You do have a right to have these conversations with your doctor. Realise, however, that your doctor may not be used to having this kind of discussion with his or her patients.

Before launching into the details of your discussion, your doctor might be more open if you tell him or her that you want to talk about philosophy and style and arrange a time to have this discussion. This approach will allow the doctor to schedule the necessary time and prepare to switch gears from the purely medical issues with which he or she may be more

comfortable, to a frank discussion of partnership.

(Note that this article assumes that the patient has a high degree of privilege and accessibility to a variety of doctors from which to choose. The unfortunate reality is that in the public health system, and in many geographical locations, the patient's ability to choose doctors is very limited. In such cases some of the suggestions in this article — to be published in coming months — may still be useful, although more difficult to implement.)

Next month we will continue this series — 'The time spent with your doctor'. We will also discuss the implications and ramifications of going on the Delta trial which is currently enrolling in Sydney.

*AIDS Treatment News\** is a bi-weekly newsletter giving up to date information from the USA on drugs, treatments and many other areas including alternatives. It is available via a reasonably expensive subscription.

However it is also available in back issue form in two soft cover books, *Vol I Issues 1 - 75* and *Vol II Issues 76 - 125*, published by Celestial Arts, Berkeley, California USA. I have seen Vol I recently at The Bookshop\*\* so they should at least be able to order it in for you.

Otherwise, *ATN* and other HIV/AIDS publications are available for reading and limited photocopying but not borrowing from the ACON library.

*Ciao for now.  
Peter Hornby*

\* *AIDS Treatment News* PO Box 411256 San Francisco CA 94141, USA ph. 415 255 0588.

\*\* The Bookshop 207 Oxford St Darlinghurst ph 331 1103. (Also King St in Newtown)

# What's Goin' On



## HIV Support/ Action group HUNTER AREA

Is held at 6.30pm on the  
4th Wednesday  
of every month at:

**ACON, Level One,  
6 Bolton St,  
Newcastle**

A welcome is extended to all  
HIV+ people to attend.

If you would like to attend the  
group or require further  
information call ACON on  
(049)29 3464

## Blood, Sweat & Tears:

### HIV/AIDS and Occupational Health and Safety

A forum presented as part of  
NSW Law Week by the Legal  
Working Group of ACON.

Monday July 27

5.30 - 7.30

Theatrette, Parliament House,  
Macquarie St. Sydney

Speakers: Peter Foltyn (St  
Vincent's Dental Clinic); Kathy  
Taylor (NSW Nurses  
Association); Michel Hryce  
(Medical Complaints Unit); Insp.  
Denis Percy, (NSW Police  
Service); Susan Stokes  
(Ambulance Service); Dr. Nicki  
Ellis (Occupational medicine).

For bookings, call Amanda Lyons,  
283 3222

## HIV RELAXATION SESSIONS

Would you like to learn various  
easy healing, strengthening,  
relaxation techniques?

Open to people with HIV,  
Carers, Partners, Family  
at NO financial cost

Come along

Wednesday Evenings  
between 6-7pm

Newtown Neighbourhood  
Centre

Cnr Australia & King Sts,  
Newtown

Sponsored by

Royal Prince Alfred Hospital,  
Central Sydney Area Health Service

Are you  
a gay man  
who is currently  
participating, or has  
participated in an HIV  
clinical trial?

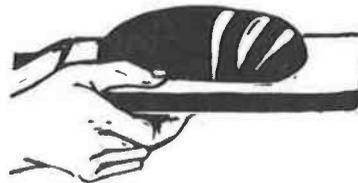
If so, we'd be interested in  
talking to you about your ex-  
periences. It takes about 30  
minutes and confidentiality  
is assured.

The study is concerned with  
the effects of trial anti-HIV  
agents on an individual's  
quality of life.

If you are interested in  
participating in this study,  
call Lorna Ryan, 332 1090  
ext 290 (Monday -Friday  
10am - 6pm) for further  
details.

National Centre for  
HIV Social Research

## LET'S DO LUNCH



The Talkabout editorial group meets  
twice a month for lunch. While  
we're at it, we talk about —  
Talkabout.

The editorial group discusses what  
should go into Talkabout each  
month. Some of us write articles or  
interview people, some of us con-  
tribute ideas and opinions. You  
don't have to be a brilliant writer or  
A grade journalist to get involved.

The next meetings will be;

**Thursday, July 23 and  
Thursday, August 6.**

Meet at the PLWHA office at  
12.45. 2nd floor, 188 Goulburn  
St Darlinghurst.

# HIV living

**THIS MONTH**

## INFORMATION NIGHTS

Presented in association with RNS Hospital

**6.30 PM — 8.30 PM**

**Department of Social Work Meeting Room  
Royal North Shore Hospital  
St Leonards**

### **Wednesday July 15**

**HIV INFECTION and the IMMUNE SYSTEM**

A lowdown on the immune system and how the body reacts to infection. What a virus is . . . what HIV does in your body. . . and what is likely to happen once you are infected.

### **Wednesday July 22**

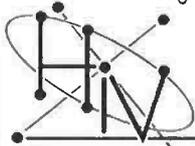
**MONITORING and PROPHYLAXIS**

Monitoring your health . . . why it's important . . . and how to do it well.  
Prophylaxis . . . what it is . . . how you'll know if you need it . . . and illnesses you can prevent.

### **Wednesday July 29**

**TREATMENTS and DRUG TRIALS**

The latest on treatments . . . how they are working and where we're going from here.  
Drug trials . . . what's being treated and why trials are important.



**SUPPORT PROJECT**

**SERVICING THE  
WESTERN SUBURBS**

*The Kendall  
Centre*

**AIDS information and  
support services**

Needle exchange

• Condoms •

Education • Counselling

• Referral • Outreach •

• Support groups •

A unit of the Western Sydney Area  
Health Service

26 Kendall St Harris Park 2150

Tel. 893 9522 Mobile 018 251

888 Fax. 891 2087

## HANDS ON

• **Massage for  
PLWHAs**

• **Training of  
volunteer  
masseurs**

**Call Richard  
660 6392**

## HEALTHY HIV LIVING

**For People with HIV family,  
friends & carers**

Every Wednesday evening  
Newtown Neighbourhood  
Centre, Newtown  
(cnr Australia & King Sts)

6 - 7pm Relaxation

7 - 8pm Information  
Evenings

Sponsored by:

Royal Prince Alfred Hospital,  
Central Sydney Area Health Service.

## Join ACON's Meditation group

ground floor  
AIDS Council of NSW  
188 Goulburn st, Darlinghurst

**ALL WELCOME**

Open to all people living with HIV/AIDS, their friends,  
supporters, carers, health workers etc.

Meditation can be useful as a means to reduce stress,  
energise the body and increase clear thinking.

Instruction and assistance in how to meditate  
is available to newcomers

**Tuesday mornings 9am - 10pm**

**Thursday evenings 6pm - 7pm**

Just turn up, or call David 358 1318

# Contact List



## GENERAL

**AIDS Coalition to Unleash Power (ACT UP)** A diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis.

Phone the Info Line 281 0362. PO Box A1242, Sydney South 2000.

**AIDS Council of NSW (ACON)** Provides services in education, welfare, support and advocacy in relation to HIV/AIDS to the gay and general community.

AIDS Resource Centre

188 Goulburn St, Darlinghurst 2010. 283 3222, fax 283 2199.

**ACON Hunter** PO Box 1081, Newcastle 2300. (049) 29 3464.

**ACON Illawarra** PO Box 1073, Wollongong 2902. (042) 76 2399.

**ACON Mid-North Coast** PO Box 990, Coffs Harbour 2450. (066) 514 056.

**ACON North Coast** PO Box 63, Sth Lismore 2480. (066) 22 1555.

**ACON's Rural Project** Telephone service for men who have sex with men. Info on HIV health services, gay networks/advocacy. Encourages the adoption & maintenance of safe sex practices in country NSW. Call Nik or John 008 80 2612 (free call). PO Box 350 Darlinghurst 2010.

**AIDS Trust of Australia** A non-government national fundraising body which raises money for research, care and education related to HIV/AIDS. PO Box 1272, Darlinghurst 2010. 211 2044.

**Australian Federation of AIDS Organisations (AFAO)** Umbrella organisation for Australian state and territory AIDS Councils. (06) 247 3411.

**Central Coast Services** Sexual health service, support groups, positive support network. For info call Peter (043) 23 7115 or Paul (043) 20 3399.

**Deaf Community AIDS Project** Call Colin Allen at ACON 283 3222 or (TTY only) 283 2088.

**Euthanasia** Voluntary Euthanasia Society of NSW Inc. PO Box 25 Broadway, 2007. 212 4782.

**Fun and Esteem** Workshops and drop-in groups for gay or bisexual men under the age of 26. Meets in Darlinghurst and Parramatta. The groups are a chance to talk about everything from safe sex to coming out. Social and fun. For more information call Aldo or Brent 283 2599.

**Kids With AIDS (KWAIDS)** and Parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772. Donations c/- AIDS Trust, 211 2044.

**Metropolitan Community Church (MCC)** International gay church. 638 3298.

**National Centre in HIV Epidemiology & Clinical Research** Federal research centre conducting trials for AIDS treatments and other AIDS related research. 332 4648.

**National People Living With AIDS Coalition (NPLWAC)** GPO Box 164, Canberra ACT 2601.

Call (06) 257 4985.

**New England Needle Exchange Program** Fits, swabs, water, condoms, lube, information and education. For locations of outlets and outreach services call (067)66 2626 message, (018)66 8382 mobile.

**NSW Anti-Discrimination Board** Takes complaints of AIDS related discrimination and attempts to resolve them by a confidential process of reconciliation. Currently employs a full time AIDS Project officer.

Sydney 318 5400.

Newcastle (049) 26 4300.

Wollongong (042) 26 8190.

**NSW Users and AIDS Association (NUAA)** Community/peer based organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free

forums/information nights 3rd Monday each month at 6pm. 369 3455.

**Quilt Project** Memorial project for those who have died of AIDS, consisting of fabric panels completed by friends, lovers & family of those to be remembered. 283 3222.

**Sex Workers' Outreach Project (SWOP)** 391 Riley St, Surry Hills. 212 2600.

**Social Workers in AIDS (SWAIDS)** A special interest group for social workers working with people with HIV/AIDS. Contact the secretary, Lib Edmonds, C/- Kirketon Road Centre, PO Box 22 Kings Cross, 2011 or the chairperson, Grahame Colditz, C/- Prince Henry Hospital, 694 5721.

**South East Region HIV/AIDS Unit** HIV/AIDS support, needle and syringe exchange and HIV education. For more information contact (048) 21 8111.

**Sydney South West Needle Exchange** For access and locations call 601 2333 or Mobile 018 25 1920.

## DAY CENTRES

**Blue Mountains PLWA Support Centre** Wednesdays 11am - 3pm (lunch). Fridays 6.30 - 10.30pm (dinner).

For further information call the Centre on (047) 82 2119 or Dennis (047)88 1110.

**Central Coast (Konnexions)** HIV+ Drop-In Centre, 11am-3pm Mondays at the old stone building, Anglican grounds 3 Mann St Gosford. Inquiries Pauline (043) 20 2241.

**Newcastle (Karumah)** Upstairs, 101 Scott St Newcastle, opposite Newcastle Railway Station. Every Thursday from 11am. Contact John (049) 62 1140 or ACON Hunter branch (049) 29 3464.

**Sydney (Maitraya)** Daytime recreation/relaxation centre for people with AIDS. Lunch Tues, Wed, Fri. (free or donation). Massage also available.

Some group meetings. 396 Bourke St Surry Hills. Inquiries (incl. membership) 361 0893. Client's phone 360 9896.

## CLINICS & HOSPITALS

**Albion Street AIDS Centre** (Sydney hospital AIDS Centre). Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. 332 1090.

**Haemophilia Unit** Royal Prince Alfred Hospital, 516 8902.

**John Hunter Hospital (Clinical Immunology Ward)** Lookout Rd, New Lambton, Newcastle. (049) 21 4766.

**Kirketon Road Centre** Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am - 8pm, Mon-Fri. Social welfare service, needle & syringe exchange 9am - midnight Mon - Fri. Cnr William St & Kirketon Rd, Kings Cross. 360 2766.

**Lismore Sexual Health/AIDS Service** A free, confidential service for all STD and AIDS testing and treatment. For further information or appointment (066) 23 1495.

**Prince Henry (Special Care Unit)** Anzac Parade, Little Bay. 694 5237 or 661 0111

**Prince of Wales (Paediatric AIDS Unit)** High St Randwick. 399 0111.

**Royal North Shore** Pacific Highway, St Leonards. 438 7414/7415.

**Royal Prince Alfred (AIDS Ward)** Missenden Rd, Camperdown. 516 6437.

**Sacred Heart Hospice** A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

**St George** Belgrave St Kogarah. Inpatient/outpatient & day treatment centres and STD clinic. Call 350 2742/43.

**St Vincent's (17th Floor South AIDS Ward)** Victoria St, Darlinghurst. 361 2337.

**Sydney Sexual Health Centre** Sydney Hospital, Macquarie St, Sydney. Appointments 223 7066.

**Transfusion related AIDS (TRAIDS) Unit:** For people with medically acquired HIV/AIDS. Crisis/long term counselling

and welfare support to clients and their families throughout NSW. TRAIDS is based at Parramatta Hospital. Contact Pam or Claire 843 3111 ext.343. **Red Cross BTS:** Contact Jenny 262 1764.

**Westmead Centre** (Westmead and Parramatta Hospitals) Westmead 633 6333. Parramatta 843 3111.

## EMOTIONAL SUPPORT

**Ankali** Emotional support to PLWAs, their partners, family and friends. volunteers are trained to provide one-to-one non-judgemental and confidential support. Ankali is an Aboriginal word for friend. 332 1090.

**Bathurst AIDS Support Group** Meets Tuesdays 7-9pm at the Women's Health Centre, 20 William St. Call Vi (063) 31 4133.

**Bega Valley HIV/AIDS Volunteer Carer Group** Provides emotional and practical support to PLWAs, their family & friends living in the Bega Valley area. Call Ann Young (064) 92 9120 or Victor Tawil (048) 21 8111.

**Civil Rehabilitation Committee** Family Support Centre. HIV education and support to families of prisoners and ex-offenders. Call Pam Simpson 289 2670.

**Friends & Partners of People With AIDS** A peer support group for friends and partners of PLWAs. 7pm, 1st and 3rd Mondays in the month at Maitraya Day Centre, 396 Bourke St Surry Hills. Inquiries Gary 369 2731.

**HIV Living Support Groups** For HIV+ people. Call HIV support officers 283 3222/2453.

**Hunter Area HIV Support/Action group** 6.30pm, 4th Wednesday every month at ACON, level 1, Bolton St Newcastle. Inquiries call ACON (049)29 3464.

**Karuna Blue Mountains** Emotional support for people with HIV/AIDS, their partners, family and friends. Call Ann (047)82 2120.

**Newcastle Gay Friendship Network** Peer support, workshops and activities for gay men under 26. Call ACON Hunter branch, (049) 29 3464.

**North Coast Positive Time Group** A support and social group for PLWAs

in the North Coast region. Contact ACON North coast (066) 22 1555.

**Parent's FLAG** Parents and friends of lesbians and gays. Meets monthly at the GLCS, 197 Albion St Surry Hills. Call Heather, 899 1101, Marie 360 3250.

**Parent's Group (and relatives)** A support group for the parents or relatives of PLWAs. Every 2nd Wednesday at 12.30. 5th floor, Notre Dame Bldg. Burton St Darlinghurst. Call Linda Barr 339 111 (page 248) or Marie Pettitt (page 256) to indicate attendance.

**Partner's Group** A support group mainly for partners of people who are in/outpatients at St Vincent's. every 2nd Tuesday, 6-8pm. Please phone Chris Connole 339 1111 (page 345) or Lesley Goulburn (page (255) if you're interested in attending.

**Positive Women** Individual or group support for and by HIV/AIDS positive women. Non-judgemental and completely confidential. Contact via Women and AIDS Project Officer or Women's HIV Support Officer at ACON, 283 3222, TTY for the Deaf 283 2088. PO Box 350 Darlinghurst 2010.

**Positive Young Men** A support group for positive gay men under the age of 26. Groups run for 6-10 weeks at a time. Groups are run by Fun and Esteem and the HIV Support Project. For information phone Aldo or Brent 283 2599 or HIV Support 283 2453.

**Quest for Life Foundation** Emotional support and education for people with life threatening diseases, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.

**SACBE - El Camino Nuevo** A support network and group to educate the Spanish speaking community about AIDS. 754 2237.

**Shoalhaven HIV Support group** Meets first and third Tuesdays in the month from 6pm to 7pm. This is a peer support group facilitated by an HIV+ volunteer. It is completely confidential. Call (044) 23 9353.

**Sydney West Group:** a Parramatta based support group. Pip Bowden 635 4595.

## PRACTICAL HELP

**ACON Housing Project** offers help with accessing priority public housing, transfer advice, homelessness, private rented housing/share housing, housing discrimination and harassment. The Housing Project Officer is available by appointment, call 283 3222, ext. 246. 188 Goulburn St, Darlinghurst. PO Box 350, Darlinghurst, 2010.

**Badlands** Residential harm reduction service providing a safe, non-coercive space for up to ten people at a time, who are at high risk of HIV transmission or may be HIV+. Residents are mainly injecting drug users and/or may be sex workers. 382 - 384 Bourke St, Surry Hills 2010. 360 7661.

**Bobby Goldsmith Foundation** A community based, registered charity providing direct financial aid to people with advanced HIV/AIDS to help meet rental, telephone, electrical, gas and some vitamin costs and child care assistance to approved clients. 4th floor, 376 Victoria St, Darlinghurst, 360 9755.

**Central Coast Positive Support Network (PSN)** Trained volunteers providing practical home/personal care for people with AIDS. Inquiries Peter (043) 23 71 15 or Paul (043) 20 3399.

**Community Support Network (CSN)** Trained volunteers providing practical home/personal care for people with AIDS. 283 3222.

**CSN Blue Mountains** hands on practical help for people with HIV/AIDS. Call Robert (047)87 7984.

**CSN Newcastle** Call Rosemary Bristow, ACON Hunter Branch. (049) 29 3464.

**CSN Wollongong** Call David Mendaue, (042)76 2399.

**Legal Project (AFAO)** Legal advice and advocacy on HIV/AIDS related problems.

Call Michael Alexander 283 3222.

**North Coast- Wollumbin CARES** Community AIDS Resources and Support. Call Simon (075)36 8842.

**Tiffany's Transport Service** For PLWAs (in the Sydney area.) 361 0958.

### IS YOUR LISTING CORRECT?

Please let us know of any relevant contacts for the next issue

## JOIN US IN THE FIGHT AGAINST AIDS. SUBSCRIBE NOW.

PLWHA Inc. (NSW) is part of a world-wide 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 PLWHA.

FIRST NAME \_\_\_\_\_ LAST NAME \_\_\_\_\_

POSTAL ADDRESS \_\_\_\_\_

POSTCODE \_\_\_\_\_

PHONE \_\_\_\_\_ (W) \_\_\_\_\_ (H) \_\_\_\_\_

- I wish to apply for membership of PLWHA Inc. (NSW)  
 I wish to subscribe to *Talkabout*  
 I wish to make a donation of: \$ \_\_\_\_\_  
 I enclose a cheque/money order for \$ \_\_\_\_\_

In the interests of your confidentiality

I agree to have other members know my name and address

Yes  No

I am publicly open about my membership  Yes  No

Annual rates are

Membership \$2

Subscription donation to *Talkabout*  
(optional for people receiving benefits)

Individual \$10

Organisation (up to 4 copies) \$20

(up to 10 copies) \$30

Please specify number of copies \_\_\_\_\_

If you want more than 10, call us.

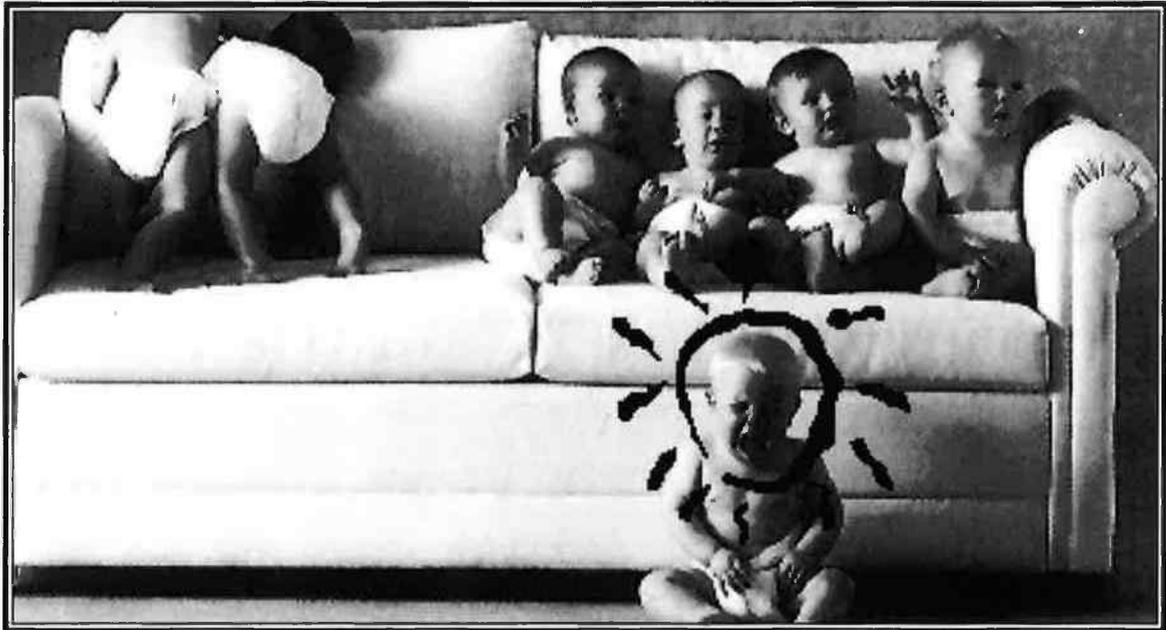
Please forward this completed form to PLWHA Inc. (NSW),  
PO Box 1359, Darlinghurst NSW 2010.

Make all cheques payable to PLWA Inc. (NSW). Donations \$2 and over are tax deductible. We will send you a receipt.

SIGNATURE \_\_\_\_\_

DATE \_\_\_\_\_

# HIV *living*

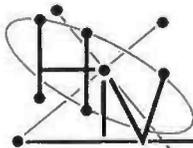


## We can support the way you're feeling

**Being young and gay and HIV+ is no picnic. But then, it's not something you have to deal with on your own. Other guys face those same confusions about sex and health and friends and drugs. That's why it makes sense to get together and talk about what it all means. It also helps.**

**Support groups for positive young men. They're safe, friendly and could be just what you're looking for.**

**Call Peter or Russell on 283 2453  
or Brent or Aldo on 283 2599  
or if you're deaf call TTY on 283 2088**



**SUPPORT PROJECT**

