

# Talkabout

Newsletter of People Living With AIDS Inc.(NSW)

*Where we speak for ourselves*

ISSN 1034-0866

## TEN YEARS INTO THE EPIDEMIC

We mourned and reflected at the Candlelight Rally on May 20th (right, in Sydney 2,000 people attended).

**We also take action**

**See inside:**

D-Day ..... p2

Importing drugs .... p26

**and we learn how  
to survive**

Low income living... p8

Housing without  
headaches .....p11

**....we even have fun!**

Part 2 of our new  
soap opera ..... p19

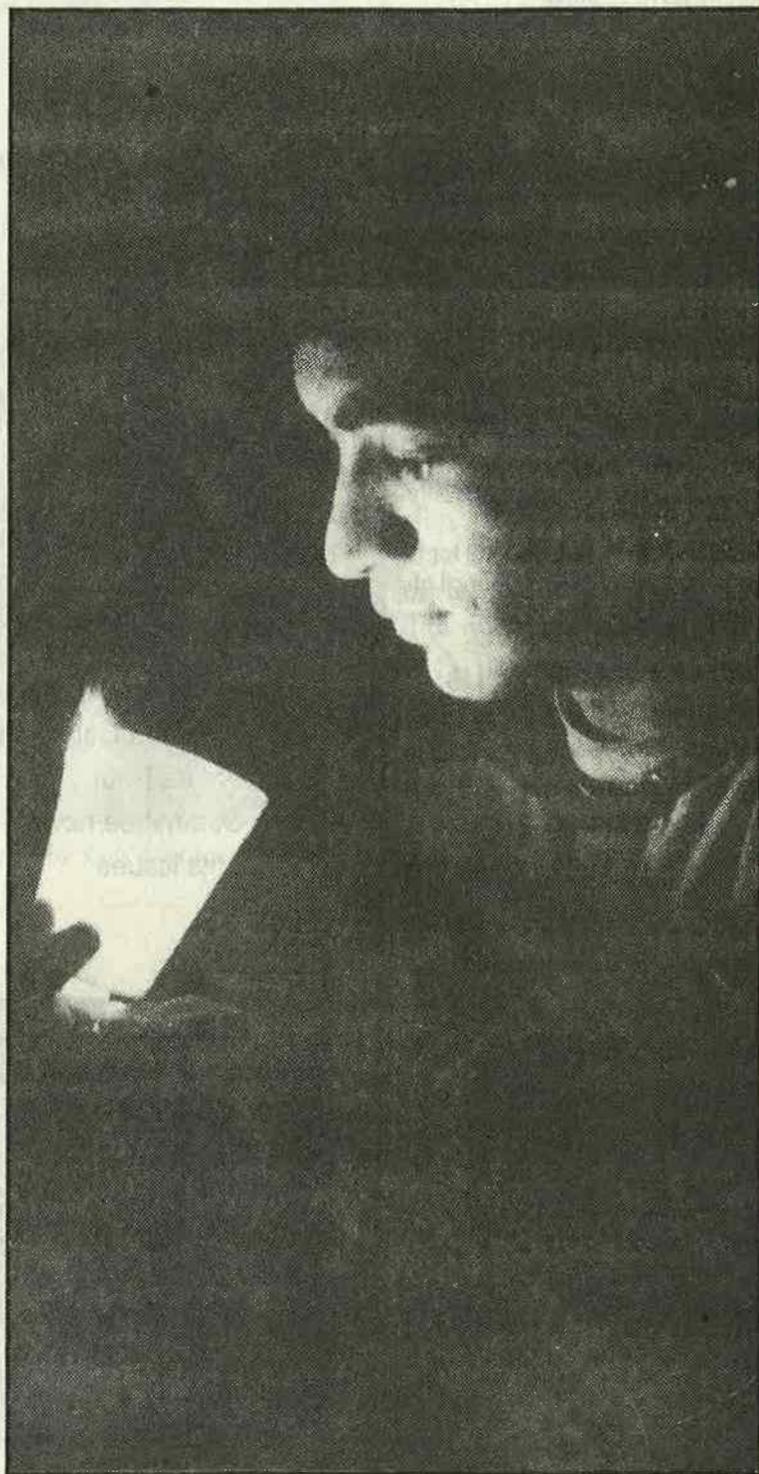


Photo: Jamie Dunbar

**DON'T FORGET TO FILL OUT OUR READERS' SURVEY p.15**

Vol 2. No. 3. JULY/AUGUST 1991

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TALKABOUT is published every two months by People Living With AIDS (NSW) Inc. All views expressed in TALKABOUT are the opinions of the respective authors and not necessarily those of PLWA (NSW) Inc., its committee or members.

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### Commonly Used Abbreviations:

PLWA: People Living With AIDS  
(NSW) Inc.  
PLWAs/PWAs: Primarily people  
infected with HIV. Also sometimes  
used to include others affected by  
the virus.

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The next issue of *Talkabout* will focus on:

**treatments  
and pregnancy issues  
Contributions welcome**

The Final deadline is August 8

Send contributions to PO Box 1359, Darlinghurst 2010.

Newsletter Working group meeting for the next issue is on:

**Thursday, August 8**

at the PLWA office, 2nd floor, ACON Resource Centre,  
188 Goulburn St. Darlinghurst.

## Update on ACT UP Update on ACT UP

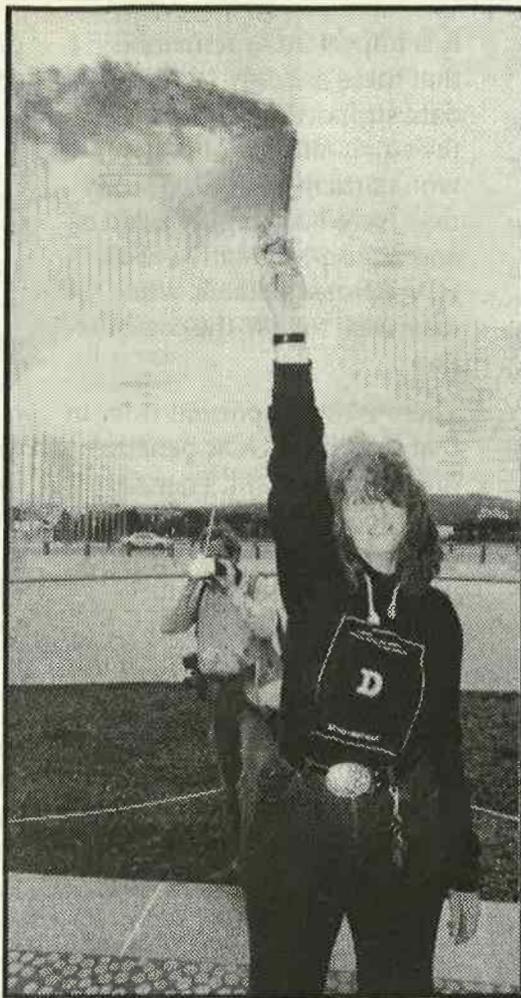
On June 6 ACT UP delivered a simple message to Brian Howe, deputy PM and Minister for Community Services, Health and Housing. The message was that potentially life saving treatments for people with HIV and AIDS be made immediately available to people in Australia.

Intensive media coverage of demonstrations by ACT UP members and supporters in Sydney, Melbourne and Perth, as well as dramatic protests at Canberra in Parliament House ensured that all of Australia heard the *real* truth about the AIDS crisis in Australia - that the Minister for Health is murdering people with HIV and AIDS because he refuses to allow speedy access to treatments available overseas.

The Minister responded to our demonstrations by saying that ACT UP was 'misleading' the Australian public about the number of treatments available to treat AIDS in this country because "most of the treatments available overseas were drugs used to treat opportunistic infection associated with the virus". **Isn't the Minister aware that opportunistic infections (OIs) associated with AIDS cause many more deaths than AIDS itself!**

Howe also claimed that treatments for OIs were available "by a variety of means". This is bullshit Brian Howe! If they are available, tell people with HIV/AIDS how they can get them!

One of the more insidious comments made by



*D-Day, Canberra: Lois does something about AIDS.*

ish and unreasonable by requesting that they have access to the best available treatments?

Surely one of the benefits of our nationalised health system is that all Australians are treated equally. Is Howe suggesting that people with HIV be treated less equally than others? Howe's comments are an attack on all people with HIV/AIDS and deserve to be condemned.

ACT UP's D-Day campaign to improve access to HIV treatments may be over but we are determined to continue our push for greater availability for treatments in Australia.

**ACT UP! WE WON'T WAIT!**

Howe on the day was that Medicare has enabled people with HIV/AIDS in Australia access to a better standard of care than that available in America. (Read: so how dare they complain!)

While this claim is undoubtedly true, what is the *real* point behind such comparisons? Does he expect people with HIV/AIDS to be *grateful* for the fact that the Australian government drug regulations *delayed* the approval of AZT for *two years* after the only treatment known to slow the progression of AIDS became available in America? Would he prefer that people with AIDS did not have access to the best treatments and care available?

Every year people in this country make numerous demands on the healthcare system. Why does Howe single out people with AIDS and infer that they are being self-

Photo: Jamie Dunbar

## ddC & St Vincent's

It has come to our attention from ACT UP that there is some confusion in the community concerning recommendations by HIV specialists for the use of ddC obtained through buyer's clubs.

This has been discussed by the HIV Medicine Unit at St Vincent's Hospital, Sydney. We have agreed to discuss the following issue with our patients so that they can make informed choices.

**1. Efficacy of ddC.** ddC appears to be an effective anti-retroviral drug at least based on its positive effects on T4 cell counts and reduction in p24 antigen ( a measure of HIV). It is likely to be licensed later this year for two indications. Firstly it will be given for people who cannot tolerate zidovudine (AZT). Secondly, it may be recommended for people who are tolerating AZT and wish to take ddC in combination with AZT. This is based on the results of the now well known AIDS Clinical Trials Group study 106, which showed durable responses in T4 and p24 antigen for people on the combination.

It is important to remember that these are only laboratory data supporting its use and the small number of patients who participated in the study may have been highly selected and not representative of all HIV infected persons who may wish to take the combination.

There is one important rider in that ddC has POOR penetration into the brain. Therefore it may not protect the brain from the direct effects of HIV and we would caution against using ddC as the sole antiretroviral agent especially in people who can tolerate zidovudine. Similarly, the use of very low doses of zidovudine in combination therapy is discouraged.

*On the balance of evidence the HIV Medicine Unit at St Vincent's hospital supports the use of ddC for the above indications.*

**2. Toxicity of ddC.** Like any drug, ddC is not without toxicity. The predominant toxicity is peripheral neuropathy which results in pain and numbness in the fingers and toes. If it occurs it can have a 'coasting' effect. In other words it can become worse temporarily on stopping the drug before there is any im-

provement. In most cases it appears reversible if the drug is stopped early enough.

Because of this toxicity it is imperative that people do not take ddC with ddI; ddI can also cause peripheral neuropathy. Therefore the chances of having a serious and disabling peripheral neuropathy while taking both drugs together is dramatically increased. Patients who are currently participating in ddI alpha Australian Videx or any other ddI study should not take ddC without consulting their HIV specialist.

**3. Dose of ddC.** The recommended dose is up to 0.75mg three times a day at approximately 8th hourly intervals. The capsule come in 0.25mg. Patients should take 2-3 capsules every 8 hours. The correct dose is not absolutely clear and this is at best a good guess based on the available information. Higher doses are associated with a greater frequency of peripheral neuropathy.

**4. Monitoring of ddC.** Patients who decide to take ddC should inform their HIV specialist or primary care doctor. T4 cell counts and p24 antigen levels should be monitored every 4 weeks to

## LETTERS

obtain some evidence of whether the drug is working adequately for the individual or not.

**5. Buyer's clubs.** It is not ideal to take a drug that is not produced by an ethical pharmaceutical company. It could be impure and therefore not fully effective or it could be contaminated with toxic substances. Moreover it costs money, some of which could be used for other important aspects of overall HIV care, such as good nutrition. We do NOT approve of this situation but under the circumstances feel there is no alternative. We are doing our utmost to make sure that ddC from the approved ethical pharmaceutical manufacturer (Roche) becomes available as soon as possible. We are aiming for September 1991 but from past experiences, delays may occur. We presume it will be available at no cost to the patient. Once it becomes available we as HIV specialists will NOT recommend that patients use ddC from buyer's clubs.

We trust that this gives the community some guidelines as to the position of the HIV Medicine Unit at St Vincent's Hospital. We hope that patients will use these guidelines to discuss the issue with their HIV doctor in a frank and honest manner. We ask that some of you consider partici-

pating in clinical trials of ddC which may take place later this year as the true role of this drug in the treatment of HIV infection is not known. Lastly, we are committed to reducing the burden of the epidemic for the HIV - affected community whom we all serve.

Yours sincerely,  
David A Cooper, Bruce J Brew,  
Deborah Marriott, Sam  
Milliken, Ronald Penny,  
Consultants, HIV Medicine  
Unit, St Vincent's Hospital,  
Sydney

### Approach with caution

I felt compelled to respond to your article 'Oral sex - Bottling the taste' published in Vol. One, No. Two.

Now that it is evident that others are interested in lobbying the condom manufacturers for more desirable tasting condoms, I would like to suggest a working group be established to bring this to fruition. I personally believe we should also lobby Australia Post to change the flavour of its stamp gum. Yuk. Can't we have penis, cum, vagina or my fave, *armpit* flavoured stamps. It's our right!

Yours etc,  
Dick Cheese

### Requests

My name is John, I am 24 years old and have been HIV+ since I was 17 years old. Recently I decided to resign from fulltime occupation due to my health and due to these hard economic times find it very hard to keep afloat. I'm writing in hope that someone out there might have accomodation available who needs someone to help with the cleaning or day-to-day activities of maintaining a house in return for moderate rent. I also offer emotional support for another HIV/AIDS person who might be able to meet my difficulty in finance.

Or if anyone needs any housework done, either for a financial reward or some other arrangement from which we can both benefit, this would be a help to me too.

Either of the above requests would make life a lot easier for me and would be helping the other person too.

John Todd, ph:(02)516 2662.

Dear friends,

I am an inmate of Maitland Jail. I am 45 years old and am interested in corresponding with a person or persons with HIV as I have just finished the CEIDA Peer HIV Educators course. Thank you for taking

the time to read this.

**John Endicott,**

**PO Box 71, East Maitland  
NSW 2323.**

Nicole Pearce has also recently completed the same CEIDA Educators course (taught by Mac MacMahon) and would also like to correspond with an HIV+ person. Nicole is 26, a transsexual in Maitland Jail. She can be written to at:

**PO Box 71, East Maitland  
NSW 2323.**

**Artist seeks gay male living with AIDS, having defiantly positive attitude, for painting project. For details, ph: Anna 523.9244**

## SHARE ACCOMMODATION



The Community Services Unit of the AIDS Council of New South Wales has set up a share accommodation register for people affected by HIV/AIDS and others seeking accommodation. This FREE service is not restricted to people infected with HIV. For more details please phone the Accommodation Officer on (02) 283 3222

## Submission (for Terry Giblett)

The morning I began working again  
reviewing laws licensing drugs for AIDS,  
the second review in six sullen months,  
Philip's lover finally lost all sight;  
At work I found Jim tired by ten, coughing,  
lightly protesting it would pass; myself  
alert at every sneeze from Stephen; and  
David not in again, his lover in  
Ward 7 undergoing tests - he'd lost  
all movement in his limbs one night last week.  
Don phones from Rome, I wait, the question comes  
'how's Mame'. Alive .... okay, I say, guilty  
not knowing more, but I get scared to ask.  
I saw Andrew on Oxford St, he walked  
slower than I found comfortable. I tossed  
up if to say hello or not, afraid  
of finding him, too, ill. He was. And Scott  
looks thin, and Jeff's gone home to Moe. Mike died  
before New Year, six deaths last year of friends.  
My tally's small, or used to be. No more.

And still they talk, these regulators and  
these Ministers, of saving us from our  
desperation; pronounce the shibboleth  
consumer safety. What's there to protect?  
Pandora's box lies open. Plague and pestilence  
have ravaged us for ten black years.

Ten years.

You failed us then. Outcasts, we seized control,  
challenged our fragile new identity  
with strictures more severe than quarantine;  
cared for our sick when you left trays of food  
on floors; embraced, held, kissed when you wore gloves  
and gowns; buried our dead while you refused  
us a last look. You have no voice in this.

These days are hard, are anvils. We are steel.  
This our ill-tempered edge keens blow by blow.

**Paul van Reyk**

# TERRY GIBLETT

**15.2.61 - 22.5.91**

It is with an enormous feeling of sadness and loss that PLWA NSW acknowledges the death of Terry Giblett.

Terry was no less than a trailblazing pioneer in the fields of education, care, support and advocacy for people with HIV infection in NSW & Australia.

Terry's list of involvements in the HIV/AIDS area reads as a daunting repertoire of energy spent and expertise shared. Coming from a background of adult education in the government sector, Terry became a volunteer with the very first Ankali training and remained an active volunteer for more than two years.

Terry also co-ordinated the first of Sydney's World AIDS Day events; was instrumental with Andrew Carter in founding the Australian Quilt Project; organised the Living Well II conference that was held in Sydney 1989, was a catalyst to the establishment of PLWA NSW and served on the committee for a period of one year; he also was the driving force behind the establishment and development of the HIV Support Project of the AIDS Council of NSW. The success and scope of his list of achievements is indeed overwhelming.

Terry taught us in many instances that as people with HIV infection we do indeed on occasion need to assert ourselves as informed people with definite rights to service provision and resources. This Terry often did on behalf of others or himself, sometimes at the expense of criticisms to his personal integrity. His commitment and dedication in these instances illustrated an exceptional strength of character. Terry also had the ability to be self righteous, stubborn and domineering.

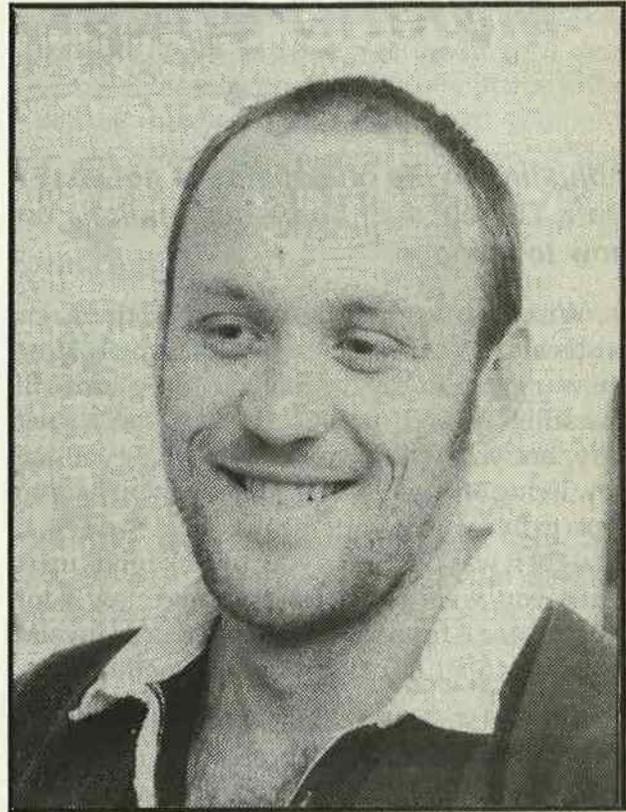


Photo: Jamie Dunbar

The people living with AIDS movement in Australia owes a great deal to the efforts and energies of Terry Giblett. Terry you challenged, inspired and loved us. We miss you greatly.

## Andrew Carter

It was with great regret that we heard of the death of Andrew Carter on June 20.

On June 10 this year Andrew received the Order of Australia in recognition of his work in the founding and promotion of the Australian AIDS Memorial Quilt.

Time has not permitted that we publish an adequate tribute in this issue, but one will appear in the next *Talkabout*. PLWA extends its deepest sympathy to Andrew's family and friends.

## Making ends meet

**Adjusting to life on benefits is not easy - Mark Tietjen\* has some suggestions on how to manage.**

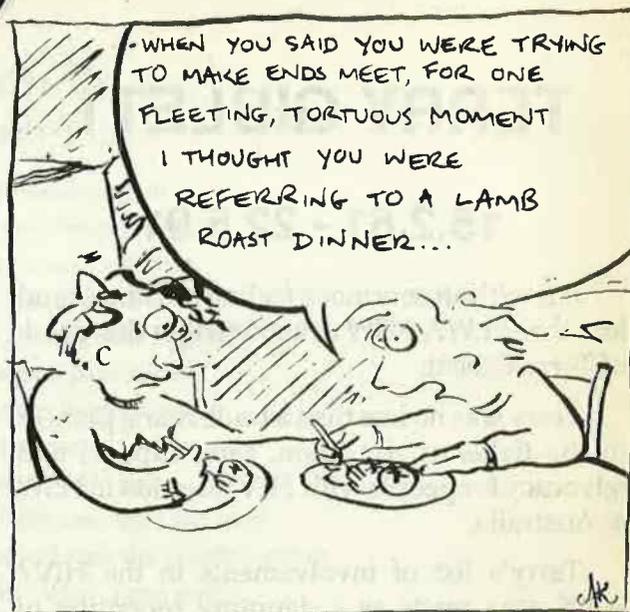
With the onset of real illness, one of the major problems PLWAs face is the loss of income. How are you going to pay the rent, pay the phone bill and still buy food, etc etc?? It takes time, it's not easy, but you will have to accept that you are now living on a very low income and you have to learn to live within your means. What to do? you thought it was difficult trying to make ends meet when you were earning wages and now your only income is from Sickness Benefits or an Invalid Pension of \$301.60 per fortnight, sometimes less.

The first step is to realise that if you are unable to work and have no resources, then these benefits are your only income and you will have to change your whole lifestyle to suit this level of income. Stay optimistic, but remember that very few people win lotteries. Learn to make some sacrifices and to cut down spending.

**PLANNING** is one of the most important aspects of surviving on a low income. We all know what it's like, even when you're on average wages. Come payday, you pay off a few bills, have a drink, do some shopping then Hey! - no money until next payday, and no food in the house.

Sit down and make a list of your major expenses. Include all the regular bills such as rent, phone, electricity etc and regular expenses such as food, vitamins etc. Work out how much you need to set aside for each item every pay day so that you will have enough when the bills arrive.

**TALK** to people and ask them how they manage. You can let people know what your situation is without having to disclose your HIV status. Beg, borrow or scrounge. If you let your



Graphics: Alison Wiseman

family and friends know how difficult it is to make ends meet, they may surprise you. Talk to the support organisations (see list). They are constantly receiving donations of all kinds of stuff to be passed on to PLWAs. Go to Maitraya Day Centre and talk to others who are in the same situation as you.

Use **COMMON SENSE**. I know someone who moved into a new Dept of Housing flat on a Friday and had no fridge and only a few kitchen utensils. So he ordered pizzas to be delivered over the weekend at about \$16 each and then expected to be reimbursed as he saw this as the only way he could eat. There are other ways.

**RENT**. Apply to the Department of Social Security and to the Bobby Goldsmith Foundation for rental assistance. Inquire about priority housing at the Department of Housing - you might be eligible for it. (See story p13). To qualify for it an "extreme need" must exist. Most applications from PLWAs are on the basis of lack of resources (no money) and health being affected by inadequate accommodation (such as overcrowding).

If you have difficulty paying your rent, **COMMUNICATE** with your landlord. Apart from food, rent should be your highest prior-

ity. If you don't pay, you get evicted and it is very hard for any of the organisations to help if you are way behind in your rent.

**FOOD.** With ill health, nutrition is important. Some organisations are happy to help provide food at low cost. Learn to shop around for the bargains. Read the leaflets that arrive in your letterbox. Supermarkets are much cheaper than the corner shop. Prepared foods are more expensive and less nutritious than preparing the same thing yourself. Go to Maitraya Day Centre on Tuesdays (soup) and Fridays (full lunch).

**BILLS.** Electricity, gas, phone. Learn to be economical in the use of these services. Three local calls a day = a \$60.00 phone bill. No organisation will give you assistance to pay phone bills, no matter whether it was you or 'friends' who made the calls. If you can't pay, you lose your phone. To keep your electricity bill under control in winter, only heat the room you are using rather than the whole house and close the doors to keep the heat in.

If you have a large bill and are wondering how you're going to manage, ring the service provider and talk to them. You would be surprised at what arrangements can be negotiated. If you explain that you have no resources and are on benefits, (mentioning the Invalid Pension helps) and how important the service is to your health and wellbeing, they will usually try and help - perhaps by letting you pay in instalments.

**DEBTS.** Credit cards, loans etc. Again, communication is important and people can be very

helpful if you explain your position. For example, you might have a large credit card debt which increases with every statement due to the interest charges. If the credit card company knows your situation they will usually stop charging interest and re-negotiate for you to pay it off at a rate you can afford (eg \$10 per pension day).

The important thing is to seek help as soon as your income stops. If you keep running up debts hoping that your financial situation might improve, you may end up with large debts which no welfare organisation can help you with.

Make the most of your situation. If you are not already on a Pension but would qualify, seriously consider it. The DSS are in the process

of trying to cut down on the number of people on Sickness Benefits and have streamlined the process of changing to a Pension. They are working hard to make things easier for PLWAs. There are many more benefits for Pensioners. You get Pensioner rates on an incredible range of goods and services.

Don't be scared of a Pension. If you are able to go back to work, the Pension can easily be stopped and re-started again at a later date. You can also continue to work part-time without losing your pension unless you earn more than \$683 a fortnight for more than twelve weeks. As long as you earn less than this amount, you remain eligible for all the benefits of a pension such as cheap fares etc.

Don't leave it too late to ask for help. Use these services - that's what they are there for.



LIVING IN REDUCED CIRCUMSTANCES

\* Mark Tietjen is a PLWA committee member who writes from his experiences working with and talking to PLWAs, his experience at BGF, a background in commerce, and from periods in his own life when he found it difficult to make ends meet. He says "I am also very much aware that much of this advice is 'easier said than done'. This can be a very emotional issue and when the world is crashing down around your ears it is very difficult to put your pride and dignity on hold and face the reality of the situation." We look forward to feedback and hints from readers on how you get by.

### Where to get help:

**Bobby Goldsmith Foundation** - a charity providing mainly financial assistance for people with category III and IV HIV infection in the form of rent assistance, assistance with electricity, gas and phone bills and loans of electrical appliances. ph (02)360 9755.

**Care Force** - financial assistance, food, accommodation, clothing. ph (02)895 8051.

**Credit Line** - run by Life Line providing financial counselling. ph (02)264 5644.

**Food Distribution Network** - deliver fresh fruit, vegies and meat at low cost. Ph (02)699 1614.

**Maitraya Day Centre** - Day centre for PLWAs. A friendly place to drop in and meet other people in the same situation as yourself. Free lunch served Tuesdays and Fridays. ph (02)361 0893, 396 Bourke St Surry Hills.

**Salvation Army** - emergency accommodation, counselling, food, clothing. Ph (02)331 600 or toll free 008 251 008 (24 hours).

**Smith family** - Financial/material help and advice on welfare and accommodation. Ph (02)550 4422.

**St Vincent de Paul Society** - financial assistance, food, clothing, bedding, furniture, accommodation. Ph (02)560 8666.

Also remember you can turn to your local friendly social worker at the DSS or your hospital.

## Expedition Alligator '91

Twenty men and women living with HIV/AIDS are undertaking an expedition from London via Darwin to Uluru (Ayres Rock)! The original concept of the expedition was envisaged by an expeditionary worker who had a wide range of experience of applying such activities to the needs of particular social groups.

After consultation with people in the field of HIV/AIDS, it became apparent that an expedition could provide a unique opportunity for people living with HIV to challenge both their own status and society's understanding of AIDS.

But let them tell the story for themselves:

*"We as a group of people living with HIV/AIDS are undertaking this expedition with the*

*intention of creating a world-wide network working together to destroy the prejudice and ignorance surrounding HIV and AIDS."*

Expedition Alligator arrived in Australia June 17. The Northern Territory AIDS Council will be assisting the expedition when it arrives and has opened an account for donations. If you wish to make a donation to help fund the expedition, please complete a deposit slip at any branch of the National Australia Bank.

The Account name is "Expedition Alligator '91"

The Account Number is 051039449  
Bank/State Branch is 085118

For further details contact Iain Butterworth or John Robinson at NT AIDS Council (089)411 711

# Housing without headaches

***Housing - what a hassle it can be. How to find a place that's comfortable, affordable, convenient, with housemates who are compatible? Househunting is something that many of us dread, but you can make it a bit easier by seeking assistance from Fred Oberg, the Housing Officer for the Housing Project at ACON.***

The Housing Project offers a range of free services to weary househunters:

If you are interested in shared accommodation the **Share Accommodation Register** is the best place to start. The Share Register lists places available in shared households. The Register is open to everyone. There are usually about 40 listings and these can change daily.

The Register does not place people in housing, nor does it offer rent subsidies. It is a referral service which can put people in contact with others who are offering accommodation within the private rental market. Fred and Peter (the volunteer worker), will also refer people on to other services at the AIDS Resource centre, such as PLWA or other ACON projects.

The Share Register operates by appointment on Tuesday, Wednesday and Thursday during office hours, but appointments can be arranged outside these times if necessary. Contact Fred on 283 3222 extension 246 to set up a time.

The **Glebe Project** provides medium term interim housing for people with an accommodation crisis. It began in 1989 when a block of six flats was donated for use for five years at a 'peppercorn' lease. So far about 30 people have used the flats, usually for periods of four to seven months while they await their Department of Housing allocation. A nominal rent is charged to cover costs. Applications are open to all people with HIV / AIDS. A prerequisite is that

applications must be Priority Housing Approved by the Department of Housing.

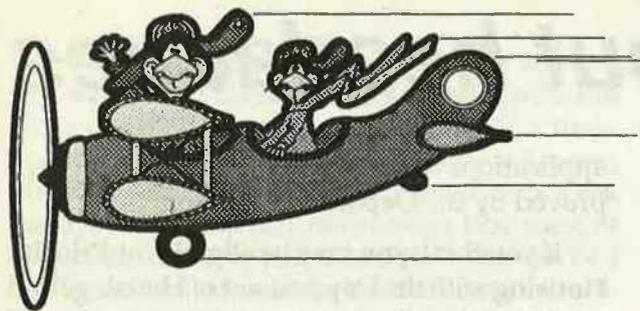
If you think you may be eligible for **Priority Housing** with the Department of Housing Fred can help you fill out your application. He will also help you prepare a package of information to go in with your application, which includes such things as a letter from your doctor, support letters from service agencies (such as ACON), income statements etc. You can make an appointment to do this at any time.

ACON is requesting two bedroom facilities be provided for PLWAs so that a room is available if it's necessary to have fulltime carers stay with a client; and that housing be within half an hour of public transport to the client's medical facilities. The Department has not yet met these requests but, says Fred, it has been very helpful and communications between ACON and the Department are pretty good. Unfortunately the waiting period for priority housing may be as long as six - eight months.

Fred also looks at **housing policy** in general and how it affects PLWAs. The Housing Project works on this with the AIDS Housing Action Group (AHAG) which is based in Victoria. There are not many services available to HIV+ people and together they are looking at developing proposals for such things as hostel accommodation.

Fred is also the convenor of the **Accommodation Crisis Group**, which is an inter-agency group of social workers, Department of Housing staff and HIV-related service workers. The group meets about every six weeks to discuss issues and update information regarding housing issues for PLWAs.

If you have any inquiries about the services offered by the Housing Project call Fred Oberg during office hours on (02)283 3222, ext 246.



# Flying High

## Wheelchair travel

**A few months ago Mike Winter wrote in *Talkabout on train travelling for people with disabilities*. Here we publish the second part of his article which deals with other ways of getting about.**

Coach travel is the cheapest way to get around the country, but it has drawbacks for people with disabilities (PWDs), especially as invariably drivers aren't the best at coping with PWDs. I would recommend coach travel to walking PWDs, but think twice for those with mobility aids or equipment, unless you really can't afford alternatives. Many NSW country areas are now linked by SRA buses. These may be a bit uncomfortable for the 'link ride', but this may be worth it to reach your intended destination. These drivers tend to be most helpful and some areas have special taxis to assist on arrival.

If you decide to travel by coach you should plan well ahead and unless you feel confident travelling alone it may be a good idea to take an aide with you. Always try to book seats toward the front of the bus, unless travelling long distances, when it's advisable to be seated as close to the toilet (if there is one) as possible.

Many coach lines do not allow eating or drinking on their coaches but this can be overcome by informing the company that you need regular food or fluid intake. Travelling by coach can be very exhausting for those with MS or other illnesses. At meal stops the

pack syndrome sets in with ravenous passengers pushing and shoving to get into a queue, and they will bowl you over without any qualms. To avoid this, pack sandwiches and a thermos flask before you leave or try to chat up a fellow passenger to assist.

If you have a wheelchair you can have it loaded into the luggage compartment. Warn the driver NOT to place items on top of it - sounds bad, but they do, and the chair could be damaged. Make sure they secure it properly.

When travelling by coach, especially long distances, remember that many arrive in cities either late at night or early morning. Often there are no people around to assist and there may not be any taxi connections either.

Air travel is a little easier, again planning is the key word. Most carriers on internal flights can accommodate wheelchairs but may charge extra for electric chairs.

Air travel is of course quicker, but you may sometimes be left on the plane while someone goes off to get a forklift to get you down from the plane! There have been a few horror stories of PWDs left on planes for an hour or so, with cleaners trying to clean around them, so it is essential that information is supplied to the airline on booking, and do not be afraid to tell stewards just what your requirements are when you board.

You can ask the chief steward to ask the

pilot to radio ahead to your destination so that they can prepare for your egress from the plane. It is worth noting for instance that not all the corridors at Sydney Airport have direct access from planes to arrival terminals. Most international terminals have access, toilets etc, however in Australia they are badly signed and in some cases not signed at all, so be prepared to ask.

Internal terminals have some disability facilities. Contact the Airport Manager at Sydney Airport, Mr Snelling, for information. The Sydney administration can also contact your airport of destination to check on access.

Small airlines and small aircraft may present problems for electric chairs. Where possible, even though you may lose some independence, use a manual chair unless the airline says they can accommodate an electric chair. To take it for granted that they can carry the chair may cause delays and inconvenience for you.

For electric chairs to be transported by air, batteries must be of the sealed type, within the Australian standards recommendations and air safety requirements. If you are unsure check with the carrier and your usual battery supplier. If the wet celled type are used arrange for a battery supply to be awaiting your arrival. This can be arranged through some community centres or health departments.

If you have special needs, (such as dietary) it is essential to inform the carrier in

advance. Toilets can present problems on aircraft, they are like the closets on trains, but this can be an advantage if you are able to stand a little as the walls will support you. Otherwise use a urinary bag which is easily disposable, such as colveen bags. Stewards are always willing to help. They are the professionals in the sky and though privacy is what we all expect, sometimes it just isn't possible so don't be afraid to ask for help on or off the toilet or assistance to and from one.

If travelling to Tasmania, the Abel Tasman from Melbourne is excellent value. It

has two suites for PWDs and access to the ship both in Melbourne and Hobart is well catered for.

On ship, lifts can take one between decks and dining areas. Inform the purser of your

needs. You may have to share a berth with another PWD, but the berths are comfortable and made to Australian and International standards. Special rates are available to PWDs so ask for them when booking. The Tasmanian Travel Centre can provide information about available facilities.

If linking the Abel Tasman in Victoria, remember that most of Victoria and Vicrail is totally accessible and concessions apply for NSW pensioners.

The Tasmanian Spastic Society, 112 Gormanston Rd, Moonah 7009, Ph (002) 72 0222 can advise you of access in Tasmania and travelling information.

Bon Voyage.



# HIV+ globetrotting

## Jonathon Smith from STA Travel passes on a few tips for HIV+ travel.

People who are HIV+ need not be deterred from travelling, provided they are aware of the vagaries of different countries' entry procedures.

The debacle at last year's International AIDS Conference in San Francisco highlighted the need for some countries to alter the somewhat ambiguous wording on their visa application forms.

At STA Travel, we've given a prize for Best Costume at Mardi Gras for the past four years. This has always been to Los Angeles or San Francisco until this year, when, in conjunction with the Mardi Gras committee it was decided to give a travel voucher to a destination of the winner's choice.

The application for a United States visa still asks the applicant if they suffer from a contagious disease, giving tuberculosis as an example. At present, only applicants for US permanent residence or citizenship are required to take a blood test.

Japan no longer requires applicants for a working visa or for residence to take blood tests.

Anyone travelling to remote parts of Africa, such as Zaire, may be advised to take a pack of their own blood with them, (this costs about \$200 for the freeze-pack), as a high percentage of blood from African hospitals is infected, if a transfusion is required. Travel insurance is highly recommended and most tour operators make it compulsory. Why leave home without it???

If a passenger needs to take medication with them they may need to alert the airline,

depending on the destination. Some of the Asian countries, especially, may not take too kindly to inspecting bags with unfamiliar tablets in them. If this is the case, we can arrange a 'meet and greet' service with the airline concerned. The majority of airlines flying into Australia will provide this service gratis.

The Department of Foreign Affairs and the Department of Health send out monthly bulletins to travel agents advising if there is a 'travel advisory notice' applying to a region or country. An excellent source of information on general health matters relating to overseas travel is the Traveller's Medical Centre in the Dymocks Building in George Street. You need to phone for an appointment.

Many of our consultants are well-travelled and have up-to-date information on the latest requirements for overseas countries.

### Just the break you've dreamt of!

#### Pine Hill Farm Holidays

#### for people with HIV

Pine Hill farm, situated in the hills above Bathurst, offers a relaxed holiday with plenty of fresh air and no stress.

You can be as energetic or as lazy as you like; guests are invited to share in the day's activities, go riding, fishing, bushwalking, or just relax by a roaring log fire.

Only a few guests are accommodated at any time. Confidentiality and comfort are assured.

**A limited number of special subsidised places are available for people with HIV** - you are invited to stay at Pine Hill for about \$15 per day (normal cost \$65).

For details and bookings, contact PLWA on (02)283 3220.

# Talking about *Talkabout*

## Readers survey

As *Talkabout* is now two and a half years old we thought it was about time we found out just who is out there reading the magazine. We know you're picking it up, because of the dwindling number of copies on our shelves here at PLWA. But do you actually read it, and what do you think of it? While we get plenty of verbal feedback on *Talkabout*, we decided it would be helpful to get some more detailed information about who is reading *Talkabout*, and why; what you think of it; and what you want from it in the future.

This will help the newsletter working group decide what should go into *Talkabout* each issue and what sort of changes we need to make, (if any). It will also be useful in helping to convince the funding body that *Talkabout* plays an important role - and we think it does - and that it should be given continued support and encouragement.

We would greatly appreciate you taking the time to fill out this survey. It is anonymous and you don't have to answer any question you don't like. You don't even have to buy a stamp if you write this on the envelope: **Repy Paid 595, Talkabout Survey, PO Box 1359 Darlinghurst 2010 NSW** (This applies only in Australia to standard size envelopes.)



AGGRESSIVE MARKETING

So pull out these pages - it won't damage the rest of the magazine -and fill it in NOW!

### Part 1:

#### WHO IS READING TALKABOUT?

1. How old are you? (please circle your answers)

- a. Less than 20
- b. 20 - 29
- c. 30 - 39
- d. 40 - 49
- e. 50 or older

2. Your gender?

- a. female
- b. male
- c. transsexual
- d. I do not wish to respond

3. What is your sexual preference?

- a. Gay
- b. lesbian
- c. bisexual

(Continued overleaf)

- d. heterosexual
- e. other
- f. I do not wish to respond

**4. Where do you live?**

- a. Sydney
- b. NSW (other than Sydney)
- c. state other than NSW
- d. country other than Australia

**5. What is your postcode?**

**6. What is your first language?**

**7. What is your situation? (circle more than one if appropriate)**

- a. person with HIV/AIDS
- b. friend, partner, relative of person with HIV/AIDS
- c. health professional involved in care of people with HIV/AIDS
- d. employed community based HIV/AIDS worker
- e. volunteer for community based HIV/AIDS organisation
- f. other (please specify) \_\_\_\_\_

**8. How did you hear about Talkabout?**

- a. a friend
- b. health care worker
- c. social worker
- d. picked it up at a service (eg ACON)
- e. picked it up at a gay venue
- f. Other (please specify)

**9. How long have you been reading Talkabout?**

- a. first issue
- b. less than 6 months
- c. 6 months to 1 year
- d. over 1 year

**10. How do you usually get your copy of Talkabout?**

- a. subscription
- b. clinic
- c. hospital
- d. doctor's surgery
- e. bookshop
- f. gay venue
- g. other (please specify)

**11. How many people read your copy of Talkabout?**

- a. self only
- b. two
- c. three
- d. more than three

**12. If you are a worker with HIV/AIDS clients, how do you use Talkabout in your work?**

**Part 2:**

**WHAT YOU THINK ABOUT TALKABOUT**

**13. Do you find Talkabout easy to read and understand?** Yes/No

Suggestions:

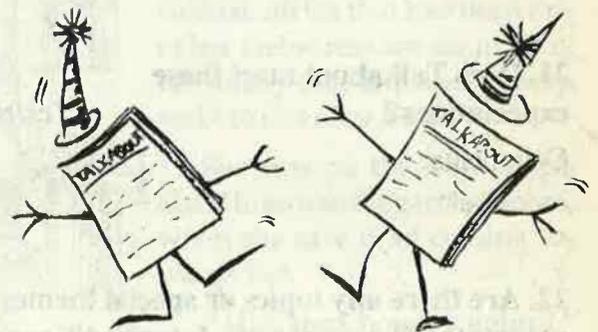
**14. Do you like the design and layout of Talkabout?** Yes/No

Suggestions:

**15. What do you like most about Talkabout?**

**16. What do you like least?**

**17. Do you like issues with special themes eg Women, Positive Sex?** Yes/No



**18. For each of the sections of *Talkabout* please do the following:**

- indicate whether you read it or not - Yes (Y) or No(N)
- rate each section you read on a scale of 1 to 5 (where 1 = dislike and 5 = like very much)
- indicate whether you would like more (M), the same (S) or less (L) of each.

	READ (Y/N)	RATING (1 - 5)	AMOUNT (M/S/L)
a. letters			
b. feature articles			
c. treatments information			
d. profiles			
e. good health			
f. soap opera			
g. diary/contact lists			
h. news			

**Part 3:**  
**TALKABOUT IN THE FUTURE**

**19. Why do you read Talkabout?**

**20. What expectations do you have of a newsletter for people living with HIV/AIDS?**

**21. Does Talkabout meet these expectations?**

Yes/No

Comments:

**22. Are there any topics or special themes you would like covered in future editions of Talkabout?**

**23. How often do you think Talkabout should be published?**

- a. monthly
- b. bi-monthly (as it is now)
- c. quarterly

**24. Have you ever contributed to Talkabout?**

Yes/No

**25. Would you like to contribute to or get involved in some way with Talkabout?**

Yes/No

**26. Is there anything that would make it easier for you to contribute to/get involved with Talkabout?**

- a. providing typing facilities
- b. picking up things from you at home
- c. offering advice/encouragement
- d. other

**27. Any other comments regarding Talkabout?**



Graphics: Allison Wiseman

By Dara Toad

## Chapter Two

*The story so far.... In the heart of Sydney the Bohemia Apartments are home to Nancy, Brad and Nigel. Kurt, a friend of Nigel, has stayed overnight after Nigel's housewarming party - on the sofa. Nancy has been thrown into a state of anxiety by the imminent arrival of her younger brother, Robbie - how can she tell him she's HIV+? Nigel observes her return with her brother - where has he seen her before? .....to answer these questions, read on.*

Nigel stood over Kurt. "Wake up. You're making the place look untidy." Kurt moaned and, without opening his eyes, rolled onto his back. Nigel could see the partial erection through his y-fronts. Too drug-fucked to care, Kurt ran his hand down his chest and began rubbing it.

"Come on, Kurt. Cut it out." Nigel bent over him and shook his shoulder. Kurt groaned and tried to pull Nigel onto him. They tussled for a moment, their faces close, their breathing sharp. Nigel finally pulled himself away and, taking the garbage from the kitchen, left the flat, and Kurt to himself.

Nancy couldn't get out of her apartment quick enough. Her apprehensions about seeing Robbie had been justified. However much she tried to be rational and calm about the situation,



there didn't seem to be any easy way to tell her little brother that she was HIV positive. Since his arrival she had managed to avoid, skirt round, skip over or simply played dumb when he started to question her about what was going on. It was getting too much, she was exhausted! She'd made her escape.

Nancy decided to dump the rubbish off (as that had been one of her feeble reasons for making her timely exit) and then go for a walk to clear her head.

She was on the front steps, about to go into the garbageroom, when she saw Brad coming towards her.

"Hi Nance, how's it going?"

"I'm dithering about here, with a bag of fake garbage in my hand and a look of mild hysteria on my face; I have to tell Robbie about my HIV status and I feel sick! Brad you have to help me. Robbie knows something's going on. He's been at me from the

moment he arrived. I can't tell him - the words just won't come out - you'll have to tell him."

"What! Why me? I don't know him. Think about it, Nancy, it's going to be hard enough for the little bugger to find out his sister is HIV positive but to hear it from her faggot friend, who incidently also has the virus, may just be a bit too much.

"Please Brad." Nancy's eyes started leaking.

"Oh alright, just stop the crying, I can't deal with weeping women."

Brad suggested that they all have dinner at his place and after creating a relaxed, informal Saturday night atmosphere he'd break the news gently to Robbie. Nancy gave him a big squeeze; he really was a good friend.

"If I've got to prepare a veritable feast, I think you should provide a couple of bottles of tasteful wine. Dump your rubbish and get yourself off to the bottle shop. I'll be slaving away in my kitchen, if you should need me."

Nancy felt a whole heap better already; what was Brad's favourite wine? She had dumped her garbage in the main disposal bin, before she noticed that someone else was there.

"Hi Nigel."

She smiled at him, as she passed through the doorway. It wasn't until she was halfway up the stairs that she realised who Nigel was. He was the last man she'd had sex with.... *unsafe sex*....

Nigel climbed the stairs very slowly. He unlocked the door to his apartment and without even looking at Kurt on the sofa, went straight to the bathroom. The white, clammy face he saw in the mirror was not his own. He splashed cold water onto it.

"She's got HIV", he spoke the words slowly and cautiously. "H.I.V... Nancy, that sweet girl I picked up at the Country Festival last year, has HIV - I've had sex with someone with HIV - I've had unsafe sex with someone with HIV - I could have it - how long has she known? - she would have told me if she knew - maybe she didn't know she had it - maybe she thinks I gave it to her - oh, god ... maybe I did."

Nigel's agonising stream of consciousness continued until there was a knock on the door. "Mate", it was Kurt's voice. "I wanna have a piss." Nigel turned to the door and, with all the venom he could muster, spat out the words.

"Piss Off."

"It's going to be a fun dinner tonight" thought Brad to himself. "On the menu we have for entree Coquilles St Jacques (little Jack's cock) followed by some champagne sorbet to wash that down served from long phallus like glasses which they'll have to suck on. Then we have rolled shoulder of veal with a grape and pine nut stuffing served with vegetables. Another champagne sorbet, followed by a dessert called Cold Passion - layers of meringue with fruit ice cream in between. And to top off that we tell Nance's young brother that she has HIV."

"Oh, well, life was made for Vesta situations. Now to organise the setting and the music" thought Brad.

The table setting was made to match the flat - over the top. A pink table cloth with purple polka dots, sparkling silver cutlery, Brad's best dinner set of Wedgewood china - white with pink embellishments. Very phallic candles - one could see Brad's obsessions. All highlighted by tasteful track spot lighting. The pictures were re-arranged so that the male nudes were spot lit on the wall opposite to where Nance's brother would be sitting - "one couldn't be too blatant" was Brad's motto.

"Hello, you must be Robbie," Brad said as he extended a friendly hand.

Robbie hesitantly accepted the greeting and mumbled a reply. He really resented Nancy making him come to this dinner. After all, this Brad guy was a poofster and Robbie didn't want anything to do with queers like him. Anyway, he probably had AIDS so Robbie would have to be careful.

After a moment of uneasy silence Brad suggested that Nancy and Robbie come in to his apartment.

The moment brother and sister walked into the flat they both knew the whole idea was a big mistake. Nancy gave Brad a very icy look.

"Brad, can I see you in the kitchen for a moment," she said with as much niceness as she could summon. Before he could reply she had grabbed him by the arm and was dragging him in that direction.

"Oh, alright darling," he said, somewhat surprised as Nancy's reaction to what he believed was extremely tasteful. Camp maybe, but definitely tasteful.

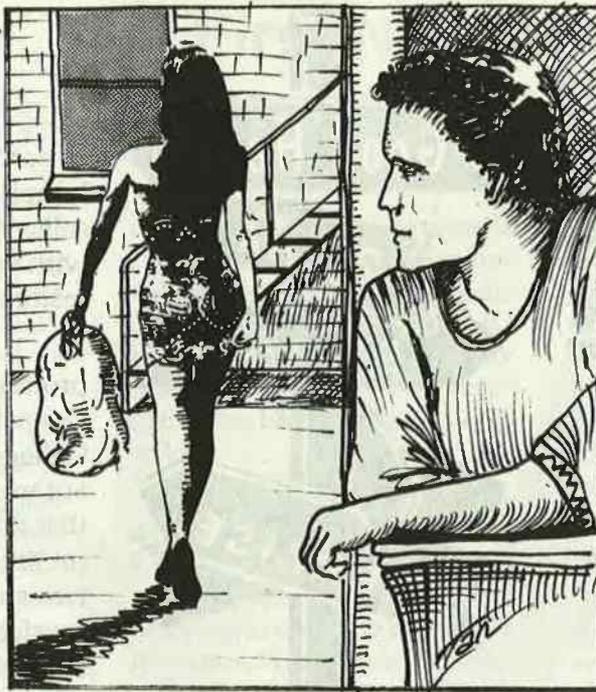
While Brad and Nancy were 'talking' in the kitchen, Robbie was aghast with shock and disbelief. He had always thought homosexuals were strange and Brad's apartment now confirmed it.

When they returned he was still standing there. He had been staring at the male nudes which Brad had gone to great lengths to highlight. He thought that it was pretty disgusting, but he had to admit to himself that the men had pretty good bodies. When Nancy and Brad returned he quickly diverted his gaze to the bookshelf on the other side of the room.

Dinner passed uneasily. Both Nancy and Brad noticed Robbie's hesitancy in drinking from his wine glass and using the cutlery. Such behaviour was all too familiar for both of them. Brad tried to make small talk with Robbie but there was little response. Brad was also disappointed that the humour of the menu went unnoticed by both guests.

Finally the big moment came.

"So Robbie, why did you decide to come and stay with Nancy?"



"He actually had a fight with mum and dad about me," Nancy answered for him. Robbie threw her a dirty look.

"Oh, would this have anything to do with your last visit Nance? You know, when you told them about you-know what?" Silence from Nancy.

Robbie stared at Brad. Brad glanced at Nancy. Nancy was looking at Robbie's reaction.

"Go on Nancy dear. Tell him." Pregnant pause.

"Tell me what?" Robbie demanded, turning

his attention to his sister.

"Robbie... I um... well you see... Look, this is really hard for me to tell you this but... well the reason mum and dad were so upset was because they found out that I have... HIV."

Robbie looked blank. "Er, what's that?"

"Robbie," Brad pip-ed in, his voice serious for the first time that night, "it's the virus that causes AIDS."

The pain ripped through Robbie immediately. He looked at Nancy, who hung her head. She could not face him. He then looked at Brad, who started to clear the table. He turned to Nancy again.

"You fucking poofter!" Robbie yelled, jumping up from the table. "You fucking poofter. You gave my sister AIDS! You bastard, I'll kill you!"

He grabbed a knife off the table and leapt at Brad.

*To be continued.....*

T

***This issue Good Health presents another report on dental health from Dr. Peter Foltyn of St. Vincent's Hospital Dental Clinic, which responds to recent fears about fillings.***

Amalgam fillings have no adverse effects on the human immune system. Nor does mercury from amalgam result in "reduced immunocompetence" or a diminished function of the system according to a study published in the March Journal of the American Dental Association.

The study, undertaken at the Medical College of Georgia, was conducted to examine claims that mercury from dental amalgam contributes to diseases ranging from multiple sclerosis to arthritis by depressing the immune system.

Participants in the study included 21 subjects with dental amalgams and 16 without. Blood sampling on three occasions was used to determine the number of leukocytes and the number and percent of lymphocytes in participants. Participants ranged from 18 to 50 to minimise possible effects of



***It's official  
- fillings  
are okay***

age-related change in the immune system on the outcome of the study. The study was also controlled for frequency of seafood consumption, viral infection and exposure to products containing mercury such as contact lens solutions and ointments.

The study found no difference in the mean number

of percentages of lymphocytes, including T-cells, between participants with and without amalgam restorations.

J. Rodway Mackert, a professor in the School of Dentistry at the Medical College of Georgia and an author of the report, noted that this study refutes another preliminary report on only two subjects with dental amalgam that has been widely circulated as evidence that dental amalgam adversely affects the human immune system.

The Dean of the Faculty of Dentistry at Sydney University, Professor Rory Hume, has in the past made similar supporting comments on the lack of evidence to show that amalgam fillings posed a risk to health.

Do not have your old fillings replaced for health reasons alone. Cosmetic replacement may be appropriate, however there is a considerable cost involved.

**Meditation and relaxation classes**

with Mac McMahon, at the Albion St Centre, Tuesdays, 6pm. Open to everybody.

## The First National HIV Positive Women's Conference

Over the Queen's birthday weekend a little piece of history was being created in Point Piper, Sydney. The first National HIV Positive Women's Conference was in full swing.

Over 50 HIV+ women, from all states of Australia and parts of New Zealand, gathered together to share information and personal experiences. There were a few hand-picked health care professionals invited to facilitate/participate in some of the workshop sessions but the main focus was on the women "doing it for themselves".

The women's knowledge about HIV ranged from some simply knowing their HIV antibody status to others, at the other end of the scale, being employed as HIV educators.

A few areas were clearly highlighted over the three day conference.

Women with HIV are experiencing very similar health problems but they are not getting effective treatments. Many of the women are using alternative therapies. I do not use the word "complementary" in this instance because they are not being offered traditional western medicines. Their general practitioners seem either not to know about specific HIV infections in women and their treatment options or otherwise appear not to be taking the presenting symptoms seriously. Obviously women from larger

cities have a wider choice of medical practitioners and therefore treatment options are more available. However it is clear there is a paucity of documentation on HIV related illness in women and much of that has been dismissed as anecdotal.

Misinformation around pregnancy issues was abundant. Clearly decisions have been swayed by the moral values and judgements of certain health care providers. Women who have dependants felt their particular needs were not being met in regards to childcare and domestic help.

The women believe that extensive and credible research and education should be happening in this country, to relate to our own population. Much of the information from the USA does not translate to the Australian situation.

The experience of isolation was a common one. The feeling of solidarity and achievement through being at the conference was very strong. It enabled the women to have a voice; to share their experiences and knowledge in a safe environment. There is a great deal to be said for "Peer Support" - it appeared to be an essential requirement for all the women.

The outcome of this is that a national network is to be set up. It was agreed that in the coming year Sydney, Melbourne and then

Perth will produce and distribute a newsletter containing any relevant information HIV+ women want to share. The hope is that it will reach many HIV+ women, not only those attending the conference and move, in some way, towards breaking down the isolation and ignorance that is so prevalent around HIV issues for women in this country.

Being the first national conference for HIV+ women, it could well have been a bit of a shambles and that would have been quite acceptable. It did have some sticky moments and the odd hiccup or two, as most conferences do, but, in general, it went pretty well.

There was lots of anger and frustration; there were times of overwhelming sadness; there were massuers on hand throughout, for the all important "self nurturing" moments; there were plenty of new contacts made and decisions formed around the need for more political actions. Education and support for HIV+ people has to become a reality.

The Outcome - there will be a second national HIV+ women's conference held next year. It was suggested that the Whitsunday Islands be an appropriate venue!

The women certainly know what they want and will be working towards their needs being met.

Amelia Tyler,  
HIV Support Project

## The Consumer's Colloquium

The Federal Government has recently established a national Centre for HIV Social Research which consists of three separate units at the universities of Queensland, Macquarie and NSW. The Centre is co-ordinated by Professor Beverly Raphael at the University of Queensland.

On May 2 and 3 the Centre held a 'Consumers Colloquium' in Sydney, to provide an opportunity for researchers involved in the unit to meet with people from the AIDS affected communities and community AIDS organisations.

Three interest groups represented at the meeting were researchers, bureaucrats and those working in the communities.

Representatives from the affected communities presented a strong and unified demand for the Centre to fully consult with and facilitate the active participa-

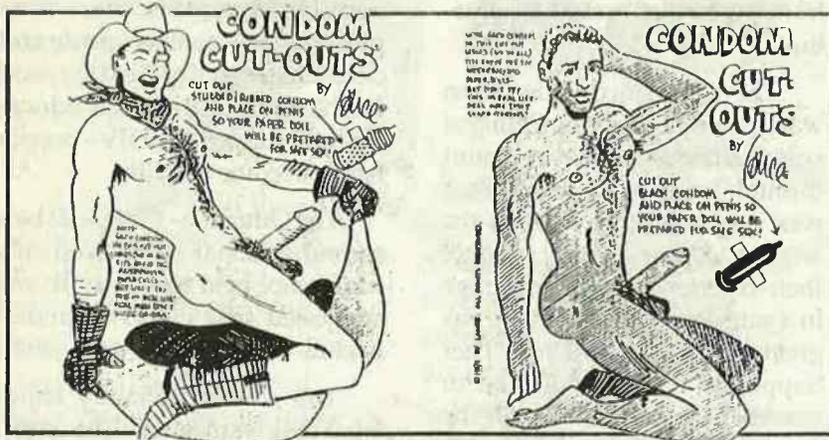
tion of the community sector in its work. The urgent need for research into the many issues faced by people with HIV and AIDS was recognised as a priority.

If the Centre is to be truly responsive to community needs it must clarify exactly how it can facilitate research projects asked of it. Those working at the 'coal face' of the epidemic need to be continually active in directing the work that the Centre undertakes.

Information generated from research needs to be adequately disseminated to those who will make the best use of it. There was a clear consensus at the close of the meeting that information dissemination should be a major function of the Centre, as well as actually undertaking research.

A research centre which is driven by the needs of a community, rather than esoteric academic interests, presents an innovative model which will enhance Australia's already excellent record in AIDS research and activism.

Robert Ariss.



## St Vinnies - more than just an op shop

The St Vincent de Paul Society is the biggest charity in Australia. They already recognise a number of the relevant issues of HIV/AIDS and have a policy of a commitment of care to people with AIDS.

On May 11 the Society held a meeting to try and establish areas of need for PLWAs and then to determine in which areas the Society might be able to help. I attended this meeting as a representative of PLWA and BGF, and Gary Smith from CSN also attended.

The questions asked of the meeting were: What should their policy be? How can they provide effective assistance? Where is the greatest need?

The Society wishes to avoid duplicating services etc that other organisations and groups provide and hopes to perhaps fill any gaps where services are lacking.

I was very impressed with the fact that the Society had targeted a few appropriate people outside their own ranks and that they were very keen to listen and open to suggestion. When they make some decisions they will let us know the outcome.

Mark Tietjen

# NEWS

# Committee news

## Taking on the big issues

The last two months have seen the committee taking on some of the big issues facing people with HIV/AIDS and looking at ways of handling the increasing workload of the committee.

The two most important issues facing people with HIV/AIDS and therefore PLWA Inc (NSW) at present are our access to drugs and discrimination. Access to drugs and treatments is discussed in this issue by Ross Duffin (see page 26).

### Discrimination

Since January we have seen an HIV infected woman refused an abortion, an HIV infected person charged \$125 by a dental surgeon for gown, mask, gloves etc. considered to be "HIV precautions" and the list goes on (and on).

The newly announced Anti-Discrimination Board Inquiry (ADB) into HIV related discrimination is our chance to do something about it. Everyone of us needs to tell our stories of discrimination to the Inquiry. There are questionnaires available from all AIDS services which are designed to make it easy to submit your stories to the Inquiry.

PLWA urges people to fill in these questionnaires and

send them to the ADB as soon as possible.

### New PLWA co-ordinator

Gerald Lawrence is now our new co-ordinator after the resignation of Don Carter and the restructuring of the position. We wish Gerald all the best and extend our warmest thanks to Adrian Ogier for his help in running the PLWA office in the interim.

### Don's Party

Our farewell to Don was a great success and we were able to give him \$300 worth of international travel. Our thanks to STA Travel and to all the volunteers who helped make the event.

### Wellcome video project

Wellcome are producing a community service video to be screened in outpatient clinics around the Sydney area. It will be a fifteen minute presentation of clinical and community services available to people with HIV/AIDS and they have approached PLWA for input.

### Outreach

PLWA has been funded to provide non metropolitan areas access to the PLWA struc-

ture. We have begun our outreach project with Nicholaas van Schalkwyk volunteering to travel to the Lismore area for a week to do some groundwork for that particular area as a pilot for the whole project. If anyone can help in any way please contact the office.

### Albion Street Liaison

Julian Gold has agreed to meet with a delegation of PLWA representatives every six weeks to feed back criticism of the Albion Street Centre and to look at a more formal process of representation in the decision making of the Centre. If anyone has any issues they want dealt with about ASC please contact our co-ordinator.

### Member participation

There has been a welcome presence of members at committee and sub committee meetings. We encourage all members who have an interest in any issues or want to become involved to come along to committee meetings.

The next PLWA Committee meetings are on Thursday July 4 and Thursday August 1, at 6pm, 2nd floor, 188 Goulburn St Darlinghurst.

# Treatment issues: getting hold of those pills!

## Importing drugs

**Is it illegal? What drugs are we talking about here? Does it mean an overseas trip? How much does it cost?**

Well, just as our government is not making giant efforts to make AIDS drugs available here, you will not find a government sponsored publicity campaign to inform doctors or people with HIV and AIDS about the effect of changes to the Therapeutic Goods Act which came into force in February of 1991.

Since February it has been legal for individuals to personally import, at their own expense, some pharmaceuticals provided they have an Australian script for the drug from a registered medical practitioner in their state.

The health care system and the government is abrogating its responsibility and leaving it up to us to organise the importation of substances that may potentially save our lives.

As a result, people with HIV have got together to provide information to doctors and individuals about how they go about using the new regulations. It isn't that we approve of a system that's making us pay for the drugs - it's just that we have no other choices. And it isn't that the system is a fabulous one - postage can be expensive and there may be questions about the quality control of some of the drugs being imported.

The major drugs which people have been importing are ddC (an anti-viral drug) and imuthiol (an immunomodulator).

So the answers to the four questions above are :-

No, it's not illegal;

We're talking about drugs which are not available in Australia;

It doesn't mean an overseas trip - it can be done by post;

The cost depends on the drug.

**If you're interested in importing a drug here are the steps:**

1. Ring your local AIDS Council for information on how to contact any groups that may be providing information on how to legally import drugs.

2. Contact that group and find out what drugs are available, which doctors have experience in managing people on these drugs, which doctors are writing scripts for these drugs and what procedures need to be followed to organise importation.

There has been some fear expressed about the potential hazards of this scheme. Of course, if appropriate trials and drug availability was happening in Australia we wouldn't have to worry about these hazards.

**Importing Imuthiol -  
see page 29**

## Drug approvals

The Baume Enquiry on changes to the Australian Drug Approval System is due to be handed to the government at the end of June. Yet another enquiry.

Probably we'll get a few small gains. This is probably our last chance for changes to the drug approval system in Australia for some time.

In all of this war about drugs it is often hard to sort out myth from reality. Here are some of the myths that are being propagated by people who want to see the current system maintained.

**Myth 1. That people can get the drugs if they want them!**

This is patently NOT true. Firstly, some categories of drugs cannot be imported. These include drugs which are injected. So you can't (legally) get Compound Q. It also includes antibiotics. So if you want azithromycin for your Toxoplasmosis or MAI - bad luck. Certain vaccines also may not be able to be imported, and with the recent hopeful news in this area this may cause further delay. Then, of course, you have to be able to afford to import these drugs.

Even if a drug is available under the Individual Patient Usage Scheme, it's often the case that your treating doctor is not aware of this. If you're fortunate enough to be informed and empowered

enough to make demands maybe you'll get the drug. In many cases it's like saying to a person dying of thirst that there's water 250 miles up the road - the water's "available" - but you mightn't get there in time.

**Myth 2. That the government is acting.**

The government motto has become ACTION = ENQUIRY. The equation is really ENQUIRY = INACTION. After the Baume enquiry, there are no more excuses.

**Myth 3. That people with HIV and AIDS are receiving priority attention and want special provisions.**

This myth was invented by the Therapeutic Goods Administration to further stigmatise people with HIV and AIDS. No policy paper written by the Australian Federation of AIDS Organisations (AFAO) argues for AIDS to be made a special case. AFAO argues that drugs for all life-threatening conditions need to be treated the same and that we should generalise the lessons that we are (hopefully) learning from AIDS.

The myth of priority attention is often trotted out, however there are no factual bases for these claims and many comparisons show that in fact people with HIV and AIDS are not getting priority attention.

The danger of this myth is that as AIDS becomes 'mainstreamed' the world lead that Australia has shown in prevention (with the visible result that the picture of our epidemic is not altering as fast as any equivalent Western country) will be thrown out the window.

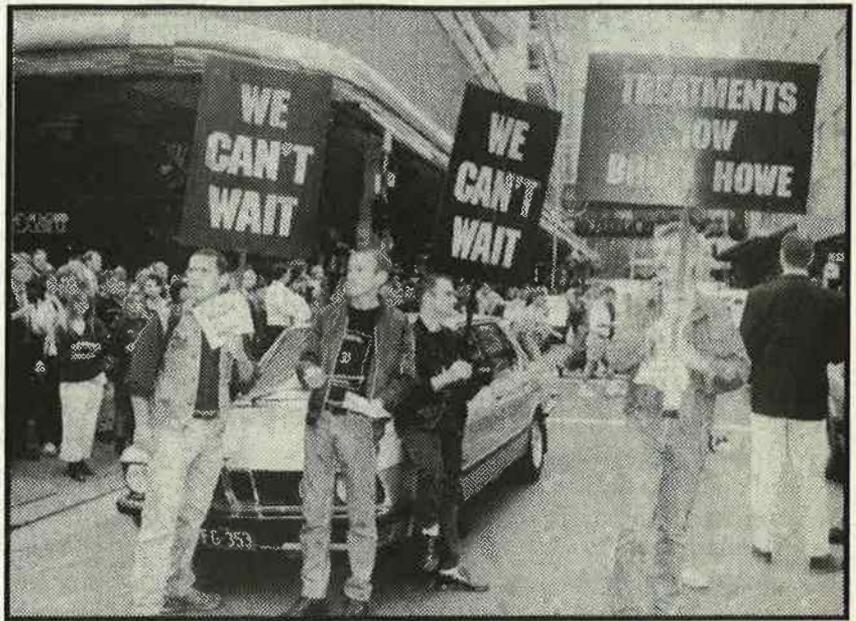


Photo: Jamie Dunbar

*ACTUP freeze Market St, May 24, to draw people's attention to treatments access issues.*

**Myth 4. That the Australian Drug Approval System Protects People.**

No government wants to be seen to be responsible for another thalidomide. Let's concede - the issues here are complex. But that's no excuse for what has become totally unreasonable delay. If there was evidence that the current system was actually protecting Australians then the arguments would not be so clear. However, all that can trotted out are pitifully few examples of drugs that were not approved. However, often the decision not to approve was unrelated to the reasons why the drug was later withdrawn overseas. None of these examples seem to apply to drugs for life-threatening illnesses.

The reality is that the Australian system has the effect of delaying approval for a couple of years after the drug has been approved

in another country. Mostly, information about adverse reactions is found from more wide spread use of a drug in clinical practice after approval. By delaying approval, the Australian system has access to more information about the drug. This strategy might be fine for a drug for the common cold - it is not fine for a drug for a condition like AIDS.

For eight years, the propaganda of the Reagan Government was that "AIDS is our number one health priority." They said this while they did nothing. It became known as AIDSpeak. We're developing an equivalent version of AIDSpeak in Australia. It's called "People can get the drugs if they want them." This is the big lie in the Australian response to AIDS. Our challenge is to make it a truth. Our best opportunity to do it is in 1991.

**Ross Duffin**

## TALKABOUT DIARY

*Talkabout Diary* is intended to publicise any regular events like meditation or self defence classes, or support groups, or anything else you want people to know about. Just send your information to *Talkabout* by post, or phone it through, (283.3220) or drop by to the office.



### Public speaking course for people who are HIV+

A course in public speaking is being organised for people with HIV. The purpose of the course is to help people with HIV develop skills in making public presentations about AIDS.

Anyone interested in this course should contact Lindsay Daines, ACON Speaker's Bureau, or Andrew Morgan, HIV Support Project, on (02)283 3222

### HIV support/Action group HUNTER AREA

Is held on the last Thursday of every month. The group meets at 6.30pm 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 please contact ACON on (049)29 3464

### PARENTS AND RELATIVES OF A PERSON LIVING WITH FULL AIDS

Have you just found out someone you love has a diagnosis of full AIDS?

We understand. We are all going through the same experience. Many of us find there are a limited number of people we can talk openly with, so we meet, we talk, share information and support each other in total confidence.

The Parents and Relatives group meets from 12.30pm to 1.30pm alternate Wednesdays at the Conference Room, Aikenhead Building, first floor, St Vincent's Hospital.

#### July/August dates

17 July 31 July

14 August 28 August

### Change of address - NUAA

16 Leswell St Bondi Junction

PO Box 822

Bondi Junction 2022

Ph: 369 3455

Open 10am - 6pm Monday - Friday

### CENTRAL COAST

#### Sexual Health Services

is offering HIV clinical services; HIV+ Support Group and Carers Support Group; local Community Support Network contacts.

Please ring Paul Drielsma or Pauline Wallace for information.  
**(043020 3399 or 20 2241.**



**SACBE es un grupo de gente de habla hispana**

Nos dedicamos a apoyar, aconsejar y educar acerca del SIDA.

En nuestra propia lengua. El español.

Nelson quiere comenzar un grupo de apoyo para todos nosotros los infectados con el HIV.

Podemos hablar del SIDA, política, tango, la Flores o de lo que tu quieres.

No dudes en llamarme al 315 7589 aunque mas no sea que para que nos conozcamos telefonicamente.

Salud, amor y pesetas.....

**IMPORTING IMUTHIOL**

Imuthiol can be imported from the Rhone Poulenc company in New Zealand. It is available in boxes of 20x 125mg capsules, at \$NZ220.00 per box.

To obtain Imuthiol you must send a letter requesting the number of boxes you want and enclosing a cheque to the value of the boxes plus \$NZ22.00 courier delivery. Cheques should be made out to Rhone Poulenc NZ Ltd.

If you want to do a telegraphic bank transfer:

The National bank of New Zealand Ltd,  
Naenae Branch, Lower Hutt.

Account name: Rhone Poulenc NZ Ltd.

Account No: 06 0581 0005802 00

Dosage: 10mg per Kg of bodyweight per week.

Once weekly treatment.

**For further information contact Rhone Poulenc in Auckland: (0011) (64)467 8629 or Wellington: (0011)(64)979 3091**

**CHEAPER SOURCES OF IMUTHIOL ARE BEING INVESTIGATED - WATCH THIS SPACE.**

**HIV Support Project  
Information nights**

**JULY**

**Tuesday July 9:** Infection and the Immune System

**Tuesday July 16:** Monitoring and Prophylaxis

**Tuesday July 23:** Treatments and drug trials

Meetings commence at 6.30 pm and end by 8.30. You don't need to book.

Meetings are held at:

**The AIDS Resource Centre**

**188 Goulburn St Darlinghurst (02)283 3222**

**LONGTERM SURVIVAL  
WORKING GROUP**

**We are a non-judgemental group with the aim of self-empowering people living with HIV/AIDS and seek to offer the following:**

1. Information on conventional, complementary and alternative therapies for treatment of HIV.
2. Information and support for suggested lifestyle changes that are useful in becoming a longterm survivor.
3. Access to information from longterm survivor groups in the United States and overseas.
4. Referral to already existing services available for people living with HIV/AIDS.
5. Re-building of self-esteem and confidence for people living with HIV/AIDS.

We challenge the notion that AIDS = death and want people to learn the reality that living with HIV is achievable.

We do not seek to offer miracles but rather an opportunity for healing life.

**Any inquiries please call:**

**Cameron Mahoney 358 4068**

**Graeme Petri 358 3119**

## CONTACT LIST: AIDS ORGANISATIONS AND SUPPORT GROUPS

### GENERAL

**Australian Federation of AIDS Organisations (AFAO):** Umbrella organisation for Australian state and territory AIDS Councils. (06)247.3411.

**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 (02)283.3550. PO Box A1242, Sydney South 2000.

**AIDS Council of New South Wales (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. (02)283.3222.

**ACON Hunter Branch:** PO Box 1081, Newcastle 2300 (049)29.3464.

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

**ACON North Coast Branch:** PO Box 63 Sth Lismore 2480. (066)22.1555.

**Albion Street AIDS Centre:** (Sydney Hospital AIDS Centre) Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. (02)332.1090.

**Bathurst AIDS Support Group** meets Tuesdays 7 - 9pm at the Women's Health Centre. Contact Vi, (063)314 133.

**Bobby Goldsmith Foundation:** A charity organisation, established in 1983 in the name of the first Sydney man to die of AIDS, providing financial and material assistance to people with AIDS. (02)360.9755.

**Civil Rehabilitation Committee Family Support Centre.** HIV education for families of prisoners at Long bay Jail. Call David Bunker (02)289.2670.

**Community Support Network (CSN):** Trained volunteers providing practical home/personal care for people with AIDS. Established in 1984. (02)283.222.

**CSN Newcastle:** Contact Andrew Hope, ACON Hunter Branch. (049)29.3464.

**CSN North Coast:** Contact Nora Vidler-Blanksby (066)29 5048 or ACON (066) 22 1555.

**CSN Wollongong:** Contact Angel Carrasco, (042)762.399.

**Deaf Community Aids Project:** Contact Colin Allen at ACON (Sydney) (02)283.3222, or (TTY only) (02)283.2088.

**Euthenasia:** Voluntary Euthenasia Society of NSW Inc. PO Box 25 Broadway, 2007. (02)212.4782.

**Friends of People With AIDS:** A peer support group for friends, lovers, partners and spouses of people with AIDS. Provides emotional support. Starts 7.00pm, 1st and 3rd Mondays in the month, at Maitraya Day Centre, 396 Bourke St, Surry Hills. Inquiries Ph Gary: 369.2731.

**Legal Project (AFAO):** Legal advice and advocacy on HIV/AIDS related problems. Contact Michael Alexander (02)283 3222.

**Living Well Support Groups:** For HIV+ people. Contact HIV support officers (02)283.3222/2453

**Metropolitan Community Church (MCC):** International gay church. Ph: (02)638.3298.

**National Centre in HIV Epidemiology & Clinical Research:** Federal research centre conducting trials for AIDS treatments and other AIDS related research. (02)332.4648.

**National People Living With AIDS Coalition (NPLWAC):** PO Box 75 Darlinghurst NSW 2010.

**North Coast "Positive Time" group:** a support and

social group for PLWAs in the North Coast region. Contact ACON North Coast Branch (066)22.1555

**NSW Anti-Discrimination Board:** Takes complaints of AIDS-related discrimination and attempts to resolve them by a confidential process of conciliation. Currently employs a full time AIDS Project Officer Sydney (02)224.8200. Newcastle (049)26.4300. Wollongong (042)26.8190.

**NSW Users and AIDS Association (NUAA):** NUAA is a 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 6pm, 3rd Monday of each month. Ph: (02)369 3455

**Parents' Group (and relatives):** A support group for the parents or relatives of people with AIDS. Please phone to indicate attendance. Aileen Goss, 2nd Floor 276 Victoria St Darlinghurst 2010. (02)332.4000. Every 2nd Thursday 12.00 - 1.30pm.

**Penrith PLWA Support Group:** Support, information & referrals. Phone Wendy at Penrith Youth Health Centre: (047)21.8330. Meetings are held weekly.

**Positive Women's Support Group:** Contact Women in AIDS Project Officer (02)283.2222.

**Quest For Life Foundation:** offers emotional support and education to people with life-threatening diseases, their families and loved ones and the health professionals who care for them. Support groups & meditation/relaxation classes are run at Crows Nest and Albion Street Clinic on Thursdays. Counselling on a one-to-one basis is also offered. (02)906.3112.

**Quilt Project:** Memorial project for those who have died of AIDS consisting of fabric panels and completed by friends and lovers of those to be remembered. (02)283.3222.

**SACBE - El Camino Nuevo:** A group to educate the Spanish speaking community about AIDS SACBE is also a Spanish speaking community support network. Contact Grant Farquharson (02)283.3222.

**Sex Workers' Outreach Project (SWOP):** 391 Riley

St, Surry Hills NSW 2010. (02)212.2600.

**Start Making Sense:** Peers support group for young men under 26 who have sex with men. Runs workshops, drop-ins and outings with the emphasis on fun. Contact Brent or Tim for further information between 3.00-6.00 most afternoons on (02)283.3222.

**Sydney West Group:** A Parramatta based support group. Contact Pip Bowden (02)635.4595.

**Transfusion Related AIDS:** A support group for people acquiring HIV through a blood transfusion. Please phone to indicate attendance. Parramatta Hospital, Marsden St Parramatta. Meetings are held on the last Tuesday of each month at 10.00am. Contact Pam or Claire (02)635.0333 EXT. 343. **Red Cross BTS:** Contact Jenny (02)262.1764.

**Transport Service for PLWAs (in Sydney area):** Contact CSN on (02)283.3222.

## ACCOMODATION

**Share Accomodation Register:** for people affected by HIV/AIDS and others seeking accomodation. Free, not restricted to HIV+ people. For details ph: 283.3222.

## DAY CENTRES

**Blue Mountains PLWA Support Centre -** Operates Wednesday from 11.00am - 2.30pm - lunch served. Fridays from 6.30-9.30pm - dinner served. Tuesdays from 10am/noon for individual or group counselling. For further information Ph: (047)82.2119.

**Newcastle (Karumah):** Operates every Thursday from 11.00am - 4.00pm at McKillop House, Carrington. Contact John (049)62.1140 or the Hunter Branch of the AIDS Council on (049)29.3464.

**Sydney (Maitraya):** Daytime recreation/relaxation centre for people with AIDS run partly by volunteers and funded by the NSW Department of Health. 396 Bourke St, Surry Hills 2010. Enquiries: (02)361.0893.

## HOSPITALS

**Prince Henry (Special Care Unit):** Anzac Parade

Little Bay (Sydney) (02)694.5237 or (02)661.0111.

Prince of Wales: High St, Randwick (02)399.0111.

Royal Newcastle Hospital (Immunology Unit): Pacific St. Newcastle, (049)266 870.

Royal North Shore: Pacific Highway, St Leonards (Sydney) (02)438.7414/7415.

Royal Prince Alfred Hospital AIDS Ward: Missendon Rd, Camperdown (Sydney) (02)516.6437.

St George Hospital: Belgrave St. Kogarah. Inpatient/Outpatient & Day Treatment Centres and

STD Clinic. Contact Stuart Linnet (02)0350 2742/43

St Vincent's Hospital 17th Floor South (AIDS Ward): Victoria St, Darlinghurst (Sydney) (02)361.2236/2213.

Sydney STD Clinic HIV Service: Monday 8.30am - 12.00 noon. Sydney Hospital, Maquarie St, Sydney. Appointments Ph: 223.7066.

Westmead Centre (Westmead and Parramatta Hospitals): (Sydney) Phone (02)633.6333 (Westmead); (02)635.0333 (Parramatta). Fax (02)633.4984.

**PLEASE LET US KNOW OF ANY RELEVANT CONTACTS FOR THE NEXT ISSUE**

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

PLWA 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 AIDS.

First name: \_\_\_\_\_

Last name \_\_\_\_\_

Postal Address \_\_\_\_\_

P'code: \_\_\_\_\_

Phone: \_\_\_\_\_

I wish to apply for membership of PLWA Inc. (NSW):

Y/N

I wish to subscribe to TALKABOUT\*:

Y/N

I wish to make a donation of: \$ \_\_\_\_\_

I enclose: \$ \_\_\_\_\_

**In the interests of your confidentiality:**

I agree to have other members know my name and address:

Y/N

I am publicly open about my membership:

Y/N

**Annual rates are:**

Membership of PLWA Inc. (NSW) \$2.00

\* Subscription donation to TALKABOUT:

(Individual) (Optional for people receiving benefits) \$10.00

\* Subscription donation to TALKABOUT (Organisation) \$20.00

**Please make all subscriptions to TALKABOUT and/or memberships of PLWA payable to PLWA Inc. (NSW).**

**Please forward this completed form with all subscriptions/memberships to PLWA Inc. (NSW), PO Box 1359, Darlinghurst NSW 2010.**

Signature: \_\_\_\_\_

Date: \_\_\_\_\_