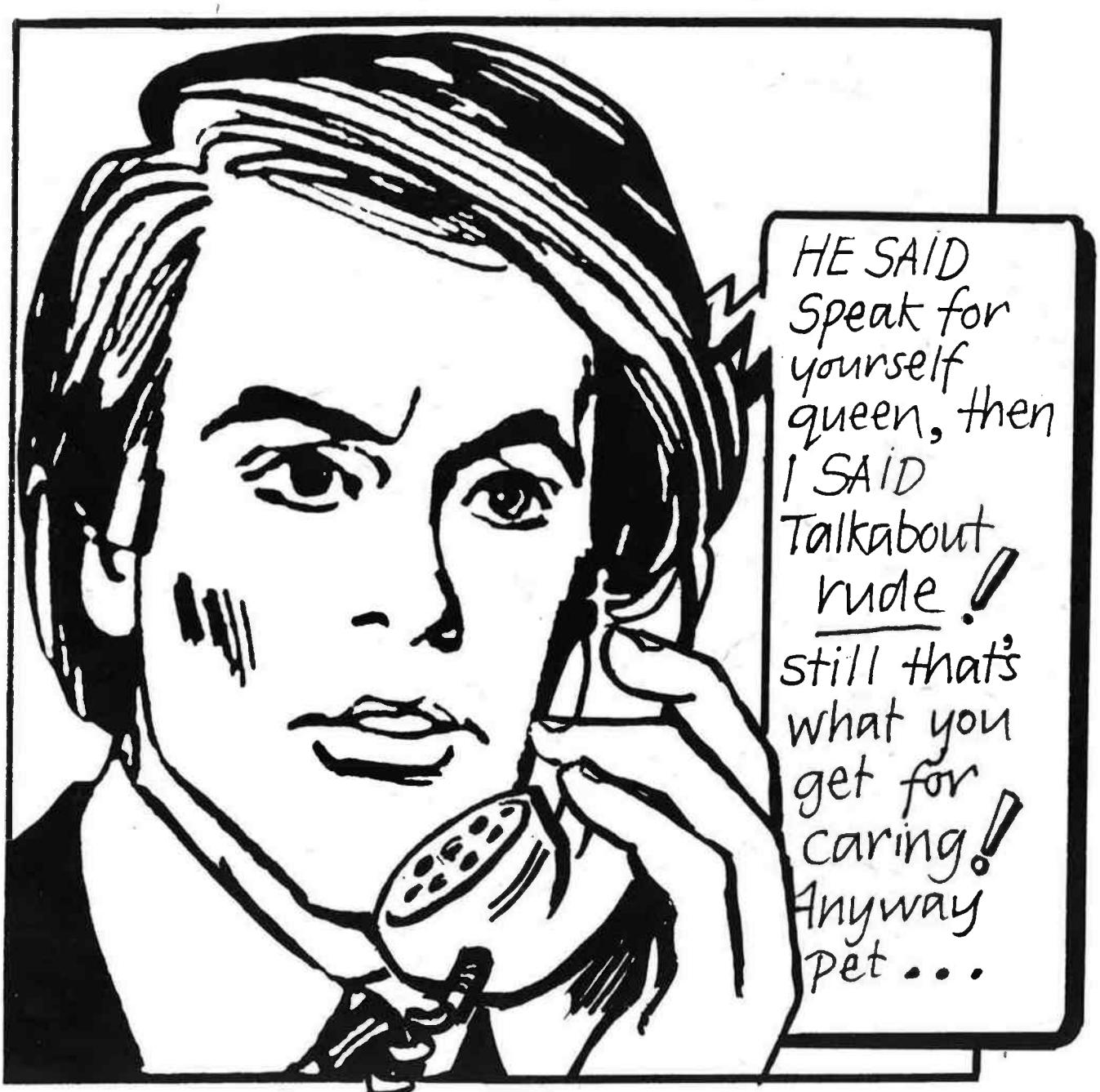
Vol. III No.III June 1992

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



Gay Talk

Gay Talk

"WHAT ABOUT A SPECIAL THEME ON GAY MEN? OR IS THIS TOO RADICAL?", ASKED a respondent to the *Talkabout* survey last year.

Too radical? Not at all. Looking back through past issues, *Talkabout* could almost be called a gay issue every time — most of the input comes from HIV+ or HIV- gay men, even though their names aren't always up in neons. Sure, the content may be of general value to anyone living with HIV or AIDS, but we're mostly writing it through gay-tinted spectacles!

There are many concerns and issues, related to HIV, that are unique to gay men — and *Talkabout* will never stop covering them as they develop.

A special issue looking at gay men, and our responses to HIV, provides an opportunity to concentrate and reflect on the concerns, celebrate the strength of our responses to this epidemic and remind ourselves, in a period of renewed attack on the 'gay lobby', ("AIDS — Have We Got It Right?" bullshit), that in this country 90% of people living with HIV and AIDS are gay men. We must *never* allow our voices to go unheard, let alone be pushed back into the closet.

We must also be mature enough to evaluate our responses and reactions and be prepared to undergo some self examination; to welcome and support those PLWHAs who are not gay men and who often have no other supports. Transsexuals and injecting drug users with HIV and AIDS are frequently denied support not only by straight society but also by the gay community. Why is it that we need to have even more marginalised groups than ourselves to kick while they are down?

We have tried to produce an issue that represents the diversity of our community and our experiences. It's impossible to get it all into 40 pages. If your story or point of view isn't in here, it can be — it's up to you.

Hopefully readers of other sexual preferences will find a lot in this issue of interest and value to them too. Perhaps everyone connected with HIV and AIDS should read Gabby McCarthy and Michelle Morrison's insights on their relationship to the gay community as positive women (p.24).

It's a long time since the idea of a gay special was raised, but you can't do everything at once. The last bumper issue we did was *Positive Sex*, a year ago. Since then there's been a lot of other things happening, (like a pretty exhausting survey evaluation). Now that we've recovered from the big transition to going monthly, here it is! The gay special. Enjoy.

Jacques Monroe

Jacques Monroe,
PLWHA Deputy Convenor

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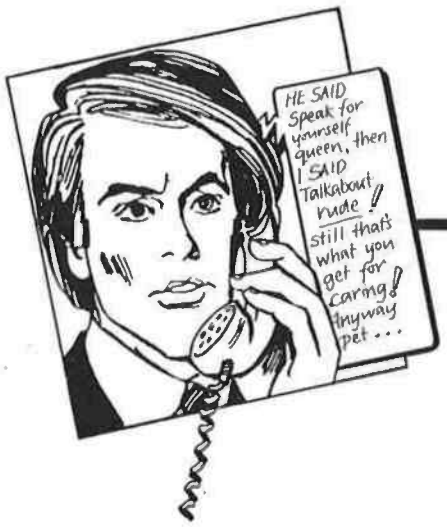

This Month's Cover

by Paul Kearns.
Welcome to Gay Talk, the first bumper gay issue of *Talkabout*.

Foscarnet review

FOSCARNET, A TREATMENT FOR CMV Retinitis, is likely to be considered by the Australian Drug Evaluation Committee at its June meeting. The drug should be made available soon after.

Foscarnet has been registered in the USA for very similar indications to those sought here. If the spirit of Baume is adhered to, the process should be routine.

It is possible that the registration may be highly restrictive and Foscarnet will only be indicated for use when gancyclovir is not tolerated or treatment has failed. Although not highly desirable, this would be a workable situation.

There is no indication of the cost of. If costs overseas are anything to go by, it may be very expensive. We hope that this would qualify it for reimbursement through the specialised drugs list. If not, the drug will be prohibitively expensive.

Delta trial starting soon

AFTER CONSIDERABLE DELAYS THE much awaited Delta trial is reported to be ready to start recruiting in the very near future.

The Delta trial is an international trial that includes a number of European countries. It is designed to parallel the study within the USA that compares the possible benefits of using combinations of ddI and ddC with therapy with AZT alone.

The criteria for entry into the study is that the individual be HIV+ with symptomatic disease (CDC Group IV) or asymptomatic with CD4 counts between 350 and 501. There are two paths of entry from this point: people who have never taken AZT or any other anti-retroviral ('naive'); and people who have used AZT for three months or more but have not used other anti-retrovirals.

Factors that would exclude anyone from entry are:

- having taken AZT for less than three months.
- having used other anti-retroviral agents.
- having used AZT and exhibited intolerance or resistance at a dose of 600 mg/day.
- Abnormal systemic functions (e.g. liver or kidney dysfunction.

The trial is then split into three different treatment arms combing AZT with ddI, ddC or a placebo.

The anti-viral naive group will recruit 1500 people, 100 of these, we hope, being from Australia. The AZT user group has 1,000 people participating. It is hoped that 200 will come from Australia.

All drugs used in the trial will be supplied by the manufacturers (Squibb, Wellcome or Roche). Should anyone have to withdraw from the trial due to AZT intolerance etc. she/he will be offered continued therapy on ddI or ddC if they wish.

For information about enrolling in this study contact the National Treatments Project. Call (02) 283 3222

— Ian McKnight

Demand ddC

CONTRARY TO EXPECTATIONS, ddC will *not* be considered for marketing at the next meeting of the Australian Drug Evaluation Committee (ADEC).

Dr. Brian Hillcote, acting head of the drug evaluation branch, said that the evaluators have not had sufficient time to examine the data. He said that the ddC marketing application will instead be considered at the next meeting of ADEC in August. Dr. Hillcote claims that even with ddC approval delayed until August, the Australian evaluators are doing it in a shorter time frame than United States evaluators. In April the independent Antiviral Advisory Committee of the US Food and Drug Administration recommended that ddC be approved for use in combination with AZT. Earlier this year Austria gave ddC marketing approval for use with AZT as well as by itself.

ACT UP disagrees with Dr. Hillcote. Calculations based on information obtained locally and by foreign intelligence show that at every step of the application process, Roche's submissions to Australia lagged behind its submissions to the USA by only an average of two months. The US evaluators completed their work by April 21. This means that Australian evaluators should be completing their work by the third week of June. Therefore the data should be completely analysed by the next ADEC meeting, June 18 and 19. Whatever the reason for the delay, lack of time is certainly not it.

ACT UP chapters across Australia are preparing demonstrations to demand approval of ddC in June.

— Lyle Chan

Combination trial starts

THIS TRIAL HAS BEEN DESIGNED TO give expanded access to people who have been using Buyers Club ddC in combination with AZT. The criteria for eligibility to this trial is that the person is:

- symptomatic, with CD4 cells of 300 or fewer, *or*
- asymptomatic, with CD4 cells of 200 or fewer

Professor David Cooper indicated that there will be no problem in switching people across from the current ddC supply to the drug that is manufactured by Roche.

The doses to be used are up to 2.25mg/day of ddC and a standard dose of 600 mg/day of AZT.

— I.M.

Candlelight success

THE ANNUAL CANDLELIGHT Memorial Rally, held on May 17, was a great success according to co-ordinator Gerald Lawrence. There was a big increase in numbers from 1991 with 3,000 people in the procession and 2,000 attending the rally.

"The evening went off without a hitch", said Lawrence. "The scariest moment was when it spitted rain during the rally, we had four people standing by to dismantle the Quilt". Fanny Farquar, in his speech at the rally, said "Oxford Sreet has been stopped by Candlelight".

The success of the rally was a triumph for organisers, who had a six week struggle with Police and City council bureaucracies. "The procession crossed three police patrol areas and they couldn't decide who was in control", said Lawrence. "When they did, they tried to restrict us to one lane of traffic along Oxford Sreet."

The restriction was placed on the rally because Kings Cross Police were concerned that an international soccer match would generate too much traffic to close Oxford St totally in one direction. However, on the night Police gave up on trying to marshall the crowd.

"Our biggest concern", said Lawrence, "was the inappropriateness of a football crowd passing a memorial procession and the potential for violence both during and after our event. We arranged for extra police for the perimeters of the park and the bottom of Oxford St and the Community Volunteer Street Patrol stayed on the street during and after the rally."

Dealing with the Councils was not much better. Fifty sheets of paper were faxed backwards and forwards to the City of Sydney and South Sydney Councils just to secure Green Park and Hyde Park and permission to hang a banner on the Oxford Hotel.

PHOTO: PETER ELFES

Part of the crowd at the Candlelight Memorial Rally on May 17.

In spite of all this, Lawrence says they were still able to organise the most successful Candlelight Rally to date. "It was great to see such a large cross section of the community involved", he said, "and to have the support and involvement of most of the venues. it was very moving to hear stories of people that had come out of their homes for the first time since losing a loved one and I'm glad they felt safe in sharing their loss. It made the organisers very proud of our community."

Demand acyclovir too

ACT UP SYDNEY MET WITH Wellcome Australia to negotiate an access program for high-dose acyclovir. A trial was terminated in December of last year that showed HIV+ people who were CMV infected and had less than 150 T cells could benefit from taking high dose acyclovir with AZT.

While the trial data have yet to be fully analysed, one statistically significant finding so far is that these people were living longer than people taking AZT alone. The data analysis will be completed by and first presented formally at a conference in Berlin in June, to mark the 10-year anniversary of Zovirax (acyclovir's tradename).

Access to high-dose acyclovir in Australia is near-impossible because of the prohibitive cost of the drug. Acyclovir is not available for this use through the Pharmaceutical Benefits Scheme.

Wellcome agreed with ACT UP that some access program to acyclovir was direly needed. However, they said they probably could not fund the entire program themselves.

One idea being considered is a joint payment plan where hospital pharmacies *and* Wellcome pay for the drug. This is like offering a discount for people who want to use it for this specific purpose. Wellcome would sell acyclovir to hospitals wanting to take part in the program for a much smaller sum. This program will work only if the discount is substantial.

Negotiations are still in progress.

—LC.

Talkabout

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DEADLINE FOR THE NEXT ISSUE

June 15

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

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Grant to BGF

THE BOBBY GOLDSMITH FOUNDATION has received a grant of $26,205 from Levi Strauss and Co. The money will be used to help provide urgently needed rental assistance to people in the advanced stages of HIV/AIDS infection.

It is the second time that Levi Strauss and Co. has made a grant to BGF. Last year it donated US$10,000 to enable the Foundation to purchase domestic appliances for clients.

Foundation president, David Austin, in announcing the grant, said that he was most grateful to Levi Strauss for its generous gesture. "The money comes at a time when the Foundation is under increasing pressure to meet requests for assistance", he said.

This year BGF needs to raise $500,000 to meet anticipated requests for help. Since its formation in 1984 the Foundation has helped nearly 850 people and provided over $1 million in client assistance. It is the only registered AIDS welfare charity in NSW and depends on the public for its funds.

Aloe Vera

STUDIES IN THE US INDICATE THAT the juice of aloe vera, or a drug derived from it (Acemannan), may be beneficial to people with AIDS and HIV.

A small pilot study at Dallas-Fort Worth Medical Centre in Texas showed that the symptoms of 16 people with AIDS were significantly reduced when given 1,000 mg. of Acemannan a day for three months. It may also prevent the development of AIDS symptoms in HIV+ people. No toxic effects have been noted in the 29 people who have now received the experimental drug.

In San Diego a nutritionist has been using a whole leaf Aloe Vera product with a number of people with AIDS. She reported increased energy levels in her patients. One patient succesfully used the product to treat throat tunours.

In Washington, D.C. studies this concentrated form of Aloe Vera was found to be effective as an antiviral against herpes. Other studies using the whole leaf Aloe vera are in progress in the US.

Has anyone been doing any work with aloe vera in Australia? Let us know. It may be worth following this up with your naturopath.

Source: AIDS Response Holistic Program, *April/May. A copy of this article is available from the PLWHA office.*

Will we see 3TC?

RUMOURS CONTINUE TO CIRCULATE about the new nucleoside analogue from Glaxo called 3TC. One rumour is that the drug will *not* be trialled in Australia, at least in the immediate future, because of the strong competition by the ACTG (AIDS Clinical Trial Group) in the USA.

However it appears Glaxo is still very interested in including Australia in the early phases of the 3TC trials. Pending the analysis of the results from the Phase 1 trials we could see these protocols get under way later this year.

The results of the current studies will probably be presented at Amsterdam meeting in mid July, so we will know more after this.

The current 'grape vine' feeling is that 3TC is effective in humans and it's principal benefit is that it appears to have far fewer side effects than AZT, ddI or ddC.

Wellcome, the manufacturers of AZT, are also developing another nucleoside analogue. We do not know if it has started human clinical trials yet, but will report this as soon as it does.

— I.M.

The Doctors' Summit

So who's got an anal fixation?

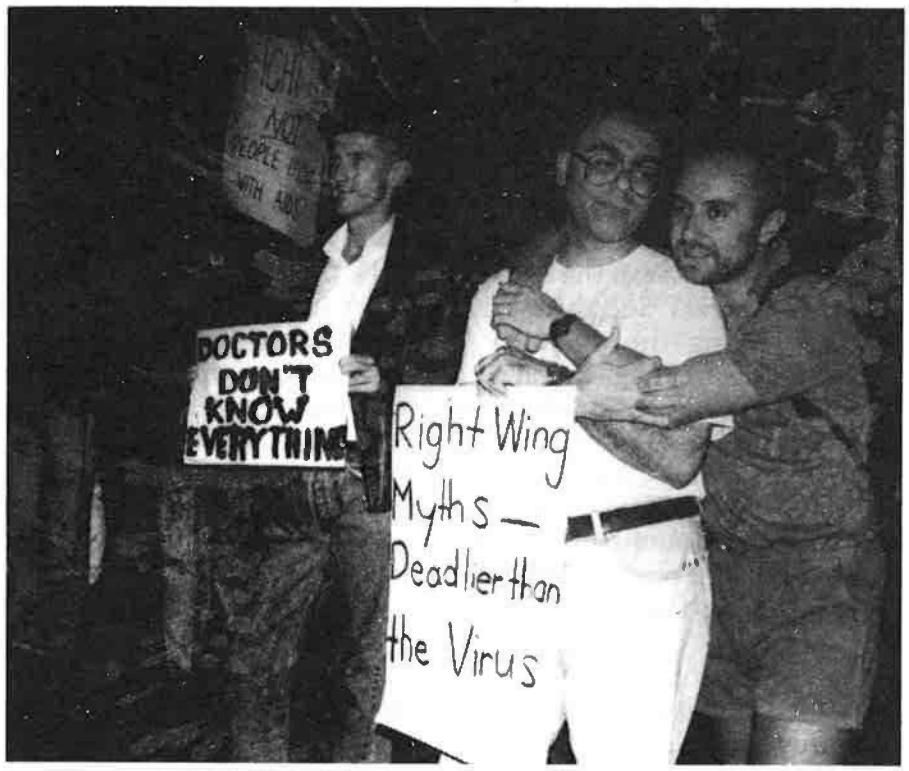
'AIDS - HAVE WE GOT IT RIGHT', the Summit held on May 14 and 15 by the Australian Doctor's Fund to debate issues raised by Professor Fred Hollows in March, was characterised by an obsession with anal receptive intercourse, a focus on transmission rather than on the needs of people with HIV and AIDS, and a lot of frustration among speakers and participants who disagreed with the views of Professor Hollows and Dr. Bruce Shepherd.

Draft programs released in April showed a severe imbalance of speakers. People living with HIV and AIDS and major HIV/AIDS groups were not represented. The Australian Society for HIV Medicine, which represents about 300 medical professionals, was not invited. There was a significant shortage of gay community doctors, both in the initial list, and at the Summit itself.

Lobbying by organisations such as ACON and PLWHA resulted in a change in the line up, which finally included Gabby McCarthy and Ross Duffin from PLWHA (NSW) sharing a spot (at 8.10am!).

Other speakers included Don Baxter, representing the Australian Federation of AIDS Organisations (AFAO), Dr John Kaldor, deputy director of the National Centre in HIV Epidemiology and Research, Professor Ron Penny, director of the Centre for Immunology at St Vincent's Hospital and Dr Sue Kippax, associate director of the National Centre for HIV Social Research.

These and other speakers spent their valuable time defending and examining facts, figures, strategies, theories, and methods of evaluation which they have probably presented at many other, more objective forums. Deputy Prime Minister Brian Howe spoke in defence of Australia's HIV/AIDS strategy, which he said was among the best in the world.



Demonstration against Fred Hollows at a benefit concert in March, after he first spoke out publicly on HIV and AIDS. PHOTO: C. MOORE HARDY

Hollows harassed Dr Kippax for her methodology, (twice) but without paying the courtesy of listening to her explanation of it on either occasion. This was fairly typical of his belligerent style at the conference, where he and speakers who supported him mostly ignored or attacked, rather than debated, any points made by speakers they disagreed with.

If it seems a little partisan to identify speakers as 'Hollows supporters', bear in mind that several speakers were at the Summit by Hollow's personal invitation - which is why he was described as the 'host', I suppose. Both the Summit, and this report, offer the temptation to 'Hollows bash', goes against the grain for people who used to admire the man for his work with Aboriginal people and in Eritrea.

Unfortunately, Hollows gave little grounds for anyone to revise their newly unfavourable opinion of him. Indeed, many of us were bemused by his apparent naivety about HIV and AIDS. And for someone who kept haranguing the audience about science and methodology, his opinions seemed based on anecdote to a surprising degree. (The phone call from a gay man who'd witnessed unsafe sex in bath-houses, the story of someone who'd seen young Aboriginal men working in a gay brothel).

The Hollows/Shepherd camp alternated belligerence with the 'hedging and alleging' style of debate. It goes like this: first you allege that 'someone' is 'empire building', or 'hi-jacking', then,

when pinned down to name or describe this person or process — you hedge. When it came to the crunch, however, Hollows did not shirk from delivering his alternative HIV/AIDS strategy:

1. Tell people to stop having anal sex

2. Close the bath-houses, beats and brothels.

Hollows did not stop to consider points raised by speakers such as Professor Beverley Raphael (director of the National Centre for HIV Social Research) that denying the diversity of people's sexual practices and needs will not make them go away, or by Dr. Chris Brook (Intergovernmental Committee on AIDS, ANCA, Victorian AIDS Advisory Committee): that you cannot change people's behaviour by changing the place where it occurs.

Driving people out of beats and brothels will simply make it harder to provide safe sex information to those men who are driven underground. The inescapable message of the Hollows/Shepherd presentation is ultimately anti-education. Don't provide people with information, alternatives, support — just tell them to stop.

Another speaker, self-confessed 'pox doctor' Leo Laden gave further support to this position by stating that safe sex is not reliable and that HIV+ people should totally abstain from sexual activity (yep, that's right, forever - or until the cure arrives).

Combine this with Laden's opinion that you can't control or influence people's sexual behaviour (they can't control it themselves; he gave a long list of strange objects he's found inside people's orifices), and the logical end point is coercion. He didn't actually state it, but what else could you conclude? If they won't stop — make them!

People with HIV and AIDS were once again cast in the exclusive role of 'carriers' at the Summit, at least by implication, if no-one was bold enough to come out and say so. Some attention was given to the need to give support to PLWHAs so that they do not 'relapse' in times of stress and have unsafe sex. Both Gabby and Ross (whose speech was read by Charles Roberts) pointed out that the worst fear of many HIV+ people is that of infecting someone else, and that most people with HIV *are* behaving responsibly. They also talked about the gay community's crucial role in supporting people affected by the epidemic.

Jenny Ross from the Haemophilia Foundation and Lorraine Ciblick, a woman with AIDS representing the the Transfusion Related AIDS Unit, spoke about the needs of their special interest groups. Both acknowledged difficulties in dealing with the gay community organisations but did not attack the gay community.

There was also some discussion about discrimination against people with HIV and AIDS (the Summit was reminded that the recent Anti Discrimination Board's report identifies health professional as among the worst offenders).

But that was about it for the needs and concerns of PLWHAs. And, curiously, few questions from the floor were directed to the PLWHAs who spoke.

This was also typical of the coverage of Aboriginal issues. Despite a professed concern for Aboriginal Australians, they got remarkably little space at the conference. Stanley Nangala, chairman of the Communicable Diseases Advisory Panel, which advises the Federal Government on HIV and AIDS in relation to Aboriginal people, spoke in support of Hollows and described strategies which are already in place for Aboriginal communities.

His main theme was that the Aboriginal community has already 'got it right' in relation to HIV and AIDS, but that governments must listen to them, so that Aboriginal inspired HIV/AIDS programs can be most effective. He said that to survive, Aboriginal people must work out ways of doing things that don't clash with their culture. He also condemned past mass HIV screenings of Aboriginal communities.

Nangala spoke almost exclusively about prevention of HIV transmission. He did not speak about quarantine, or address its implications for Aboriginal people who are HIV+ or have AIDS — such as: what does it mean for Aboriginal people to be forced to disclose their serostatus, and possibly their gay identity, to their communities? Will isolation of HIV+ Aborigines further entrench any discrimination that they already experience from their communities? Isn't it the case that isolation can only be effective if there *is* a mass screening of communities?

Nor did Professor Hollows address these issues, except to say that mechanisms existed in outback communities whereby young men returning to their communities from the city could be isolated from the rest of the community (why bother coming back, if you can't then visit anybody?). Few other speakers tackled the question except to acknowledge concern.

Hollows, who denied that he had any problems with homosexuality and mentioned working with gays who supported the Aboriginal health movement in the 60s and 70s, accused the gay community of having become conservative, reactionary and "desperate to protect their own interests". This, he said, was one of the reasons he spoke out in the first place.

Don Baxter disputed this. He said that gay men do have a

significant input to and influence on HIV/AIDS policy development, as they should, since they are the most affected by the epidemic. But openly gay men are in fact a minority on all major policy making government bodies, he said. They do not possess the power or influence attributed to them by proponents of the 'gay hi-jack' theory. He also said that the rights of infected people and the development of an effective HIV/AIDS strategy are not, and should not be, mutually exclusive.

Baxter also defended the gay community against comments by Melbourne Barrister, Peter Rush, that gay lobbyists' insistence on their right to donate blood resulted in a contamination of the blood supply in the early 1980s. Mr Rush misrepresented the gay community's negotiations with the blood bank over screening out homosexual donors, said Baxter. Unfortunately, Baxter's response was not equally reported in the press—perhaps because reporters rely on copies of speeches, rather than attending the whole event?

Shepherd's media release after the Summit stated that the event had "successfully brought together a wide range of AIDS groups but revealed several major problems with the HIV/AIDS National Strategy". HIV/AIDS activists sometimes call for people to feel a greater sense of urgency about the epidemic, but I suspect not quite the sort of urgency that Shepherd's selection of 'problems' might arouse. The overall message was that people with HIV could become increasingly infectious in the next few years as they advance into AIDS; that these people may behave unsafely due to intoxication; that Australia is not doing enough to combat AIDS; that AIDS could bankrupt the largest life insurance company in Australia; and that a small yet powerful lobby group — guess who? — is endangering public health through its insistence on its rights. Don Baxter might also be identified as a 'problem', because he "sought to question the integrity of the Summit". (Baxter had suggested that Shepherd's involvement was a cynical re-election ploy.)

In fact there was no consensus at the Summit that these are the key problems. The media certainly wasn't fooled by Shepherd's press release. Most coverage focussed on the controversy surrounding the event.

The Summit now seems a nine day wonder — a lot of fuss and then it's over. Those of us who attended from PLWHA certainly felt it was an annoying and distracting intrusion in our lives. Unfortunately, its impact may be more far reaching. The new Chair person of ANCA, which develops national HIV/AIDS policies, Dr Don Grimes, has been reported as taking Hollows' allegations seriously. If the general public does not see through the Hollows/Shepherd smokescreen of misinformation and rumour, there could be serious consequences for future national policy.

It places a stronger pressure on those of us who are living and working with HIV and AIDS to keep making it clear that we have 'got it right'. Our vital task for the future is to keep on improving on what we've already achieved.

—Jill Sergeant

Copies of Gabby's and Ross's speeches are available from the PLWHA office.

Talkback

Just say: it ain't that simple

THIS LETTER IS IN RESPONSE TO the article by B.S. in 'Homefront' in the last issue of *Talkabout*. The article raised the issue of recreational drug use both in the gay community and by people with HIV. It is an issue that needs to come out of the closet and be talked about more. It is an issue that causes lots of angst. I, like B.S. request anonymity because of a past history of 'illegal' activity in this area.

The purpose of this letter is not to take B.S. to task for the choices he has made - it is to put forward a different set of experiences which are quite opposite to those of B.S. For B.S., the model was support group = self-empowerment = decision to use recreational drugs = enhanced quality of life. This has not been my experience.

My battle has always been to find what is appropriate and what is 'staying in control'. Yes, I have had lots of fun times with recreational drugs. Yes, I don't want to give those things up — totally. But there is a down side as well. Sometimes I have used too frequently and this has had an impact on my ability to do work and on my bank balance. It has also, I believe, had an impact on my health — not necessarily directly — but through the association with smoking, irregular sleeping patterns and irregular diet.

Regular occurrences of drug fucked Tuesdays (and the associated flus and colds, because recreational drug use may present a window of opportunity for these and other infections), are an experience that I can do without.

Just say "No".

In the last five or six years I have gone through cycles of recreational drug use that have varied from frequent to less frequent. Then I decided to stop smoking and this also meant having to stop recreational drug use for a while. The increased sense of well-being I now feel has more to do with doing less recreational drugs than with stopping smoking. I have hardly used recreational drugs for six months. My sense of well-being has improved. Like B.S I refuse to feel bad or guilty. B.S. refuses to feel this way for doing drugs. I refuse to feel this way for not doing them — but, surprise surprise, this is exactly how many of the people who are emotionally close to me have tried to make me feel.

B.S's letter triggered me to write in precisely because of these experiences.

I want to put forward the following observations:

• Recreational dug use in the gay community and amongst people with HIV exists at very high levels when compared to the rest of the community — yet there is a cultural value that you only openly talk about this as a positive experience like B.S. and you get yelled at or booed if you talk about some of the negative experiences — yet these do exist — to deny them is complete fantasy.

• Doing less drugs is often a difficult experience as there is often little support for this decision and often it does involve giving up on existing support mechanisms as these are contingent on mutual peer support for recreational drug use.

• Peer pressure and articles like this and the one by B.S. do influence decisions and we haven't openly talked about what the rules should be. This is an area where the individual needs to have their own decisions respected, but in no other area I can think of is there so much subtle and blatant pressure to conform to group norms. We need to openly discuss rules of behaviour that empower individual control — ie. remove peer pressure from the equation. Don't talk anyone into or out of decisions but licence discussion that enables people to talk through decisions they have made without using these discussions to impose our own choices.

• As a community we tend to use the lack of concrete evidence that recreational drugs are associated with progression of HIV disease to assert the reverse contention — that recreational drugs are proven not to be harmful. I think this is pure fantasy but that is purely an individual opinion in an area that is full of 'we don't know'.

• As a community we have been under dreadful strain. This is not going to improve in the foreseeable future. It is possible that high levels of recreational drug use are associated with this. For me, our community is in denial about this because recreational drug use is OK and we don't want the imposition of 'just say no' morality on our community. As a community we need to talk more openly about recreational drug use — not as a 'problem' or as something with moral values attached — but as something which has large impacts on the quality of many of our lives and where the community norm is 'don't talk about it'.

In my experience the greatest problem about doing less recreational drugs is finding substitutes. Here are a few suggestions — find a group of people who want to use at about the same level of yourself and support each other to stick to those decisions, organise alternative weekend activities with your friendship network that don't involve drugs, join a sports club or social group, begin a new relationship, take regular holidays, find out what 'control' is for you and what you need to do to achieve it, get support (eg. a counsellor, a support group), confront peer pressure from your friends, have weekends away... It's not easy — and that's both an issue for us as individuals and for our community to tackle honestly and openly.

REQUESTS

MY NAME IS BRIAN HODGE. I'M 25, HIV+, blond, blue eyed, medium build. I have a good personality and sense of humour and I'm very shy.

I've been in prison for a couple of years now and I'm looking for guys 28-35 to write to, or maybe they would like to visit me in jail. I'm very lonely in here so if anyone out there would like to drop me a line please do. If all goes well I hope to find the right guy I can love and care for.

You can write to Brian c/- PO Box 13, Matraville, NSW, 2036.

We welcome your letters.
Send them to:
Talkabout
PO Box 1359
Darlinghurst, NSW, 2010

Attitude

by Michael Staiff*

Save all gender-challenged, hearing-impaired marine mammals living with lifelong manageable infections!

SINCE BEING DIAGNOSED HIV+ six years ago many issues have raised themselves from their lurking Stygian pits and manifested onto this plane through me. I don't intend here to address any of the regular dreary old issues that occupy the time of so many of us throughout our HIV Living days, but rather to concentrate on one issue that so far has never been addressed, to my knowledge, in any way by anyone HIV Living or working in the field: namely, the issue of obsessive political correctness endemic in those working directly in HIV/AIDS.

For me this issue had to be overcome even before diagnosis, as the politically correct thing to do in 1986 was *not* to get tested. It was the AIDS Council of NSW's official position to advise those considering being tested for HIV antibodies not to do it, as there were no therapeutic options of any value beyond living a healthy lifestyle and reducing stress, but that potential discrimination from an HIV+ diagnosis was a very real threat indeed. But for this budding young executive, personal reasons impelled me to take the test anyway, in spite of its political incorrectness. I had to know whether it was a realistic prospect for me (at the age of 23!) to continue working on building a career in a highly stressful field given I might, if HIV+, only have a couple of years of life left to live. For that seemed to be the message at the time.

So, my entrance into the world of HIV/AIDS was through a politically incorrect action.

Over the years I have become more and more involved in the nexus of the AIDS scene, and though many of its aspects have disturbed me, the one that I find hardest to deal with is the rabid, paranoid, obsessional zeal with which the politically correct line is sought and followed. This mostly happens in the choice of words and images in relation to its functions - sometimes to absurd degrees. For example, as a gay man HIV Living, I find it deeply offensive to be reminded constantly of the impact anything I do or write might potentially have on women infected with HIV. Women constitute less than 3.5% of the HIV infected population, yet receive in some cases more credibility than the 93.5% of gay men who comprise the majority of HIV/AIDS Living people. Let's face it, 93.5% *isn't a majority it's a landslide!*

Yet infected and potentially infected women occupy a large part of the AIDS bureaucracy's consciousness. Possibly this is yet another example of actuated internalised oppression (ie. we deserve to be infected with a life threatening virus because we're only no-good scum faggots, after all), or perhaps it's a really weird example of some kind of Freudian mother guilt. Indeed, if I manage to escape death threats from even raising the point about how relevant women are to HIV/AIDS in Australia I will be lucky. But someone should say it.

Don't get me wrong, I do think the work of the AIDS Council of NSW is very important, and I think it's a wonderful resource centre, but doesn't it strike you as a just a bit odd they have a project for pretty young queens about town, a project for older gays perhaps not so much about town, a project for women, a project for those who take drugs by injecting them into their arms, and even a project for deaf people, but no project specifically for gays between the ages of 26 and 45 yrs old who are HIV Living? And yet the bulk (again not so much a majority as a landslide!) of those diagnosed HIV+ fall into that description. Think about it.

And while mentioning deaf people, another example of the lunacy of ever-insistent politically correct exactitude recently surfaced when the ACON project which, de facto if not by direct intent, does deal mostly for the uncatered for 93.5% gay men, published some material and neglected to include a TTY phone number for the deaf. Surely a grave omission! But the project concerned uses as its principal method a group counselling technique known as Active Listening. No one has explained

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* *Name not withheld for fearlessness. . .*

to me yet how volunteers who are Auslan unaware (the signing dialect used by Australian deaf people) are supposed to actively listen to deaf people. And yet many of us were made to feel as if we'd committed some heinous breach of propriety, something akin to spitting on the royal personage, and had left ourselves open to some vague charge of treason for which the penalty might be being flayed alive and having our skins nailed to the door of the Deaf Society.

An amusing terminological example cropped up recently. We all know who junkies are: they range from kids in the street to presidents of the United States. But who exactly are "those who for recreational purposes, self-administer non-prescribed medications"? Junkies, I suspect.

Is it perhaps that the issues raised by HIV and AIDS are so large and apparently insurmountable that it's easier to nitpick around the words and concepts we employ than to face the full horror of the situation? But I tell you, sometimes it feels a bit like being nagged by a whole lot of fundamentalist christians whose chief concern is not the issue at hand but rather some nebulous form of personal salvation.

But the most galling aspect of the politically correct crusade by our dogmatic thought police is the sure knowledge that those HIV/AIDS Living have not a snowflake's chance in hell of ever seeing the presupposed utopia that these zealots are intent on creating. It's simply irrelevant (to people living with the prospect of their own bodies turning into monsters from the pit) whether or not the language and concepts we use are racist, sexist, deafist, or anyotherist. Survival will continue to be our main priority. Perhaps that is one of the many lessons of AIDS. That the only purpose of life is to live.

I'll leave you with a moral dilemma for the politically correct ideologue: if you were told that the AZT you take came in capsules of gelatine made from sperm whales, would that really affect your decision whether or not to keep taking AZT? Ask your doctor.

Do you have an Attitude *about something?* Attitude *is the place to hold forth on something you feel strongly about. Be angry. Be controversial. Get up people's noses.* Attitude *gives you more space than a letter. Say it now.*

Tribute

Peter Base

THE COMMITTEE AND STAFF OF PLWHA were saddened to hear of the death of Peter Base on Thursday, May 21.
Peter died peacefully at the Sacred heart Hospice.

Peter was an original founding member of PLWA (NSW) and a management Commitee member 1991-92. He was involved in our Albion Street liaison project.

We hope to publish a full tribute to Peter in the next issue of *Talkabout*.

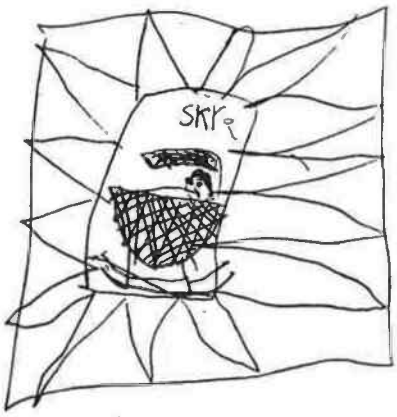
Our sympathy to Peter's friends, especially Jamie Dunbar, who was Peter's primary carer in the last months of his life.

Skye

SKYE, WHO WAS ONE OF THE FIRST children with AIDS to go public about her illness, died in Prince of Wales Hospital on May 6. She had been in hospital since January and spent her ninth birthday there in February.

Skye became a spokesperson for people with AIDS through the media exposure she received around CounterAID in 1990. She was also interviewed by *Talkabout* last year for World AIDS Day.

Skye's representations of the issues for people with AIDS as seen through children's eyes were some of the most potent we have seen. Skye's message was one which denied the media's attempts to treat her as an 'innocent victim'.



Skye's drawing of herself as a baby, with the sun behind her cradle.

Skye accepted the fact that she was going to die a child and got on with living to the fullest extent possible. My most vivid memory of her is of her using her drip stand to skate through the corridors of the Prince of Wales hospital.

— Lloyd Grosse

Blair: When I found out I was HIV+ I was 24 years old.

Jill and I spoke to threee young gay men about being HIV+. They highlight some of the particular issues that I felt I also faced as a young gay man.

Young Gay Positive

Blair: What's it been like since you found out you're HIV+?

Russell: Life is still pretty crazy at the moment, I've only been diagnosed for ten months and I've been in hospital almost constantly since the second day after I found out I was positive. It's only now that things are starting to calm down and I can have a clearer look at the future.

Blair: Is it different because you're young?

Russell: I think so. I'm 26, and even though I have a positive attitude to HIV and the future, I sometimes think - what other people might achieve in 60 years of their life, maybe I have to condense down into 10 or 15. It certainly brings things that you might have on back burners forward really quickly. You want to get out there and do everything as quickly as possible.

I think it's harder in my instance because I've been in hospital and been confronted with the medical profession continually. That's a real drain on anyone's positive attitude.

Graham: I'm 25. I was diagnosed about 16 months ago, I was 24. I haven't been really sick and my T-cells have been way above 500 ever since diagnosis, so I haven't started with drugs, it hasn't been an issue. Me being gay is not discussed by my family and I didn't go to them for support. I wouldn't get all the support that I want or need from them. For the first few months I was going out on a drug binge and wasting myself away, losing a lot of weight and being pretty unhealthy. Then I started doing a support group for young men. Ever since that I've been involved with ACON and I know a lot more people that are HIV. I feel that people with HIV have a different understanding than people who are negative. They give really good support.

Glen: I'm 22 now, and I became positive when I was sixteen. I was told on the AIDS bus, actually. That was just horrendous. They didn't tell me anything really except "you're positive" - and they let me go. I cried at first. Then I went to my family for support. I was rejected in a way that really hurt me. My entire family is just so anti gay, so homophobic.

I came to the support group last year in September, and for me it's been a pretty major change. Being around other young positive people is just such a wonderful experience, to share with other young people, I think it's so important.

I feel I have grown up with AIDS, basically. I don't know how I would have looked at life other than being positive. I think I find it difficult now to plan ahead. That is the hardest thing of all, for me. To not experience life. I feel quite robbed.

Russell: My parents don't know that I'm gay, they don't know that I'm HIV+. My mother still thinks that a lesbian friend that I have is still my girlfriend and that we'll end up getting married. I wouldn't even try to even approach my family for support.

That might be half my problem as well, but my parents come from a country town, they're not aware, they're not educated people at all. They would see me telling them I

was HIV+ as a definite death sentence. They would probably pressure me to come back to them. I think they would be supportive, but not in the right sense.

I think it's really important too, to be really together and really strong when you do tell someone like your parents, because their reaction is going to drain a lot of strength out of you, and if they see you sick or weak or not coping with it, that's only going to add to their interpretation of HIV being a deadly thing.

Glen: If you want to do anything or help in some way in the AIDS field, it's difficult. You ask people for advice and where to go and what to do, and you're not taken seriously because you're just young. People forget there are lots of young people out there and if anything, I think life is harder for us because we haven't seen what life is like.

Graham: Yeah, you have to grow up a lot faster.

Glen: You do, you've got no choice. Your reality is that you're young and positive and it is tough. It's very tough.

Russell: I think it's amazing to face the issue of your mortality at sixteen. I couldn't even comprehend how I would cope, if I think back to when I was sixteen.

Jill: Where did you go for support?

Glen: I just ignored it for five years. But over the last five years I've seen the gay community change, from them being bitchy and nasty on Oxford Street. Of course that's still there, but people like that stand out more than ever before. I think it's got a lot better, people's tolerance is changing.

Russell: I think once you find out you're positive you tend to go towards other positive people to get that real understanding, that real connection. There is a bonding there. Especially for young people. No-one else knows what it's like to face mortality at sixteen or twenty, when you're supposed to have your whole life ahead of you, and you're just getting started and bang! this comes along.

Blair: So do you think maybe you've stopped bothering about the gay community and are looking more at HIV community?

Russell: I think there are two defined communities.

Graham: I don't hide the fact that I'm HIV, and if there's anyone out there that don't like it that I am, and that I'm open about it, fuck them. I don't want to know them. Even if they're gay. It's destructive, it's a drain.

Blair: Is it hard to be open in the gay community?

Glen: Yes, it is. You're patronised.

Russell: I find most of my straighter friends are more patronising than gay people. I find in general that even gay people who are HIV- are reasonably understanding and supportive.

There are some though that have a really misconstrued view of HIV and sex. I was talking to two guys who are HIV- about sex. They weren't aware that I was HIV+ until somebody at the table told them I was — which was really poor. These were young guys, and they had this perception that HIV would never affect them. They thought that if they casually picked up anyone for sex that the person of course would tell them if they were HIV+. It was just really amazing, the misconceptions they had.

Glen: Your trust, I think is taken away. There are times when someone who's negative will tell you they're positive - it really mixes you up when that happens. You tell them you're positive and they say they are too, but you find out the next morning they're negative.

Russell: Why would they do that?

Graham: There are some people out there who just think getting the bug's good. They think they're going to get sympathy and meet more friends and have more fun.

Glen: Life doesn't get any easier being positive. It's hard enough without being positive.

Blair: You were saying before that negative people just assume that if you're positive you'll take control.

Russell: That's right, and that you'll look after the condoms or whatever, and even inform people before sex. I think on a casual basis there is absolutely no need to tell the person - if it's going to go on for a second time I think you should always tell somebody, but for people to have the perception that they leave those with HIV in control is really dangerous. Because there are people who are HIV+ who wouldn't take precautions.

Glen: I think anybody out there who says they haven't been unsafe is a liar. I know I haven't been safe one hundred percent of the time, I'm only being honest about that. On the other side of the coin, it does take two to tango and I risked as much as they risked. I didn't know their status, they didn't know mine. Ultimately, if you engage in sex you're putting yourself at risk. Don't assume they're negative, assume they're positive.

Graham: A couple of years ago, I didn't have heaps of partners, just casual, one night stands — and they didn't make any attempt to have safe sex, and neither did I. Back then, my results were coming back negative.

Blair: So even though you were negative, you kept on having unsafe sex.

Graham: Well, at that time, if they didn't make the first move, I was thinking, well, they must be negative too. I know it's a stupid way

of doing things, but you do it. Especially if you're not thinking straight, if you've had drugs, you've been drinking, or you're stoned.

Russell: When you're young, everything's new, young people can't be responsible one hundred percent of the time. It's not natural. We're all learning.

Glen: That's the stage when you do learn. A sixteen year old boy doesn't sit down and talk about safe sex, especially to his friends, let alone anybody else, because it's taboo to talk about sex. You just don't have that sort of communication with other young people. And other people won't tell you about it. Your own ignorance is exploited by older people I think.

As a young person, you don't always make the right decisions, but you can't be blamed for that. It's part of growing up. Too often older people point the finger at young people for making mistakes.

Jill: What sort of pressures are on you now about safe sex?

Glen: For me, safe sex is being selfish for myself. I feel that everybody else is a risk to me, more than I am to them. They've got all the opportunistic infections, I'm the one that doesn't want to catch them. Unsafe sex is out — it has been for a long time, but it's taken a long time to get down pat, for me.

Russell: Since I've found out that I'm positive, I think I've lost a lot of confidence, especially with hospitalisation and not being well. If you take people home, and maybe have casual sex with them, and then they call you the next day and say: "I'd like to see you again", that's great, but then I make a point of saying, "before we go any further, I'm HIV positive". And on two occasions it's been, "Oh. I'm sorry to hear that, but I hope we can still be friends" — but the sex side of it, all that passion and

all that lust, that was there before — it's gone. Just like that. Cancel it out.

I myself was like that before I found out I was positive and I can understand that reaction, but at the moment I try not to put myself in that situation where I'm going to get hurt, or rejected.

If you're really honest, it's much easier, and much more anonymous, to go to a place like Numbers, have a head job, and leave. I think a lot of people who are HIV+, who aren't feeling really confident will go and use that type of thing.

You feel depressed after a night of just casual sex. It's not fulfilling. Love or understanding makes it much better. There has to be something more than just lust. I think people who are HIV+ are looking for that now. To feel comfortable in a relationship.

Graham: That's where I'm lucky. I didn't have much sex for four or five months before I did the group, and then I met Blair, and I've been with him about eight, nine months. But if I hadn't met Blair I don't know what I'd be like now. I'd be feeling the same way as these guys.

Glen: I know when I meet other young positive people, it's nice to be able to know you're not the only one going through it, that there are other young people out there in the exact same situation. It's nice just to be open and honest with someone else.

Blair: Something I remember when I was younger too, was that HIV and AIDS was very much associated with older men, it was very much an older men's disease. I know I thought, I can't get it because I'm young, and when I first found out I had it, thinking, I must be the only young person in the world that's got it. Do you guys feel that being young you're like a minority, or you're hidden?

Glen: We are, But the thing is, all the new infections these days are coming from younger people — so where are they?

Graham: I think they're gradually coming out, I really do. Especially now ACON's organising these antibody parties.

Glen: I think young people have to come out in their own time, in a way that's comfortable for them.

Blair: What's the problem for

young people coming out, do you think?

Glen: The problem is knowing where to access the information. Since I've come out in September, I want to help, I ask for direction, but the services are definitely geared towards older people.

Blair: Is there a difference between older and young men who are HIV+?

Graham: Young men still want to go out and party. They want to take care of themselves, but they don't want to change their lifestyles as much. Older people have done a lot more, been through more, so they're not missing out on a lot.

If I changed my lifestyle completely, I mean my social activities, I'd be cheating myself, and I'm not prepared to do that. I'm going to have fun, as long as I keep myself healthy, and eat right, and just do things in moderation.

Blair: One of the things that annoyed me, when I was doing support groups with a lot of older men, was that I was just battling with the idea of going to work from day to day, and with the others it was "Oh, shall I take this senior job" or "shall I buy myself a house". These were people with really established careers, and that put me apart from many older men.

Russell: That's exactly right, that's how I've felt. I have what's called a 'good job', but since I've found out I'm positive, I have no enthusiasm about it, I take as much time off as I can. Other young men in my position would usually be climbing the ladder, but I don't have any ambition to do that, I just want to stay low stress.

Glen: It's difficult to find work anyway, and being positive doesn't make things any easier. You might only want to do a couple of days, and people don't understand that.

Graham: Russell and I did a young men's group, last year, and after that I did another group, and I only went one night. Every guy was about forty, forty five, even older. What have they got in common with me? Nothing. What young bloke's going to come in here and want support from a bunch of old guys - even though they're in the same situation as us. There should be more support for younger men.

Russell: I agree with you, I don't feel perfectly comfortable talking to older men, but that's natural with young men in any situation. Socially, you probably have more younger people in your life.

But at ACON, I've always really got good support, and I've never really thought about young people not having the support that they need, because I've always found support everywhere that I've ever gone to look for it.

Graham: But look at how many positive young men there are out there. You don't see many of them coming here.

Russell: But how many of them know that they're positive?

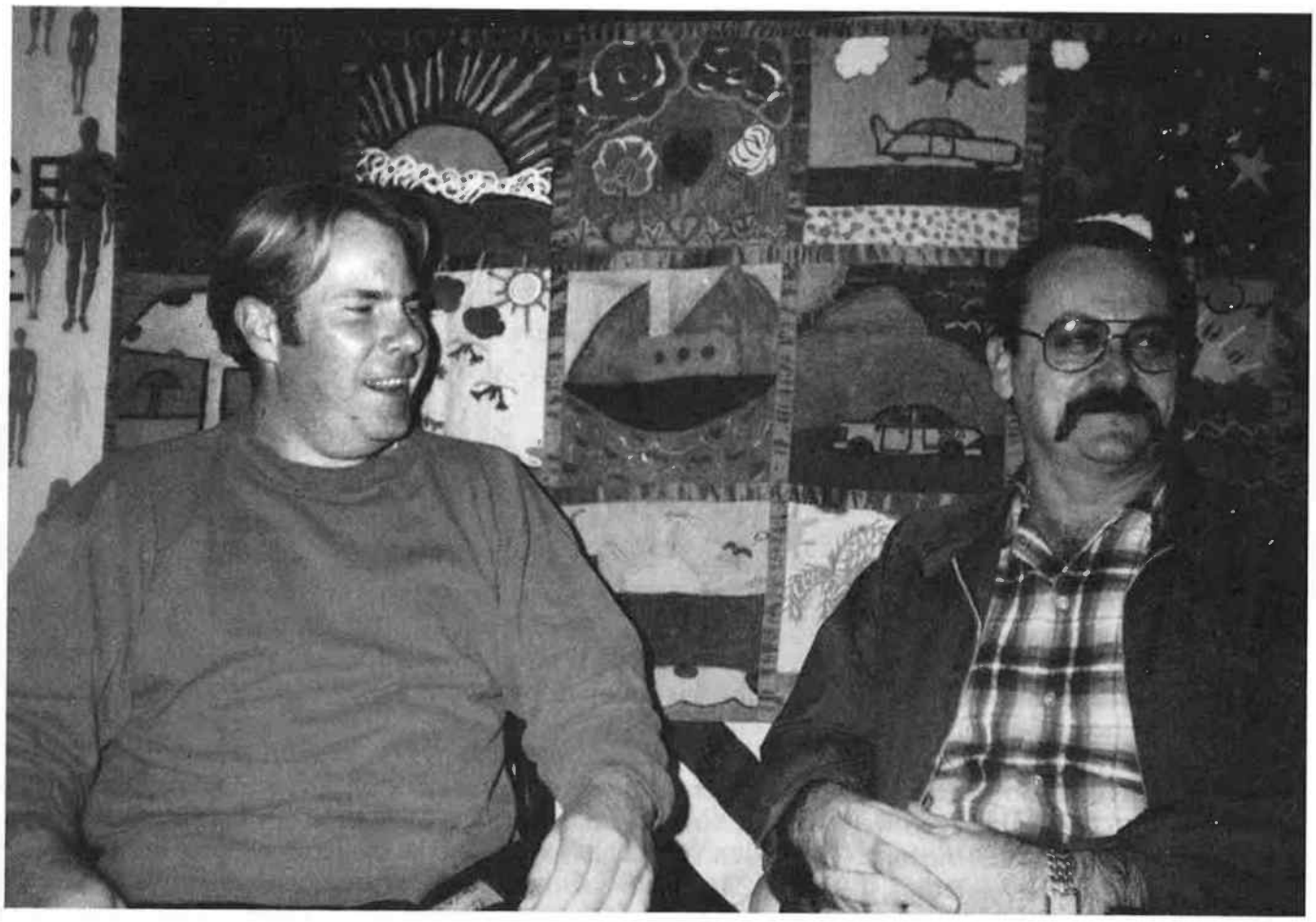
Graham: But you do know. It was five months before my test came back positive, but I knew that I was positive, I just knew. My body changed, there were things happening, I knew. I think they just don't want to know, because there's not enough support out there for them.

Russell: That's because people perceive that there aren't any young men out there with HIV.

Glen: We need a voice. I feel there needs to be some sort of comradeship, in the sense of being able to support each other and stick together. They need to find out what sort of services young people need, rather than just generalise them.

Graham: I went to the support group because I had nowhere else to go, and I was going right downhill. I couldn't go to my family support. I was wasting my money on drugs. I didn't face the fact that I was positive.

You have to get support from somewhere. If I hadn't found support, I would have been dead a lot sooner that I should have been.



John (left) and Graham with a panel from the AIDS Memorial Quilt which commemorates children who have died from AIDS.

Caring for kids

Camp Goodtime is an annual camp for kids with AIDS and their families organised by the Paediatric AIDS Unit of Prince of Wales Children's Hospital. Many of the volunteer carers at the camp are gay men. Two of these men, Graham King and John Dennis, told Jill Sergeant why they care for kids, and what it's like.

Graham

I FIRST HEARD OF THE KID'S CAMP through Ankali. A circular went around to all the volunteers. I was interested, I suppose, because so many of my friends have died over the years, and I'm HIV myself. I'm one of the lucky ones, because I was diagnosed back in 1983 and, touch wood, I've had no opportunistic infections.

Then we started getting reports in Australia from America where kids were being born with it, or infected through blood products. That's when I became interested in that side of it, to see what was happening in Australia. Also, my nephew is a haemophiliac, and I thought — maybe it could happen to him.

I'd been asking Ankali if there were any children that they were looking after, and at the time there weren't. It was just before the kid's camp, the first one in 1990, that they did get one or two children, and I declined at the time, because it's one to one you see, and I already had someone. I'm going into my sixth year now, with Ankali.

At the camp I was assigned to a family with one child who was HIV, haemophiliac. He's nine,

going on ten. I was from Western Australia, so were they.

I just seemed to hit it off with Ross. I think it was on the Sunday Ross was feeling down and we were talking. We ended up talking about him being HIV, which was the first time over the weekend that we'd had a talk about it. I was quite surprised how open he was, talking about it. He wasn't angry at anybody, which really surprised me. Then he come out and he asked me "are you?" I said, "well, just between you and me, we'll have a little secret, yes, I'm the same as you, I'm HIV."

He never asked me whether I was gay or anything, I don't think it mattered to him, but his face lit up, he was talking to an adult who was HIV, who knew more about it than him. I think after about an hour the conversation tapered off, he wanted to go and play, so we went out and played. His big forte then was tennis, so — tennis. I haven't played tennis since I was in high school — that's close to thirty years ago; showing my age there! After that conversation we just clicked, that was it. His mother couldn't believe how much he'd changed after that weekend.

We kept up the friendship after the camp, with phone calls and he made me promise to write to him. I said, "as long as you promise to write back." He wanted to write every day, but I couldn't see that happening, and we made it once a month.

The first Christmas after the camp, in 1990, I was going over to WA and I rang up his parents and said, "I'm coming over, don't tell Ross". Christmas afternoon I went over to see him. Ross didn't know I was coming. The front door was closed so I just pushed the doorbell, and all I could hear coming from inside was: "I'm going to answer it", says his brother, "I'm going to answer it", says Ross. And their dad says, "It's just my mate from Telecom, he'll be arriving about now." Ross opened up the door and his face lit up, I got hugged to death.

"He never asked me whether I was gay or anything, I don't think it mattered to him, but his face lit up, he was talking to an adult who was HIV."

I think his mum suspects I'm gay. The question's never come up. I don't think it particularly worries her. It doesn't worry me if she finds out. If she asks, I'll tell her. I don't think I have to tell her. Ross has never even broached the subject. I don't think he's worried about it, he's got someone to talk to about HIV, that's what's important to him.

He doesn't bring it up a lot. He used to have a lot of trouble at school, he'd get treated as something special, "he's a haemophiliac, he's got AIDS, so be careful, just watch out for him", sort of thing. So he was getting very spoilt at school, in a way. The kids seem to accept it more than adults do.

Children suffer more than adults do. As an adult you can deal a lot with pain psychologically, whereas a child can't. You can try and get a child to understand what they're going through. Be honest with them from the start, and you'll find that they're more honest with you than they are with anybody else.

I found that when helping with another child who has a lot of trouble dealing with pain. I sat down with him one day at the camp when he was in a lot of pain with stomach cramps, and we just talked and talked, and after a while the pain went, because he was talking about the pain, how it was affecting him, why he hated the pain and things like this — because the medications weren't helping. I think it relaxed his mother too. She was sitting outside and she could hear what was being said, and you could see her calming down. I think the Ankali training has worked, that idea of being able to talk things out, but not advising anybody of what to do. They're talking it out so they're actually working out any problems they've got themselves.

It is rewarding. Kids are more open than adults. Like Ross asked me once, "how do you get it through using needles?" So I had to explain that to him. He said, "well okay, I got it through using Factor 8, why didn't they pick it up before?" Very logical, sensible questions to ask. With the Factor 8 I just said, "I don't know Ross. I could find out for you, if you like." And he said, "No, it's okay, I'll just wait till I get back to Perth."

It is different, working with kids. I think it's their truthfulness. They don't know how to hold back. Okay, kids will hold back a little bit, but after the first two or three hours, it's as if you were always there, part of their life, because you understand what they're going through, and they know you understand that. Kids make friends a hell of a lot easier than adults do. It takes a long while for an adult to trust another adult.

When I told Ross I was HIV, and I said, "that's a secret between you and me", he said, "Yeah, yeah". Then he walked back up to the dining room, he ran straight up to his mum, he says, "Graham and I've got a secret". She said, "are you going to tell me?" He said, "No. I'm not allowed to, I'm not going to tell you what it is." And to this day, as far as I know, he's never told his mother.

"Kids are kids, I can't help but have more empathy for them. I'm not necessarily saying they're innocent or anything like that, but it seems unfortunate that most of the kids who have it will die before they're, say, 12 years old. But I feel exactly the same about kids dying from leukemia, or cancer."

I had no qualms in telling him. I felt he needed to know that he was talking to somebody else who was HIV. I think the reason we've hit it off so well is because I am HIV. I know what's happening to his body, he knows what's happening to my body, we're both in the same boat, even though we caught it different ways.

I would be doing this all the time if I had the opportunity, but with Ankali, if you've got a client, it's a one to one relationship. It's relaxing for me too, because it's a different kind of caring, to caring for an adult.

John

How and why did you become a carer for children?

A friend of mine is a social worker and she gave me the name of Trish Langdon.* I chased up Trish and she mentioned about the camp and suggested that I do CSN for a while and then she'd consider me as a volunteer.

So you actively pursued it. It was something you really wanted to do?

Yeah, yeah, definitely. I'm studying to be a sociologist so I'm interested in the welfare industry anyway, and I'd always wanted to do some work with kids. I suppose kids with AIDS, me being gay, are a bit closer to my own home.

Had you done any caring work before?

Well actually I run a group home for intellectually disabled people, so there's a lot of palliative care there as well as a lot of instruction or teaching.

When did you get involved with the camp?

It was April, May last year, about six months before the second camp started. When we were doing the training Trish described each family that was going to the camp. There was one family that was read out and the boy was a developmentally disabled boy and I decided to volunteer my services for him for the weekend. I was also involved with another family, who I kept in contact with afterwards. They're living over in Perth, which makes it a little bit difficult — but they write pretty neat postcards.

Why did you want to get involved with kids?

I like being around kids. I'm a gay man, so there's little likelihood that I'm going to have a family of my own, so for those reasons I guess.

Have you done any caring through CSN for adults?

Yes I have. I had a full time care last year, that went for about three months, then there are a couple of times when I've been called in to fill in for other people, and I've got a full time care again now, which has been going for a bit over a month.

How different is it to caring for kids?

Oh god, vastly different.

As much as the kids recognise that they're ill, they're still kids. They play, they need to get out there and *live*. Whereas the adults are more or less winding down their life. As far as palliative care goes, the kids that were on the camp were a lot more healthy, they had a lot more energy, they were more able to get out and about and do things. So consequently we're assisting to some degree with

cooking and dressing and bathing them, but not to the same degree that you would with an adult. I have no doubt that there are times when the kids also need full time assistance.

But you're also there to take the load off the parents, aren't you?

Yes, yes, certainly, and bearing in mind that some of these parents are living with AIDS as well, so they need the break too.

What sort of relationship did you develop with the kids that you were caring for?

Oh, just friends, basically. it's kind of weird, because over the four days you're spending virtually 16 hour days with the kids, so obviously they get to know you rather quickly, and you get to know them rather quickly too. At the end of the weekend it is rather hard, and you're left with this gap, sort of what do I do now? At the same time, they're kids belonging to other families and you have to respect that. You can't just take over or expect any role or position within the family.

Would you go back?

Oh yes, definitely, there's no doubt about that.

What are the rewards?

Being able to be a kid again, I suppose, for a couple of days - we go to the beach, play cricket, tennis, all that sort of thing. The other rewards are that I've mixed with some of the other volunteers after the camp. I see one of the guys now as a good friend — so, branching into another network of friends.

Do the kids' parents know that you're gay?

Well if they don't then I think they'd be fairly blind. It wasn't an issue that was really discussed up there.

Have you got any flak for doing this — from any source?

The only flak that I've got is from the parents at work - there has been one person that's mentioned "oh, you are careful, aren't you, that you're not going to get AIDS and bring it back to us". But apart from that they've mostly been quite supportive. Apart from my boss, who said, "you're not going to get *too tired* from all this volunteer work are you?"

It's a very enjoyable camp to be involved in. It's a shame, in a way, that people do come from all over Australia, because otherwise we could have more day outings and things like that. We had a Christmas party last year, where the Sydney families got together, which was nice.

Would you like to care for a child on a more regular basis?

Yes, I think I'd find that quite rewarding.

How does it affect you emotionally to be around children who are HIV+? Does it affect you differently to being around adults?

Yes, I think so. Kids are kids, I can't help but have more empathy for them I suppose. At the moment I'm still pretty sure I'm HIV-, I might change if I contracted it and became HIV+. I'm not necessarily saying they're innocent or anything like that, but it seems unfortunate that most of the kids who have it will die before they're, say, 12 years old. But I feel exactly the same about kids dying from leukemia, or cancer, things like that. It's just the situation they're in.

**Trish Langdon is a social worker at the paediatric AIDS Unit, Prince of Wales Children's Hospital.*

Project Male-Call

008 802 881

The gay community has done really well so far in preventing the further spread of HIV. However, there are still a significant number of new infections each year.

To work out what is actually happening now in the epidemic we need to know more. In particular, we need to know about the knowledge and attitudes, sexual behaviour and lifestyles of gay men and other men who have sex with men.

Project Male-Call is a confidential telephone survey being conducted by the AIDS Research Unit of Macquarie University.

The information gathered from the survey will have a vital impact on future education programs and HIV/AIDS policy directions. It will:

- allow *each* man who has sex with men to make a contribution to preventing the further spread of HIV.
- help target men who may have missed out on information and education
- provide a national benchmark on sexual behaviour, knowledge and attitudes, which can then be used to assess changes in follow up surveys
- provide a more accurate picture of the diversity of the gay community
- provide more accurate information about the diversity of men who have sex with men
- help in the fight against AIDS and HIV.

Simply by taking part in this survey you can make your own very personal contribution to fighting the spread of HIV.

It's free, completely anonymous and only takes a phone call.

Call the project number from anywhere in Australia, 10am - 10pm (E.S.T.), 7 days.

National results will be published in the *Sydney Star Observer* and other newspapers.

008 802 881

What am *I* doing?

Andrew

His own brand of activism

This month Robert Ariss begins a new series profiling positive people who have contributed to the fight against AIDS. Over the next few months we will talk to activists, policy writers, bureaucrats, educators, researchers, artists, health care workers and others who have, in their own inimitable way, helped to make life with HIV that much better.

This month we talk with Andrew, a policy writer for a federal government department.

Andrew has known he is HIV positive for about as long as anyone can — since the time the test became available in 1985. Like many who were diagnosed at that time, he was given the information by his doctor over the telephone with no formal counselling, and virtually no meaningful interpretation of what a positive HIV test meant. His lover was similarly diagnosed 2 weeks later, and so they became one of Sydney's first positive couples. "We were not expected to live beyond 1987", he remembers, "two years is what we'd given ourselves".

Andrew's experience with HIV related discrimination began soon after his diagnosis. He was refused elective surgery for a back complaint. The story had only just begun, however, as he then found himself faced with an ignorant and terrified rehabilitation centre staff not allowing him occupational therapy or use of the centre's swimming pool. "In my own little way I started there, making big noises, and managed to get to use the swimming pool and do the occupational therapy. I hassled them and basically got them to teach their own staff".

"No one would touch me and I needed this operation. It took a long time to find someone to do it. I had to thump on the table and demanded my doctor find someone who would do it." And indeed, within a few hours Andrew found himself in St. Vincents, being medicated for the operation the following day.

And so began Andrew's own brand of activism.

SOON AFTER THIS EVENT ANDREW'S lover became sick, a situation which allowed Andrew to ignore his own condition, he says. "I avoided my own HIV status by concentrating on him. Because I was otherwise healthy, it was a nice easy way to forget about myself. And I did that for a couple of years. The possibility of AZT trials came up a few times, but I was adamant I was not going on it. My attitude was — I think about AIDS two or three times a week as it is. I don't want to think about it two or three times a day. It was total denial".

New opportunities presented themselves, however, when Andrew was persuaded by a friend to attend the National AIDS Conference in Hobart in 1988. Andrew was concerned about issues around AIDS in the workplace and decided to attend the workplace seminars scheduled in the conference program. After some persuasion, he secured limited support from work to attend.

People with HIV and AIDS who attended the Hobart conference will remember it as a key moment in the history of AIDS in this country. As Andrew recalls, "that was the birth of PLWA as we know it, a very exciting time. Suddenly people with the virus were up there demanding to be heard". Andrew remembers heated debates between those who were "merely HIV positive", and people with AIDS. "I gave one of my impassioned speeches at one of those sessions, saying we're all in the same boat. I had to go through the whole thing too — death and dying, discrimination, trolleys in hospitals and big red contamination signs. The difference was I was lucky enough to be healthy. We shouldn't be creating false delineations between ourselves.

Upon returning to Sydney, Andrew became involved in the formation of PLWA (NSW). He recalls those halcyon days as fraught with long debates about the functions of a PLWA organisation, and how to represent people with HIV/AIDS in the media. "Was it going to be a political group or a support group? I found that exciting to start with. But I didn't last very long because of the confusions. The whole thing started to get bigger than Ben Hur and I started getting overwhelmed, feeling frustrated that I didn't have enough time to put into it".

At the same time a close friend of Andrew's died and he went through a 'time out' period. Time out was brief, however. Andrew took a holiday in London and

experienced the newly formed ACT UP London and was encouraged to bring the news of this new style of activism back to Sydney.

"The first meeting of ACT UP Sydney", he recalls, "was remarkable. There were a lot of people there, and it was exciting to see. But despite all of that stuff in the press that people were getting angry, there was a remarkable lack of expressed anger. I don't think Sydney or Australia can support an ACT UP in a way that it's worked overseas. We still want to see changes, but in terms of how the government has responded, it's so much better than other countries. And Australians by nature are not vocal. They generally let things happen. She'll be right mate".

This did not stop Andrew from becoming involved in the early ACT UP campaigns, notably the week-long action at the IV National AIDS Conference in Canberra, lobbying for a streamlining of the Australian drug approval system. "I found that period very exciting", he recalls, "but I soon found myself withdrawing from that kind of direct action".

"The concept of ACT UP being there is important. They may come across as over-the-top but they play an incredibly important role. They're very brave to get up in front of a camera and be identified. I don't have that sort of courage. I was not prepared to come out as positive. My main fear is my parents and dealing with people at work".

THIS RELUCTANCE TO COME OUT has not, prevented Andrew from being active in AIDS. On the contrary, he argues, not being open about his HIV status at work may have helped him achieve a significant goal in developing an AIDS policy for the government department in which he works.

"What I've been doing is pushing my own barrow for the last four years about AIDS in the workplace, getting the department where I work to see the need to develop a policy on AIDS, and then working on developing one. It was very slow and very frustrating, using the industrial democracy process, pushing it as an occupational health and safety issue. Making the work place safe and harassment free.

"I plodded along getting the policy accepted. We then had to think about how we were going to train and educate staff. I had to veto the management's idea of using just a video for training. What I had to argue for was an expansion of the training proposal to make it a complete education process, to include a whole range of issues and not just transmission information. Unfortunately that had the effect of delaying the publishing of the policy a year.

"Doing this work has allowed me to come out at work as gay. Essentially people don't need to know that I'm HIV positive. The reason why I've not come out is that if I was coming from that position I would get far more emotional about it, and I would start feeling that the debate was getting down to a personal thing. And that would be difficult for me. I find it much easier to fight for other people than to fight for myself. If I was identifying publicly as a person with HIV I would lose that ability to fight. They tend to move you out of things if you're perceived as being too involved. But I was perceived as someone who had done a lot of work in the area, and was able to do the work with some objectivity. I was involved, but not too emotionally involved. It was a nice balance."

Some have been critical of Andrew's work. "People say — that's all very nice but it's taken too damn long. It should have been done years ago!". But Andrew defends his position. "Although it's taken a very long time I think it's been very successful. What I've been able to achieve over the last four years by doing this slowly is that I've managed to take other people with me. People now want to be involved instead of having been forced into it. It's being seen as an important issue. The result is that the impact will last much longer. It's got senior managment support. It's something that can't be got out of. It has to be done".

I ASKED ANDREW HOW HE FELT, AS a positive gay man, about the way the gay community has responded to the epidemic. "I'll have to give you two answers to that", he says with a smile.

"On one level, on a personal day to day level, unless you've created your own HIV positive network of friends, its not an HIV positive friendly place to live. It's still something that scares people. When you go into a pub it's not something you chat about openly unless you get with a group of people who are out about being positive. I think we've still got a them and us mentality. An example that recently upset me happened in a bar. They had a memorial on the wall to people who had died from AIDS. It was subtle. I was proud to see it there. And when I went back the next time it was gone. That made me sad.

"Overall, though, the gay community has done wonders. It's done extraordinarily well. There's lots of things there, information, people getting involved. In many ways AIDS is synonymous with being gay and I don't see that as a negative thing. It's there. It's an important part of the gay community".

Next month we profile Matt Bradshaw, previous NPLWAC Needs Assessor, and newly resident to Sydney.

Tit Rings and Cane Fields

I GATHERED MY THINGS TOgether and sloshed across the saturated ground to our car. It was blood test day, and then I'd be off for my second visit to a practitioner of oriental medicine who works with HIV+ people. The four hours driving time would afford me, as usual, time to think. You see, my partner and I moved to the country from Sydney about three and a half years ago, and coping with the tyranny of distance is part of a rural lifestyle.

I know lots of HIV+ country people who travel long distances for the expertise and/or anonymity they require to manage their health. In our local area of the far Northern Rivers we have only recently had close access to a doctor who could prescribe AZT. Some people drive to the Gold Coast or to Lismore for treatment, and in both cases we're talking an average two hours return highway driving time. Some people drive to Brisbane (4 hours) and I know some who journey to Sydney for their regular check-ups!

I don't know that tongues in the country wag with greater velocity than they do in the city, but since news has a shorter human distance to travel in rural areas it doesn't take too long for a substantial percentage of the population to know a whole lot of information in a relatively short period of time. Consequently, some people devote a great deal of time and energy to the quest for anonymity. I know one person who would literally die than go to a doctor and risk being discovered, becoming a topic of malicious gossip and suffering social isolation and discrimination. Whether these beliefs are founded in fact or fear I can't really say, but the fear of such for some is a reality, and for some that is all that is needed to make the worst scenario of being 'discovered' a fact. Personally, I'm looking forward to shifting my medical treatment from the Gold Coast to our local doctor and being able to complete in a couple of hours what it now takes me half a day to do.

I turned onto the Pacific Highway and headed toward Tweed Heads and the pathologist.

For some reason the day of my diagnosis popped into my head. It was late 1985 and I had gone to my doctor in Darlinghurst to have a set of tit rings inserted. I had seen him a couple of weeks earlier about having it done and at that time had the HIV antibody test. The results were back, I was positive. As the emotional earthquake subsided and the gaping hole at my toes closed, I recall standing there with my rings in the palm of my hand and asking myself as much as anyone else, "What should I do with these?".

My doctor, gentle man that he is, took my hand in both of his, closed his fingers over the rings and said, "I want you to listen to me very carefully. It is now your decision to start dying or to continue living. If I were you, I'd have those fabulous rings inserted and make them your first positive step toward staying well and getting on with life." From the very first moments of diagnosis I had been empowered, supported and shown love.

Pop. Into my head came memories of my dear friend Jim, who had been diagnosed positive a few weeks later. By contrast his doctor had outlined the course the disease would take leading to his eventual death. Jim was very impressionable and easily lead and followed his doctor's "instructions" exactly. Jim died three years ago.

As I drove past the cane fields, I gave my left ring a tug as a positive affirmation and repeated to myself, "Remain in control and empowered, be supported and supportive, love and be loved."

Larry
"Somewhere"

If you're not *gay . . .*

Many services for people with HIV and AIDS originally set up by the gay community are now being used by an increasing number of PWHAs who are not gay men. Some gay men have expressed fears that this may mean their services become less 'gay friendly'. On the other side of the fence, some PWHAs, whether from homophobia or just fear of the unknown, are uncomfortable accessing predominantly gay services.

Gabby McCarthy and Michelle Morrison are HIV+ women who have both used and worked in gay community based organisations. A 'gay edition' of Talkabout *seems an appropriate place for them to share their perspective on the issue.*

Michelle

I'VE BEEN WORKING IN OR AROUND HIV/AIDS SERVICES about five years and accessing them for about seven, although only twice prior to working in the area. I accessed these services to find out about this virus, but didn't feel comfortable about what I was told nor how I was received. That was in Adelaide around 1985. I was the only positive woman around for some time.

Walking into an AIDS Council was very difficult. Women who entered were assumed to be social workers, nurses, carers. No-one thought that I might be positive so the reception I received was different to say the least. I had many gay friends, which was good. They were as supportive as they could be, but they didn't understand that HIV was different for me. None of my gay friends had yet been diagnosed, I was the first one diagnosed with HIV amongst them — quite a turn around.

It was different for me for two main reasons: I was sceptical that the virus acted the same way because of biological differences; and as a woman, I needed to be able to talk to other women, other positive women. Men can only understand so much.

Working in services that are dominated by gay men can be very lonely sometimes.

Gay men — men in general — often don't realise how vastly differnt being HIV+ is for women. Childbirth for a start is a major issue. Gay men have come up with this argument a few times, to me, that they also have the right and the choice to have children, and they have — I don't dispute that. But what they don't have is the responsibility of carrying a child within them and of maybe transmitting the virus to this child.

There is also the factor that there is the gay community, (or even communities), but there are only about 700 women with HIV in Australia and many of these are just statistics. We don't even know where or who they are. Therefore positive women do not have that sense of community. A dance party would be a non-event if set up for positive women. Perhaps this is because of the diversity of positive women, from women who got it through transfusions to injecting drug users; or because positive women, for many reasons, are still too frightened to 'come out' even to other women.

We talk about a HIV community and I feel that the beginnings of that are in place. I feel a part of this community and perhaps that's because I am out about my HIV status. My support comes from men and women, but more from gay men. Many of these men also refuse to hide the fact that they are HIV+ and understand the good and bad associated with this. That support has always been there for me, but especially in the past two years. My concept of the HIV community is peer support, backup, information and fun; a community where many forms of support are available; and where individuality is respected.

There is more support now from gay men than there used to be. Unfortunately in Australia the separatist attitudes still stand, whereas in America the lesbians and the gays have banded together to fight AIDS. I have a real problem with separatism, it's unnecessary and creates major problems of its own. Everyone needs to stand together, straights, lesbians, gays, to fight this insidious virus and the issues that surround it, or those of us who are positive will get snowed under, get sick, and perhaps die due to overwork and burn out.

We as women need the support of gay men; there are not enough women out there who will get up and do it, it's as simple as that.

The fliers for the Antibody Party the other night were of men. They didn't do it on purpose — they just don't think. One of the guys said to me, "but will there be any positive women there?" I mean, who am I? They just forget.

Many gay men are caught up in their own issues and the deaths of their friends and lovers — many of those men have been my friends too. Sometimes I don't feel it's my right to pour out my problems, they got masses themselves.

The guys have always been the ones standing next to me, there's never been any women, up until this year. I personally don't think I would have got through half of the shit without my gay friends

and the services they've set up. If it wasn't for them, I shudder to think where I'd be.

I think it's great that the gays have accepted a woman co-ordinator for PLWHA. It shows how far we've come. It wouldn't have happened a few years ago, they would have got right on the band wagon.

We've got to learn to fight side by side, and to work side by side, and slowly this is being achieved. It's the only way any of us are going to get our needs and wants met; it's the only way things are going to get done, ultimately.

Gabby

THE FIRST PERSON I RANG WHEN I found out I was at risk of HIV was a gay man, and from him and other gay friends I got a potted history of the gay community's involvement in AIDS. Having had that background and having always been aware of the impact of HIV on the gay community, I expected that every service I accessed would be primarily focusing on gay men, and I was aware that most of the services I was accessing were there *because of* gay men.

I feel that there's a real gay ownership of the services, and a reluctance to let go of that, and a fear that if too many non gay people start accessing the service that gay men will lose control, or it will become an inappropriate service for them, which are very real fears. But excluding me from accessing services means that I'm also excluded from contributing to them.

The reality, for me, is that PWHAs who are not gay men are going to be a minority in this country, into the medium to long term. And most of the non gay people I know are aware of the gay community's contribution to the services that they are accessing and don't actually feel a burning need

PHOTO: ADRIAN FLOOD.

Gabby McCarthy addressing the Doctor's Summit on May 15.

to take anything away from the gay community. We're not all Lorraine Ciblick. We'd just like the services to be appropriate for everybody who'll access them. And there'll never be enough funding around for us all to have specific little services that cater just to our needs.

We have to learn to work together and make the services appropriate for everybody, and allow people who aren't gay to contribute. It's time we stopped relying just on the gay community to provide those services. That doesn't mean we've stopped recognising the impact that HIV has had on the gay community, or that gay men will be excluded, it's just about bringing in some more energy.

As I've got more involved and got to know more gay men who've been involved in AIDS for longer, the thing that I'm really aware of is that there's sometimes a feeling that gay men are being excluded or forgotten, particularly at conferences — there's all these special interest groups, and gay men feel forgotten or not recognised. When I think about the impact HIV has had on the gay community, I don't think I will ever even begin to understand —getting involved nine years after the epidemic first hit the gay community — what it is people have gone through, and where those feelings are really coming from.

I had gay friends before HIV, so it wasn't a really big transition for me. And it's a really safe space for me, the gay community. I can be Gabby, who happens to have HIV and is involved in lots of HIV community stuff, which means lots of gay community stuff. I don't get hassled by heterosexual men, I don't have to worry about what people think of me, because there's none of those sexuality issues there.

I've taken on a commitment to continuing involvement in the HIV community so that it becomes a safer space for my peers — for other women.

There's TRAIDS and there's the Haemophilia Society, but if you're not a haemophiliac and you didn't get it through a blood transfusion, where do you go? You go to places like Albion Street and the Day Centre, and BGF and ACON.

I know for a lot of people an HIV diagnosis means that they are going to come in contact with a whole range of people that they haven't freely associated with before. And as well as all the stuff that's going to come up about their diagnosis, they'll have to deal with coming into contact with a whole lot of people that they're not familiar with and don't necessarily understand. And they're not going to be as nice, or as politically correct as they should be. Those issues have been fairly easy for me.

I think there needs to be a level of understanding on both sides. There are a lot of gay men out there who've never really had a great deal to do with women, so when they suddenly see women arriving on the door of Maitraya, they're not sure how to handle it either.

Let's accept that at times each of us is going to make the other feel uncomfortable, but learn to work through that and to adapt to it.

Gabby

TALKS

IT DOESN'T SEEM POSSIBLE THAT another month has passed. I've been so busy the days disappear before I get half the work done. When I think about everything I've done, I suddenly feel as if at least six weeks have passed.

The highlight (lowlight?) would have to be The Australian Doctors' Fund AIDS Summit. PLWHA felt that any forum that canvases such alarming 'solutions' can't be ignored. We sent a letter to the conference organisers asking for PLWHA representatives to be included in the speakers program. To my surprise they agreed, although only one time was available, and that was at 8.10 am on the Friday morning.

Initially we requested space for a gay man with HIV and a woman with heterosexually acquired HIV, because these were the two areas that Fred Hollows had focussed on. As only one space was provided we decided to have 10 minutes each.

I wouldn't say that Ross Duffin and myself volunteered to speak, but agreed by default. At times I felt I'd volunteered to throw myself into a pit of vipers (what sane person volunteers for that!).

By chance I had decided to do a story for *A Current Affair* that would go to air in the same week. I felt that I had little to lose by speaking at the Summit and speaking to media about the Summit. Even so the week leading up to the Summit was pretty stressful as I constantly wondered whether I had made the right decision. These feelings were only reinforced when people kept telling me how brave I was to be doing this.

I delayed writing my speech until the week of the Summit. It turned out to be a fairly therapeutic process. The first draft was what I wanted to say and the final draft was everything I could say without being attacked. Getting it all out of my system in advance helped considerably. So did the amount of support I received from all sorts of unexpected places. Thanks everybody.

On the day it was just too early for me to be nervous. I didn't wake up until afterwards. The speech had a good reaction from those who were there and I had lots of requests for copies from those that weren't (including Fred Hollows).

Knowing that the Summit was really a media circus I went prepared to speak to the media. I deliberately avoided the more sensational and biased media. There really isn't any point speaking to them. I've had lots of good feedback from people who saw or heard me, although I haven't run across myself in the media anywhere.

While I have mixed feelings about the whole event (we certainly didn't change some people's prejudices) I have come away with some good feelings. Finally after three years of feeling angry and frustrated when these issues are raised in the media it felt really good to be in a position where I could have my say. Discovering how much support is actually out there for people with HIV/AIDS has been great too. On a personal level my self-esteem has increased enormously It wasn't an easy forum to be openly HIV+, but it didn't stop me from being there, and it didn't keep me quiet. Knowing that I can do this sort of thing will make it easier in the future.

A lot of personal issues have come up for me this month, not all related to the Summit, and I've had a lot of people telling me not to take it too personally. Once I'd got over my various stress attacks and thought about things more calmly I came to some startling conclusions. For me there is no way I can't take things personally, I have a process of taking things personally in order to make decisions.

Part of this position is to represent the needs of PWHAs, and one of my best assets for this is my own sero status. Before I make a decision or comment I consider how I feel about it, and how other people with HIV/AIDS that I know might feel about it. I've started referring to it as a policy of taking things personally.

For me this is what PLWHA is about. We are an organisation that has the unique ability to speak about the personal effect of HIV on our lives. It is important that we keep reminding everyone that HIV isn't just about the big picture or wider issues, it's about individual people. It's about our lives.

New Committee members

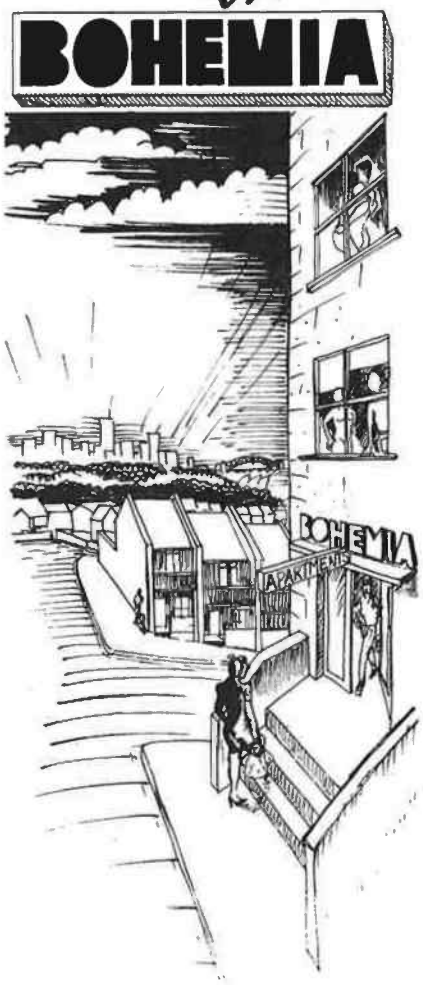
Wayne Holt and Michelle Morrison were recently seconded to fill the vacancies on the PLWHA Management Committee.

Ooops!

It has been drawn to our attention that an unfortunate typographical error occurred on page 2 of the May *Talkabout*. Robert Ariss was described as the new *Talkabout*'s godparent. This should, of course, have read 'Dogparent'.

We apologise for any distress this may have caused.

Anguish in BOHEMIA



CHAPTER TEN

by Ms Ada O. *

The story so far: Nancy, perhaps disturbed by lack of support, suffered a terrible nightmare while Robbie and Wayne fucked for the first time. Brad and Nigel both pursued beds in their different ways - Brad in a hospital, Nigel on a country road. Was Nancy's dream a veiled prediction? Read on...

Big Sister's Little Brother

"WHAT'S UP ROBBIE? YOU HAVEN'T been very alive these past few days." Nancy uttered from the kitchen as she poured the coffee. Robbie didn't even hear her. His thoughts were 10,000 miles away.

"Robbie? Hey, is anyone there?" This snapped him out of his daydreaming. He mumbled an apology and Nancy asked again.

Defensively, Robbie said that nothing was the matter, he just wasn't feeling very well. But Nancy persisted.

"Well, do you know what's wrong? You look pale. Perhaps you have the flu. Have you got a headache? I've noticed you haven't been eating much and -"

Robbie snapped that he didn't know what was wrong.

"Okay, no need to snap hon. I was just asking."

As Nancy moved closer to the lounge, she noticed Robbie was crying. She instantly went into concerned sister mode, and resting the mugs on the table wrapped her arms around her baby brother.

Robbie sobbed an apology, saying he didn't mean to snap.

"I'm scared Nance," he said. She asked him what he had to be scared of. He hesitated before replying.

"Well," he said between sobs, "I've been feeling feverish. And my throat has swollen." Nancy felt his throat. Yep, it was a bit puffy. She suggested he might just have the flu.

"No Nance." Again he hesitated. "I've got this revolting feeling I've seroconverted."

It took a few seconds for these words to sink in, but then panic swept over Nancy. "But, but, but," she stuttered, "how? I mean, are you sure?"

Robbie responded that he wasn't sure, but he just *felt* like it was true. He added that he had been to see a doctor and was waiting for the test result. Nancy started to freak out, demanding to know if Robbie had unsafe sex and if he did how could he be so stupid.

"For christ's sake Nancy. Of course I haven't. We've only ever fucked twice and we've used condoms. The only thing I can think of is oral sex."

"It's that leather man!" Nancy exploded. "I knew this would happen! I told you he was no good for you. He's given it to you! I told you - "

"Get over it Nancy!" yelled Robbie. "Jeez you surprise me. I can't believe you of all people are into blame. How do you feel when people blame you!?" And with that he stormed into his bedroom.

Nancy burst out crying.

Nigel sticks out his thumb

NIGEL HAD DROPPED OFF HIS HIRE car at the depot, and slinging his backpack over his shoulder, whistled his way through the sunny and busy streets of his hometown. Just why he'd driven hundreds of miles from his Darlinghurst home, ostensibly to visit his family in north-west Victoria, Nigel wasn't quite sure.

**Ms Ada O. is a collective of real men who prefer to write under a pseudonym. Dora Dams was mistakenly credited with authoring the previous episode of AIB, and Talkabout apologises for unwittingly deceiving its readers.*

He decided to have something to drink before fronting at his mother's house, and crossed the street and made for the hotel. Rapt in his own thoughts, Nigel barely noticed the stares and occasional frowns he was attracting. It was probably his clothes - country people always stared at him. Maybe some of them recognised him, but he'd changed a lot since he'd left this dump of a town.

Swinging through the saloon doors Nigel breathed the familiar odours of stale beer and cigarette smoke, and regretted that there wasn't a cocktail bar for at least a hundred miles. The bar was quiet, as it always was mid-afternoon. He strode to the bar and ordered a beer. The barmaid's jaw dropped. Staring at him in disbelief, she stammered, "Ah, ah..."

"Just get me a schooner," Nigel let a cranky tone creep into his voice. The barmaid dropped the glass she was polishing, and ran from the bar.

"It's Nigel! The guy from school... we'll all get AIDS! I saw him on *A Current Unfair!*" she yelled from the backroom.

The few saloon patrons were now all staring at Nigel. He shifted awkwardly on the spot. From the backroom Mr Whitehead, the hotel owner, emerged, red-necked and overweight from years of alcohol use, his eyes aflame with a mixture of anger and fear.

"Just get out of here, mate!" Mr Whitehead spat. "Haven't you caused enough trouble?"

"But.." Nigel stammered.

Mr Whitehead grabbed a walking stick leaning against the bar and advanced towards the hapless and weary Nigel. He staggered into the street in a blur, and was suddenly hit on the back of the neck with a cream bun. He turned only to catch a meat pie in the face. Sticky and saucy he stumbled away, dazed at the discrimination people who got compo for having AIDS who went on Nana Bent's program had to suffer.

Nigel rounded the corner of the street he grew up in, and suddenly stopped dead in his tracks. In the middle of what was the front garden of his boyhood there now stood a large FOR SALE sign with a sold sticker plastered across. Slowly the dull realisation of his present predicament dawned: his parents had sold their place and moved without telling him, probably because of their shame and the small town mentality of their neighbours, as a direct response to his appearing on national TV and talking about having AIDS. Of greater immediate concern was his weary, thirsty and now sticky condition.

He stood there unbelieving for a moment, not sure of what to do. In a state of shock he started walking down the highway, away from the hell that was once his home town. How could his parents move without telling him? How could he appear on national TV without telling them?

He trudged for forty-five minutes toying with these guilty thoughts, and in desperation decided he'd have to get back to civilisation as soon as practicable.

Nigel stuck out his thumb to hitch a lift...

Doctor, doctor

ROBBIE WENT THROUGH EVERY *New Idea* as he sat in the waiting area. He didn't see any words or pictures, he just looked at them. When he had run out he moved on to the *Time* magazines. Eventually he looked up. The three people sitting opposite him were all watching him, amazed at the speed with which he was flipping through the magazines.

His heart jumped when the surgery door opened and the doctor strode out. She said a few words to the receptionist then picked up a file and moved towards Robbie.

"Robbie, would you like to come in?" she said in almost a whisper. But even before she had managed to finish the sentence Robbie had sprung up and bounded towards the office.

"Well," the doctor said as she sat down. "You've come for your test results haven't you?" She opened an envelope and removed several papers, quietly leafing through them. It seemed like an eternity to Robbie. He broke out in a sweat.

"Hmmm," the doctor mumbled after reading the results. "Well Robbie, I'm afraid I don't have good news for you."

Robbie fainted.

Nigel gets a truckload

NIGEL CLIMBED INTO THE CABIN of the Mac semi-trailer.

"I need to get to an airport," he said looking pleadingly at the burly but not totally unattractive driver.

"We'll see what we can do, mate," the driver replied, breaking into a grin at seeing the remnants of pie and cream bun on Nigel's face and neck. "The name's Rod," he beamed, revealing a missing tooth.

Nigel gazed out at the endless pasture lands, his mind numb from the day's events, but his spirits lifted when he thought of sitting in Bohemia Apartments with his friends, sipping a long drink. Rod was humming along to a Patsy Kline tape, and Nigel found himself wondering how the young driver had got that large scar on his cheek. Nigel cast a glance at the man's tight fitting Levis, and chest hair peeking out from beneath his western shirt. The driver looked like a slightly battered and lived-in porn model, so strong and carefree. Nigel even found himself fantasising being raped by Rod.

They were in the middle of

nowhere. Rod slowed the semi and pulled into the lonely parking station. Turning to Nigel, Rod pulled a sawn-off shotgun from beneath the seat, and unbuttoning his Levis with the other hand, said: "Get your pants off, kid..."

Manhattan Prelude, molto funeroso

"IT'S ALL GOT TO GO", NANCY exclaimed. Brad slumped into her two-seater sofa and watched while she pulled unmentionable items from an old hope chest.

"Junk. Hideous junk," she scowled as she produced a small black pillbox hat.

"It's mine", squealed Brad, getting to his feet. "Now all I need is the little black dress and I'll have the perfect outfit for our next funeral."

"Don't even think about it, Brad. I've only just got over Jack's." Nancy reflected, twisting a chiffon scarf between her fingers.

"Well, that's what two days on a trolley does to you," Brad murmered. "Which reminds me, Nance. I ran into the guy who's moving into his apartment. I think you'll approve, he's . . ."

"Straight?", she exclaimed hopefully.

"No, a pianist. And very sweet. I invited him in for Manhattans".

"Here? You invited him here? But the place is a mess and there aren't any cherries." Nancy started stuffing the piles of clothes and Tupperware back into the chest with the same frantic disgust she'd expressed while pulling them out.

"Don't panic, darling. I'll go buy some".

Brad swanned from the apartment leaving Nancy muttering under her breath. Falling into the two-seater she grabbed her mail from the coffee table and leafed through it absent-mindedly. Stopping at a postcard, she read the two lines:

"Forget the Manhattans, Nancy. The Tequilas are on me, Nigel."

Her heart thumped as she turned it over. Where have I heard that before? she puzzled as she studied the scenic shot of prickly-pear.

At that moment the apartment started to lose sunlight and within a few moments she was plunged into darkness. Nancy gasped and looked at the window which was now completely black. Slowly a shaft of light appeared near the sill and grew. Incredulously she watched as a nine-foot baby grand was being hoisted past her apartment window.

"The pianist. Of course", she laughed to herself. Brad'll be back with the cherries soon and - oh, damn there's no bourbon." Nancy grabbed her purse and ran from the apartment slamming the door behind her. On the front steps of the Bohemia she ran into Brad who was about to come in.

"Bourbon, Brad. We've run out of bourbon."

At that instant someone yelled and they heard a loud TWANG from above. Directly above their heads, four stories up, the baby grand began its descent, quickly and accurately.

TO BE CONTINUED

Homefront

Dignity and Diarrhoea

TOWARDS THE END OF LAST YEAR I noticed that my digestive tract developed a rather unorthodox way of doing things; which is to say, I saw more of my toilet than I cared to. This unfortunate state of affairs developed over a period of several months. Had it come overnight I might have done something about it right away, but those slowly developing things always seem just bearable enough to put off for another day.

Since I have always been one to favour a sit-back-and-wait attitude, that is exactly what I did. My less than luke-warm relationship with the medical profession didn't help either.

Finally, after about six weeks of manifest diarrhoea I decided that it was time to act. The first doctor I contacted suggested that the diarrhoea could be due to a number of problems, tests for which were rather elaborate and inconvenient (what did he think living with the shits was?). So he gave me a prescription for anti-diarrhoea pills and sent me on my way.

Well the pills did the trick. When I took them the runs stopped, although it didn't really improve my feeling of wellbeing. And it didn't solve the problem, just manicured the symptoms. It certainly didn't affect my lousy appetite. I temporarily assigned myself to my fate. My resolve that something needed to happen grew after repeated nightly 'accidents' required me to change my sheets on a more than regular basis. I wonder what my laundry lady must have thought I do at night.

After my move to Sydney I gave one of the local GPs a try. I got a referral to a gastrointestinal expert for the next day. He requested three stool samples. Do you have any idea how difficult it is to manoeuvre a 'sample' with the consistency of pumpkin cream soup into one of those little containers? All I can say is don't try this at home. I actually felt sorry for the poor lab assistant who has the privilege of analysing this mess at the other end.

A week later I was on the table for an endoscopy and colonoscopy. the procedures themselves were only minor inconveniences, however the fact that one has to refrain from eating for 24 hours prior and drink some horrid tasting cleaning fluid made it quite an ordeal.

Anyway the effort proved successful. I had cryptosporidiosis, a parasite common in PLWAs. The first course of action was three double doses of Flagyl a day for four weeks. No problem there. I'm so used to taking pills that a few more didn't really make a difference. After that a week off, followed by a four week course of Paromycin (two tablets four times a day).

I also decided to utilise some complementary therapy. Thanks to *Talkabout* I heard of Thioctic Acid, a vitamin which supports liver function. (March 1992). I asked a friend in the US to get me some, as it is not available in Australia.* Declared as vitamins the stuff made it through customs to my mail box without a hitch. I'm taking a 100mg once a day, combined with a multivitamin and some slippery elm powder (available from health food shops). Slippery elm powder tastes like saw dust (essentially, that's what it is), but mixed with yoghurt or cereal one manages. I use acidophilus yoghurt. The advantage of this is that it revives 'good' bacteria in your stomach that normally gets killed by the use of antibiotics (which many people take as a PCP prophylactic).

This elaborate combination seems to please my digestive tract enough to elicit co-operation. There are still occasionally days when a few more visits to the toilet are necessary. An increase in slippery elm powder usually takes care of that.

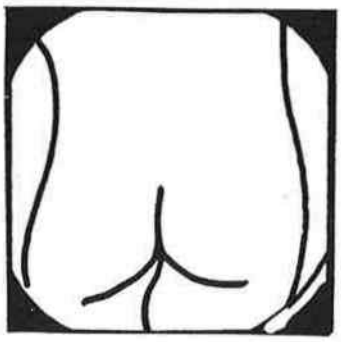
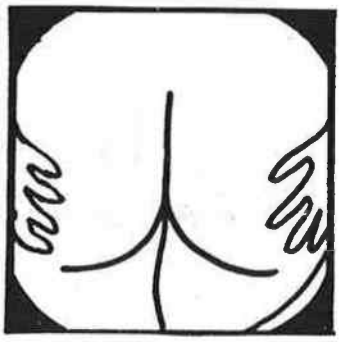
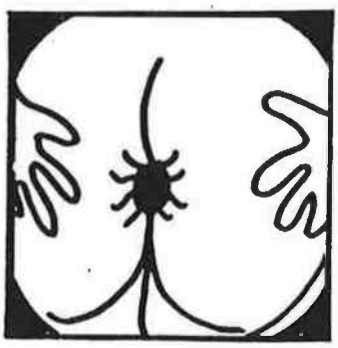
I'm aware that this is probably only a temporary relief until the next bug finds its way into my system, but until then I'm determined to make the most of it.

In closing I would like to add that my current set of doctors has turned out to be understanding, knowledgable and to top it off also has, equally important, office staff with those qualities.

- Matt Bradshaw

**available from Ecological formulas, 1061-B Shary circle, Concord, CA 94518. Tel (512) 827 2636.*

Readers are welcome to contribute to *Home Front*, which is a space to talk about your personal health strategies for living with HIV.

Check out those bums

FRED HOLLOWS IS OBSESSED WITH anal sex. He can't stop talking about it. Despite what he says, we talk about it a lot too. Some of us also enjoy doing it. Despite its prominence, the anus is often ignored as an area where disease can (and does) occur in people with HIV. While regular vaginal examinations are part of the monitoring guidelines for women with HIV, regular anal examinations don't seem to given the same importance.

Even when there is awareness of the need for an anal examination from either the doctor or their patient, they are sometimes still not done. Often this is because of fear of embarrassing the patient (and from my observation this often occurs despite — or because of? — a close doctor-patient relationship) or the patient being coy or the patient not wanting their doctor to know they have been having anal sex (even though the symptoms may have nothing to do with this). Old hangovers about the bum being dirty persist and can interfere with the maintenance of good health.

There are a whole lot of conditions such as haemorrhoids, anal fissures (little breaks) and traumatic tears (breaks caused by trauma). These can occur in anyone but are more common in people who have anal sex. They are mostly treatable and if not treated can set up ideal conditions for other infections.

There are also a number of infections that can occur such as herpes, anal warts, gonorrhoea and

chlamydia. These are also mostly treatable. In people with HIV, opportunistic infections such as CMV or Kaposi's Sarcoma can be seen in the anus.

While the advent of safe sex has hopefully decreased infectious sexually transmitted diseases that can occur in the bum, it has also caused a new condition that occurs in some people - irritation of the rectum caused by the rubber of condoms.

I have often heard people with HIV complain about "HIV bottom" or "HIV bum" — tied in with a belief that their symptoms are "just the virus". Sometimes they have not had an anal examination for some years and when encouraged to go to their doctors find that their symptoms are in fact quite treatable.

Another factor which has influenced treatment of anal disease in gay men has unfortunately been homophobic attitudes by some surgeons. A prominent US surgeon some time ago produced a study which purported to show that there was no point in performing some anal surgical procedures on gay men because success was less likely (and a number of reasons were hypothesised for this). The findings from this study were subsequently not confirmed in a later study by the Centre for Disease Control in Atlanta — but unfortunately some surgeons persist with beliefs that anal disease is untreatable (or not worth treating) in gay men.

So the important messages:

i) for all people with HIV (and for gay men who have anal sex) - get that bum checked out regularly (ie every six months)

and

ii) if you have symptoms around the bum get them checked out (and if necessary get referred to a clinician skilled in procto-sigmoidoscope).

If you're too embarrassed to do that with your usual doctor or find you can't insist then either go to a doctor where this is not a problem or try to talk over the issues with your usual doctor.

It's time to get those bums back out of the closet. In the seventies as gay men we used to talk about anal sex and health a lot. In the eighties we weren't meant to talk about anal sex (except to say that when it does happen make it safe). Disease can occur in the anal area of people with HIV regardless of whether they have anal sex or not. Lots of us still enjoy anal sex and it is an integral part of our identity. Often this is one of those things we lose as we get ill - but sometimes with proper care and attention it needn't necessarily be so.

— Ross Duffin

Doctor, Doctor

I THOUGHT I'D START THIS MONTH with a vague movie review. Went to see a druggie movie called *Rush*, which has the laudable presence of Jason Patric and is very true, I imagine, to a good part of the illicit drug experience.

It's about two undercover cops who attempt to bust some dealers in a small US city and one of the cops gets hooked. The movie is sort of okay to good — *but* — there is a moment where one of the cops goes to purchase something in capsules from the guy who manufactures it. Well I won't totally spoil the scene for you but from now on I'm calling my AZT 100mg caps 'Blue Ringers'. Does anyone else have any good names for their medications?

I suppose most of us have heard of *Choice*, the magazine of the Australian Consumers Association (ACA). *Choice* has a really remarkable ability to test drive a product about three months after I've trudged the streets and bought it. The ACA has published an interesting book called *Your Health Rights** which has recently been revised and released in paperback. *(ACA/Random Century, $14.95)* The publishers describe the book as "the handbook you need if you've ever been intimidated or confused by the health care system. In clear, straightforward style . . . *Your Health Rights* tells you exactly what rights you do have with regard to issues such as consent to and confidentiality of treatment".* We hope to reprint relevant extracts from this book in *Doctor, Doctor* in the near future, as it is particularly relevant to the Australian experience.

By the way, the HIV Needs Assesment Project at ACON has a second part to their questionnaire called 'Looking After Yourself', which covers "your relationship with doctors and other health practitioners, your ideas about health maintenance and your experiences with treatments".

The more feedback and information we get on these issues the better. Ring Peter Gay at ACON on 283 3222 and ask him to post you a copy. Hopefully *Doctor, Doctor* will be able to publish some of the results of the survey.

A really worthwhile source of information on drugs, side effects and many other medical concerns of HIV/AIDS is an American publication called *AIDS Treatment News***. Recently they published an article called 'Managing Your Doctor', by Michelle Roland. Over the next few months we will publish extensive excerpts from this article. Our thanks to ATN for their permission to do so.

* *Available from ACA, 57 Carrington Rd, Marrickville, NSW 2204. Call (02)558 0099.*

** *If you are interested in subscribing to ATN, write ATN Publications, PO Box 411256, San Francisco, CA 94141 USA. Phone 415 255 0588.*

Managing your doctor

Introduction

MANY PATIENTS FIND THEMSELVES dissatisfied with one or more aspects of their relationships with their health care providers. For some, the problem is the amount of time and attention they receive during office appointments or in-patient visits; for others, philosophical differences in treatment approaches leave them feeling misunderstood or unsupported in their decision-making process. Still others find their symptoms undiagnosed and/or untreated for long periods of time.

In this article, we will present some suggestions about how to develop a constructive working relationship between patients and their physicians. In order to do this, we will attempt to explain how doctors are trained to think and how you, as a patient, can assist them in their thought process while having your questions answered to your satisfaction.

What kind of patient are you?

The first step in developing a good relationship with your doctor is to identify the role you wish to play in this relationship. The next step is to find a doctor who feels comfortable working with patients in this way. In order

to find such a doctor, you must know what you are looking for.

Many people with HIV infection want to work as full partners with their doctors in managing their health. For such people, frank discussions of diagnostic and treatment possibilities are very important. Others would rather have the doctor do most of the thinking about what could be causing the symptoms and how to treat them without being included in this thought process. They would rather play a more passive role and accept the doctor's suggestions without a great deal of interaction.

This distinction is most often not quite as clear cut as it may sound. Many people fall somewhere in the middle, wanting to be included in the decision making process, but not really wanting to know all of the details along the way. For these patients, brief explanations about what the doctor is looking for will suffice, followed with a more in-depth discussion of treatment options once a diagnosis has been made.

Determining which role you want to play does not mean that you need to be bound to that role irreversibly. There will be times when you want to know more or less than usual; the challenge will be in identifying those times and being able to communicate your needs to your doctor as they change. Most people, no matter how large a part they to play in managing their health care, will at times find this role, and the information that comes with it, very scary and threatening. The emotional impact of such information should never be minimised, no matter how active you are in your health care.

Next month: "Finding the right doctor for you". Until then, ciao for now.

— Peter Hornby

Talking Drum

Your questions answered

HERE WE GO WITH THE FIRST OF another new feature, to which we hope readers will heartily contribute. In fact the success of this column lives totally and only in the active participation of all you out there in *Talkabout* land.

It's a sort of a Dear Abby column. Ask an HIV/AIDS question — it can be about sex, doctors, drugs, food, alternatives, discrimination, indeed, anything at all about which you want some information or advice from other PLWHAs who have 'been there, done that', and would like to share their experience. We'll publish your question and then, in the next issues, some of the answers we've received. (Subject to space and repetition of advice).

I first realised the value of this reservoir of HIV/AIDS 'gossip' about nine months ago, when I was being transported ever so slowly in the Tardis (alias the lift at ACON — you spend so bloody long in there you need to time travel!!).

Another guy with the same first name as me got into the lift and after the usual exchange of greetings he directed his glance towards my mouth and seeing a crevice (or was that a crevasse) about one centimetre long opening out of the left hand corner of my mouth, asked me what was going on. I replied I didn't know what it was and nothing was stopping it. It had been there a month and it was slowly opening up and getting worse — maybe my whole cheek would split apart, I concluded.

Anyway, this guy, who was HIV+ too, had been there before me and he said" I don't know what you've got, (I actually had angular cheleitis), but I know what will stop it." And he suggested a cream called Kenacomb Otic, which is only available on prescription. So I went to my doctor, told him the story and he told me what I had, prescribed that very cream and a week later I was looking good and all healed.

So there's a lot of us out there who've been through various HIV/AIDS mills at various times. What about sharing our experiences. I mean I'm even thinking of telling you how I avoid crabs after a dubious night out, or how to avoid tinea after a night trudging through the salon de steam - but you'll have to write in and ask, if you want to know.

— Peter Hornby

To start the whole process off, here's a Dorothy Dixer:

An HIV friend always has problems with warts on his fingers — nothing seems to stop them — some treatments may get rid of them for a while, but they keep coming back. Any suggestions?

Send questions and answers to Talkabout, PO Box 1359, Darlinghurst, 2010.

Bobby Goldsmith Foundation

THE BOBBY GOLDSMITH FOUNDATION is a community-based registered charity which provides direct financial help to people with advanced HIV/AIDS. Its main goal is to maintain its clients' quality of life.

BGF is named after Bobby Goldsmith, who was well known in the Sydney gay community, particularly after wining several gold medals for swimming at the 1982 Gay games in San Francisco. Bobby was among the first Australians to die from AIDS and following his death in June 1984, a group of his friends who had been helping to care for him at home realised that with the growing number of HIV/AIDS cases there would be others who might need similar assistance and therefore went about setting up a more formal organisation.

The Foundation, which today is the only registered AIDS charity in NSW, published and distributed the first brochures in Australia on AIDS and safe sex practices. As a result of a BGF initiative in December, 1984, the AIDS Council of NSW (ACON) was formed. The Foundation also provided the initial funding for the Community Support Network (CSN).

Since its formation BGF has provided over $1 million of financial assistance to nearly 850 clients with advanced HIV and AIDS.

BGF supplies subsidies to help meet rental, telephone, electrical, gas and some vitamin costs as well as child care assistance. It also loans electrical home appliances to approved clients.

Most clients are referred to the Foundation by social workers at the major hospitals, but some apply for help directly. To be elibible for assistance applicants must be classified as having HIV category III or IV or AIDS and be receiving sickness benefits or a Disability Support Pension from the Department of Social Security.

BGF is directed by a committee of elected volunteers and managed by a small, dedicated staff. It is non-partisan and provides its services free of any social prejudices.

For further information please contact the Foundation at 376 Victoria St, Darlinghurst, phone 360 9755.

The Ankali Project

THE ANKALI PROJECT TRAINS volunteers to provide emotional support to people living with AIDS, their lovers and spouses, their family members and close friends. The project is staffed by five fulltime co-ordinators and currently has 242 active volunteers. The staff of the project try to match clients requesting a volunteer with someone that they will have some compatibility with, so the needs and interests of a client are explored at the time of initial assessment.

People request an Ankali volunteer for a variety of reasons, and client — volunteer relationships develop in many different ways. Some of the things that people use their Ankali volunteer for include: talking through issues outside established friendships and family relationships; socialising; sharing interests; regular phone contact; and hospital visits. The project also recognises people's bereavement needs and can provide professional counselling by a staff member and/or an emotional support volunteer with whom to discuss grief issues.

For more information, call 332 1090.

Kirketon Road Centre

THE KIRKETON ROAD CENTRE IS A community based primary health care facility of Sydney Hospital. It was established in 1987 to meet the special needs of the Kings Cross community.

The Centre provides free health services to the local community, especially 'at risk' youth, sex workers, injecting drug users and people affected by HIV and AIDS.

Comprehensive health care services are provided in a warm and welcoming atmosphere. The Centre operates with a philosophy of harm reduction and wholism. A team of nurses, doctors, counsellors and social workers aim to provide a 'one stop shopping' service with a reliable referral network. The Centre operates an outreach program, a needle and syringe exchange and supplies free condoms and lube

Confidentiality is guaranteed. No appointments necessary.

Location: the corner of William St and Kirketon Rd, Kings Cross. Phone 360 2766.

What's Goin' On

HIV Support/ Action group
HUNTER AREA

Is held at 6.30pm om 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

HIV RELAXATION SESSIONS

Would you like to learn various easy healing, strengthening, relaxing techniques to help in HIV?

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

CHALLENGES and OPPPORTUNITIES

4th Annual NSW HIV/AIDS Education and Prevention Conference
June 9, 10 and 11

MAJOR SUB-THEMES ARE:

- HIV education and prevention in 1992
- Sustaining safe behaviour (developing education strategies for infected and uninfected people)
- Integration and mainstreaming of HIV services. What is it? How well does it work? How can we take advantage of it to maximise the effectiveness of our programs?

Inquiries call 751 3619
fax 891 2087

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 experiences. It takes about 30 minutes and confidentiality is assured.

The study is concerned with the efefcts 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

HEALTHY HIV LIVING

For People with HIV family, friends & carers

Every Wednesday evening

Newtown Neighbourhood Centre, Newtown (cnr Australia & King Sts)

6 - 7pm Relaxation Sessions

7 - 8pm Information Evenings

- 10 June HIV Community Services
- 17 June Symptom Awareness

An 8 week Group for HIV-positive people will start 24 June. Bookings for this group are required (Ph: 516 6437).

(No bookings are needed for relaxation or information evenings)

Sponsored by Royal Prince Alfred Hospital, Central Sydney Area Health Service.

HIV living

Information Nights

AIDS Resource Centre
188 Goulburn Street
Darlinghurst

6.30pm - 8.30pm

Wednesday June 10

DEPARTMENT of SOCIAL SECURITY

What qualifies me to receive the various pensions and allowances that cover sickness, disability and bereavement? What about my financial investments? What are my rights? How do I appeal?

Wednesday June 17

DISCRIMINATION/LEGAL ISSUES

What is discrimination and how do I take action? What is power of attorney? Is a will necessary? What if I'm too sick to make treatment decisions? Where do I get legal advice and assistance?

Wednesday June 24

OVERSEAS TRAVEL

Where can I go? Are vaccinations safe? Can I take my treatments with me? What if customs finds my AZT? What if I get sick? Where do I buy medication? How do I find health and support services?

AFAO National Treatments Project publications

HIV Briefs an occasional pamphlet about AIDS treatment issues designed for PLWAs, their carers and their health service providers.

The HIV Herald a monthly newsletter which collates overseas information and puts it in an Australian context.

Both these publications are free from the National Treatments Project

Call (02)283 3222 to go on the mailing list.

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

Camperdown HIV group

What is it like for you living with HIV?

How do you deal with your concerns surrounding HIV?
Do others understand what it is like having symptoms of HIV infection?
An HIV group enables you to:

- meet, support and learn from others in the same situation;
- learn more about treatments;
- know what you are entitled to;
- know how to access services;
- explore your thoughts and feelings on a broad range of HIV issues

— in a safe, confidential and secure environment.

Newtown Neighbourhood Centre, cnr. King & Australia St., Newtown
Wednesday nights from 7-9pm,
straight after an HIV+ relaxation group at 6pm.
This is a closed group and numbers are limited. If you are interested in attending, call the facilitator, Mark Cashman on 516 6437 by June 17.
Community Transport is available.

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.

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.

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 people with AIDS, 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.

Civil Rehabilitation Committee Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Call Pam Simpson 902)289 2670.

Friends & Partners of People With AIDS A peer support group providing emotional support for friends and partners of people with AIDS. 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 Group (and relatives) A support group for the parents or relatives of people with AIDS. 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. Or write 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 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, 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 as well as 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 7115 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.

Tiffy'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

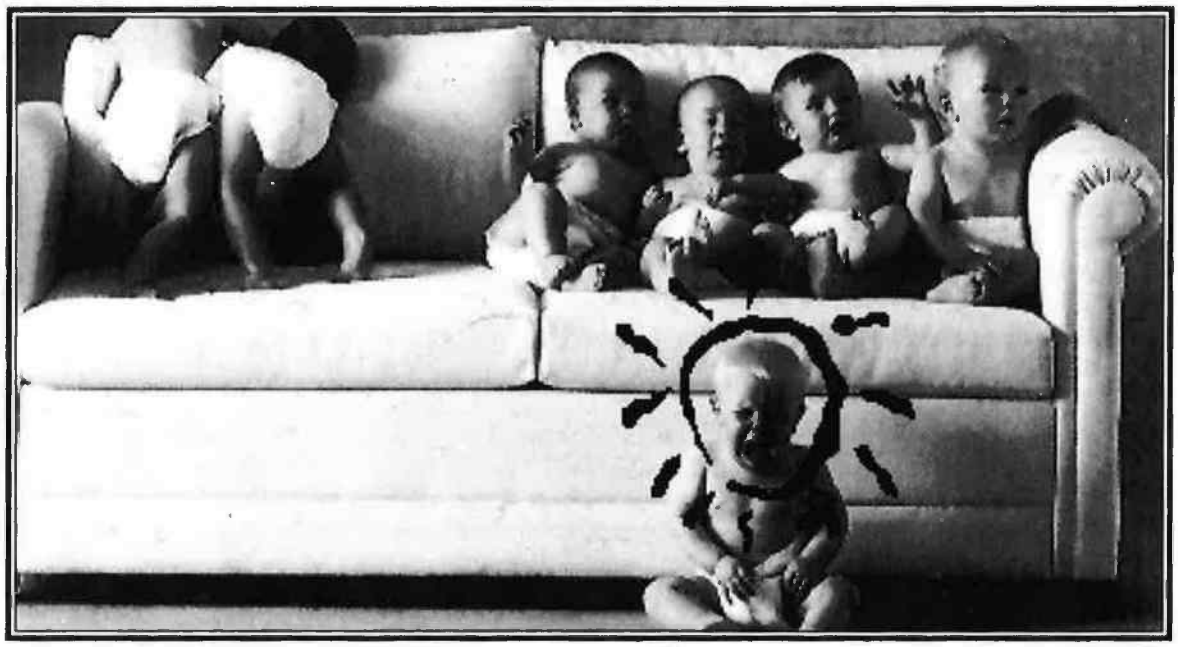
Please specify number of copies _____

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

HIV SUPPORT PROJECT

FUN AND ESTEEM PROJECT
ACON