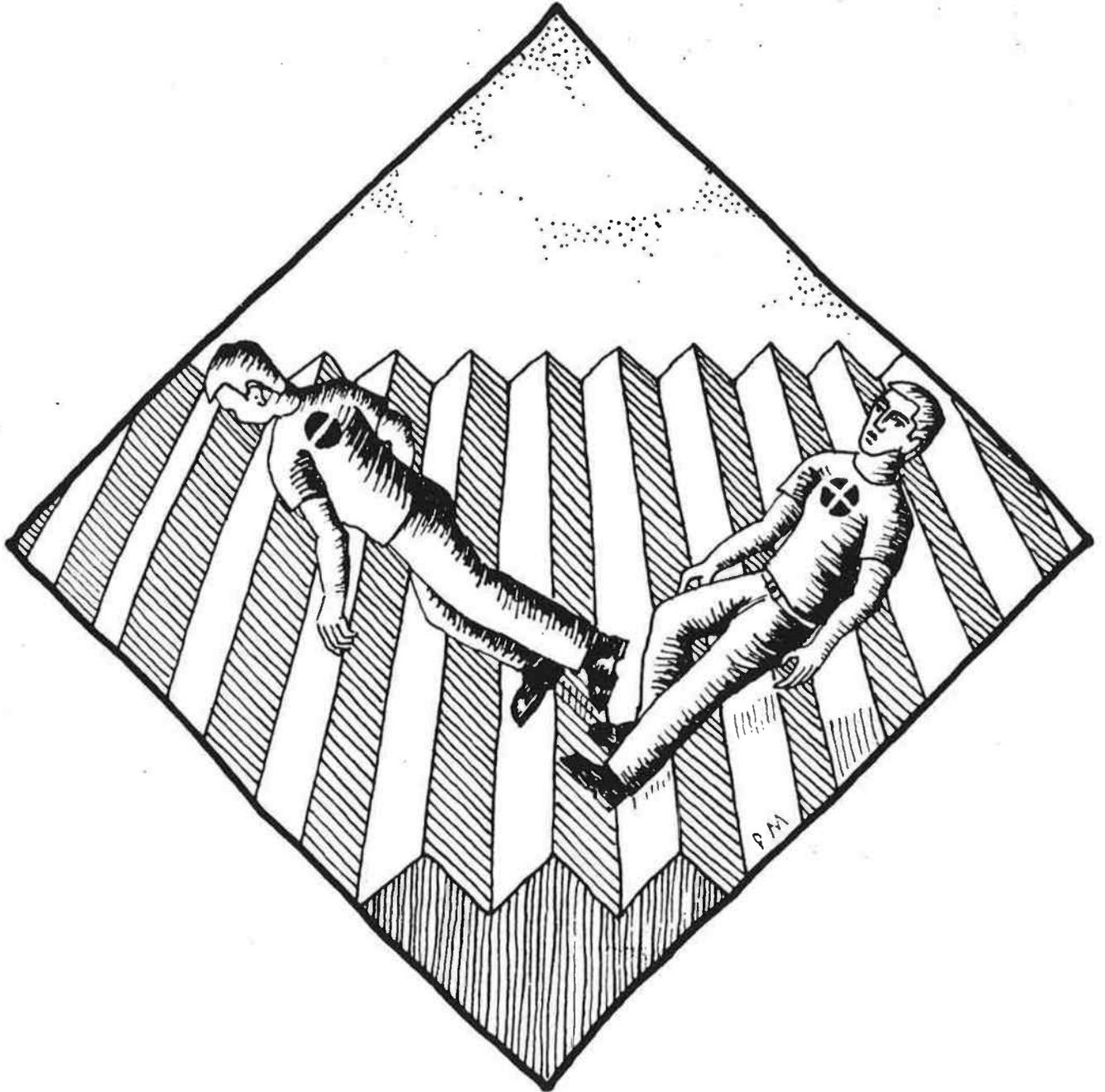


Vol. III No. VI September 1992

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



HIV On The Job

Editorial

by Wayne Holt, Co-convenor of PLWHA

ADB Report

The long awaited report of the Anti Discrimination Board (ADB) into HIV and AIDS related discrimination is to go before parliament in the September session. The proposed reforms before the parliament include 74 recommendations affecting law, public services and beefing up the position of the ADB.

Community networking in support of the ADB Report

Groups from a range of community organisations have been co-operating to lobby for implementation of the ADB Report.

Groups which have had an input or been represented have included Mardi Gras, Bobby Goldsmith, the Gay and Lesbian Rights Lobby, ACTUP, ACON, the Gay and Lesbian Counselling Service, Capital Q, the Sydney Star Observer, Volunteer Community Street Patrols, Gay and Lesbian Teachers and Students (GALTAS), Pride, CSN, the HIV Support and Strategy Unit (ACON) and PLWHA.

A special thank you is due to Geunter Plum who has helped make this ADB report a reality.

Churches Working Party

A group to liaise between PLWHA's and the mainstream Churches has been formed in Sydney. It has secured representation from the Roman Catholic, Uniting, Anglican

and Continuing Presbyterian faiths. The tasks of the Working Party in the short term are to tackle the use of the media by individuals like the Rev Fred Nile, Mary Bignold and Bob Santamaria to whip up community hatred.

There are other reasons for putting together such a group. One is that PLWHAs are a diverse group which includes lesbian and gay Christians. Recognising that we are a pluralist community is part of our coming of age. If we cannot accept our own diversity we face a very difficult battle in calling for tolerance in the wider Australian community!

Political reality also suggests that, in the event of a changeover to a federal coalition government, many of the services currently handled inside the national health system may well be "devolved"/handed over to the churches. This will require a difficult and complex dialogue, with a very different agenda with public servants.

The church organisations contain many people, I suspect a majority, who wish us well and who are prepared to offer practical and consistent help. There are no prizes for guessing however, that PLWHAs, like gays and lesbians, have enemies within the Churches.

A priority for this working party is to extend practical help and a message of positive Christian understanding to Christian PLWHAs, gays and lesbians. Another achievable outcome is to marginalise the

work of spiritual bankrupts like the Rev. Fred Nile.

Action on Drugs Approvals

Drug manufacturer, Wellcome Australia, have shunned recent requests to market the drug Acyclovir at a reasonable price to people living with HIV and AIDS.

Drug trials conducted over the last year show that high doses of Acyclovir, which is currently in wide use as an anti-Herpes treatment, can prolong the lives of PLWHA's.

Wellcome Australia has a pricing structure for the drug which is 40% higher than other countries. A year's supply at the required dosage would cost \$17,000. Thanks a lot Wellcome.

PLWHA has been invited to take an active part in a rally on discrimination issues. It is being organised by Labor MLC, Paul O'Grady. Topics for the forum include community prejudice on HIV and AIDS, employment hassles, lesbian parenting, access to goods and services and so on. It's a step in the right direction.

Victory on Confidentiality

Revised guidelines on confidentiality have been issued by the NSW Department of Health. (See David Lowe's letter in Talkabout, August 1992 - Ed.) These guidelines were put together as a direct

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This Month's Cover

by Phillip McGrath. HIV and employment: discrimination, to work or not to work... Keith Marshall takes up the issue in *HIV at Work* (page 10) and Peter Gay in *True Confessions* (page 12).

Wellcome fluffs it again

WELLCOME'S LATEST EARLY treatment campaign in the gay press continues to cause anger among people with HIV.

The first stage of the campaign, run earlier this year, was roundly criticised as blatant product advertising. It simplistically equated early intervention with early use of AZT. The 0055 line to which readers were referred was in some cases misleading and inaccurate. It caught the attention of the Therapeutic Goods Administration who threatened legal action if it was not withdrawn.

ACON also met with Wellcome and raised concerns with the text of the 0055 line. Wellcome were to revise the text, but this new series of ads has emerged instead.

The new ad drops the Wellcome logo and any reference to the 0055 number. But what was presumably an attempt to be supportive of people with HIV, ends up in these corporate hands as condescending at best and trivialising at worst.

More of this kind of insensitivity or exploitation and Wellcome will rapidly lose what standing it had within the HIV/AIDS community.

New study of young men with HIV

THE ISSUES OF HIV POSITIVE young men are the focus of a new research project of PLWA Victoria and the Victorian AIDS Council.

The study will provide invaluable information to service providers and AIDS Councils as well as helping to

secure funding for specialised programs for young men with HIV.

Young gay men are an increasing proportion of new HIV infections in this second decade of HIV/AIDS. 15 - 20% of Australia's 15,000 HIV infections are among young gay men under 25. 30 - 40% are among young men under 30. Yet, there are no specialised services specifically targeting these young men's needs. Largely silent and unseen, these young men have been consistently neglected in studies of gay men and people with HIV/AIDS.

This new study focuses attention on the lives of young



men with HIV for the first time. To date, medical concerns have dominated the research of HIV people.

This study explores the ways in which HIV is integrated into a young person's life and sense of self. It goes further by relating the effect of HIV on a young man's sense of self to his personal life (sexuality, relationships, health, personal strength, ways of coping) and his social context (support of friends, lover and family, involvement in gay and HIV positive community).

Mark Goggin, who has worked on youth projects at the Victorian AIDS Council for

the past two years, is currently interviewing these young men. He hopes to interview 80 - 100 HIV positive men young gay men aged 30 or younger in Melbourne and Sydney.

Mark see the interview as, "engaging, thought provoking and a unique opportunity to talk about your experience, reflect on your life and how you've coped with HIV."

Interviews take 1-1½ hours and participants are paid \$20. Confidentiality is assured. If you are interested in being interviewed, would like more information or someone in mind for the study please call Mark in Melbourne (03) 483 6759 (July-August) or Sydney (02) 283 3222 (September-October).

The Disability Reform Package and people with HIV/AIDS

THE COMMONWEALTH GOVERNMENT introduced the Disability Reform Package on 12 November 1991. The package brought in a number of changes for those receiving income support because of a disability or illness. The Invalid Pension was replaced by the Disability Support Pension, and Sickness Benefit by Sickness Allowance.

Disability Support Pension may be provided where an impairment, or a number of impairments, is rated as 20 per cent or more according to the tables included in the legislation, together with an inability to work for at least 30 hours per week for two years or more because of the impairment.

Sickness Allowance is paid for a temporary inability to work,



PHOTO: DAVID JAMES, COURTESY OF CAPITAL Q

Blue Mountains PLWHA tree planting at Medlow Bath Park in memory of people who have died from AIDS.

usually up to 12 months, but can be extended up to two years.

People with HIV/AIDS who are unable to work may be eligible for either of these payments.

The reforms aim to encourage people receiving the Disability Support Pension (DSP) to work to the extent that they are able. This has meant removing some of the disincentives of the old system. For example, people can now earn up to \$250 per week without an automatic review of their eligibility (though the payment will be reduced on a sliding scale according to earnings). For those who are granted DSP, and then return to work, they will keep their Health Benefit Card entitlements for a further 12 months. As well, if they need to claim DSP again, the procedures for regranting are much more simplified than was previously the case.

Another element of the package is easier access to the programs of the participating government departments. This is done by local teams of specialist staff: the Disability Support Officer representing DSS; the Disability Jobseeker Adviser representing the Commonwealth Employment Service; and a Commonwealth Rehabilitation Service case worker representing the Department of Health, Housing and Community Services. All these acronyms and titles may be dauntingly bureaucratic. However, one can meet with the team, explore what's available, and together make a plan that co-ordinates income support and access to services that the departments provide. This is a much more friendly system, and one which is completely voluntary.

I am implementing this Disability Reform Package in

the CES in New South Wales and the ACT. If HIV/AIDS has meant a career change for you, and you are interested in employment or training programs, contact the Disability Jobseeker Adviser through your local CES, or call me on 02 379 8000.

— David Finch
Disability Reform Package
Coordinator (NSW/ACT)
Commonwealth Department of
Employment, Education & Training

STOP PRESS

ddC has been approved in Australia.

See story page 28.



Amsterdam

HI ED AND ALL. I'M AT AMSTERDAM, coincidentally when the conference is on playing in the seedy cafes with Andrew Morgan and Lou McCallum et al.

Heres a photo of the ACT UP rally which preceded the opening on 19th July.

ACTUP! Amsterdam's theme was "People with AIDS do it Everywhere" highlighting border issues and the control of people with HIV's movement globally. Not only the difficulty of some people getting to the conference, but some for going back home. (Like Burmese prostitutes murdered by their own government by being injected with cyanide. - Ed.)

Liz Taylor, \$200 dinners and other events have been the highlight for the rich westerners here.

Sorry, quality is poor but camera is unwell - where's Jamie Dunbar when I need him?

Hugs to everyone.

Love,
Dodge Traffic
(formerly Don Carter)

Mainstreaming

MAINSTREAMING, THIS IS NOTHING new, it's a word which has been used to supposedly give people with disabilities opportunities to live in the mainstream of the community with support services to help towards maintaining independence, dignity and a better quality of life. In the theory books



Demonstrating in Amsterdam. PHOTO: DODGE TRAFFIC.

it looks grand, in reality it's a joke, even more if service providers know one is gay, or they even suspect one is gay or worse, one's disability is HIV related. Independence comes at a cost, that cost sometimes outweighs the benefits of reaching for mainstreaming, as services become stretched and staff of such support services are sacked and not replaced.

Discrimination can be seen in the lack of services to people with disabilities who are also gay. This can be very intimidating for a person with a disability who then finds that the cost of being "mainstreamed" is not just lack of health and domestic services, but isolation within the the society in which they live/survive.

The one important thing to

remember is that the *person* with the disability/HIV must be empowered to make their own decisions; and service providers must listen to us when we ask, tell or inform them, as to what we need, want or can actually do for ourselves, and what we CANNOT do for ourselves. Most of all treat us with the dignity you expect yourselves.

Mainstreaming is a cheap alternative to institutionalisation, and was a welcomed one in 1985. By 1992 one still wonders why some services have been cut or axed completely, and why gay people have historically been denied some of those services.

If my own history is anything to go by, then when AIDS became a real issue in 1982 to 1985, I found

I was without services including occupational therapist, and other support services because it was assumed that if I am gay and disabled, my disability must be HIV related. I later experienced in hospital, when it became apparent nurses were not going to nurse me after an operation (1988), this then fell upon my lover/carer to do; and it should be known I had been living "mainstream" since 1982, but little or no services were afforded to me because I am gay.

Mainstreaming is nothing new to Margaret Duckett; NSW educators have been mainstreaming clients with various disabilities for some considerable time. The problem relates to "sexuality" by presumption. First of all, PWDs are not seen as sexual beings so if one announces one is "gay" and "disabled" the disempowerment and lack of mainstreaming services is almost complete, or one is automatically heterosexual and without sexual expression.

As for equality of access, this again may present problems for HIV disability or gays with disability given the past ten years history of such inequity experienced by gays with disabilities, myself included.

There's nothing wrong with mainstreaming. It looks good on paper, in reports etc, but in reality mainstreaming falls squarely on the persons with HIV disability or all other people with disabilities. One wonders if history will repeat itself yet again! And do we have the money to afford services that were once given. I don't! I go without.

*Michael J Winter.
PWD Now without carer, but still
mainstreaming to oblivion.*

Positive Time

RE: PRESENCE OF A PLWHA ON future interview panels for ACON

staff positions.

With reference to the above, we strongly suggest that in order to better fulfil its charter, ACON should include a PLWHA as an active participant in the selection procedures which determine new staff appointments.

We the members of Positive Time Group (PTG), a group of PLWHAs living on the far north coast, are angered to find that we were not considered in the recent employment of our ACON branch co-ordinator. It would be totally unacceptable for selection panels for positions involving provision of services to aborigines or women, for instance, not to include representatives of these groups.

Based on this rationale, it can be seen that having a PLWHA contributing to this important decision making process is one way of reaffirming ACON's commitment to client involvement and a recognition of the need to empower those clients.

We would also suggest that this procedure be incorporated into the ACON constitution and become adopted as the preferred method of ensuring continued input by PLWHAs in the staff selection process.

*Yours faithfully
For the Positive Time Group
John Wilkinson
S. Campion
R. Hiscock
J. Langworthy
P. Ross-Boyle
B. Wright
R. Thorpe
Phil Hausfield*

Survey Ends

ALTHOUGH STILL RINGING, THE phones at *Project Male-Call* have finally closed. Financial constraints meant that we could not go on collecting data. However, we have 2687 completed interviews which makes *Project Male-*

Call the largest Australian survey of male to male sexual practice ever undertaken.

There is, of course, a lot of work to be done to sort out the demographics, but a preliminary analysis indicates that there has been a good representative sample of men, both urban and rural, who have sex with men. The in-depth analysis will produce valuable information on sexual practices, attitudes and beliefs about HIV and AIDS, knowledge and practice of safer sex, relationship status and negotiation of safer sex.

With the solid numbers from each state it will be possible to provide a fairly reliable indication, State by State, as to what is happening with men who have sex with men, and to make some comparisons between the States. This will, of course, be of interest to community groups, AIDS Councils, State Health Departments and the Commonwealth Department of Health, Housing and Community Services.

We are certain that this survey will be a benchmark in the history of HIV/AIDS in Australia. As they become available the findings of this important study will be communicated to relevant organisations and general information regarding the project outcomes will be published in the media in due course.

The assistance, encouragement and support from AIDS Councils, businesses, the media (particularly the gay press) and committed individuals has contributed enormously to the success of the project and for this we are greatly appreciative. In this time of HIV/AIDS fatigue the level of commitment to *Project Male-Call* from everyone has been particularly gratifying.

Talkabout

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DEADLINE FOR THE NEXT ISSUE

September 16

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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We would very much like to thank you for your involvement and assistance with the project and look forward to the opportunity for future liaison.

Thank you again.

Yours sincerely,

Kim Benton (National Manager)

Nigel Carrington (NSW Recruitment

Officer)

Project Male-Call

Housing Discrimination

ON RELOCATING TO SYDNEY I found a great, newly renovated, three bedroom house, large backyard, close to transport and a large shopping centre. All this in Newtown for only \$235.00 per week. Being new to Sydney I didn't know a lot of people, but I set out looking for two ideal flatmates to share this great place.

"Try ACON" I was told "they've got a great share accommodation network for positive people." So without delay I contacted ACON's accommodation section, where I was informed that ACON no longer handles share accommodation enquires. As there are now services set up in the private sector which offer this service to the lesbian and gay community, ACON feels it should only focus its efforts on people who require emergency accommodation (you're not sick enough yet for our help).

After negotiating a price for the services of this business I was run through a questionnaire to outline the type of person that I am, what type of home environment I would like to live in, and what type of person I want to live with. All of this seemed quite straight forward, then I was asked "do you mind living with a person who is HIV+?" my answer was no. I didn't question it at the time, though I thought it was very odd that only one disease was singled out by this organisation and not a highly contagious or a socially disruptive disease such as asthma,

epilepsy, herpes, hepatitis or even diabetes - just a few that come quickly to mind. "You will get a flood of people, a place in Newtown for 80 bucks a week, and you sound like a nice guy."

In under a week I received a phone call, my first prospective flatmate. The man on the other end of the line runs through the details of this anonymous body. In my excitement I don't really take in the initial details until he says, "this person doesn't want to live with someone who is HIV positive, and he's not a smoker, but doesn't mind living with them." The line goes silent. Do I tell this man about my positive status, I wonder if any healthy people want to live with me, I wonder if this asshole who doesn't want to live with me even knows his own status.

"Well I doubt if I'll be able to get a cure before he comes over", I remark sarcastically.

"What do you mean?", is the bewildered reply.

"I'm HIV positive, and he doesn't want to live with someone who's positive."

"Ohhh, well I'll phone him and tell him the place is taken, he sounded like a bit of a dickhead anyway, really dumb. Well I'm glad you told me about that, I'll know not to send any people like that over."

"Ok, are there any other people?"

"No, not today, but it won't be long. There are always people looking in Newtown and for \$80.00 a week that's great."

Another week and still nobody has physically come to look at my place, so I phone the agent to let him know that I haven't progressed to full AIDS over the weekend. Still with no prospective flatmates I decide that I'm willing to see people who are not gainfully employed, as my money is running low and I cannot keep forking out for the full rent. The next day two

more referrals, one comes and looks that Friday, he tells me he'll get back to me after the weekend; he's got a few other places to see first.

Monday, I contact the agent again. "Where's the flood of flatmates you told me about?" He explains that the most common reason that flatmates are not compatible with me is that I want a non-smoker and some others don't want to live with someone who is HIV positive.

We had a lengthy discussion on how ridiculous it is to even have to discuss HIV status with a potential flatmate, particularly when no questions are asked about other aspects of clients' health. I was offered the excuse that the agency has had a bad experience when one flatmate found out that the person they were living with was positive. Apparently it was a really ugly situation.

I cannot agree with his thoughts on the matter or the agency's process. Had I not taken responsibility for my life by testing he would not have known my status and, as I am still healthy, would probably have assumed I am negative. Being HIV+ has many less ramifications than other diseases which they do not mention in their questionnaire.

However, I was most disappointed to find that the ACON accommodation section didn't think that my concerns warranted their talking the matter over with the agency concerned. They assured me that the agency would only be acting in my best interests. However, I am the one who foots the bill for being discriminated against.

Peter
Newtown

Customs - which is the worst?

I HAVE RECENTLY RETURNED from a trip to the US. Before I

left I was advised of the best points of entry into the US and what I should say or carry with me. I was very apprehensive. When I was returning to Australia I was pleased at the thought that when I had passed through Hawaii the last of the problems were behind me. Little did I know.

On returning to Australia with two friends, we all had excessive luggage and were, for general reasons, apprehensive about customs - were we within the limits? I knew I was carrying things that, as a gay man, I saw as normal possessions, things that I suspected customs may not cope well with, even if they were legal. Items such as Amyl, studded leather ball stretchers and books with explicit covers and contents. As I suspected, most of these items attracted attention but it was not until the questioning started that things got interesting.

The first question was, "what do you do for work". Now this one always gets a good reaction when I answer retired (even from gay men I might add). When will they learn to add two and two? I was impressed when this man took at least a few minutes to ask what I did with myself if I was retired. When I pointed to the books on AIDS and said that I volunteered for "AIDS charities, there was a moment's pause and the studded leather ball stretcher which had been put to one side was dropped into the bag, a meagre attempt was made to place a few items back in my bag at arms length and my bags were pushed to one end of the counter. As he stepped back he said in an abrupt fashion, "when you finish packing the door is over there".

The discrimination in this case was quite subtle but it is an indication of the customs officers' attitudes to gays and lesbians and HIV and AIDS. It showed a distinct lack of sensitivity as demonstrated by his rudeness and abruptness of manner. The impression I got was that he was disappointed that I was a citizen as, if I was not he might have more power to hassle or obstruct me.

While I was in San Francisco I became (controllably) infatuated with two American men and thoughts fleetingly crossed my mind about the complications if I wished to move countries. One T-Shirt summed it up for me when it said, "No Mandatory Testing - Gays and Lesbians One Nation", the reality is that our ties of 'nationhood' through common culture are stonger with gays and lesbians around the globe than with our heterosexual peers within traditional borders. Coming back to my country, Australia, I was made to feel dirty and unwanted. If I had a HIV+ lover from another country he would find Australia just as unaccessable as a place to reside as I would the USA. This instance does not make me proud to be Australian.

Gérald

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

HIV at Work

Keith Marshall takes up the issue...

"I'm working hard to get enough money to buy a ticket to London, where I'll get a job"

YOU ARE HIV POSITIVE

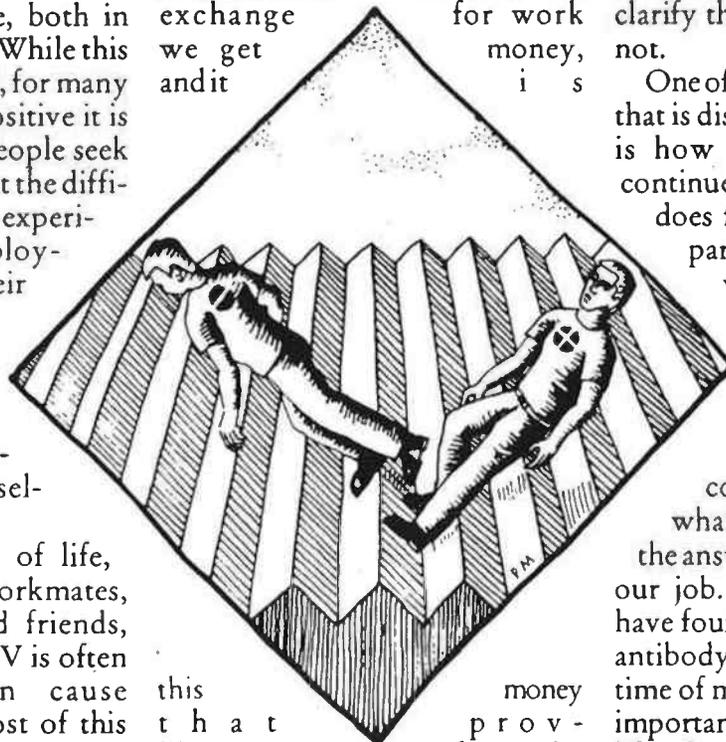
"I'm still going to work hard to get enough money to buy a ticket to London, where I'll get a job"

THIS ADVERTISEMENT CURRENTLY being run by a leading pharmaceutical company seems to imply that HIV will have little, if any, impact on both current and future employment for people who are HIV antibody positive, both in Australia and overseas. While this situation would be ideal, for many people who are HIV positive it is not the reality. Many people seek counselling to talk about the difficulties that they may be experiencing with paid employment as a result of their HIV antibody status. This article is intended to note some of the more common themes that positive people discuss with counsellors.

As with most areas of life, telling employers or workmates, like telling family and friends, about a diagnosis of HIV is often something that can cause considerable stress. Most of this worry centres on two major concerns. Firstly, concerns about how the other person, be they a boss or a colleague, will react to this information. It is often more common to imagine a bad outcome in which workmates shun and avoid, or bosses stop the advancement of careers. This is not universally the case. This type of reaction will often depend on the level of HIV/AIDS information that the colleagues have. They may well be AIDS-

phobic, although it is encouraging to note that many employers have called counsellors to ask advice on how to deal with an employee's disclosure of being HIV positive.

The second concern is usually about how long work will be possible before there are changes in health which make work increasingly more difficult. Like all the uncertain questions about HIV there is no easy answer. The essential truth of paid employment is that in exchange for work we get money, and it is



this that provides many of the necessities of life, such as food, housing, clothing, medication and so on. Some people fear that a disclosure to their employer will mean a forced early retrenchment, difficulty in getting another job, and an associated deterioration in quality of life. This need not necessarily be the case, as many larger employers are becoming aware of HIV and the way it can impact on work performance e.g. needing extra

time off work for medical consultations, and have developed workplace policies that state that an employee with HIV continues to have the same rights as an antibody negative colleague.

There are no standard guidelines for disclosure of antibody status in the work place, but often checking with the union or the Occupational Health and Safety Officer can help determine whether there are company or industry guidelines, that can help clarify the decision to disclose or not.

One of the other major concerns that is discussed with a counsellor is how long someone should continue to work. What someone does for a living is an integral part of the way that they view themselves. If someone is being introduced to a new person it is likely that shortly after exchanging names will come the question "and what do you do?". Usually, the answer we give is the name of our job. For many people who have found out that they are HIV antibody positive, there comes a time of major re-evaluation of the importance of work in their overall life plan. If there is going to be a change in life timeframe, how big a part will work play compared to say overseas travel, spending time with family, partying or learning to parachute. Many people express this as a desire not to be working in the same job, busting a gut to keep going, when and if there is a change in their physical health. This is particularly so when there is a lot of talk about the adverse effects of stress on the immune system functioning. Many people

consider that work, or the nature of their work, is stressful, and that to maximise health they need to reduce this stress as much as possible, maybe even stop work as soon as it is financially possible. It is useful to involve the medical practitioner who is providing health monitoring in any decision to change work, either by stopping or reducing hours or changing the type of work done.

There may come a time when the decision on continuing to work becomes less of a possibility and more of a likelihood. This is usually associated with a change in physical health. To avoid a potentially difficult decision when illness strikes, it is useful to have thought beforehand about how life without work will be. In other words, the decision on whether to continue working or not will not just be based on stopping the current job, but on what activities could be undertaken instead. Often when contemplating this issue people focus solely on whether or not they wish to continue in their current job. By looking at how you might like to spend your time if you were not working, you can not only be more clear about whether continuing work is your preferred option, but can also avoid the potential boredom that may accompany stopping work and having "nothing to do".

Inevitably, one of the areas that will be considered when thinking about stopping work, or changing to part-time instead of full-time work, is future income. Background research to help make this decision will usually involve such things as checking out the conditions under which a superannuation scheme you or your employer have been contributing to will make lump sum payouts. Most schemes now have an HIV clause, which usually requires someone with HIV to have been a member of the scheme

for at least two years before any payment is made.

The other source of income that should be checked out is the government assistance available through the Sickness Allowance and the Disability Support Pension (See News: Disability Reform Package, p4. - Ed). Checking out the eligibility requirements from the Department of Social Security, either by asking their Social Workers, or reading the DSS AIDS booklet (available from most offices) may help clear up any doubts about remaining in the work force.

These are a few of the issues that may be considered when looking at HIV and employment.

Ultimately it will be an individual decision as to how HIV and employment interact. Some people will choose to continue to work regardless of any changes in physical health, others will choose to stop work as soon as possible. To reach this decision in a way that is clear and satisfactory for the person concerned it is often extremely useful to do some checking around. Find out if the employer has an HIV workplace policy, what friends or colleagues have done, think about how you would like to be spending your time, where future income will come from and consider this to help determine how HIV will influence, if at all, your work.

To help improve our services to the
community

The AIDS Council of New South Wales

has introduced a systematic
complaints procedure.



If you are less than satisfied with our
services we would like to hear from you.

Call (02) 283-3222 or write to
PO Box 350, Darlinghurst, NSW, 2010
for more information.

(TTY for Deaf people, 283 2088)



AIDS Council of New South Wales Inc.

True Confessions from an *HIV positive* career Boy:

This isn't one of those "If only they'd loved me more I would have enjoyed my job more" stories, but an acknowledgement of the real problems that being HIV positive can bring into your workplace and consequently into your everyday life, especially if you're the person who is HIV positive.

HERE ARE MY EXPERIENCES AND comments on this issue as a gay male HIV positive worker. Since becoming HIV positive 6 years ago, I worked as a child care worker for 4 years while studying for my degree. I also worked in a gay venue as a barman, and I have just finished a 7 month position as the project officer for the HIV Education Needs Assessment Project at the AIDS Council of NSW.

I am presently working as a research officer on a project at Sydney University which aims to equip final year teaching students with the skills and positive attitudes necessary to teach school students about HIV/AIDS. My work is enormously important to me and so is the happiness of all gay men living or effected by HIV. Or, should I say, all people. No, first and foremost for me are the FAGS in my life, as fabulous as we are in spite of the bug to beat the grimmest of twisted Hollywood B grade flicks. As I've often said "Whoever wrote the script for this movie must be one hell of a twisted sister, definitely not one of my girlfriends, honey!!"

As a child care worker I kept a vigil of silence about my HIV positive status and was terrified that someone would find out and

expose me in some hideous display of moral outrage at my presence around children. This was one hell of a fear on top of the knowledge that my being gay was seen as a threat to children. But I loved the kids and they loved making Day Glo Mardi Gras masks and pictures of bears in tutus, so I stayed. Of course, everyone would comment on how good I was with children, so I certainly wasn't going to jeopardise my stimulating, though exhausting, job because of other people's irrational fears and prejudices. However, one day I did confide in a co-worker, a fabulous Madonna-type party girl who was becoming a close friend. From that day onwards she would respond to me effusively in a room full of people about "HOW WELL I WAS LOOKING". A major exaggeration because I had just begun taking AZT at the time and felt ghastly and looked very drawn. She was a fabulous girl who cared very much but couldn't find an appropriate way to express it in a homophobic and, at that time, AIDS phobic world.

Unfortunately, no matter how fabulous people are, or how much they care, knowing how to respond to a person living with HIV who you are working with can be confusing and stressful. I acknowledge this. To begin with, our expectations of our relationships with people at work are usually different from what we expect from close friends or family. Given the way that HIV has a tendency to complicate

things, maybe we even use work as an escape from some parts of our personal lives which may be complex or difficult. However, HIV can change all that and revealing our status to workmates can immediately place us in a position where our status becomes the prime issue. People either go into totally disempowering sympathy mode, or become coolly and steely indifferent and the reason we are there in the first place - to do our job - becomes shrouded in a hideous maze of HIV dominated muck that everyone gets lost in!

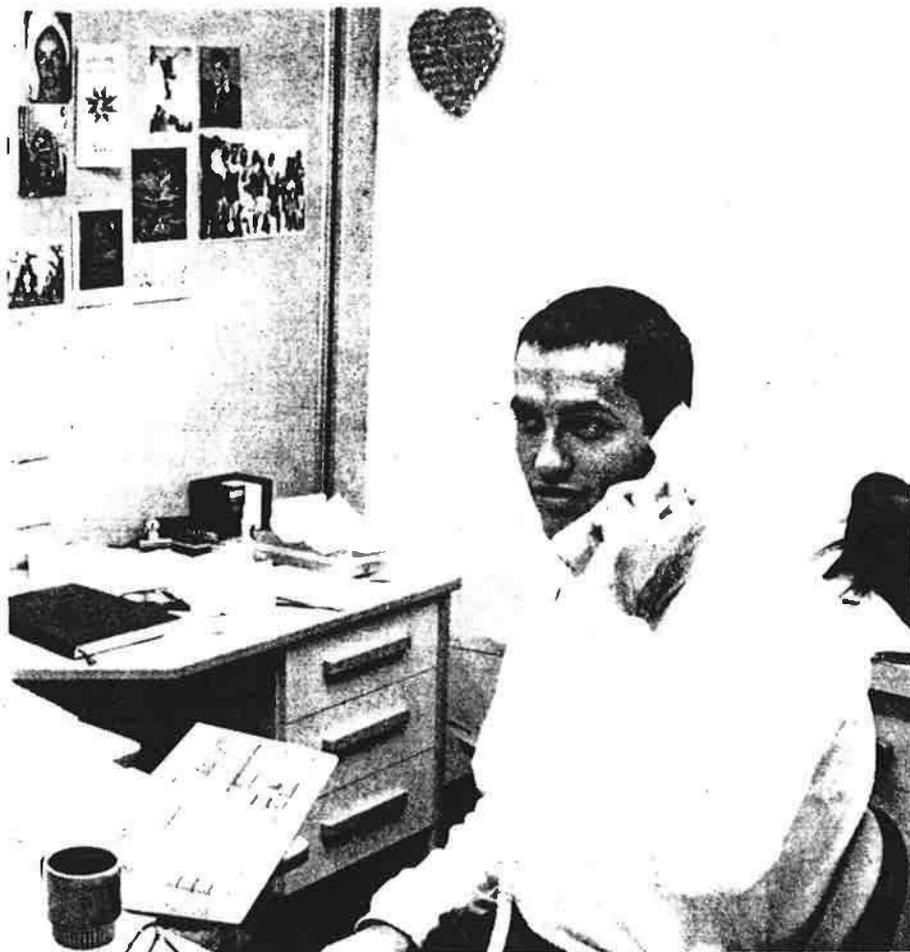
This is simply my experience of being HIV positive and working. Other people may have had much worse experiences or may not be working but nonetheless experiencing very odd or alarming responses to their HIV status. I am writing this to, hopefully, give other people with HIV something they may be able to connect with, and also to draw attention to the position that we put other people in when we reveal our status to them at work.

So what can we make of this quagmire of mixed emotions? To assert that something is difficult or problematic offers no solutions. Unfortunately, I'm a solutions kind of girl so, in this article, I may tread on a few well-sequined toes, as lovable as they may be. I am not satisfied with our confidence as HIV positive people to assert the way we would like our HIV status to be perceived at work. I feel that

we are still in a shaky position to say the least, given the ignorance of many employers about HIV/AIDS and the tendency of many people, whether they are conscious of it or not, to disempower us immediately they find out we are HIV positive. They do this by changing their expectations of us in terms of our work performance and by assuming that we are already very ill.

Of course it is not only people who are HIV negative (does that term have a double meaning, I wonder) who are HIV negative. Now what is this mad queen trying to say?? Well darlings, my experience with the ice to freeze all ices type of attitude to how HIV is effecting my health and my life came from a couple of HIV positive co-workers whose hard, blase style certainly made chopped liver of my day on a few occasions. Comments like, "I love your jacket. If you die before I do can I have it?" can really flatten even the best of hairdos !!

"Now where is the solution, girlfriend", you are asking! Well, I feel a burn-out meter needs to be installed. Particularly in situations where people are very stressed and very hurt, such as is often the case at ACON, because of the intensity of what goes on there. Of course no such thing exists, but it is possible to acknowledge the effect of your behaviour on other people. Over the top displays of inappropriate sympathy can make an HIV positive person feel tragic and helpless. Of course, HIV negative or HIV positive co-workers may genuinely care about you but not know how to show it in a way that feels OK both for them and you. We can't really ask another person, "Was that OK for you darling?" about the way we respond to their illness or the feelings of loss that may be consuming them, because we are not used to asking other people



Peter Gay. PHOTO: DAVID JAMES.

how they feel about our behaviour. That sort of thing is seen by many people as too confronting. However, if we are to keep on working and be supported by our employer and co-workers in a way that feels right for us, then we must let people know how their responses to the frightening experience of being a person living with HIV feels for us.

In some situations, such as my experience working in a gay venue (which wasn't the Oxford, whose management and staff are truly fab and that is all I'm saying about that) you know that trying to educate your co-workers about your need NOT to have your obituary written for you by the end of your shift (!!!) would be an impossible task. However, if you are fortunate enough to work with, or know people who will realise

your need for the sort of support that feels right for you then do it !! And of course to all those truly fabulous people who care and want to support people living with HIV, thank you. Perhaps it would be interesting to see some of your dirty laundry some time darlings. I know I get tired of this old HIV story. It lacks the sort of mystery and intrigue and glamour I'm fond of in a really good script. Oh, there I go again, forgetting that we are real people and that we do matter. What else can I say except, "Go for it girls (and boys, for those offended by such camp humour), we certainly can strive to treat each other with a lot more sensitivity and maybe create the sort of world we should have if only that damned script writer had had their hair done first !!!"

Peter Gay

Militant Pride

Bruce Brown speaks at Queensland Gay Pride Day, June 1992

This is a transcript of Bruce's speech...

QUEER SISTERS AND BROTHERS AND our friends:

My name is Bruce Brown. I'm a radical militant queer with AIDS and I'm glad to be here to speak on behalf of ACT UP.

The AIDS Coalition to Unleash Power is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis. We protest and demonstrate. We are not silent.

We are all here to celebrate our gay pride on this Stonewall Day 1992. Celebrate, that is, bearing in mind that every time we celebrate our gay pride, we must at the same time protest the injustice we face every day, and demand full recognition of our gay culture. Full legal right to live our lives. The right to lead our sex lives as we choose - not as politicians, the Church, or the courts decide we may. The right of queer children to their heritage, to heroes and heroines and better role models than those that straight, racist, women-hating, queer-bashing society currently offers to its children. To the right to life for those of us who are bearing the brunt of an epidemic which would have never happened if that same hate-filled, spirit-destroying, anti-life straight society didn't consider fags, whores and junkies expendable - consider them expendable in 1981, and still consider them expendable, if you listen to the likes of some so-called Great Australians today. Full right to our history, a history that breeder society has continually

tried to rewrite, from the Bible right through to *Basic Instinct*. The right to see ourselves in the media as we know we really are, not as the "general population" want to see us. And yes, even the right to serve our country, in the military if we see fit - the same brave military that's so scared of fairies and dykes.

The conspiracy which has denied us those rights operates on a code of silence - bitterly enough, our own silence as well as theirs. That silence, as Aboriginal people, the homeless and poor, people with serious illnesses, the physically challenged, and members of other groups who have long been marginalised and denied their rightful place in society know, is lethal. It is that silence - in effect, the acquiescence of shame and guilt - that has conspired in the deaths of hundreds of thousands with AIDS. Learn one thing today, but learn it well - SILENCE = DEATH. That little tidbit could save your life. Learn instead that ACTION = LIFE. Take action: refuse to cooperate. Deny society your silence. Our silence is their comfort.

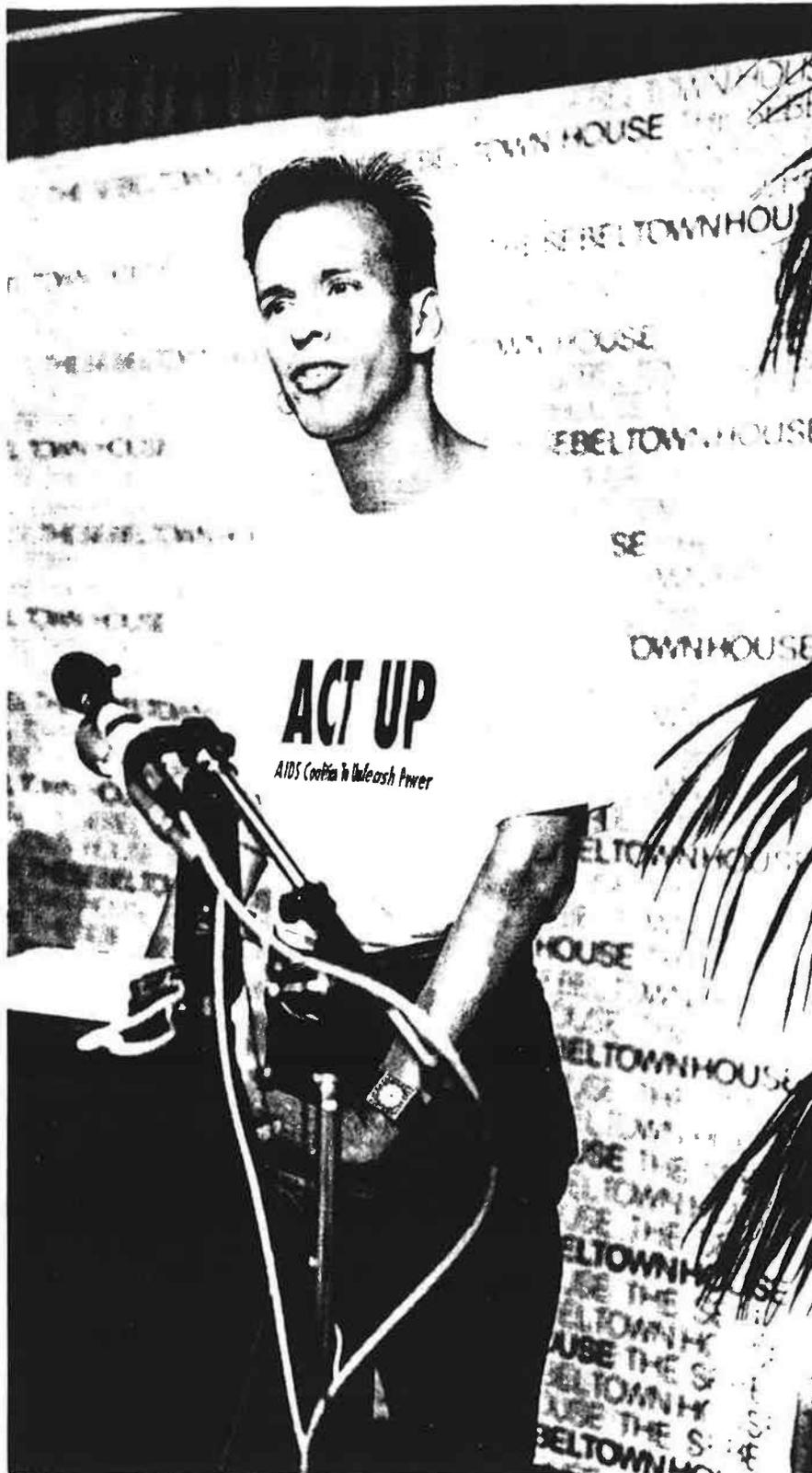
In fact, let's proclaim our activities here today a "teach-in" for a very sick society, a society which really desperately needs to learn about things like "action" and "life" instead of the "silence" and "death" which it peddles through its hypocritical churches, its depraved school systems and its sensationalist media. A society which needs to learn that our orientation is not their decision. That, contrary to straight folklore, it is not straights and their children who are in danger from queers, it is entirely the other way 'round'. That straights pose the danger

to US. That WE are being bashed by them and their children. That queer children need to be saved from straight parents! That heterosexuality is a common complaint, for which homosexuality is a rare cure! That it's in to be out!

I'm here with you today to say that there is now a group of people in Queensland who say these things, say them loudly and proudly. A group that says that "silence" is out and "action" is in. A group that has been empowered by the knowledge that individuals can make a difference, and that together, individuals can change things for the better. A group that refuses to participate in its own genocide. I'm here to tell you that you have a wonderful, vibrant, group of people here in Brisbane who care how things are and how they aren't. They're called ACT UP/Brisbane.

And just to clear up a common misunderstanding: AIDS issues are absolutely inseparable from gay rights issues.

Since ACT UP was first formed in Australia in Sydney in 1990, we have challenged our apathetic, mercenary, spirit-crushing society at its worst. We told the government in no uncertain terms that Australia's regulations for approving new drugs for life-threatening illnesses were lethal - that a system meant to protect people was actually killing them. Told them and won! In June last year, the Therapeutic Goods Administration needed a radical housecleaning. That Australians with serious illnesses deserve speedy access to new therapies. That experimental therapies for HIV/AIDS should not remain the preserve of a few lucky souls in



Bruce Brown speaks out. PHOTO: JAMIE DUNBAR.

San Francisco and New York - that we want them here, now!

We've told Australia that its treatment of HIV positive people is a national disgrace - that HIV-related

discrimination is "The Other Epidemic". And together with the Australian Federation of AIDS Organisations, we've called for strong national disability anti-discrimination

legislation protecting people with HIV, their friends and carers, and those imputed to have HIV.

We told the Deputy Prime Minister the "partnership" in AIDS that he always speaks about - a "partnership" between government and the affected communities - wasn't working. Wasn't working because while our community had more than lived up to its share the government was doing nothing. We told him that when he claims that Australia's response to AIDS is marvellous and points to what is happening in the United States for contrast, he should remember that what is happening in the United States is a shame, a disgrace, a human rights outrage, and that Australia's response isn't "wonderful" because it is "better" than America's non-response.

We told Fred Hollows, Bruce Shepherd and Julian Gold that their homophobia and their games of medical politics are not wanted as a part of the Australian response to HIV; that their career moves will not be made at the expense of the lives of Australians with HIV, gay men or otherwise; that the real Australians of the Year are those battling homophobia, discrimination and stigmatisation on top of HIV infection.

ACT UP is part of that "partnership" which the Deputy Prime Minister, in his way, acknowledges. ACT UP has a unique role to play in Australia, as it has throughout the world. We are the cutting edge of the community's response. We are the army of people with HIV. We say, the AIDS crisis can end. We ask for what people need, not what we "think we can get". Here in Australia, ACT UP says to the rest of the AIDS movement: try harder. We say: you are funded to do the job: get to work. We say: this is your conscience speaking!

So, we say to you today: this is *your* conscience speaking. When are *you* going to ACT UP?!

result of lobbying by PLWHA representative, Dr Geunter Plum.

The new guidelines spell out in clear terms to administrators, doctors and support staff their duties and responsibilities in relation to privacy and professional standards of confidentiality.

Lick Those Boots, Boy!

Sydney based leather club, SPMC, has reaffirmed its commitment to providing access for PLWHAs to club activities. The club has made a substantial commitment to providing help and assistance to PLWHAs both in terms of cash donations, the work of its members in arranging community projects and by operating a shuttle service for PLWHAs between Darlinghurst and other inner city locations to the SPMC clubrooms on function nights.

Arrangements are also being negotiated provide group transport for the increasingly popular Club Runs. In addition, there are prospects of a jointly organised dance function or something similar between PLWHA and the Club in the coming months.

Rural Outreach

A big challenge for the coming year is to build up a stronger network with rural NSW.

Local Councils continue to be difficult on a range of public health issues; this seems to be consistent for Municipal as well as Shire Councils. A rational discussion about beat behaviour and the needs of men who have sex with men but do not identify as gay, depends upon information and education

which currently is piecemeal and inconsistent. The continual cycle of harassment, hostile ordinances, and a lack of community consultation point to the need for action.

There are some important issues for PLWHAs and other interested parties to be aware of if we are to see a result at the end of the day. The most important issue is to respect the individual nature of each local group. ACON's rural outreach project has been effectively involved in, peer education, talking with rural networks and doing valuable health education work.

ACON's work ought to be supported, but there is a need to go beyond simply isolated groups with information, and to involve rural groups in decision making and policy setting. (See Positive Time Group's letter in this issue - Ed.)

This is a priority area for PLWHA in 1992/93.

Mother Hubbard's Cupboard: Federal and State Funding on AIDS

Remember the old nursery rhyme? Well, imagine it in the context of getting enhancements out of state and federal governments for HIV and AIDS programs. There is an alarming trend on the part of some public servants to say that AIDS as an issue has been "put to bed". The schools have their sex education kits, Joan and Joe Average are warned as to the dangers, condom sales are up.

For upwards of 25000 Australians living with HIV, the issues have not been "put to bed". We are living with HIV, and too

many of us are dying of AIDS because treatments which could be made available are held up, endlessly "under consideration" or withheld.

We've had the Federal budget and State budgets are due within the next few weeks, and we should use these to formulate our tactics over the next year.

Eastern Area Health Service

On August 21st PLWHA attended the first HIV/AIDS Strategy Consultative Meeting with Eastern Area Health Service. Some of the issues that emerged were:

*The area health service overall is losing \$20 million per year in funding and this is indicative of the crisis in health overall.

*The area's Needle Exchanges are dispensing 12000 - 14000 clean needles per month. There is a 57 to 60% return rate of used needles out of the Bourke St Advisory service.

*PLWHA questioned why Badlands, a major service in the area, was not present and asked that they be asked to attend in future.

*Major problems with relocation of the Maitraya Day Centre were discussed. Maitraya's funding comes through the Area Health service and it has been given notice to quit its current premises by the 10th of October. There have been serious difficulties finding appropriate accommodation but negotiations are advanced on a site in Woolloomooloo. It is being suggested that access be improved by having a bus available 5 days a week.

*The area uses generalist home nurses (not specialist AIDS nurses). They operate

out of Darlinghurst, Waverley and East Gardens Community Health Centres. All the Home nurses have volunteered to work in the HIV /AIDS field and have undergone sensitivity training. There is a requirement re sensitivity to issues with HIV/AIDS in advertisements for these positions and in their job descriptions. No agency staff are used in these positions.

Nurses are providing an increased service till 9.30 pm normally and someone is on call 7 nights a week. If clients need services like split procedures ie: a treatment in the morning and the evening, this can be done by the home nurses rather than spending 14 hours in a hospital. Treatments such as intramuscular injections and others can be done in the home. Every attempt will be made to keep clients in their home.

*Concern was expressed around issues of housing for people with HIV/AIDS. In the Housing Department's S1 and S2 areas that cover the Eastern Area Health Service there was a total of 1300 housing placements in 1991 (all categories), of these 600 were classed as "disability", 400 as "medical". ACON's figures tell us that 200 to 250 HIV+ people were housed in 1991 in this area. Eastern Area Health is concerned that people may be inappropriately housed and is especially concerned about the issues/problems of housing for people with Stage 4 HIV (AIDS). Particular concern was expressed in the recent Crisis, in that the Housing Department has no new housing stock. The Mayor of Waverley has offered assistance with "step down" accomodation.

*Wayne Holt
Co Convenor*

Just a reminder about the
Youth HIV Project
featured in August Talkabout (on page 8)

We are interested in talking to more people who are HIV positive, under the age of 25 and who were diagnosed before the age of 21. (Please see August Talkabout for details about the study.)

If interested, please call Guy or Kay 399 4999 or 399 2968 (or if calling from interstate please ask the operator to reverse charges and call 02 399 2966).

We pay young people \$30 for an interview.



A PERSONAL GROWTH WORKSHOP

September 19 & 20, 1992 from 10am-6pm

*Come on a gentle journey of
self-discovery in a friendly,
supportive environment.*

We explore issues of concern
and relevance to being Gay Asians.

MORE INFO CONTACT ARNEL (02) 283 3222

HIV and Prisons

Jo Western: on the inside talking out

THE SITUATION WITH REGARD TO HIV infection throughout the NSW Department of Corrective Services leaves a lot to be desired.

In the beginning there was the decision to segregate HIV infected prisoners. The then Minister Mr Michael Yabsley amended the above decision and integrated HIV+ inmates. I am not against integration. In fact I would rather see all HIV+ inmates treated in the same way as HIV- prisoners.

In 1992 the Minister for Justice Mr Terry Griffiths made a decision to implement cell sharing with an infected prisoner, subject to an agreement with the non-infected inmate that they wouldn't get up to anything that may lead to HIV infection.

The Department of Corrective Services does not fully understand how a small environment such as a prison can have the effect that prisons can become a place for HIV to become widespread.

It is common knowledge that, since the establishment of the first settlement in New South Wales, which consisted mainly of prisoners (or convicts as they were called), prisoners indulge in homosexual acts. This and intravenous drug use, result in rape/sexual assault crimes within the penal system.

I consider that the Minister for Justice should be able to see past the bureaucratic poppycock and instead of becoming a part of the problem become a part of the solution.

The Minister has to come out of the closet when it comes to dealing with HIV infection within the NSW penal system. Until then the Minister will only believe what he wants to believe and that will only make it worse on the infected prisoners.

I make these recommendations for the NSW prison system relating to HIV infection:

1. That all HIV+ prisoners have the same rights as the PWAs within the community itself. These rights should include:
 - a. the right to refuse any medication prescribed to them by a medical practitioner.
 - b. the right to seek alternative medicine which they feel will benefit their health.
 - c. the right to have access to facilities which are available to the rest of the community.
2. That all HIV+ prisoners have access to HIV support groups with other PWAs present, as well as access to other support groups within the general community.
3. That all HIV+ inmates receive the adequate and appropriate treatment.
4. That all inmates undertaking an antibody test have compulsory pre and post-test counselling with a person satisfactory to them.

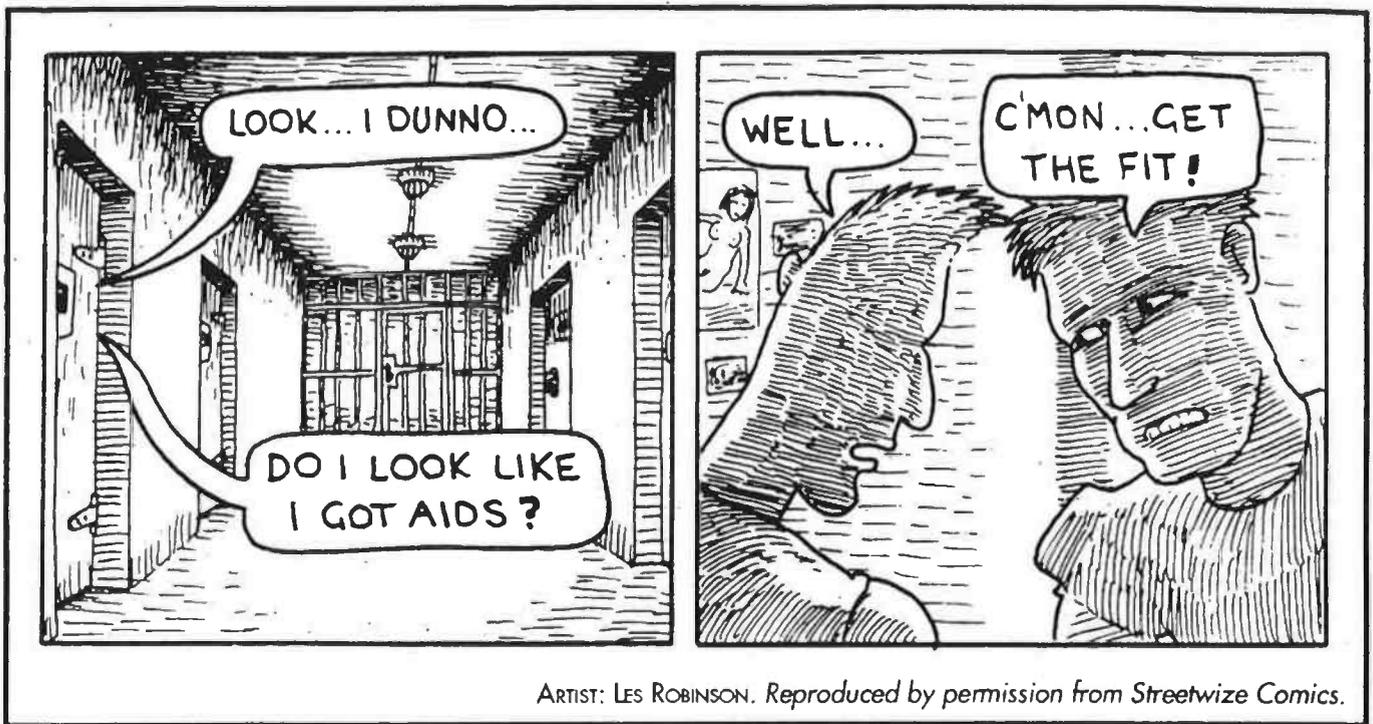
In recent years HIV has become a weapon within the penal system as seen at the Long Bay Prison Complex, Matraville, when a prison officer, Mr G. Pearce, was stabbed in the buttocks with a blood filled syringe. However, as well as the question of his infection with HIV due to that needle prick, there is also the issue of how the prisoner got hold of the syringe in the first place to carry out such an assault?

Intravenous Drug Use

FOR SOME PATIENTS, IT WILL BE the use of illicit drugs which places them at risk of infection with HIV. In such cases, the values held by doctor and patient may be diametrically opposed. IV drug use is a special case of dependency which is complicated by illegality.

Until rehabilitation is freely and willingly embraced by a patient, health education has little chance of success. While a change in living skills can be suggested, the all-embracing commitment to the drug(s) will occupy the patient's attention. The behaviour pattern of drug use is so powerful that it usually excludes other patterns being established.

People must understand that the prison system is a small community within itself and the spread of HIV is halted by the



prisoners themselves.

In 1988 or 1989 the Minister for Corrective Services, Michael Yabsley, set up a project called Prison AIDS Project, to educate some inmates about HIV/AIDS. The project consisted of a four day project in which the prisoners were taught:

- Epidemiology;
- Infection control;
- Safe/safer sexuality;
- Safe/safer drug use;
- Assessment of risk;
- Pre and post-test counselling skills.

After four days they became peer educators to educate other inmates about HIV/AIDS. Due to this there is probably more prison knowledge about the transmission and prevention of HIV/AIDS than the general community realises.

It is a popularly held belief that the prison system has become an incubator for the transmission of HIV. However, there is more risk of contracting HIV outside the prison system. I suggest that people who like sitting in an armchair being a critic realise that the prison system may have some

faults (what system hasn't) but HIV/AIDS ignorance is not one of them. The community must understand that people in prison are human and that even though some prisoners are PLWAs they deserve the same rights as anyone else does within our society. These are:

- to live without discrimination;
- to be able to die in dignity and freedom;
- to attend support groups such as People Living With AIDS (recommended) AIDS Council of NSW and Albion Street AIDS Centre (recommended);
- to be able to live out their lives with the best medical treatment.

The Department of Corrective Services and the judicial system must understand that keeping a PLWA incarcerated until he/she dies is inhuman. The World Health Organisation stated in November 1987, "...In addition, prisoners with AIDS should be considered for early release to die in dignity and

freedom."

Unfortunately, Uganda, to the best of my knowledge, has been the only country that so far that has taken action on this statement. The only reason I can see that Australia does not follow is because the prison population in NSW is the highest in the country.

The November 1987 statement also said, "Prisoners should not be subjected to discriminatory practices relating to HIV infection or AIDS such as involuntary testing, segregation or isolation, except when required for the prisoners' own well-being."

However, in 1989 the NSW conservative government through the Attorney-General made it compulsory that an antibody test be done upon entry and six weeks before exiting the prison system, totally violating the 1987 statement by the World Health Organisation. This government decision was aimed at one of the powerless and voiceless groups within our society - prisoners!

HIV/AIDS Glossary

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

A condition in which the body's immune system loses its ability to fight off infection and thus becomes vulnerable to opportunistic illnesses. A diagnosis of AIDS requires the patient to experience an AIDS-Defining Condition, which is any one of the major opportunistic illnesses. (Although what constitutes an AIDS-Defining Condition is controversial.)

AUSTRALIAN DRUG EVALUATION COMMITTEE (ADEC)

The principal group of individuals who assess the safety and toxicity data and hence recommend approval of a drug to be licensed for marketing in Australia.

ANAEMIA Condition of having a low number of red blood cells.

ANTIBODY Antibodies are proteins in the blood and are part of the immune system that attacks any substance that is foreign to the body. Certain cells called B-lymphocytes recognise these substances as foreign and then manufacture antibodies that can inactivate and remove these foreign substances. The foreign substance invading the body is called an **ANTIGEN** (see below). For most antigens, the time required to create antibodies is one to two weeks. For HIV however it may take up to three months.

ANTIBODY POSITIVE Those people who have been exposed to HIV and who have developed antibodies to the virus are said to be

antibody positive, or seropositive.

ANTIGEN Any foreign substance in the body which stimulates the production of antibodies.

ANTIGEN POSITIVE A positive antigen test indicates the presence of active viral particles and therefore indicates an increased risk of progression to AIDS.

ANTIGEN NEGATIVE This indicates that there are no free HIV particles present and therefore indicates a lower risk of progression to AIDS.

ANTIVIRAL ACTIVITY The action of an agent that stops or suppresses the activity of the virus.

ANTIVIRAL-NAIVE Refers to a person who has never taken any anti-HIV drug before, such as AZT, ddI or ddC.

ASYMPTOMATIC An infection or phase of an infection, without symptoms. For example the carrying of antibodies to HIV but without any display of symptoms of HIV infection.

ATTENUATED VIRUS Virus that can no longer exerts its damaging effects on the body and has lost its ability to reproduce.

AZT INTOLERANT A condition where someone taking AZT experiences side effects that are so severe that she/he can no longer put up with the therapy, or is at serious risk if therapy continues..

BAUME RECOMMENDATIONS As contained in the report "A Question of Balance" by Professor Peter Baume. This landmark report overhauls the Australian drug approval and regulatory system to make treatments more accessible, especially for people with life-threatening illnesses.

BONE MARROW Soft tissue located in the cavities of bones which is responsible for the manufacture of red blood cells.

BUFFER replace with A substance commonly added to medication to change the acidity in the stomach in order to increase absorption of the medication.

CANDIDIASIS (CANDIDA) A yeast like infection caused by candida albicans that infects mucous membranes, skin and internal organs. A common opportunistic illness with HIV.

CAPILLARIES The smallest blood vessels in the body.

CD4 COUNT (see T4 cell count)

CENTERS FOR DISEASE CONTROL (CDC) The peak US body for epidemiology. The CDC has the responsibility of defining AIDS as well as other categories of HIV infection and these definitions are widely used outside the US.

CENTRAL NERVOUS SYSTEM (CNS) The brain, spinal chord, and the lining tissues.

CLINICAL TRIALS EXEMPTION SCHEME (CTX) The process whereby applications for new drug clinical trials are reviewed and approved.

CONCOMITANT MEDICATION When two or more different medications, for the same or differing conditions, are taken at the same time.

CO-FACTORS Substances or elements of lifestyle or environment which are thought to possibly contribute to HIV disease. e.g. recreational drugs, alcohol use, smoking, poor diet, high stress, repeated viral infections.

COMBINATION THERAPY The use of two or more types of treatment in combination, alternately or together, to achieve optimum results and reduce toxicity.

CRYPTOCOCCOSIS An opportunistic illness caused by a fungus called *cryptococcus neoformans*. It frequently causes meningitis, an inflammation of the lining of the central nervous system. Symptoms include headaches, blurred vision, confusion, depression, agitation or impaired speech. Cryptococcosis is potentially life-threatening.

CRYPTOCOCCAL MENINGITIS See CRYPTOOCOCCOSIS

CRYPTOSPORIDIOSIS An opportunistic illness caused by the protozoan parasites *cryptosporidia*. The main symptom is chronic diarrhoea.

CRYPTOSPORIDIA (Singular *Cryptosporidium*.) See CRYPTOSPORIDIOSIS

CYTIDINE One of the types of building blocks that make up genetic material (i.e. DNA and RNA).

CYTOKINES Naturally-occurring proteins that regulate or modify the growth of specific cells

CYTOMEGALOVIRUS (CMV) A virus related to the herpes family that can cause fever, fatigue, enlarged lymph glands, and a mild sore throat. In AIDS, CMV infections can produce hepatitis, pneumonia, retinitis, and colitis. It sometimes can cause blindness, chronic diarrhoea and be potentially life threatening.

DEMENTIA Symptoms include memory loss, visual disturbances, motor impairment and personality changes.

DIAGNOSIS The process of determining the cause and nature of an illness.

DISSEMINATED A disease or infection that has spread to a number of tissues or organs in the body.

EARLY INTERVENTION The interruption of the progress of a disease at the early stage of its infection within the body. Usually to prevent the onset of illness or more serious symptoms.

EFFICACY The relative ability of a drug or substance to perform a function within the body.

FOOD AND DRUG ADMINISTRATION (FDA) The agency of the US government which controls and regulates the human testing of drugs before giving approval for marketing.

FUNGAL INFECTION A range of distinct diseases caused by one celled organisms called fungi. Histoplasmosis, oral and vaginal thrush, and cryptococcal meningitis are examples.

GASTROENTERITIS Inflammation of the lining of the stom-

ach and the intestines.

GRANULOCYTE COLONY STIMULATING FACTOR (G-CSF) A synthetic hormone that stimulates growth of granulocytes, a particular type of white blood cell. The drug is used to relieve neutropenia.

GRANULOCYTE MACROPHAGE COLONY STIMULATING FACTOR (GM-CSF) A synthetic hormone that stimulates growth of both granulocytes and macrophages [cells that can be reservoirs for HIV]. It can also be used to treat neutropenia.

HAEMOPHILIA Hereditary blood disorder which prevents blood clotting due to a deficiency of factor VIII, a blood coagulation factor. People with haemophilia in Australia were at risk of HIV infection prior to April 1985, when the blood supply was secured through routine HIV testing of the national blood supply.

HEPATITIS Liver inflammation caused by the hepatitis virus.

HERPES Inflammation of the skin caused by herpes viruses. Herpes Simplex I and II (HSV-I and HSV-II) infection are common opportunistic illnesses in people with AIDS, the dormant virus being activated by immunosuppression.

HUMAN IMMUNODEFICIENCY VIRUS (HIV) A human retrovirus considered by most to be the main cause of AIDS.

HIV INFECTION State of being infected with HIV as indicated by a positive HIV antibody antigen test.

HTLV-III The original name given to HIV by Dr. Robert Gallo of the US National Cancer Institute.

IMMUNE DEFICIENCY Inability of the immune system to resist infection. In AIDS and HIV related illness this is caused by immune suppression due to the action of HIV.

IMMUNE RESTORATION The rebuilding of the body's immune system.

IMMUNE SUPPRESSION Inducement of immune deficiency, either deliberately [e.g. in transplant operations to prevent rejection] or by disease, drugs, stress, ageing, malnutrition or other factors. May also be referred to as immunosuppression or immunocompromisation.

IMMUNE SYSTEM The body's mechanisms to resist infection. Lymphocytes, a class of white blood cell, recognise and destroy any foreign substance (called an antigen). In HIV related illness, a subset of CD4-cells (T-cells) is affected by HIV causing immune deficiency.

IN VITRO STUDIES replace with: Studies conducted purely in non-living environments, such as the test-tube.

IN VIVO STUDIES Studies conducted in animals or people.

INTRATHECAL The application of drug or substance directly into the central nervous system. i.e. the brain or spinal cord.

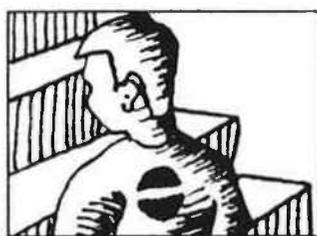
INTRAVENOUS DRUG USE (IDU) Injection of non-prescribed recreational drugs such as heroin, cocaine or speed. HIV can be transmitted to IDUs with the sharing of an unsterilised needle or syringe with other individuals.

INTRAVITREAL Application of drug or substance directly into the eye or ocular capsule.

KAPOSI'S SARCOMA (KS) Thought to be a rare form of skin cancer, recognised as raised or tender red to purple spots on the skin. It may also occur internally within the lungs, stomach etc. This can be in addition to or independent of the skin lesions.

LYMPH NODES A small "peasized" organ in the immune system, with the function of manufacturing white blood cells. The lymph nodes are located in the back of the neck, below the jaw, under the armpit and in the groin.

LYMPHADENOPATHY SYNDROME (LAS) Inflammation of the lymph glands, common in HIV



related illnesses. Also known as Persistent Generalised Lymphadenopathy.

LYMPHOCYTES White blood cells that recognise and destroy infection. B-cell lymphocytes produce antibodies, and CD4 lymphocytes active parts of the cellular immune system in response to foreign substances, particularly viruses.

LYMPHOMA A cancer of the lymphatic system. Lymphomas are opportunistic tumours. People with AIDS generally have a variety called Non-Hodgkins Lymphoma. These tumours tend to involve areas of the body such as the brain, liver, kidney and lungs. Lymphomas are potentially life-threatening, but various treatments are available.

MACROPHAGES A type of cell of the immune system that ingests (i.e. swallows) a foreign substance that has entered the body.

MENINGITIS An infection of the meninges, the membrane that surrounds the brain and spinal cord.

MYCOBACTERIUM AVIUM COMPLEX (MAC) See MYCOBACTERIUM AVIUM INTRACELLULARE.

MYCOBACTERIUM AVIUM INTRACELULLARE (MAI) Infection beginning in the gut and spreading to other parts of the body. Symptoms include night sweats, high fevers, cough, weight loss, malabsorption of food and diarrhoea.

NATIONAL CENTRE FOR HIV EPIDEMIOLOGY AND CLINICAL RESEARCH The major co-ordinator of clinical trials for HIV in Australia. It also collects and analyses epidemiological data.

NUCLEOSIDE ANALOGUES A family of drugs, of which AZT, ddI, ddC are a part. They operate by partially preventing the replication process of the virus from being completed.

OPPORTUNISTIC ILLNESS Infection or tumour that occurs because the damages immune system cannot fight it off. Such illnesses do not generally occur in people with intact immune systems.

PANCREAS An organ connected to the intestine that produces a number of intestinal juices and various regulatory hormones.

PANCREATITIS Inflammation of the pancreas, usually due to an infection but also possibly as a reaction to a drug e.g. ddI.

PERFORATION The creation of a hole within the wall of an organ.

p24 ANTIGEN A marker of HIV reproduction activity. It is measured in the blood. P24 is a protein fragment of HIV.

PERIPHERAL NEUROPATHY Disorder of the nerves leaving extremities of the body numb to sensations such as touch, or sometimes painful. Sometimes associated with some treatments for HIV/AIDS e.g. ddI and ddC.

PERSISTENT GENERALISED LYMPHADENOPATHY See LYMPHADENOPATHY SYNDROME.

PHOTO PHOSPHORESIS A technique for withdrawing antibodies etc. from an individual. It is being used in the development of antibodies in HIV negative individuals for use in an HIV vaccine.

PLACEBO A tablet or capsule that does not contain any drug. Placebos are used to "blind" clinical trials so that the patients don't know if they're taking active drug or not.

PNEUMOCYSTIS CARINII PNEUMONIA (PCP) A common parasite which infects the lungs of people with HIV infection and low T4 cell counts (< 200) Sometimes, PCP infections may occur elsewhere in the body (skin, eye, spleen, liver or heart).

PRODRUG An inactive form of a drug that gets converted to the active form when taken into the body.

PROPHYLAXIS Treatment intended to prevent the onset of an infection or disease.

PROTEASE INHIBITORS A class of drugs that stops an HIV gene called protease from func-

tioning. HIV needs protease to make its proteins active, so a protease inhibitor in effect inactivates the virus.

RANDOMISED TRIAL Participants are randomly assigned to receive one of the treatments designated within a clinical trial.

REMISSION Abatement or lessening in severity of the symptoms of a disease, or the period in which the abatement occurs.

RESISTANCE Diminished effectiveness of a drug on a certain infectious organism, which is able to change in structure enough to avoid the drug's action against it.



RETINITIS Inflammation of the surface at the inside back wall of the eye (retina). If left untreated it may result in blindness.

RETROSPECTIVE STUDY A study that looks at information that has already been recorded in the past.

RETROVIRUS A class of virus including HIV. Retroviruses do not have DNA, the molecule that contains genetic information that cells use to reproduce themselves. Instead retroviruses have RNA, and use an enzyme called reverse transcriptase to transform RNA into DNA.

SEROCONVERSION The process of going from seronegative to seropositive, that is, having detectable antibodies within the blood.

TAT GENE INHIBITOR

A drug that is currently being developed to stop the TAT gene of HIV from working. HIV requires the TAT gene to maintain its high reproduction rate.

T4 CELL A type of T-lymphocyte. The T4 cells enhance the immune response to an infection through a complex series of interactions with other types of lymphocytes (B cells and T8 cells) antibody producing cells and infectious organisms.

T4/T8 RATIOS The existence and complicated action of two types of white blood cell, one of which naturally suppresses the immune system and the other naturally mediates immune reaction. Together these T-cells keep the immune system in balance. In people with HIV, the T8 levels are usually normal or elevated, while the T4 levels are decreased.

THERAPEUTIC GOOD ADMINISTRATION (TGA) Government body responsible for regulating the use of pharmaceutical drugs and devices in Australia.

TOXICITY A measure of what quantity of a drug or substance is poisonous to the human system.

ULCERATION The eruption of a surface of a mucous membrane lining or the skin surface.

VACCINE Administration of a usually modified form of a disease agent, in order to induce the natural immunity.

VIRUS One of the simplest forms of life. Microscopic in size, viruses require a living cell of a host in order to reproduce. The presence of viruses in cells can cause illness or even death of the host organism.

Anguish in

BOHEMIA

CHAPTER 13

by Ms Ada O.

The story so far: Nigel has returned home to discover Leonard's piano and heart are broken and Nancy and Brad are in King Elvis Memorial Hospital because the piano broke them. More pain is on the horizon for Brad with the imminent arrival of his mother, Beryl from Brewarrina. Meanwhile, Nancy's life support machine is beeping Kum-bah-yah. Is this the end of Brad and Nancy? Will there be any lamingtons left by the time Beryl arrives in Sydney? Will Leonard ever recover from the tragedy of losing his baby grand? Only by reading on will we discover these answers and a whole lot more...

"Can I borrow a cup of condoms?"

NIGEL WAS WEARYING OF THE DAILY, coma-patient vigil - peering endlessly at the piano-squashed - in King Elvis Hospital emergency ward. Arriving home at Bohemia Apartments he jogged up the stairs, whistling as he went. He didn't know why he felt so light-headed, but these days the misfortunes of others seemed to cheer him up.

As he entered his own flat he thought of the traumas of the last week: how he'd discovered his parents had moved without telling him, how he'd been picked up hitchhiking by the trucker, Rod, who'd shot out the seat of his Levis to save him from a tarantula, and how arriving back in Darlinghurst he'd learnt the



terrible fate that had befallen Nancy and Leonard's piano. Leonard! What had become of him? thought Nigel.

Nigel pulled open the microlight venetians, and the warm spring sunshine streamed into the room. It looked a little dusty and un-lived in, but he'd soon fix that.

Try as he might to concentrate on the domestic chores neglected since before his departure on his voyage of personal discovery, Nigel could not get the pathetic image of his new upstairs

neighbour, Leonard, from his mind. How sad Len had seemed, and how much the poor man obviously missed his piano.

Nigel decided to cheer him up, and ran up the stairwell, unable to stop himself whistling.

Leonard answered the door, as desultory as ever.

"Oh, hello Nigel, come in," he sighed.

"Won't stop long, I just stopped by to borrow a cup of condoms, Len," Nigel ventured, watching to see if Leonard missed a beat. He didn't, and Nigel followed him into the flat and into Leonard's bedroom. There Leonard fumbled with a pack of condoms, and glanced about for a cup. Nigel came up behind him and gently rested his hand on Leonard's shoulder.

"It's OK," Nigel whispered, passing the cup he'd brought with him. Leonard burst into tears, and threw his arms around his guest. They fell on to the unmade bed, in each others arms.

Nigel thought to himself momentarily that he'd invented the best pick up line ever, but then returned to the moment.

Two hours, and a cup of condoms later, Nigel glanced at the cuckoo clock over Leonard's bedhead. Leonard was just emerging from a shower.

"I have to go back to the Hound-Dog emergency ward at the Hospital," Nigel announced. "That woman who tried to break the fall of your piano has lapsed into a coma - they think she won't live. Wanna come?"

"Are you a therapist or something, Nigel?" Leonard



inquired enigmatically. "Sure, I'll come - if I'm not intruding?"

"Of course you won't be intruding. Welcome to anguish in Bohemia!" Nigel replied slipping on his boxer shorts, and heading for the shower.

Brad's eyes flickered open as he slowly came to. His first thought was that he had died and was in heaven, for before him silhouetted in a bright light stood a gigantic martini. But this martini seemed to be saying something.

"Bradley Bruce Lewis, what have you done to yourself you silly boy? Well, never mind, I'm here to take good care of you."

"But martinis don't talk," Brad mumbled loudly, albeit incoherently.

"Martinis? Bradley, darling, what are you talking about? Heavenly father, that accident has made my boy delinquent!"

Brad tried to focus more clearly and as he did the martini melted away and was replaced by a short woman in a floral sundress clutching a large carpet bag in one hand and a Tupperware container in the other.

That's not a martini and this isn't heaven Brad thought alarmingly as he bolted upright.

That's my mother!

"Of course it's your mother, pet. I came as soon as I heard. You poor thing, it must have been a terrible experience for you."

"Mother," Bradley exclaimed as he broke out into a nervous sweat, "you really shouldn't have!"

"Nonsense! I'm your mother and I'm here to look after you and that's that." She held up the Tupperware container and waved it in front of him, laughing. It was empty except for some last remaining shavings of coconut. "I'm such a silly chook. I made you some lovely lamingtons but I got so hungry on the bus I ate them all. Oh well, *c'est la me* as the French say."

"I think that's *cest la vie* mother," Brad sighed resignedly. Suddenly he remembered what had happened and how he had tried to push Nancy from under the falling piano. He panicked. "Nancy?! What's happened to Nancy? Where is she? What have they done with her?!"

Beryl was extremely shocked by this outburst and broke down weeping, thinking her son was raving. She collapsed next to his bed and embraced him tightly.

"Oh no! My poor boy. My

poor, poor Bradley. You'll never be the same again. But don't worry, I won't let my baby suffer. We'll get you the best medical treatment in the world. Your father might have to sell the store, but we'll get you the best help."

"Good god mother," Brad hissed as he pushed her away and jumped out of bed, "stop being so hysterical! I've got to find Nancy. Now where's my pillbox hat?"

Beryl looked at him agahst. Brad returned her stare with an impatient look and his hands on his hips.

"Well don't just stand there! Help me find my pillbox hat!"

Bedside Manners

"IT IS PLAYING KUM-BA-YAH!" Robbie was adamant.

"Calm down, hon," Wayne was getting a little concerned. They had been sitting at Nancy's bedside for 36 hours straight listening to her life-support machine. Robbie was convinced it was playing the familiar Post-Vatican II hit song.

Sister Mary-In-Charge swished about them hooking up containers of strangely coloured liquid and giving them kindly looks.

"She looks so peaceful." The

Sister's gravelly voice reassured them only briefly, for at that moment the door opened and an entourage entered.

Brad came first, in a wheelchair pushed by Beryl. They seemed to be arguing about him wearing the pillbox hat he had perched on his head. Beryl was using every trick she could think of to convince him to take it off. "It's just not *in mood*, Bradley", she was saying, "and useless for sun protection. Those megalomaniacs will get through that veil quick as look at you."

Beryl and Brad were followed by Nigel and Leonard who smiled vacantly and stood by the window looking dreamily out to sea. Robbie thought they looked very chummy, and this annoyed him slightly.

The last couple to enter the doorway made Robbie jump up from his chair.

"Mum! Dad!" he exclaimed pushing through the crowd.

His parents stood in the doorway holding a bunch of carnations and a fluffy teddy bear. They were obviously distressed, not by what had brought them here, but by what they saw. Robbie's mother looked at the couple holding hands by the window, the very strange looking man in the wheelchair wearing a lady's hat and the hairy man in black leather with earrings, and rolled her eyes.

"Nancy", she remembered. "Where is my daughter?"

"In bed, mum", Robbie offered plainly.

Robbie and Nancy's mother made her way through the odd assortment of visitors to the head of Nancy's bed.

"Oh, my poor Nancy", she said. "What has happened to you?"

"She's in a coma," Sister Mary-

In-Charge stated firmly. "The sleep before the end, I'm afraid."

There was silence then. Everyone focussed on Nancy's mother. They followed her gaze as she looked at the tubes and cords connecting her daughter to the life support machine, and they watched as her eyes moved down the power cord to the plug in the socket on the wall, and all eyes centred on the on-off switch.

The beeping life-support machine played a plaintive refrain: Someone's sleeping, Dog... Come-Bay-Here ... Someone's sleeping, Dog ... Come-Bay-Here ... Someone's sleeping, Dog... Come-Bay-Here... Oh, Dog, Come-Bay-Here.

"Bradley", Beryl murmured to her son. "That nun's got a moustache."

TO BE CONTINUED...



Home Front



Self dosing decisions (A personal perspective)

MAKE SURE THOSE DECISIONS ARE informed!

The issue of compliance in relation to drug trials has been often talked about. It becomes particularly apparent when trials are being used as mechanisms of treatment access. However, the issue of 'compliance' with recommended dosages of drugs in clinical practice is far less understood.

I know from working in this project that many people with HIV make their own decisions about what dose to use of particular drugs. A few case scenarios illustrate the sort of decisions that people make.

Scenario 1. Half my friends think AZT is poison. The other half nag me to take it. I take one pill a day. It keeps both lots half happy.

Scenario 2. I'm still convinced that the dose of AZT is too high. I'm worried about side effects. I take 200mg a day. I've got 400 CD4 cells and I'm antigen negative. My HIV is not very active so I only need a smaller dose.

Scenario 3. Every time I take AZT I'm reminded of my illness. I take it when I remember.

Scenario 4. AZT makes me feel rotten. I lose my sex drive. I take it mostly because it keeps my lover happy.

These real case scenarios are

illustrative. Sometimes decisions are made on the basis of some knowledge. The history of AZT developments impacts on peoples decisions. There are a lot of other factors that influence compliance as well. Not doing what the doctor says can be like taking control.

The purpose of this article is not to say that everyone should be doing what doctor says or that the recommended dose is necessarily the correct dose. However, it is to issue a warning - that self dosing decisions should be made on the basis of the available evidence and that some health beliefs which underpin self dosing decisions are wrong.

A few factors which should influence self dosing decisions are:

1. Not only do drugs have doses which are too high, they also have doses which are too low. They sometimes have a threshold below which they do not work. There is no point taking a drug if the amount you are taking is below the minimum effective dose.

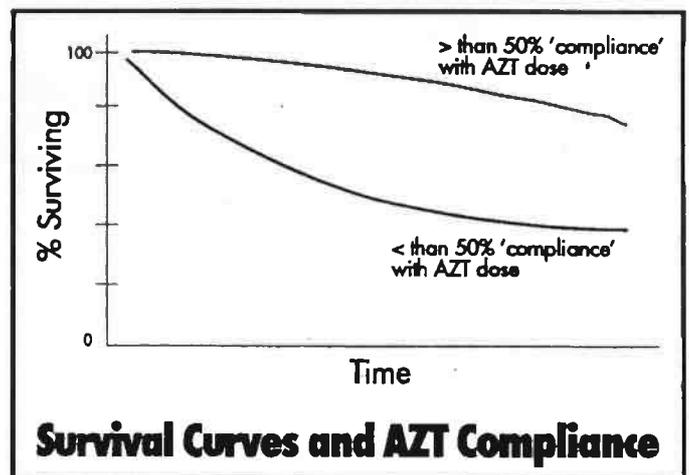
2. Taking some drugs at below the recommended dose can provide the optimum conditions for breeding resistant strains of organisms.

3. In order to maintain the minimum effective dose of a drug it is not only how much drug you take, but how often you take it.

The impact of non-compliance is illustrated in the diagram below. This was from a study presented in Amsterdam. It shows that people 'complying' with the recommended dose survived longer.

The purpose of this article is also not to say take AZT. However, if you have made that choice then I think we can say that we now know, based upon the available evidence, that if you are using AZT then the correct dose is around 500-600mg per day and maybe even higher in order to prevent or treat AIDS related dementia.

Ross Duffin



Fair Treatment



ddC approved - well, sort of.

ON AUGUST 13-14 1992, THE Australian Drug Evaluation Committee (ADEC, the peak evaluation body of the Therapeutic Goods Administration) approved ddC for marketing in Australia. Their decision has gone to Minister Peter Staples for ratification.

However, that's only half the story. ADEC recommended to the Minister that ddC be approved *only* for monotherapy. This means that ddC will only be licensed for use *by itself*, not in combination with AZT. ADEC claims that they had insufficient time to assess the data on combination therapy.

While a monotherapy approval does not necessarily make it illegal for a doctor to prescribe it in combination (some people think that it does), it does mean that funding bodies which normally pay for the drugs are not obliged to do so. If funding bodies refuse to pay for ddC, then the responsibility for payment falls on either the patient or the prescribing institution (e.g. hospital). If the price in the US is anything to go by, ddC might cost upwards of US\$150.00 per month.

But money issues aside, ADEC should have approved ddC for combination therapy *because the data supports it*. According to the Therapeutic Goods Administration (TGA), they were not impressed by the data from the one study (ACTG

106) which was presented to them. In a way, TGA cannot be blamed for not accepting the ACTG 106 data as sufficient. ACTG 106 was a very small study, with weak controls and slightly unorthodox doses.

However, ddC's manufacturer Roche Products had recently managed to get additional data to support combination therapy. The data are from a trial still in progress, called BW 34,255:02 and sponsored by Burroughs Wellcome, which is studying the effects of combination therapy and monotherapy on the development of viral resistance. [see accompanying story, "The mysterious BW 34,255:02."]. When the data were offered to TGA, they hummed and hawwed and said no thank you, and then a few days later they said yes please (and now they say they didn't have enough time to look at the combination data...so infuriating).

This decision by TGA and ADEC is likely to be greeted with disappointment and anger. People who need ddC generally need it for use with AZT, not by itself. The TGA has, once again, demonstrated its amazing ability to be out of touch with the people it's charged to care for. Too bad they don't give out gold medals for outstanding contributions to number of AIDS deaths.

The mysterious BW 34,255:02.

WARNING: THIS SECTION IS MORE technical than most treatment articles in Talkabout. However, since BW 34,255:02 has not been

discussed in Australia before, I figured someone ought to do it.

BW 34,255:02 is a study that has been much alluded to in recent months by the AIDS research community, but it wasn't until a special meeting before the US Food and Drug Administration in April that any information was unveiled.

Sponsored by AZT-manufacturer Burroughs Wellcome, BW 34,255:02 is a trial studying the effects of combination antiretroviral therapy on the emergence of viral resistance. The trial involves 6 groups around the world, including Dr. David Cooper of Australia's National Centre in HIV Epidemiology and Clinical Research.

At the time of entry, all volunteers had a CD4 count of less than 300, a Karnofsky performance score of greater than 60, and less than 4 weeks of antiretroviral therapy.

The 3 arms of the trial are:

1. AZT (600 mg);
2. AZT (600 mg) + ddI (200 mg);
3. AZT (600 mg) + ddC (2.25 mg).

Only the data from the first and third arms are available, because this interim analysis was only done at the request of the US Food and Drug Administration, which was unwilling to license ddC for combination therapy based solely on the ACTG 106 data. Before going further, it must be said that this preliminary analysis is not conclusive in itself, and was done to *supplement* the ACTG 106 data.

The two arms had about 43

volunteers each. Volunteers had only been in the trial of up to 24 weeks. The mean entry CD4 count was just under 150 for both arms (with the AZT-alone arm being a hairline higher). The volunteers on combination therapy had their CD4 count peak at 225 cells, at about 8 weeks into therapy.

The peak rise in CD4 counts was 85 in the combination arm, compared to about 45 in the AZT-alone arm. So people on the monotherapy peaked "slightly later but slightly lower, starting from a slightly higher baseline" (quote from Dr. Chip Schooley, one of the study's investigators). The rise in CD4 counts in the combination arm was sustained for longer (over 20 weeks) than the monotherapy arm (only 18 weeks).

While extremely sketchy (certainly an understatement!), the information from the BW study does confirm what was seen in ACTG 106: that there is a CD4 increase (from baseline) of 40 - 50 cells over what is seen in AZT therapy alone, and sustained at least for a 20-week period (ACTG 106 showed the increase was sustained for up to one year). The BW study helped the FDA committee dispel the notion that the ACTG 106 results were a fluke.

At least one commentator has noted the delicious irony in having one drug company (Burroughs Wellcome) provide data in order to get the drug of another company (Roche) approved for marketing. G'dali Braverman of ACT UP San Francisco quipped, "BW coming in to save the day for Roche. Will wonders never cease."

- Lyle Chan

A Therapeutic Vaccine for HIV?

MOST VACCINE PRODUCTS ARE

given to people in order to prevent infections - they are given to people before becoming infected. These are known as prophylactic or prevention vaccines. In HIV disease, it has been proposed for some years that it may be possible to develop vaccines that modify (and improve) the immune response in people who already have HIV infection. These are known as therapeutic or post-infection or treatment vaccines - the vaccine product is given after a person has been infected.

The development of both types of vaccines (prophylactic and therapeutic) are important in HIV. Indeed, they may be the same products. However, trials of prophylactic vaccines for any disease have practical and ethical problems associated with them. In HIV, the practical and ethical problems of such trials are immense. The ethical and practical questions for therapeutic vaccines are different and easier to solve. As a result therapeutic vaccine trials have commenced and we will find out about them long before we find out about a prevention vaccine for HIV.

Post-infection vaccines are still the subject of considerable debate. This is partly because our understanding of HIV pathogenicity (how HIV causes illness) is incomplete. The gaps in our knowledge also lead to some difficulty in interpreting the results of clinical trials of these agents.

Despite this debate, there are considerable expectations from many people with HIV that clinical trials of therapeutic vaccines will commence soon in Australia.

There are many different types of potential vaccines. They include whole virus that has been inactivated (ie killed), live virus that has been 'attenuated' (ie changed to make it relatively harmless), subunits of the virus (ie

component parts of the virus) and live recombinant viruses (where part of the HIV gene is inserted into another attenuated live organism like a poxvirus). Recombinant technology was used very successfully in developing the Hepatitis B vaccine.

The vaccines which are receiving most attention in HIV (because they are the most developed) include two subunits of the envelope of the virus - gp120 and gp160, a recombinant poxvirus and the 'Salk' vaccine (killed virus with the envelope removed). Using some of these agents in combination is also being investigated.

Three groups which reported results of vaccine trials at the 8th International Conference on AIDS included Robert Redfield of the Walter Reed Army Institute of Research in Rockville, Maryland, Fred Valentine of the New York University Medical School and John Turner from the Salk Institute.

Redfield's group first published in the New England Journal of medicine in 1991. In this trial they gave people with HIV a recombinant gp160 vaccine, varying the frequency of injections. People who produced new antibodies to this product were known as 'responders'. 17 of the 30 people in the trial were responders. Responders were more likely to have CD4 cell counts above 600. Responders showed no decline in CD4 cells over a 12 month period - a significant difference when compared to historical controls. Non-responders showed the same CD4 decline as historical controls.

Data from this group was updated in Amsterdam - now representing three years of follow-up. By increasing the frequency of injections 29 of the 30 people have now responded, including people with CD4 cell counts in the 200-

400 CD4 cell range. There is no evidence of 'resistance' or decreasing effectiveness. The vaccine shows cross-strain efficiency.

The Valentine groups trial was placebo-controlled with one half receiving HIV antigens (recombinant gp160) and one half receiving Hepatitis B antigens. Subjects were both HIV and Hepatitis B antibody positive. They used the 'lymphocyte proliferative response' as a marker for determining whether the vaccine product was causing immune response changes. Usually a person's lymphocytes respond by dividing or proliferating in response to an antigen they have encountered before. Those who took part in this trial had normal proliferative responses to common microbes but a negligible response to HIV antigens. After immunisation with HIV antigens - but not Hepatitis B - these people had a good lymphocyte proliferative response to HIV. The Valentine group now intends to conduct a larger clinical trial.

The Salk group presented data based on two years observation. They found that response to their vaccine product was not totally CD4 related - some responders had CD4 counts below 200 and some non-responders had CD4 counts above 700. 55 of the 60 patients either maintained or increased their CD4 counts. Again, a larger controlled clinical trial is intended.

These results are very promising. However, many questions remain. If these vaccines induce a new immune response in someone with HIV that their infection has not provoked, then that might be of benefit - however there is as yet no evidence for this. The vaccines are often very different from the actual viruses that

people have in their bodies. The mechanisms which prevent viral infection are usually quite different from the ones which control it. Humoral immunity (ie involving antibodies) is important in preventing infection and cell-mediated immunity is important in controlling infection - these vaccines mostly produce an antibody response. Further, although CD4 cell counts are stabilised, the clinical significance of this has yet to

be demonstrated with these agents.

This incomplete understanding is sometimes unfortunately used as justification for delaying commencement of clinical trials of these agents. Just as incomplete understanding has not delayed clinical trials of agents like AZT, neither should it delay clinical trials of these agents.

- Ross Duffin

"My doctor says high dose acyclovir
might prolong my life.
But Wellcome won't provide the drug,
so I can't have it."

YOU ARE HIV POSITIVE.

Wellcome Australia continue their
evil profit campaign
against people with HIV by denying them
access to high dose acyclovir.

Take control - fight back.

You can fight back against greedy
corporate AIDS profiteers like Wellcome.

For more information ring ACT UP on 281 0362.

ACT UP. FIGHT BACK. FIGHT WELLCOME.

Gloria's Food



Macrobiotic Cooking

By Roger Green.

WE ACCEPT THAT DIET AND LIFESTYLE factors will affect immunity. The macrobiotic approach unloads the body of the biochemical work of buffering or balancing the pH (acid alkali) by avoiding very acid meats, sugars and processed foods, with all their chemical additives. As a consequence, the body is able to actually heal instead of merely keeping up, which is generally the case.

Our modern diet is often deficient in many vitamins and minerals that are essential to a healthy immune function. But macrobiotics doesn't rely on any single weapon, such as drugs, but addresses the human being as an entity composed of body, mind and spirit all of which need to be nourished properly in order to restore health.

Diet therapy is ignored by most researchers today despite abundant scientific evidence. Certain nutrients such as zinc, selenium, beta-carotene and others strengthen immune response making white cells more effective against disease.

Conversely, the absence of certain nutrients and an abundance of fat, protein, simple sugars and toxins weaken immune response. The macrobiotic approach to healing requires a diet rich in nutrients and free of toxins. Our diet determines the quality of the blood which feeds our cells, organs, thoughts and feelings.

Macrobiotics not only relies on all nutrients associated with positive immune response being available, but the effects of life force, or Yin and Yang energies being available to the body to enhance this. The immune system is associated with the Yang energy of the body, hence Yang foods such as Miso are used to boost this response.

We all use life force intuitively in daily life. For instance, when we shop for food, rather than choose tired, limp vegetables we instinctively reach for the fresh, bright vibrant ones. When ingested, the energy from these will permeate our bodies and our lives.

Miso

THIS IS THE DARK PUREE MADE from Soya beans, unrefined sea salt and usually fermented barley or rice which have been aged together. Miso contains living enzymes that facilitate digestion, strengthen the quality of the blood and provide a nutritious balance of complex carbohydrates, amino acids, vitamins and minerals.

Miso has been scientifically proven to be effective against cancer, heart and liver disease, radiation sickness and immune deficiencies. It is very beneficial to the gastro intestinal track where the role of micro organisms in protecting against infection

through the body's mucous membranes comprises an essential aspect of the body's first line of defense.

Miso is a good supply of usable protein in the form of amino acid to the body and contains B vitamins and helps replenish 3-4 kilograms of intestinal bacteria including lactobacilli. This strengthens our ability to inhibit potential pathogens. According to epidemiological studies, our indigenous lactobacilli and natural antibiotics called bacterium provide protection against infection. Also importantly it alkalizes our blood and helps remove toxins.

Here are some simple recipes to begin Miso eating.

White Miso soup

- 1 large onion
- 1 strip wakame
- 1 corn cob
- 3 large shitake mushrooms (soaked 3-4 hours before use)
- 5 cups water

Bring water to boil with corn approx. 10 mins on medium flame. Cut onion into half moons and add directly to soup or saute in skillet until translucent, then add to soup. (Onions should be slightly salted while sauteing). Remove corn from soup and let cool. Add finely sliced shitake mushrooms without the stems to soup with



their soaking water, being careful no grit etc. is transferred. Cut corn from cob and add to soup. Add wakame to soup after 4 mins of cooking. (Wakame should be cut into small pieces, discarding stem). Mix approx 1 tsp white miso per person into a small portion of soup. Add to soup, cook on low flame approx 30 secs to 1 min, then turn flame off. Miso should never be brought to boil. Garnish with parsley or spring onion.

Italian Butter Bean Soup

2 onions cut into half moons
 1 large stick celery sliced thinly on diagonal
 1/4 red capsicum sliced lengthwise
 niblets from 1/4 cob of corn
 1 medium carrot diced
 1 tbs sesame oil or sunflower oil
 1 cup dried butter beans
 white miso

Soak beans overnight. Saute

onion, celery and capsicum in oiled pan. Sprinkle the italian herbs and a pinch of salt over and continue to saute for 5 mins. Add beans, corn and 6 cups water. Bring soup to boil and turn down flame and simmer for 40 mins. Add dices carrot and continue to cook for another 0 mins or until beans are soft. Mix white miso/brown rice miso with liquid from soup. Add miso to soup to taste. Turn flame off and wait 5 mins before serving. Garnish with a sprig of green.

Almond rice

2 cups brown rice
 3-4 cups water
 pinch sea salt
 1/2 cup raw almonds

In a pot or pressure cooker place rice water and salt. Bring to boil, cover and cook 30-45 mins. Meantime dry roast the almonds and while they are warm cut them into slivers. When rice is cooked,

remove from pot gently and layer with slivered almonds, ending with a layer of almonds on top.

Arame Noodle Salad

1 pkt udon noodles
 water
 salt
 1/2 cup arame, soaked and sliced
 2 corncobs
 1 med carrot, cut into flowers
 shoyu
 mirin
 parsley

Bring a large pot of water to boil. Add noodles, stir and let come to boil again. Add water, let come to boil again and "shock" once more. Repeat. Then let simmer for 10 mins. In all, noodles are "shocked" 3 times. Test for doneness with noodles by tasting - it should be al dente. Remove and run under cold water then let drain. Sprinkle with sesame oil to prevent sticking. Place arame in a pot and simmer. After 10 mins add carrot flowers. Simmer 10 mins more, add corn kernels, shoyu and mirin. Stir through well and let liquid simmer away. In a bowl mix well noodles, arame dish and parsley. Check that it is tasty and serve.

Polenta and Pumpkin Bread

1 cup polenta - roasted in cast iron pan until nutty smelling
 1/2 cup chopped butternut pumpkin
 2 cups water
 pinch sea salt

Oil a pie dish or bread pan. Mix all ingredients together and place in oiled dish. Cook in 350 degree oven for 1/2 hour or until set. Serve with miso soup.

Roger Green is a Macrobiotics counsellor and teacher at the Australian School of Macrobiotics and has for many years counselled people with serious health problems using the Macrobiotic approach to healing.

Doctor, Doctor



THIS MONTH WE FINISH THE SERIES taken from *AIDS Treatment News* in the USA on dealing with your doctor. Readers should bear in mind that this article was written for an American audience where the health care system differs somewhat from that in Australia. Nevertheless, the overall approach has a lot of validity for the Australian situation.

How do Doctors think?

DOCTORS ARE TRAINED TO THINK in four main steps. Understanding this thought process can help you learn how to ask questions in a way that will help your doctor think better and provide you with answers to your questions.

First, the doctor takes a history, or asks questions about your current complaint and pertinent aspects of your medical history. At this time, the doctor tends not to examine you, but rather just to talk. This may seem a little awkward, as you may want to show the doctor what it is you are describing. He or she will probably ask you to show where your discomfort is, but will not focus on the physical exam until after asking you as many questions as he or she can think of.

This may be an area where people feel cut short or ignored. The doctor is again working with conflicting needs: the need to listen to you and let you talk and the need to keep on schedule. You can help by trying to point, and the doctor can help by being attentive

to you. Doctors are told all throughout their training that the majority of information they need to make a diagnosis will come from the history, so they should listen well.

You can also help in this area by reminding the doctor of important facts of which they may have lost track, like weight loss over an extended period of time, recent and past medication changes, adverse reactions to medications, visits to other doctors, recent lab tests or x-rays that have been ordered, etc.

Next, the doctor does a physical exam based on the information from the history. Again, this may seem awkward, because the doctor's thought process has shifted; he or she may not want to talk much while examining you. Some doctors will be able to put you more at ease during the physical by keeping up the conversation. Others may concentrate intently on the exam.

Once the doctor has collected the data from the history and physical, he or she makes an assessment, which should take the form of a differential diagnosis. This is the stage where he or she considers all the possible causes for your symptoms and physical signs found during the physical exam.

Finally, the doctor decides on a plan to determine which of the possible diagnoses is the correct one and how you should be treated.

You can play a crucial role in the last two stages: trying to figure

out what is causing the problem and deciding how to treat the problem. This is the thinking that the doctor usually does in his or her own head, or while writing in your chart. If you want to be involved in the process, these are the kinds of questions you can ask: What are the possible diagnoses you are considering to explain my symptoms and physical findings? What makes you consider each of these possibilities? Is there anything else we should be considering? How will we figure out which of these possible diagnoses is the correct one? What tests would we run? How expensive? How accurate? Are there some tests we should run more than once (stool samples for ova and parasites for example)? What are the risks and benefits of each test? In what order should we do these tests? What treatments should I consider at each stage: before we have a diagnosis and after we have figured it out?

The most important thing you can do to help your doctor think through the problem and to help you feel assured that you are getting the best possible care is to map out a plan with the doctor. What will you do first? If you cannot make a diagnosis after doing that, then what will you do? Then what? Then what? You can go through the same process with treatment possibilities once a diagnosis has been made. What are my treatment options? If I try this and it doesn't work, or the side effects are too bad, then what could I try? Then what? are there any other medications I

can take with the treatment that might make the side effects more tolerable? What side effects should I expect?

Following up

CHANCES ARE THAT YOU WILL STILL have questions when you leave the doctor's office or later as you think about all the information you have received. Write your questions and concerns down and bring them with you to your next appointment.

Working with an assertive patient can be threatening to even the most enlightened doctor. To soften the "threat", try to validate your doctor and to take his or her needs into consideration. Find something you like about what the doctor is doing before you jump into all your questions and concerns. Tell him or her that you'd like to talk about several issues and that you are aware there may not be time to cover all of them during this appointment. Ask how much time you do have, and if you can schedule another appointment soon to discuss the issues which are not highest priority. Make sure you know what your priorities are so you can have as many of your needs met as possible during each appointment.

Finally, ask yourself what questions you always seem to have after an appointment. What consistently frustrates you? Try to take those questions and frustrations and figure out how to talk to your doctor about them so that you can decide together how best to take care of all the parts of you.

*Ciao for now,
Peter Hornby*

ddC Rap Song

Words by Peter Shelley, Music by Renate Eykel

we've been waiting years for what yanks can now use
in the fight against HIV, infected lose
they're testing so slowly, the next meeting's in fall
it makes you sure wonder - are you testing at all?

Chorus

'valuation committee give us ddC
I thought we lived in a democracy
yo! DEC let us have some ddC
to try with our DDI/AZT

Hollows grabbed headlines with his bad attitude
screaming hijacks and bias in March '92
his bark stole the limelight but what everyone missed
was his speciality's eyes not sexual practice

his pal Bruce is chief honcho of the AMA
but as a shepherd of men his flock's gone astray
other doctors treat AIDS as a public health case
and ain't workin' to tear down our Medicare base

in the summit both dudes cried ring in the beats
close down the steams and police Oxford Street
stop anal sex now - it's too risky these days
the diseases are spreading to breeders from gays

their concern for our welfare is coated with hate
their poison says blame them don't re-educate
they'll soon promote colonies, like lepers alone
bring back the pink triangles on clothes to be sewn

their talk is all smoke for their hidden agenda
their ethics and oaths stained-yellow pudenda
Bruce is up for election, Fred needs some more dough
they use us to further themselves, don't you know?

they're dangerous men 'cos the DEC listens
and hold off approval while tears fill St Vincents
what's promised in August may never come through
and then will we ever get anything new?

there's news of 3TC and the new foscarnet
acemannan's said to be some benefit
new drugs can be tested overseas for our cause
but we're suffering and dying from caution and pause

DEC look up from your reading and paperwork please
the best of your country is down on its knees
they praise the quilt project but give it no money
soon we'll all be dead on it. Then who'll carry it, honey?

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Peter Shelley works at the Albion Street Centre and is a writer.

What's Goin' On



HIV living

Information Nights

AIDS Resource Centre
188 Goulburn Street
Darlinghurst

6.30pm - 8.30pm

Wednesday September 9

HIV Infection and the Immune System

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

Wednesday September 16

Monitoring and Prophylaxis

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

Wednesday September 23

Treatments and Drug Trials

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

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

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 effects of trial anti-HIV agents on an individual's quality of life.

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

National Centre for
HIV Social Research

HANDS ON

- Massage and Reiki for PLWHAs
- Training of volunteer masseurs

Call Richard
660 6392

Join ACON's Meditation group

ground floor
AIDS Council of NSW
188 Goulburn st, Darlinghurst

ALL WELCOME

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

Meditation can be useful as a means to reduce stress, energise the body and increase clear thinking
Instruction and assistance in how to meditate is available to newcomers

Tuesday mornings 9am - 10pm

Thursday evenings 6pm - 7pm

Just turn up, or ring David (02)358 1318

S I L K R O A D

A social and support group for Asian gay and bisexual men which meets every Friday.

Activities include workshops, discussions, social activities, etc.

More information available from
Arnel on (02) 283 3222

RED CROSS

Cosmetic Care Specialist Service

A service that trains people with Kaposi's Sarcoma (KS) to apply covering makeup is available at Ankali Cottage. A trained consultant assists the individual to choose the correct skin tone, and in correct application and removal of the makeup.

Use of makeup can assist individuals in raising their self-esteem.

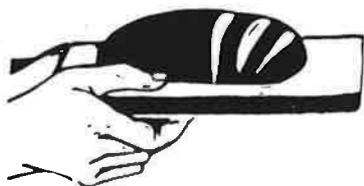
The service is free.

**APPOINTMENTS
are necessary.**

**Telephone (02) 332 1090
- ask for Ankali Cottage.**

**Enquiries can be made
by calling the Cosmetic
Care Coordinator at
the Red Cross on
(02) 229 4296.**

LET'S DO LUNCH



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

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

The next meetings will be:
Thursday, September 24 and
Thursday, October 8.

Meet at the PLWHA office at 12.45, 2nd floor, 188 Goulburn St Darlinghurst. Call Jill on 283 3220 if you have any questions.

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.

Club 2430 (Manning Area Gay and Lesbian Support Group). Social functions, newsletter, monthly meetings. Contact Bill or Barry (065) 537502 or

Liz (065) 511315. PO Box 934, Taree 2430.

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

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

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

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

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

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

National People Living With AIDS Coalition (NPLWAC) GPO Box 164, Canberra ACT 2601. Call (06) 257 4985.

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

NSW Anti-Discrimination Board Takes complaints of AIDS related discrimination and attempts to resolve them by a confidential process of reconciliation. Currently employs a full time AIDS Project officer. Sydney 318 5400. Newcastle (049) 26 4300. Wollongong (042) 26 8190.

NSW Users and AIDS Association (NUAA) Community/peer based

organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free forums/information nights 3rd Monday each month at 6pm. 369 3455.

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

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

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

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

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

DAY CENTRES

Blue Mountains PLWA Support Centre Wednesdays 11am - 3pm (lunch). Fridays 6.30 - 10.30pm (dinner). For further information call the Centre on (047) 82 2119 or Dennis (047)88 1110.

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

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

recreation/relaxation centre for people with AIDS. Lunch Tues, Wed, Fri. (free or donation). Massage also available. Some group meetings. 396 Bourke St Surry Hills. Inquiries (incl. membership) 361 0893. Client's phone 360 9896.

CLINICS & HOSPITALS

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

Haemophilia Unit Royal Prince Alfred Hospital, 516 8902.

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

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

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

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

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

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

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

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

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

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

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

Transfusion related AIDS (TRAIDS)

Unit: For people with medically acquired HIV/AIDS. Crisis/long term counselling and welfare support to clients and their families throughout NSW. TRAIDS is based at Parramatta Hospital. Contact Pam or Claire 843 3111 ext.343. **Red Cross BTS:** Contact Jenny 262 1764.

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

EMOTIONAL SUPPORT

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

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

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

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

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

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

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

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

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

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

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

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

Parent's Group (and relatives) A support group for the parents or relatives of PLWAs. Every 2nd Wednesday at 12.30. 5th floor, Notre Dame Bldg. Burton St Darlinghurst. Call Linda Barr 339 1111 (page 248) or Marie Pettitt (page 256) to indicate attendance.

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

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

PO Box 350 Darlinghurst 2010.

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

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

906 3112.

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)239353.

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.

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

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

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

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

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

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

CSN Wollongong Call David Mendave, (042)76 2399.

Hands On Massage and Reiki for PLWHAs, Training of volunteer masseurs. Call Richard 660 6392

Legal Project (AFAO) Legal advice and advocacy on HIV/AIDS related problems. Call Michael Alexander 283 3222.

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

Tiffany's Transport Service For PLWAs (in the Sydney area.) 360 2043.

IS YOUR LISTING CORRECT?

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

JOIN US IN THE FIGHT AGAINST AIDS. SUBSCRIBE NOW.

PLWHA Inc. (NSW) is part of a world-wide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice.

Help yourself and others affected by HIV to create a positive, friendly and supportive environment in which we can all live with HIV & AIDS — join PLWHA.

FIRST NAME _____ LAST NAME _____
POSTAL ADDRESS _____

POSTCODE _____
PHONE _____ (W) _____ (H)

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

In the interests of your confidentiality

I agree to have other members know my name and address

Yes No

I am publicly open about my membership Yes No

Annual rates are

Membership \$2

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

Individual \$10

Organisation (up to 4 copies) \$20

(up to 10 copies) \$30

Please specify number of copies _____

If you want more than 10, call us.

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

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

SIGNATURE _____

DATE _____