

# Talkabout

Newsletter of People Living With AIDS Inc.(NSW)

*Where we speak for ourselves*

ISSN 1034-0866



**WE CAN'T WAIT - TREATMENTS NOW !**

***PLWAs led the Mardi Gras Parade this year for the first time, calling for improved access to AIDS treatments. Pictured in their pill popping T-shirts are PLWA committee members Terry Giblett, (seated), his sister Deborah Giblett and a friend.***

Volume Two, Number One: MARCH/APRIL 1991

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### Commonly Used Abbreviations:

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

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The next issue of *Talkabout* is about

## POSITIVE SEX

If you're HIV+ and have something you'd like to say about sex, get out your pen and paper now. This is your chance to do it in print.

Final deadline for written or graphic contributions is **April 10**.

Final deadline for ads and notices is **April 15**.

Send it to PO Box 1359, Darlinghurst 2010.

If you would like to become more involved in *Talkabout*, the newsletter working group is open to all readers. The main thing that happens in this group is that we discuss the themes and content of future issues. You don't have to be mega-skilled, all you need is ideas.

Newsletter Working group meetings for March/April are at 5pm.

**March 14, April 4 and April 18**

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

## Storming the ADB

On February 14, 30 ACT UPers, many wearing surgical masks and yellow rubber gloves, stormed the Anti-Discrimination Board and confronted its President, Steve Marks, over the Board's lack of action on HIV-related discrimination matters.

Marks defended the Board's record and gave sketchy details of plans for a public inquiry. ACT UP has assured the Board that it will be closely watching future developments to ensure that any public inquiry or legislative changes will be effective in helping to stop discrimination.

## Drug availability - Astra spreads AIDS drugs!!!

The other major focus of our work has been HIV and AIDS treatment availability. In December we launched a campaign against the AIDS profiteering of multinational drug company, Astra, who make the drug Fos-carnet which is used as a treatment for Cytomegalovirus

(CMV). The manufacturers were charging \$3,000 for ten days supply of the drug. The company backed down and agreed to supply the drug free of charge for a year. The company will be applying for the drug to be approved in this country. We'll have to wait and see if this

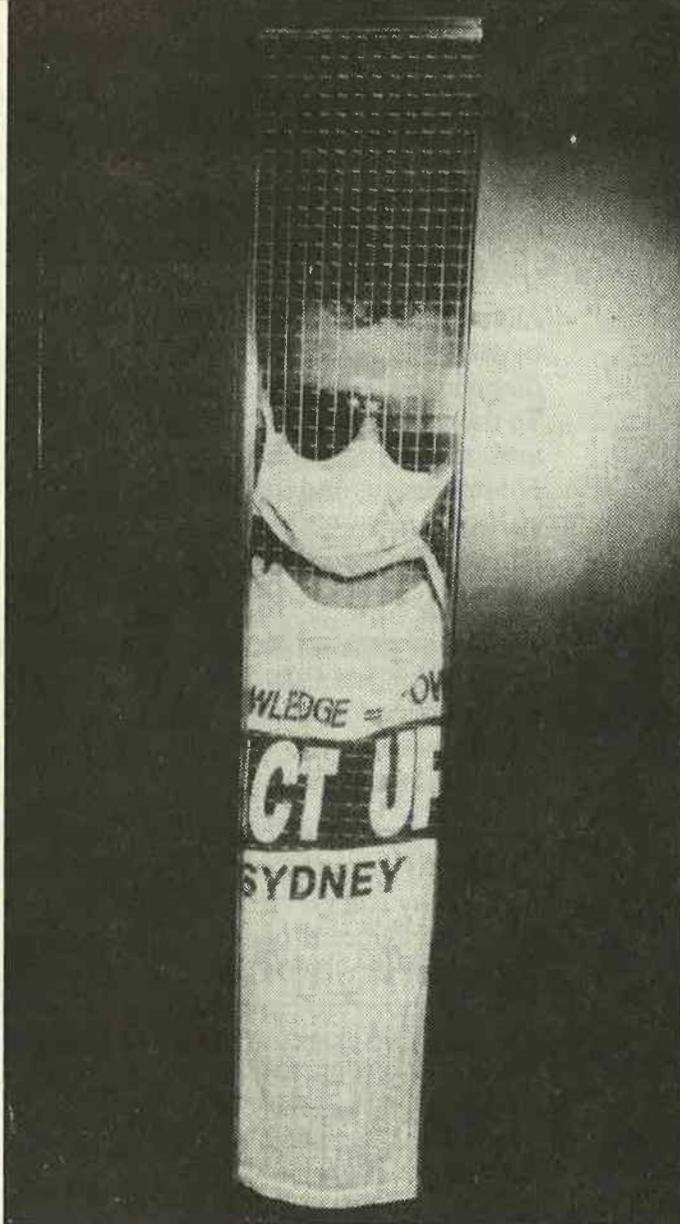


Photo: Jamie Dunbar

ACTing UP at the Anti-Discrimination Board.

important drug can make it through the Australian drug approval nightmare.

## AIDS drugs - "No more business as usual"

We were quick to respond to Health Minister Howe's disappointing response to the ANCA working party on HIV and AIDS drug trials and held an emergency picket at the minister's public appearance after the report was released. Two weeks later, an affinity group of ACT UP calling itself 'Insidious Acts' took control of the telephone system of the Department of health and Community Services. We rang up the media, the minister's department and also advised incoming calls that we were disrupting "business as usual in the department to-

day because business as usual in this department is killing people with HIV and AIDS in this country."

If you'd like to ACT UP, give us a call on 281 0362, come to our fortnightly meetings or visit us in our new office space on the 4th floor, 56 Foster St. in the city.

## Hivs & Hivnots

Recently I attended my first conference, "Living Well III", in Adelaide. I came away enlightened and encouraged but at the same time some speakers made statements which made me wild.

For many years there has been a massive gulf between the general community and the gay community. The last thing we need is divisiveness within our own community. I got the impression at four workshops on the Saturday that we are splitting into two separate groups - 'Hivs' and 'Hivnots'. The titles were coined by one of the speakers.

One speaker suggested it was preferable that only well Hivs should be carers of sick Hivs!

Another stated that only Hivs understood or had any conception of the whole gamut of problems faced by them.

My reply to them is "The Hell they should or do."

As with any community when there is serious sickness about there are those who will bury their heads and, as with all cowards, pretend it doesn't exist. When people they claimed as friends be-

come infected they run. The streets are full of desperately lonely, unhappy people who have been thrown out by their lovers and/or families as a result of their HIV status - however acquired.

I live with my friend of twenty four years who was diagnosed HIV+ four years. To those Hivs who have the audacity to suggest that an Hivnot has no understanding nor conception of the problems faced by an Hiv I have this to say:

That is the greatest load of bullshit that has ever been uttered in connection with AIDS since this vile virus was released on the human race!

I can tell you, with no sense of self pity nor rancour against my friend, I live with this virus 24 hours of every day. I may as well be HIV+ myself. I have all the disadvantages and then some. I live through and with my friend's fears and demons. We Hivnots get a few extras for good measure - a sort of macabre garnish to an already unpalatable meal.

Fortunately, as yet, my friend has not had to be hospitalised and with the help of his doctor, I have been able to cope with what illness there has

been. When my friend gets very tired soon after he has got up from a ten or twelve hours dreamless night's sleep and sleeps for another two or three hours I am not so fortunate. To all intents and purposes I am alone in our home and no matter how busy I keep myself, at times the demons doubt, fear, grief, and, yes, guilt, attack. If, as often happens, I wake in the middle of the night and cannot hear his light snore I get up to make sure he is alright. Hot milk at 3am is a habit gained. A full night's undisturbed sleep a habit lost.

Loneliness is probably the worst. Just as many Hivs live with loneliness so do many Hivnots. It is no less a loneliness when you are at home with someone you love only a few feet away sleeping as if dead. If they do die the Hivnot is left with a void which, depending on one's age, will be almost impossible to fill.

Just like you we are living on top of a time bomb with a faulty mechanism. We, too, greet every cough, ache, pain, lump, weight loss, however small, with dread.

Optimism is one of our biggest weapons but it is also

## LETTERS

one of the hardest to maintain. After four years there are times when one feels like giving up. That is quite impossible.

I am not the only Hivnot caring for an Hiv - there are probably thousands of us. I can only hope that at the next Living Well Conference I will not hear the sort of unfeeling, insensitive and, yes, self-pitying crap as dished out by some of the speakers at Living Well III.

We untrained, 'amateur professional' carers are doing our best but in the face of so much negativism it becomes very difficult. As many solo Hivs will know when there is no-one to turn to at short notice it becomes damn near impossible. I guess I am lucky as I now have, in addition to our doctors, my sister's shoulder to lean on during the rough spots.

With the benefit of hindsight would I go through it all again? In a word, YES.

*(Name withheld by request)*

## Questions of Early Intervention

Last *Talkabout*, Robert Ariss wrote his personal response to the information delivered by Martin Delaney about advances in AIDS treatments.

Robert stated there were a number of reasons why he did not do early intervention yet.

The question of starting treatment and dealing with a medical delivery system that does not deal adequately with all of our needs is a difficult one faced by all people with HIV and AIDS. Avoiding or delaying making this decision is of course our choice, as Robert correctly states, but we need to be clear why we are taking this decision.

I had a totally different response to Martin Delaney's information. The evidence in support of AZT at low doses (300mg per day) for early intervention is becoming stronger. The first evidence from combination trials (AZT and ddI or AZT and ddC) shows what we expected - that AZT and ddI together or AZT and ddC together are significantly better than either alone. Further, in combination, not only is the benefit greater but side effects are reduced because of the lower doses. Of course there remain questions about the long term use of these drugs.

What Martin Delaney does is say that the best advice that can now be offered is to keep your immune system at its current level so that you can take advantage of better treatments when they become available. For me, this

means when combination treatments finally become available in Australia I'll be in the queue.

Robert takes this interpretation as a removal of choice and thinks that this removes our freedom to explore alternative paths to health without the risk of ridicule. I don't believe him. I think Martin Delaney was in fact excellent at reinforcing the need to consider all issues that make up the concept of 'health' and not to rely on the concept of a 'magic pill' to fix all 'lifestyle' problems.

I think as activists in AIDS treatments our role is to provide and interpret the information that's available. That necessarily means putting some values on it. We cannot pretend that this does not influence people's choices. My values are that I want to influence my friends to take an active interest in early intervention and support issues and to be at least clear about any choices they are making and why they are making them. And for me as an activist, rather than saying I'll opt out of treatments because of the way in which the medical profession conceptualises health, as Robert does, I'd say let's change that conceptualisation and make sure that we and our friends do in fact have a true choice.

Ross Duffin

# **Mainstreaming - what you see isn't what you get**

Over the past year, community health services in NSW have been in the process of mainstreaming the services provided to HIV/AIDS clients. The goal of mainstreaming is that generalist nurses will take HIV/AIDS clients into their general caseload, and the services will employ one or two specialist nurses as HIV/AIDS consultants. The generalist nurses would be given additional training and support in HIV/AIDS. Under mainstreaming other services (such as Home Care, CSN volunteers, transport services etc) will be more effectively coordinated for use by HIV/AIDS clients.

One of the main reasons given for mainstreaming is that specialising in AIDS has placed a lot of stress on the nurses. AIDS nursing often requires that nurses give a very high amount of support to clients. Diversifying their caseloads, and at the same time reducing the variety of tasks they currently perform as HIV/AIDS specialists, may provide protection from burnout. Some of these tasks could be carried out by physiotherapists and social workers employed by Community Health Services, or by volunteers and workers from the existing home care services. Community nurses would concentrate on medical care and the giving of treatments.

Mainstreaming is the strategy endorsed by the NSW Health Department's recently launched report on its five year plan for HIV/AIDS care and treatment services. Anne Malcolm, the head of the Community Services Unit at ACON, thinks that mainstreaming has the potential to provide a much better service than the existing one in a year or so if it is properly funded and managed.

While it may sound good in theory, in practice there has been a general concern in the community of PWAs and AIDS workers that the process of mainstreaming has thus far been poorly managed, to the detriment of clients, their voluntary carers and the specialist nurses themselves.

CSN has had comments from clients and carers that the service has not been good and that clients have been missing out on the quality of care they should be getting, particularly in the Central Sydney Area Health Service (CSAHS) which is understaffed and not having a specialist nurse has sometimes had to call on the goodwill of CSN and Eastern Sydney Area Health Service (ESAHS) nurses.

The problem is not the generalist nurses. By all reports those who are now taking on HIV/AIDS caseloads in the ESAHS and the CSAHS have been providing an excellent level of care and are keen to improve their knowledge and expertise. But all the goodwill in the world cannot compensate for training, support and adequate staff numbers. Concern has however been expressed that in other Sydney or country areas generalist nurses may not have such a high level of commitment, knowledge and interest in HIV/AIDS, which would be to the detriment of PWAs.

It appears that the problems have arisen because of poor communication between the Health Department, Service Managers and nursing staff, and a lack of planning how to most effectively (and painlessly) implement mainstreaming. A major criticism of mainstreaming is that it has been set in motion too quickly and without an adequate program for orientation and training of generalist nurses.

Mainstreaming has been rather painful, and the service most affected by the process, (which also has the largest HIV/AIDS clientele), is the ESAHS.

Since 1986 the ESAHS has built up a team of eight specialist HIV/AIDS nurses, including two Clinical Consultant nurses who handled hospital discharges and caseload planning as well as playing an educational/consultative role. The plan for ESAHS is that it retain two clinical consultant and two specialist nurses (one of each for the two zones within the area), but currently it has only one clinical consultant and one specialist nurse. Over the past year, six of the nurses have resigned.

PLWA has heard complaints from a variety of sources that Community Health management does not take notice of the specialist nurses' opinions and advice on the care and special needs of PWAs, or adequately represent their point of view to the Health Department; that there was little recognition of the stresses involved in AIDS nursing or support for the nurses; that mainstreaming occurred too quickly and without properly informing or consulting the nurses; that vacated positions have not all been filled (there is now only one clinical consultant and one specialist nurse remaining); that specific HIV/AIDS funding has been absorbed into the general budget of the ESAHS.

It is crucial that the services recognise that

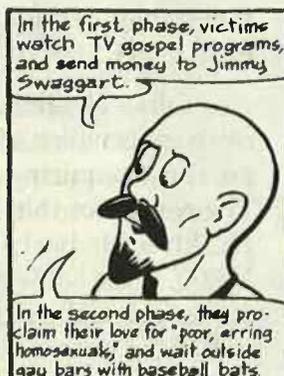
PWAs do have special needs unlike those of other clients and these must be taken into account when planning their services. Studies from overseas show that PWAs have needs which require more nursing care than other groups in the community.

It appears that there has been little or no consultation with PWAs about their needs. PLWA is concerned that the de facto reduction in staff at ESAHS may have affected the quality of care available to HIV/AIDS clients (and probably also to other clients), and result in undue pressure on remaining nursing staff and volunteers. Even when the understaffing situation is rectified, we are appalled that it has been allowed to happen at all. We are also concerned that only one Clinical consultant is currently employed, which must mean a reduction in some of the services available. One person cannot do the work of two. Who, if anyone, is filling the gap?

The lack of specialist nurses at ESAHS may also have implications for the other area health services, particularly in outer Sydney and the country, as these nurses were providing education and support to more isolated services.

PLWA will be approaching the ESAHS to discuss these concerns about mainstreaming and ask them to clarify what their plans are for the future of HIV/AIDS services. PLWA will also be contacting the Health Department on this issue.

### Murphy's Manor



### Kurt Erichsen

From Strip AIDS USA

## AIDS - A Masculine Disease?

It is estimated by the World Health Organisation that, of the six million people infected by HIV, women account for some two million. By November 1990 the National HIV Surveillance Report recorded that 43 of the total 1406 deaths from AIDS in Australia were women, and of the cumulative number of 2,347 cases of AIDS, 72 were women.

These statistics are not reliable, however, as women with AIDS may die of illnesses specific to their sex, such as Cervical Cancer or Pelvic Inflammatory Disease, and these diseases are not included in the Centre for Disease Control list of AIDS defining diseases.

As for women with HIV, the picture is even more uncertain. While NSW, NT and SA had not reported their cases by November 1990, nationally 14,417 HIV positive people are known of, and 466 of these are women. On top of this, the national records list 4,342 cases whose sex is not known for reasons such as doctors not recording sex on report

***"Women who are HIV infected often disappear from the eyes of health workers and support services after the first test."***

forms. We can assume most of these are in NSW and some percentage are inevitably women.

The epidemiological picture of AIDS is, therefore, very inaccurate when it comes to gender. Recently the National Centre on HIV Epidemiology and Clinical Research reported on a hitherto unknown program of anonymous screening of new born babies for HIV. A total of 10,217 babies were tested for

HIV and none recorded a positive test. Good news, said the report, "there is not a widespread epidemic of HIV infection among heterosexual persons in Australia at the present time".

Despite the obvious objections to the breach in civil liberties that such screening entails, the attempt to draw epidemiological pictures from such methods is very dubious, says S  in n   Chrochuir, Women's Project Officer at the AIDS Council. The testing was done to tell us about rates of infection among 'heterosexuals', and had no implication for the babies or mothers concerned. The method only reaches those women who carry their pregnancy to its full term, and wrongly assumes all women with babies are heterosexual.

Despite the misleading statistics, frontline experience reveals an increasing epidemic of HIV among women in Australia. New diagnoses of HIV are turning up at testing clinics more and more frequently, much to the surprise of health workers. And unlike HIV+ males, women who are HIV infected very often disappear from the eyes of health workers and support services after the first test. Very few women avail

themselves of ongoing health monitoring, and even fewer make it into clinical trials.

Officially, the only exclusion criteria on drug trials which affect women specifically are those requiring a negative pregnancy test. The reason for this, according to the National Health & Medical Research Centre (NC & MRC), is the same as exclusions in treatments for cancer such as chemotherapy, that is, the risk of the possibility of inducing infertility or

spontaneous abortion, or producing unknown effects on the unborn. So far, only laboratory data from observations on animals has suggested such possibilities.

The exclusion rules appear to not be absolute, however. One woman enrolled in the Australian low risk AZT trial became pregnant and elected, after considering advice, to continue with the pregnancy. Doctors respected this decision yet decided to reduce her dose for the remainder of the pregnancy.

According to the NH&MRC the numbers of women with AIDS enrolled in Australian trials are low but nevertheless the figure is reflective of the low rate of infection in Australia (less than 1%). However, given that known numbers of positive women are hugely inaccurate, we could conclude that if women had equal access to AIDS treatments, many more would be enrolled in trials than are at present.

San Francisco's Project Inform argues that, with respect to women, "Each drug must be looked at case by case examining all of the issues" rather than imposing standard protocol restrictions to each drug that becomes available. "Each trial should be designed so that it is sensitive to the needs and realities of women, while guarding against the possibility of harm to a foetus.

"These issues should be looked at early in the clinical trial process when small numbers of patients are included, not when the drug is in large trials or already approved. In the context of the HIV epidemic, state-of-the-art care and clinical research go hand in hand.

"A clinical research agenda for women must be two-fold. First women must become an integral part of every HIV/AIDS clinical trial for antivirals and for treatments and

prevention of opportunistic infections. Pelvic examinations, pap testing, and gynaecological care for women must be included as part of every research protocol.

"Because of the widespread exclusion or under-representation of women and the fact that these types of testing and exams have not

***"There is virtually no well-documented information on how drugs for AIDS and HIV related conditions will react in women's bodies."***

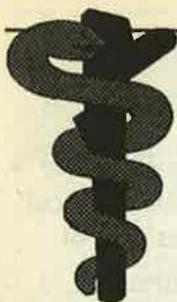
been done, there is virtually no well-documented information on how drugs for AIDS and HIV-related conditions will react in women's bodies.

"What impact do AZT, ddI and ddC and the rest have on menstruation, pregnancy, the cervix? This does not mean only that outreach efforts should be directed at women, and the numbers of women in trials increased, but that the trials must be responsive to both the health and the social needs of women."

As the epidemic increasingly affects women in Australia, clinicians, health workers, lobby groups and people with HIV and AIDS should consider the issues of gender more seriously. To date the research on AIDS has by and large constructed the epidemic and the disease as a masculine one. As Sain ni Chrochuir says, "information about PWAs is really about men with AIDS".

Vast amounts of research are invested in diseases such as PCP and KS which are common to men with AIDS, yet virtually nothing is known about those infections common to women such as vaginal candidiasis. Where women are represented in

*...continued overleaf*



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# Phobia-free doctors get yours now

When you have HIV, doctors suddenly assume a new importance in your life. Finding the right one is essential. Having a doctor whom you can trust can help you to reduce your need for hospital based services which are often less personal, more stressful and sometimes geographically distant.

The ideal GP is sympathetic with good, up to date knowledge of HIV/AIDS and doesn't suffer from AIDSphobia or its frequent companion, homophobia. You can discuss and plan any medical interventions with them, and know they'll be around when you

need them. If you've found the ideal, you're lucky. If you haven't, you'll be interested to know about a new service which has been set up by the Community Health Section of the Eastern Sydney Area Health Service.

Bill Genn is the GP liaison medical officer for HIV/AIDS, and his role is to try and improve the quality and amount of medical care GPs provide to HIV infected people.

Bill is taking a number of steps to ensure that HIV+ people can have the best GP for their needs:

\* He will refer people to local GPs known to be sympathetic and helpful.

\* He has advised GPs in the area that he is available as a source of information on general practice management of HIV/AIDS. He also goes to visit interested GPs to discuss HIV related issues and to provide educational material.

\* If people admitted to the AIDS units at St Vincent's or Prince Henry Hospitals don't have a doctor he will try to link them up with one.

Bill asks that people let him know about helpful doctors, especially if they are outside the inner city area where it's often more difficult to find sympathetic GPs. If people are having bad experiences with GPs, Bill would like to know about that as well, so that he can be aware of the areas of difficulty, help if possible and take up general issues with the relevant organisations involved in planning of services.

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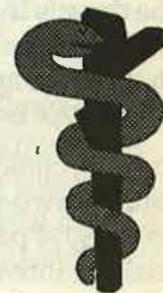
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public discussion of AIDS, it is usually as vectors in the transmission of HIV rather than as people with HIV who have complex and varied needs.

Positive women are presented with a difficult paradox. On the one hand women must have access to as much information and be empowered to make informed decisions about, for example, what drug trials to enter and how those decisions relate to specific issues such as pregnancy.

On the other hand, science is providing us with very little information about the effects of HIV and the impact of AIDS drugs on the female body. The problem is one we all face... how to make valid decisions about our own health, access treatments that are available, yet not surrender ourselves as guinea pigs to the indifferent machinery of clinical research.

- Robert Ariss



# LONGTIME COMING

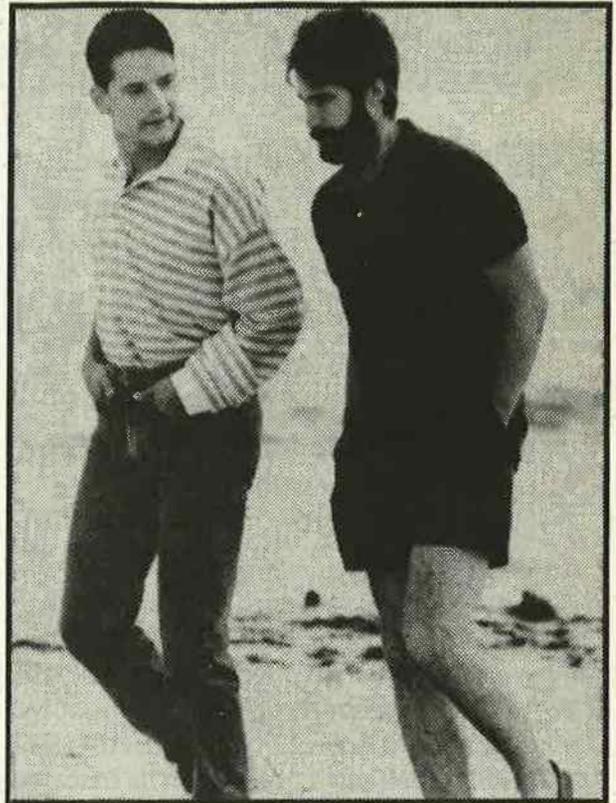
More often than not, film and theatre portray gay men as two dimensional patsies. We're either fluent wits or tragedy queens. This is even more disturbing when those responsible are gay themselves. Do we really spend most of our time being fabulous and the rest feeling sorry for ourselves? I hope this has more to do with how we think the straight world wants to see us, than how we see ourselves.

Being gay is worth taking seriously. So it was liberating to watch a film where gayness is treated as naturally as it really is.

*Longtime Companion* doesn't muck around with gay stereotypes. Neither is it Spielberg sop served up with lashings of soaring strings and drawn-out melodrama. It's made of sturdier stuff. If it makes you cry it's because the film-makers have managed to capture some of the reality of living with AIDS. It's about the epidemic and how it effects a group of friends in New York, from the unknown early days (when even kissing seemed risky) to the anger and activism of today. We see men in bed together and it's not 'shocking', nor is it particularly erotic. They kiss and hug because they care about each other. They do a lot of things everybody else does. They just happen to be doing them with other men.

There are some wonderful scenes. In fact, *Longtime Companion* works because it is made up of scenes which fade in and out over the years in a way which is similar to how you remember the past.

There are painful bits. David nurses his lover Sean at home. He helps him to live and



when the time comes, to die. Their friend Willy, who is first to lose a close friend, is torn between affection for those he loves and fear of the virus. It's agonising to watch him wash his cheek after Sean kisses him.

It's funny too. Willy cruises a man he likes. They both turn back, repeatedly, but always at different times. Just like real life.

The film doesn't let up. We cannot escape the daily reality of living with AIDS. But that's the way it is, and *Longtime Companion* is not afraid to show it like it is ... for a small group of gay men (and one straight woman) in New York. Yes, it's clean-cut. It's not Darlington. It's not a global picture. We get snippets of other groups. Hispanics and children get it too. But the film doesn't try to do it all. It calmly documents. And it's personal, just like living with AIDS is.

- Adrian Ogier

*"What are you doing that for?"*

## PROFILE

### Grant Farquharson

*Grant is ACON's new Spanish speaking counsellor and HIV/AIDS educator*

A friend of mine gave her brother, who was in hospital recovering from a near fatal illness, a book of short stories by Latin American writers - Gabriel Garcia Marquez, Isabelle Allende, et al. A rather depressing gift, you might think. On the contrary. It turned out to be just the right thing. Latin American fiction, with its macabre plots and extravagantly grotesque imagery, is acutely sensitive to the atrocities and corruption of Latin America's past and present. A catalogue of tragedy and oppression, it is also a powerful and inspirational celebration of life and the human spirit.

These writers immediately spring to mind when talking to Grant Farquharson about his life and work in Chile and Peru, because it's clear that like them, he has gained hope, inspiration, strength and compassion from his experiences with the people of Latin America. These are pretty good qualifications for working in AIDS.

Grant, who took up the ACON position of Spanish speaking counsellor /educator last November, has worked as a Roman Catholic priest with poor working class people in Chile and Lima for the past thirteen years. For seven years during the Pinochet regime he worked in Chile. "I was involved with people who were economically marginalised and I saw the effects

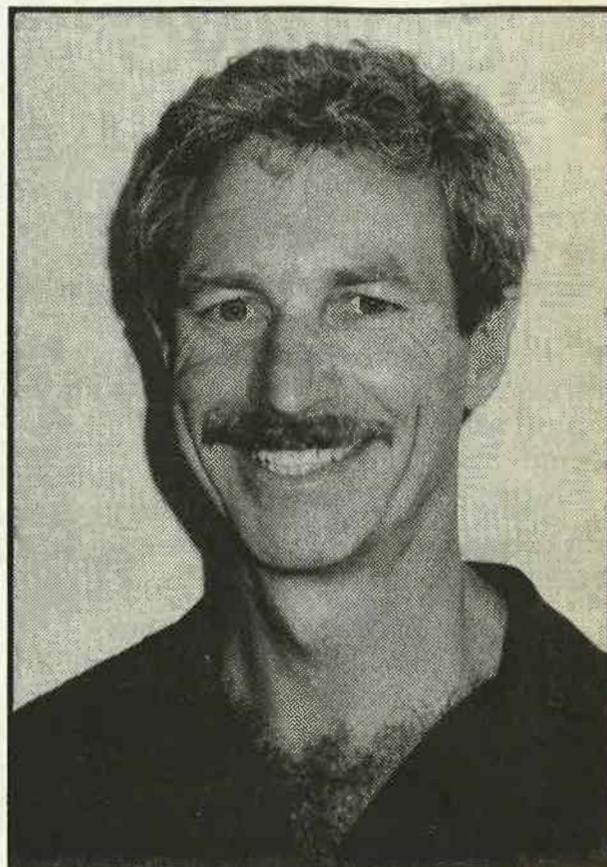


Photo: Don Carter

that had on people's lives, on their self esteem, and their struggle to find some meaning in their lives. I was also involved in political struggle and education with people trying to change their political, economic and social situation."

A crucial experience was his activity with an anti-torture group which would stage short, ACT-UP style protests once a month, targeting the news media, known places of torture, the Minister of the Interior and others. They would have three minutes to make their point and then disperse before the police arrived with tear gas and water canons.

"That experience was important for me," says Grant, "because I learned that it's possible

to change the way people think about things. That movement showed Chileans that torture exists in Chile and that it's not acceptable. I also learned that if we want to change the world in which we live ...it's hard."

After Chile, Grant worked in Lima. Motivated by a need for a better understanding of Latin American history and culture he studied sociology at Lima University for four years. During that time, he says, "I became a lot more aware of the social dimensions of injustice, of the social mechanisms that oppress people, that marginalise people".

It was while he was in Lima that Grant decided to come out. "I became more convinced of my need to consciously, willingly, strongly opt for being gay." In fact he even did his thesis on "the process of identity formation in a marginalised group" - the homosexual community in Lima.

Both homosexuality and AIDS are sensitive topics in Latin America. "It's a terrifying topic for people", says Grant, "people just don't want to accept the fact that there is homosexuality in Peru so the whole question of AIDS becomes very tricky." Although as a foreigner Grant has been well aware of what was happening with AIDS in the rest of the world, it is little more than a year since AIDS became a public issue in Peru and Chile.

Grant returned to Australia late last year, and one of the reasons for his return was that he left the priesthood. "It was in South America and especially around the whole area of homosexuality that I became aware that the church plays a very oppressive, non-liberating role. I

could no longer live with the contradiction between being gay and what I stood for as a Roman Catholic priest."

Grant has left the public ministry of the church but he still sees himself very much as a priest, although in a rather different sense. "I believe in the deepest mysteries that exist in our world, I believe that there's a sacredness and a beauty about our world that needs to be celebrated. We need to be poets of creation, we need to try and touch this beauty, this sacredness in our world, and look to share that, to celebrate that. To me that is part of my very existence and I consider that to be my priesthood. I believe I was ordained for that.

"I feel the Roman Catholic Church was the place I learned about my priesthood. I've left not in the sense of discarding it, but in the sense of passing through it. It's been a stage in my life, and it's been good preparation.

Grant decided while still in Latin America that when he returned to Australia he wanted to work in the HIV/AIDS area. It didn't take him long to find just the right job. His role is to provide individual and group counselling and support for HIV+ Spanish speaking people in NSW, both over the phone

and face to face. He will also be responsible for educating the Spanish speaking communities about HIV and AIDS prevention, treatment and other issues, and for working with SACBE (see box).

Grant regards his experience in political and adult education in Chile and Lima as a valuable preparation for this work. "I think that the challenge in HIV/AIDS education is to bring



people to an awareness of what AIDS means in society, what it does to people, how it marginalises people and what we can do to change that. AIDS as a social concept is used by society to oppress already marginalised people and its important to realise that and subvert its power as an oppressive concept."

Asked the usual question AIDS workers face, "what are you doing that for?", Grant is very clear about his reasons: "My own process of coming to delight in being gay and be proud of being gay has been one of the most important experiences of my life. I want to be able to participate with other people who have journeyed along the same road, so I wanted to work with other gay people.

"I also wanted to work with Latin Americans, because after thirteen years with them - I guess I could say I've come to love them, but I think what's happened is that I've come to love three Latin American people who have been very important in my life, they've taught me a lot about life. I think that was because of who those

people are, but I think it's also something to do with Latin America.

"I think Latin America, because of its history, its culture, and because of its experience of suffering and oppression, provides incredible insights into what human life is all about. There's an incredible wealth in the culture, the minds and attitudes and values of Latin Americans - I'm only talking about the poor, because I had very little to do with the wealthy classes.

"I somehow wanted to try and continue my links with Latin America, I wanted to be of service. To pay back, if possible, a little of what they've given me.

I was thinking before I returned to Australia that people living with AIDS are marginalised by society. In a sense they're the equivalent of the socially and economically marginalised in Latin America. Having had this enriching experience there, I was thinking that it's with these people that I'm going to feel that sacredness, that depth of human experience. I

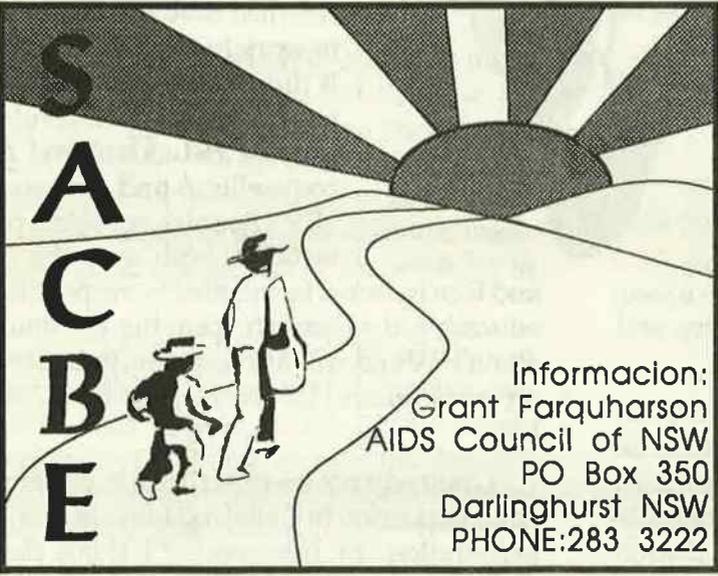
believe that human experience is far greater among marginalised people than among those that hold the power in this society. There's something really special about people who are forced to live on the periphery of society."

Jill Sergeant

- SIDA - AIDS - SIDA -

PARA LA COMUNIDAD HISPANOAMERICANA

APOYO PARA PERSONAS CON HIV/AIDS



Informacion:  
Grant Farquharson  
AIDS Council of NSW  
PO Box 350  
Darlinghurst NSW  
PHONE: 283 3222

- EDUCACION - APOYO - INFORMACION -

Contact the PLWA office (283.3220) if you would like a copy of this article in Spanish.

Para obtener una copia de este artículo en español, se puede llamar (02)283 3220.

## Un recurso nuevo para las comunidades hispanoamericanas

El noviembre pasado, el Aids Council of NSW (ACON) contrajo a Grant Farquharson como "counsellor" y educador comunitario para las comunidades hispanoamericanas. Su trabajo consiste, en primer lugar en ofrecer orientación y apoyo personal y confidencial a las personas afectadas directa- ó indirectamente por el HIV ó el SIDA (AIDS en inglés). Además está desarrollando un programa de educación sobre HIV/AIDS para las comunidades de habla español.

Durante los últimos 13 años, Grant ha vivido y trabajado como sacerdote católico con las comunidades populares de Santiago de Chile y en Lima, Perú. Según él, su experiencia en educación popular, (estilo latinoamericano), ha sido una preparación excelente para un trabajo en

el area de AIDS/SIDA. "Por estar marginalizadas por la sociedad, las personas con el HIV ó SIDA/AIDS, tienen algo en común con las personas de América Latina que han sido marginalizadas por razones sociales, culturales y /ó económicas," dice Grant.

"Creo que la experiencia humana tiene una profundidad mayor entre las personas periféricas de la sociedad..... Pienso que América Latina, por su historia, su cultura y su larga historia de sufrimiento, de explotación y de opresión nos ofrece entradas importantes para poder entender mejor el sentido, tanto personal como social, de la vida humana. Existe en las culturas, en las memorias colectivas, en los actitudes y los valores de los latinos una riqueza impresionante."

Una de las razones por la cual Grant se presentó por el trabajo fue su deseo de seguir trabajando con latinos. "De algún modo, quise mantenerme en contacto con América Latina; quise ponerme a servicio de la comunidad latinoamericana y si fuera posible compartir algo de las penas y las alegrías, la búsqueda solitaria y la solidaridad de amigos. Son las experiencias que en América Latina transformaron mi vida, y me enseñaron que caminar juntos es mejor que estar parado y solo."



## YOUR CHANCE TO CHANGE OUR LIVES

The PLWA committee get together to push the issues and lobby the organisations which affect you - people living with AIDS in NSW.

### WE NEED YOUR SUPPORT TO SUPPORT YOU

So, follow these three simple steps...

1. Become a member of PLWA.
2. Show your interest in being on the committee (phone Don Carter on (02)283 3220).
3. Come to

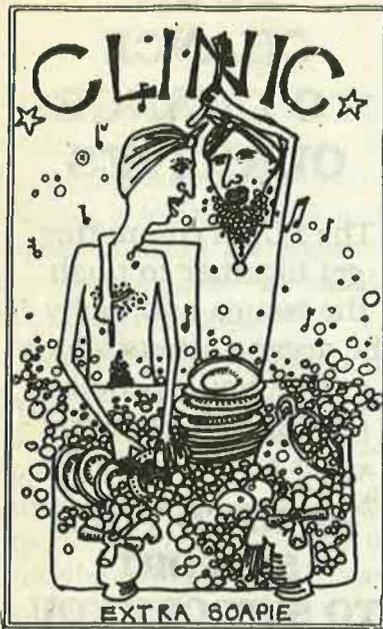
#### THE PLWA ANNUAL GENERAL MEETING

7pm, Thursday  
April 11

AIDS Resource Centre,  
ground floor,

188 Goulburn Street,  
Darlinghurst.





## THE CLINIC

By Gene Harlot

### The cast:

#### Narrator

Dull, fat, boring and a real geezer.

#### Martha

Sex maniac and ex singer in a country and western band.

#### Rebecca

Junkie, prostitute and woman of Martha.

#### Neill

Raving queen with very short hair.

## ACT ONE

*The Scene: Neill and Martha are on the train travelling from Westville to Queens Circle in search of the Users for Users Union.*

**NARRATOR** - Martha's woman has been detained as a risk to the public's health. Why do you ask? Well, it seems that if a man were to catch HIV/AIDS off a woman then it must be the woman's fault! No one particularly likes junkies and hookers so they figured that no-one would protest - but little do they know that behind the scenes, the Users for Users Union has been following the situation all along, pulling strings, pulling deep dark secrets out of even deeper and darker closets.

Neill and Martha are a strange little pair, not really politically aware but socially unaware they will never be!

But enough of that, let's cross over to the 4:06pm train from Westville so you can see for yourselves.

**NEILL** - The Users for Users Union has demanded that the Stealth Department's public disgrace bill be trashed immediately. But what will that do, they'll still find another excuse to lock up people like us! They're holding our Rebecca prisoner coz they reckon she's a

murderer. What about those clients who try to rip off their frangers, do they really expect not to get AIDS? And anyway I reckon that those User for User people are just using Rebecca to get publicity anyway!

**MARTHA** - Yeah! I reckon it's not even run by users at all!

**NEILL** - Maybe, but I'm sure there's some real cool dudes there who'll help us if we hassle them. Maybe we need to act up a bit ourselves. If they are using our Rebecca we should protest or something.

**MARTHA** - Hey yeah, what a great idea. Lets find this place and demand action and if they're not helping Rebecca or us we'll find out who funds them and complain!

**NEILL** - Hey baby, the Stealth Department funds them. The same dogbreaths who are holding our Rebecca for being a junkie prostitute with AIDS.

**MARTHA** - Catch twenty two! All I want is my gorgeous Rebecca back. They have no right to treat my woman like that.

**NEILL** - They haven't got the right to treat anyone like that. Hey - we're at Queens Circle station now. Lets go and find the Users Union right now!

**CURTAINS  
INTERMISSION**

## ACT TWO

**NARRATOR** - Queens Circle is of course, home to Neill and Martha. They bump into a regular dealer and score some shit. Not having clean fits they decide to elevate a little bit and save the rest for a more opportune moment.

The audience enjoyed their intermission and are now back, Maltezers in hand ready to roll them down the aisles of the theatre.

Martha finds the entrance to the Users Union and helps Neill climb the ten flights of stairs (he's a bit drug fucked).

**NEILL** - (to himself) Ya need a fuckin escalator in this place, hows a queen supposed to look glamorous when she arrives.

**RECEPTIONIST** - (chewing gum and doing his nails) Yeah - what can I do for ya's?

**MARTHA** - I'd like two 3 packs, 6 swabs and 6 waters and we want to speak to someone about getting our Rebecca out of jail!

**RECEPTIONIST** - Who's Rebecca?

**NEILL** - She's the woman who was framed and locked up in the Niagara Rest Home!

**RECEPTIONIST** - Oh yeah - you musta missed out on the latest news! There was a revolution in the Stealth department and the arseholes responsible have all been

assassinated, they will never work again! And that Sister Obese bitch who as it turns out wasn't a sister after all has been promoted to the ministership. Apparently the government is coming up to election time and wanted the issue dropped. Oh and Rebecca has been offered a job as beauty adviser to the Minister.



*Rebecca was offered a job as beauty advisor to the minister.*

**MARTHA** - Oh Fuck!!! I forgot to soak some chick peas this morning! She'll be really pissed off. I'd better go down to the Vegcaf and buy some dinner, and run down to the bottle shop for a cask, Oh - and I think we've run out of Dental Dams!

**NEILL** - I hope she's still got that ten thousand the TV dudes gave her, I'm really aching to score again.

**MARTHA** - Fuck off baby, I'm gonna take her up to the farm, there's no way I'm letting my woman work for

that skinny little runt of a Stealth Minister, no way - not my woman!

We got heaps of pot growing up there and with that ten thousand we can build a cute little dog house for Diesel and Fi-Fi!

**NEILL** - Yeah, but what about me? My Gino dropped two weeks ago and youse two are the only people I've got left, and I aint goin' to live with that old bag of a mother of mine in Melbourne - bloody horrible place!

**RECEPTIONIST** - You can have me baby!!!

**NEILL** - How big's your dick?

**RECEPTIONIST** - 12 inches give or take a foot.

**NEILL** - But, but, I'm HIV, is that a problem?

**RECEPTIONIST** - So what! - that's what condoms are for!

**NARRATOR** - So Martha rushes off home and finds a note stuck on the fridge door, "I've sold the house and I'm waiting up at the farm for you".

Neill and the receptionist meet each other at Sweethearts after work and never part again.

And the Clinic closes down due to lack of interest!



## Review

# People Like Us

***I sometimes think that you don't really know what dance is all about until you see a company like the One Extra perform. Beside them, other companies frequently appear contrived and shallow.***



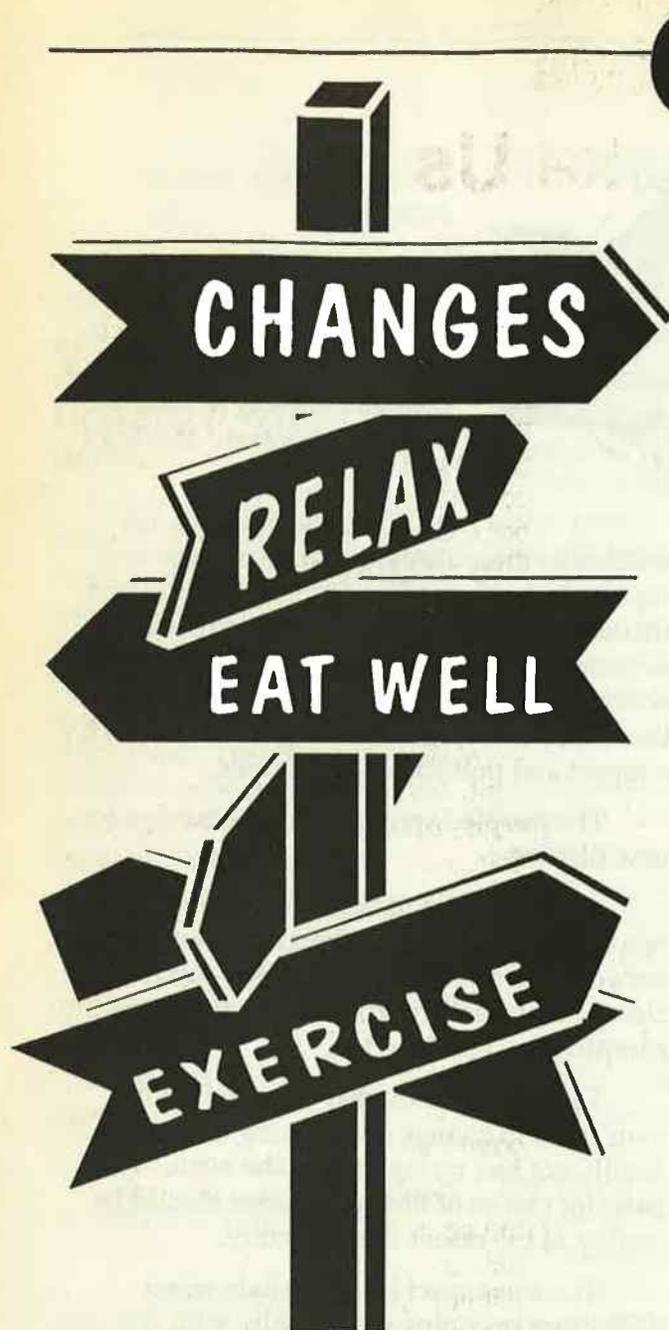
*In rehearsal: L-R Paul Codeiro & Patrick Harding-Irmer, flying: Tony Poli.*

The One Extra's new show, *People Like Us*, which opens in Sydney in March, continues their tradition of innovative, courageous work. It is about motherhood, migration, and AIDS. The central group of characters in three loosely connected segments are a mother, her children, the children's partners. They contend with love and sexuality, drug dependence, cultural difference and HIV/AIDS.

The beauty and the strength of dance is that it doesn't need to be literal. The body can express with purity and force the realities that words often obscure. At its best, dance is a reflection of our spiritual and emotional lives, an acknowledgment of our experience in all its diversity. Artistic Director Kai Tai Chan has assembled a fine cast who understand this very well. Five women provide an evocative musical background - chanting and open throat singing.

*People Like Us* is powerful. In the segment specifically on AIDS, it acknowledges the grief, the different kinds of loss, the affects HIV and AIDS can have on sexuality, identity and relationships, as well as anger, struggle, strength and support. It may make you cry - I did at a preview - but it may also provoke a strong sense of relief that the lives and experience of PLWAs are being so publicly and sincerely affirmed.

***Jill Sergeant***



## ***Lifestyle changes and HIV -***

***tips for new players***

**T**

***People with HIV/AIDS are often told that if they make lifestyle changes they can maintain a higher level of good health for a longer period of time.***

***Unfortunately, it's not all that easy to change the habits of a lifetime.***

***Naturopath and volunteer ACON researcher Neal Fitzgerald has been researching just how people cope with making major lifestyle changes. He interviewed ten HIV+ gay men about the benefits, difficulties, and ways of making change easier.***

The men I interviewed had made many and varied lifestyle changes. They included dietary change, resting more, taking up meditation and relaxation, exercise, cutting down on drugs and alcohol, changing sexual habits, changing work and living arrangements and generally reducing stress levels.

Some had given up paid work completely, while others had started working part time. Some had started taking vitamins, minerals, herbs or homoeopathics as well as or instead of conventional medical drugs. Actively building a support network, coming out as a HIV positive person and helping others with HIV were common strategies. Developing emotional skills, keeping a diary and increasing spiritual awareness were mentioned.

Consulting complementary practitioners and, in some instances, doctors, talking to friends and others with HIV and reading were the main sources of information about lifestyle change.

Benefits of the changes made included a greater self awareness and self esteem, an increased sense of control, feeling better generally and reduced anxiety levels.

Drawbacks and problems people experienced included a feeling of isolation from

peers who were not making lifestyle changes, setting unrealistic goals, lack of support from orthodox medical practitioners, decreased financial resources and burnout from helping others too much. The painful process of change and decision making was made difficult by inadequate and confusing information in an emotionally charged situation often with little useful support.

*"The whole process involves incredibly complex mental gymnastics. There is a simple level of changing things on a physical level, but how you...integrate them into how you think about everything, is the hardest thing".*

*"I like to take the information and chew it around and see if it works for me...I made the mistake (with the candida diet) of going head first into something because somebody told me... and took it without evaluating who I am and where I am at the moment".*

Those who had explored lifestyle change before diagnosis often found it easier to continue changing than those who had not. Making realistic and gradual changes helped people maintain their lifestyle change programs. Support from lovers, family, others with HIV and counsellors also helped. Affirmations, meditation and spiritual beliefs helped some.

A lack of positive messages about lifestyle change or role models of people who had successfully made changes made it more difficult. Meeting others with different priorities or approaches to lifestyle change could sometimes be confusing. Peer pressure to go against lifestyle change commitments, especially from HIV- people who don't understand the HIV+ person's commitment to



lifestyle change, was also difficult.

*"There's a lack of external modelling ... it's been difficult to find something I can link on to and say that these are the sorts of changes I'm going to make and this is the direction I should go in."*

People had often felt isolated in their lifestyle change process and reported significant benefits in achieving and maintaining changes by building support networks through attending support groups, seeing counsellors and coming out as HIV+ to those they trust and becoming involved in HIV support and political organisations.

The people I spoke to gave some tips for new players.

It's important to be flexible, adopt a relaxed approach. Try to find a balance between the excessive stress of too rapid change or unrealistic goals without sinking into complacency and inaction.

Take the attitude that you are treating your body to change and looking after your health, not just trying to stop the virus. The basis for choice of lifestyle change should be quality of life rather than quantity.

You can expect black periods when difficulties in coping emotionally with change and HIV may arise but don't feel that all is lost, rest assured that these will pass. Make sure you've got support to help you through this time.

Above all you should realise that each person will find their own strategy, their own personal journey and that you have the ability and power to choose what's best for you.

*"It's that whole control issue, and that is really what it is about, is to allow people to take control of their lives".*

## New legal service for PLWAs

**A free legal advice and advocacy service is now operating in Sydney, exclusively dealing with HIV/AIDS related legal issues.**

Solicitor Michael Alexander is employed by the AFAO Legal Project to offer a nationwide service, which has been funded by the Commonwealth Department of Community Services and Health following the 1989 White Paper. The service is based at ACON, where it is supported and supervised by the ACON Legal Working Group.

Advice is given on all areas of the law that relate to HIV/AIDS, including:

- \* discrimination
- \* insurance and superannuation
- \* breach of confidentiality
- \* complaints about medical treatment
- \* non-consensual testing
- \* immigration and travel
- \* wills and powers of attorney (advice only)
- \* family law issues
- \* social security

Further assistance and representation can be provided in some cases and referrals will often be made to other appropriate services and agencies.

Generally speaking Michael cannot prepare wills and powers of attorney.

"Unfortunately, if I started doing wills I wouldn't have much time for anything else," says Michael. "Preparing a will for a person with HIV is no different from a will for anyone else. The important thing is that the solicitor is sympathetic." The Legal Project has referral lists of appropriate solicitors in various areas.

One of the aims of the Legal Project is to run test cases in various areas of the law which remain untested in relation to HIV. Discrimination is one area where a lot of work needs to be done.

"A very large proportion of the calls to the Legal Project involve discrimination in one form or another", says Michael. "But only a very small proportion ever get notified to the Anti-Discrimination Board. I'd like to see the Board getting a lot more complaints. The more they get, the more the government will have to acknowledge that discrimination against people with HIV/AIDS is a very real and very large problem."

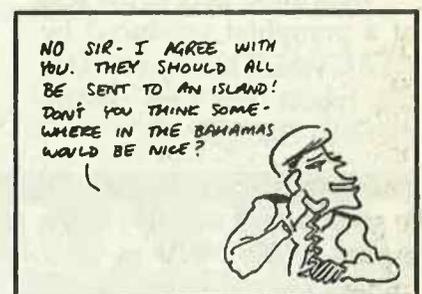
Whilst it is a client-oriented service, Michael acknowledges that some problems cannot be solved within the framework of the existing law. "We recognise that many laws need to be

changed to provide justice to people with HIV/AIDS, and to accommodate their needs. In conjunction with other AIDS organisations and activist groups, we have to fight for law reform. The information I can gather in the course of my case-work will provide useful ammunition in those fights."

The AFAO Legal Project also has an educational role. David Patterson is employed as legal research officer whose main job at the moment is completing an HIV/AIDS Legal Manual, to be published in the next few months.

The manual will be a useful resource for lawyers and others working in the area, and is likely to mean that more lawyers are better informed about HIV/AIDS legal issues. An updated edition of the pamphlet *AIDS and Your Rights* will also be available soon.

Michael can be contacted on 283 3222. Advice can be given over the phone, or an appointment can be made to discuss more complicated or personal issues.



# ANCA Urgent Working Party on HIV/AIDS Treatments Report

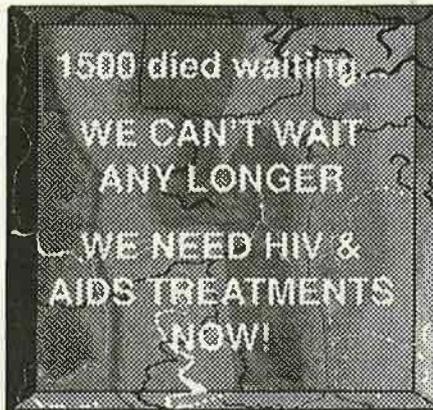
## MINISTER'S RESPONSE INADEQUATE

The much awaited report of the ANCA urgent working party on HIV/AIDS Treatments was given to the Federal Minister For Community Services and Health, Mr Brian Howe, late in December 1990.

The Minister's response, which he gave to the Australian National Council on AIDS at the end of January, fails to address most of the recommendations in the report and in many areas falls far short of coming to terms with the demands of people with HIV and AIDS.

A coalition of groups known as ATAC (AIDS Treatments Action Coalition) has formed to take action to ensure the implementation of this report. If this doesn't happen this time then the most significant opportunity for people with HIV and AIDS that we have had so far will have been lost.

Reprinted here is the text of a pamphlet produced by ATAC which briefly explains the report and the recommended changes.



In Australia today, people with HIV and AIDS are forced to wait for treatments which could save their lives. This situation is inhumane and must change. A report just out, commissioned by the Minister for Community Services and Health, Mr Brian Howe, makes 42 recommendations for changing the current Drug Regulation system.

The changes are large, but there's a lot of pressure on the Minister to make them. There's also a lot of resistance. The minister needs to know he has community support. Read on to see how you can help stop more of us from dying waiting.

### OUT-DATED SYSTEM FOR APPROVING DRUGS

When drug companies apply to market a drug here, they have to give all their data in a format which is not required anywhere else in the world. It then takes about two years for the drug to be approved. During this time, people with life threatening illnesses are denied the treatment.

As Australia is such a small market, applications are usually lodged after the drug has already been approved in Europe, Japan or the United States. Countries like Canada and New Zealand recognise these decisions made overseas. Australia does not.

The report recommends that Australia recognise high quality overseas approval systems, thus removing the two year delay.

### A TRIAL OF A SYSTEM

When drug companies want to run trials here, they

# TREATMENT NEWS

also have to provide unique and complicated information. This doesn't offer them much incentive. It takes much longer to approve a drug trial here than it does in other countries. Many HIV and AIDS drug trials are conducted internationally. Because of this delay, Australia doesn't get to be part of these trials. Often they are fully enrolled before they're approved in Australia.

The report recommends that the Australian approval system for drug trials be similar to the European one.

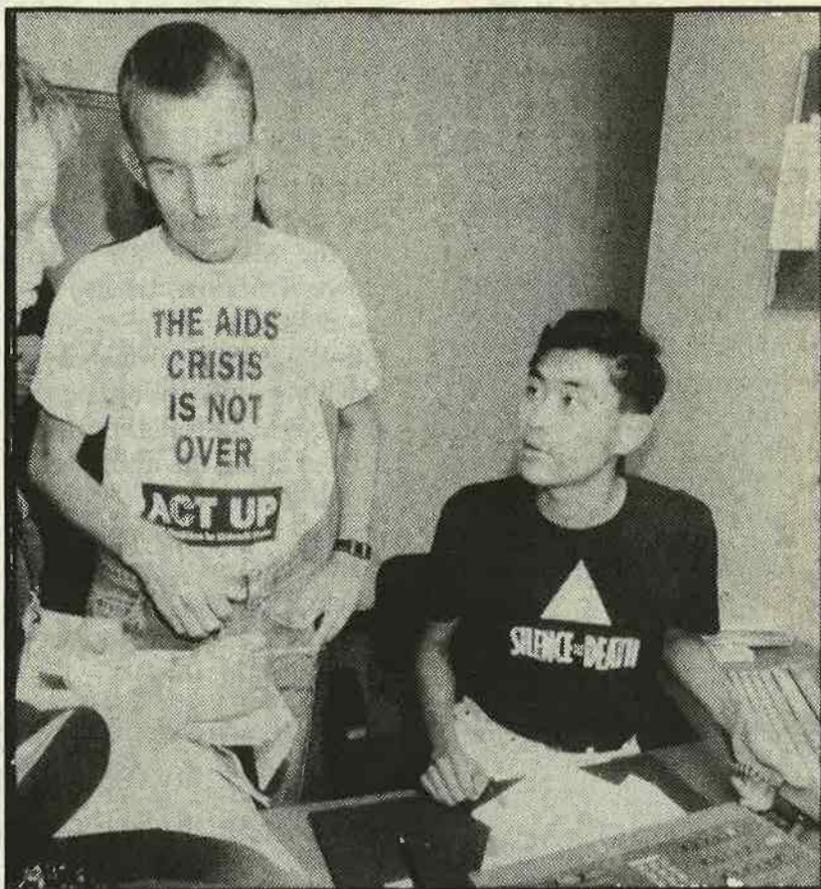
### FINANCING TRIALS

Australia currently relies entirely on drug companies to sponsor trials. Therefore many important ones, like those combining drugs from different companies, just don't happen here. The current amount spent on trials annually is a pittance. \$200,000. That's less than \$10 for every person with HIV.

The report recommends funding of \$3.2 million for locally conducted trials and a community trialing network.

### THE INDIVIDUAL PATIENT USAGE (IPU) SYSTEM

The IPU scheme means individuals can get drugs which aren't yet approved or available through a drug trial. In each case the doctor must



Jamie Dunbar

*Members of ACT UP made their presence felt at the Department of Health recently. They took over the phone lines in protest at Howe's response to the ANCA report.*

apply to the Department of Community Services and Health. In each case the drug company involved must agree to supply the drug. The scheme is bureaucratic and cumbersome.

The report recommends changes to make the IPU system more user friendly.

### THE ARGUMENTS AGAINST CHANGE

"The current system protects the Australian public

from drugs which may potentially harm them."

The Therapeutic Goods Administration (TGA), the people in charge of the current system, can't point to one drug they have protected us from.

"Consumers support the current system. It was consumers who demanded it so the Thalidomide disaster wouldn't happen again."

People with HIV and AIDS, people with cancer, people

Continued from page 23

with Parkinson's Syndrome, people on renal dialysis and people who have had organ transplants are all consumers who want the current system to change. While there must be a mechanism to ensure that drugs are safe, this can't be at the expense of people with life threatening illnesses. It is possible to have a system which is efficient and effective. The current system is neither.

## The Minister responds

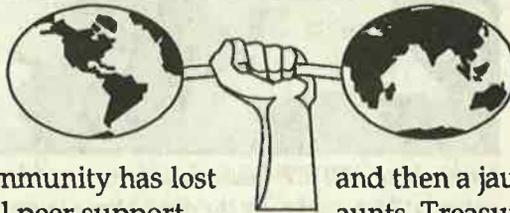
So far the only response of the department has been a four page press release issued by the Minister, Mr Brian Howe. The press release announces yet another enquiry into the drug approvals system in Australia, recommends changes to the trials approval system along the lines in the report (although no details have yet been announced) and mostly ignores the bulk of the other recommendations in the report except for increased funding of local trials.

## Where to now?

Every effort is now being made to ensure that this report is implemented and the effort behind its production is not wasted and it is not simply allowed to lie around on shelves to gathering dust.

You can help by writing letters to the Minister for Community Services and Health, Mr Brian Howe, calling on him to implement the report without delay. A campaign of steadily growing pressure is being devised and publicity will be produced as appropriate.

## Tiff's



## abroad!

The HIV affected community has lost a pioneer of the successful peer support groups following the resignation of Terry Giblett from the HIV Support Project of the AIDS Council of NSW.

From the project's establishment in April 1989, Terry, an adult educator, has been the drive behind the project which organises the HIV Information Night program and the peer support groups. Last year saw another position funded for the nationally acknowledged approach to peer support but Terry had some further setbacks to his health and recently decided on retirement.

Terry, a committee member of PLWA Inc (NSW), has planned a jetsetter's start to his retirement with long relaxed visits with family in WA, friends in Melbourne

and then a jaunt abroad with his maiden aunts, Treasure and Hilda.

Terry's face became one of the first public faces with HIV infection after articles in the *Sydney Morning Herald* and the *Sydney Star Observer* acknowledged his battle for better services and client rights. A founding committee member of PLWA Inc (NSW) he was also the 'other Terry' in the first covert OZ/ACT UP meetings with the late Terry Bell and others.

From everyone at the AIDS Resource Centre, the People Living With AIDS movement throughout Australia and the *Talkabout* Eyewitness News Crew we wish you, Tiff, a great time with your travel plans, and a relaxed and lengthy retirement.

Don Carter

## PLWA Committee news

➤ PLWA has ventured into merchandising with T-shirts (modelled below by glamour girls Suih and Don). The T-shirts are being sold to raise money for direct assistance to PLWAs. We'll keep you posted on just how this is going to happen. The initial production costs were covered by a donation to PLWA. This is a form of ethical investment.

➤ PLWA is often asked to address groups and organisations. At a recent engagement Robert Ariss spoke at the Australian Nursing Federation's Train the Trainer program.

➤ Members of the Committee have spoken at meetings of the Funeral and Allied Industries Union of NSW on the issue of the viewing of bodies of people who have died of AIDS. The union has now reached an agreement with some funeral directors in Sydney and Wollongong that bodies may be viewed. For details contact the PLWA office.

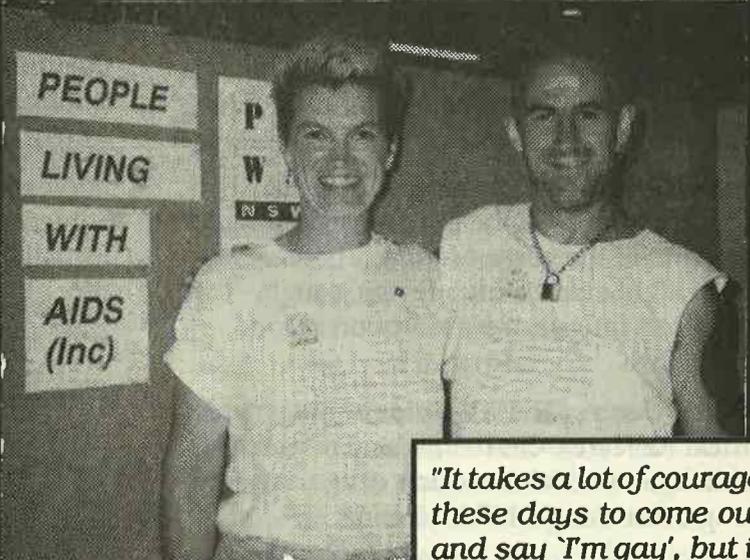
➤ One of PLWA's co-convenors, Ross Duffin, has been appointed to the Program Advisory Committee for the annual NSW HIV/AIDS Educators Conference, which will be held May 15 - 17.

➤ PLWA has been involved with the Commonwealth Department of Community Services and Health's evaluation of its National HIV/AIDS Strategy. Consultations have taken place on: men who have sex with men, people with HIV infection (hospital and non-hospital based services), access to treatments and HIV testing.

➤ PLWA is also conducting an ongoing consultation with the

DCS&H which is preparing for a major education campaign to combat discrimination against people with HIV/AIDS.

➤ Don't forget the PLWA Annual General Meeting on April 11 (see Page 15). There will be some vacancies on the committee, so if you're interested in filling one of these contact Don at the PLWA office. There will be drinks and munchies at the end of the evening.



**MADONNA SAYS:  
GET ONE NOW!**  
PLWA T-shirts are available now from our office at 188 Goulburn St Darlinghurst. In red hot or blue, they cost \$20 or \$15 concession.

*"It takes a lot of courage these days to come out and say 'I'm gay', but it takes a fucking warrior to come out and say 'I have AIDS'. These are the people who deserve awards... You're my heroes."*

**- Madonna**

Photo: Don Carter

# Glossary of AIDS terms

## Part Two L - Z

**Lymph Nodes:** Site of the production of lymphocytes, primarily in the groin, neck and armpits.

**Lymphadenopathy Syndrome (LNS):** Inflammation of the lymph glands, common in HIV related illnesses.

**Lymphocytes:** White blood cells which recognise and destroy infection. B-cell lymphocytes produce antibodies, and T-cell lymphocytes activate parts of the cellular immune system in response to foreign substances, particularly viruses.

**Lymphomas:** Malignancies of the lymphatic system, sometimes seen as a complication of HIV related disease.

**Mycobacterium avium intracellulare(MAI):** Infection beginning in the gut and spreading to other parts of the body. Manifestations include night sweats, high fevers, cough, weight loss, fatigue, malabsorption of food and diarrhea.

**National Centre Of HIV Epidemiology and Clinical Research Centre:** Federal research establishment which conducts drug trials for, among other things, HIV infection.

**National Centre of Social Sciences:** carries out social science research in relation to HIV and AIDS.

**National Centre of Virology:** Does research into AIDS.

**Nucleoside Analogues:** Family of drugs, of which AZT, DDI and DDC are a part.

**Opportunistic Infection:** Infection induced by a compromised immune system.

**Pancreatitis:** Inflammation of the pancreas resulting in severe abdominal pain.

**Parallel Track:** New system in the development and trialing of new drugs. Allows clients access to new drugs once they have shown promise while the drug is still under further investigation in controlled studies.

**Perinatal transmission:** The passing of HIV from mother to unborn child either through the umbilical cord during pregnancy or through breast milk.

**Peripheral neuropathy:** Disorder of the nerves leaving extremities of the body numb. Sometimes associated with some treatments for AIDS, including AZT.

**Persistent Generalized Lymphadenopathy (PGL):** see Lymphadenopathy.

**Placebo:** An inactive substance used as a control in an experiment. Placebo controlled trials are the standard form of testing for experimental new drugs against HIV infection.

**Pneumocystis carinii pneumonia (PCP):** Opportunistic infection most common in people with AIDS. Caused by a common parasite, pneumocystis carinii, infection is life threatening in immuno-suppressed patients.

**Prognostic Indicators:** Clinical tests which indicate an increased likelihood of

progression of disease. Tests for AIDS or ARC include Lymphocytes (T4 & T8), antigen and antibody, beta-2-microglobulin, platelet counts, haemoglobin counts and Erythrocyte Sedimentation Rate (ESR). Taken together such tests provide a more reliable indication of progression than if done in isolation.

**Prophylaxis:** Treatment to prevent a disease before it occurs.

**Protease Inhibitors:** New class of anti-HIV drug in development which targets the virus specifically, avoiding unwanted effects on other parts of the body.

**Randomised Trial:** Participants are randomly assigned to receive one of the treatments under study.

**Resistance:** In theory, the development of strains of HIV in the body which are not affected by drugs after prolonged use.

**Retrovirus:** Classes of virus including HIV. A historically recent medical discovery, retroviral replication works in the reverse to other pathogenic viruses by converting RNA to DNA in the host cell.

**Sero-conversion:** The process of going from no detectable antibodies to having detectable antibodies (ie going from Ab- to Ab+). In HIV infection often accompanied by a flu-like illness.

**Sero-positive:** see antibody positive, Ab+.

**Sero-negative:** see antibody negative, / Ab-.

**Side-effect:** unintended effect of a drug, whether it be unwanted, harmful or poisonous (toxic).

**STD (sexually transmitted disease):** A disease which is transmitted through sexual contact. HIV is sexually transmissible, but is also transmitted through blood to blood contact, or peri-natally.

**T-cells:** Specific sets of lymphocytes which are key cells in the immune system.

**T8-cells(T-suppressor cells):** Lymphocytes which act in concert with T4 cells in an immune response. The ratio of T4/T8 cells is used as a guide in determining the state of the immune system.

**T4 cell count:** measure of the state of the immune system based on the number of T4 cells present in the blood. An average count ranges between 600 and 800 per 1000 mls. A count less than 200 indicates severe immunosuppression and a count less than 500 qualifies a person for AZT treatment.

**Toxicity:** A measure of what quantity of a medicine is poisonous. Clinical trials determine the amount of a drug which can be taken safely without toxic effects.

**Transfusion:** Process of giving blood, or parts of the blood (plasma, serum, red blood cells etc) from one person to another.

**Vaccine:** Administration of a, usually, modified form of a disease causing agent, in order to induce 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 death of the host organism.

**Window period/incubation period:** The time between infection and sero-conversion. An infected person can test antibody negative in this period because no (or insufficient) antibodies have been produced by the immune system to be detected by the HIV antibody test. The average window period is approximately six weeks.

**PLEASE ADVISE US OF ANY  
ERRORS, OMISSIONS  
OR NEW TERMS**

## TALKABOUT DIARY

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

### New ACON branch planned

There is to be a Mid North Coast branch of ACON established very soon, possibly April 1st. The area covers Port Macquarie to Coffs Harbour. There is a temporary worker already in the area, Marilyn Marks. For information, referrals, support etc. you can contact Marilyn on (066)514.056

### The Frontline View of the National HIV/AIDS Strategy

*A selection of papers from the National Conference on HIV/AIDS, August 1990, Canberra*

Paul Van Reyk (editor)

This collection of papers contains all presentations made at the 4th National HIV/AIDS conference by staff, committee members and volunteers of the AIDS Council of NSW and other selected presentations ACON feels should have a wider distribution. It represents a range of critical yet vitally constructive responses to the theme "Beyond the National Strategy".

It is available by writing to or phoning the Education resources officer, ACON, PO Box 360, Darlinghurst NSW 2010, Ph: (02) 283 3222. Cost: \$2.50 (plus postage: \$1.90 NSW / \$2.50 interstate).

### FIRST ANNOUNCEMENT

### 3RD ANNUAL NSW HIV/AIDS EDUCATORS CONFERENCE

MAY 1991 - SYDNEY

The 1991 Conference will be held May 15 - 17 at the Masonic Centre, Sydney

The three day Conference aims primarily to involve those working in HIV/AIDS education, research, evaluation, care and support people living with or affected by HIV/AIDS.

Please note registrations will be limited to 200 people. Full registration fee will be \$120.00 with a daily rate of \$60.00 p/d. A pensioner or student concession rate will be available.

If you are interested in attending, or wish to make a presentation at the Conference, registration forms and abstract forms are available from:

**Ms Julie Bates**

**Program Advisory Committee, AIDS Bureau**

**NSW Health Department**

**Locked Mail Bag 961**

**North Sydney NSW 2059.**

**Expressions of interest must be received no later than 21 March 1991**

**NSW HEALTH**  
DEPARTMENT

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

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

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

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

#### **March/April dates**

**13 March 27 March 10 April 24 April 8 May**

### **INFORMATION NIGHTS FOR HIV INFECTED PEOPLE**

**Tues, March 5:** HIV infection and the immune system

**Tues, March 12,** Monitoring and prophylaxis

**Tues, March 19:** Treatments and drug trials

**Tues March 26:** Sex (By popular demand)

**Tues April 9:** Social Security and Legal Issues - an information night where all your questions can be answered about social security benefits and legal issues.

**Tues April 16:** Caring for someone with HIV/AIDS - an information night that looks at all of the services available for people with HIV/AIDS.

**Tues April 23:** Common HIV related conditions. Everyone has heard about the big illnesses associated with AIDS, but there are lots of other conditions such as skin itches and rashes, dental problems and gut aches that seem to be associated with HIV. This evening looks at those conditions and how they can be dealt with on a practical level.

The evenings commence 6.30pm and end by 8.30pm, at the AIDS Resource Centre, 188 Goulburn St Darlinghurst

### **Badlands Services**

have approached PLWA inviting us to appoint a representative who will attend Badlands Management Committee meetings to represent PLWA interests. If you are interested in doing this, please contact Don at the PLWA office 283 3220.

## **Conference for HIV Positive women**

**organised by the Quest for Life Foundation**

**Conference for +ve women, by +ve women**

**June 7th - 9th**

**In a central location in Sydney**

**Cost includes accommodation and food \$100**

**Non-residents \$50**

Many subsidised places are available. Please don't let finances stop you making inquiries.

Early registration is necessary for planning, the Conference is limited to 70 women. For fare assistance early contact is needed so it can be organised.

This is the first Women's conference for women to come together to talk about our issues.

Suggestions for conference topics would be appreciated. Some possible topics are sexuality, treatments, services available, techniques for maximising people's attitude, children.

**Contact Quest For Life Foundation, Jennifer (02)906.3112 for more information and feedback.**

## CONTACT LIST: AIDS ORGANISATIONS AND SUPPORT GROUPS

### GENERAL

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

**AIDS Coalition to Unleash Power (ACT UP):** A diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis. Phone the info line (02)283.3550. PO Box A1242, Sydney South 2000.

**AIDS Council of New South Wales (ACON):** Provides services in education, welfare, support and advocacy in relation to HIV/AIDS to the gay and general community. AIDS Resource Centre, 188 Goulburn St, Darlinghurst 2010. (02)283.3222.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

**North Coast "Positive Time" group:** a support and social group for PLWAs in the North Coast region. Contact ACON North Coast Branch (066)22.1555

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

**NSW Users and AIDS Association (NUAA):** NUAA is a community/peer based organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free forums/information nights 6pm, 3rd Monday of each month. Ph: (02)357.1666.

**Parents' Group (and relatives):** A support group for the parents or relatives of people with AIDS. Meets alternate Wednesdays, at 12.30pm, from March 13, Conference Room, Aikenhead Bldg, 1st Floor, St Vincent's Hospital.

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

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

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

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

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

**Sex Workers' Outreach Project (SWOP):** 391 Riley St, Surry Hills NSW 2010. (02)212.2600.

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

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

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

**Red Cross BTS:** Contact Jenny (02)262.1764.

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

## ACCOMODATION

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

## DAY CENTRES

**Blue Mountains PLWA Support Centre - Oper-**

