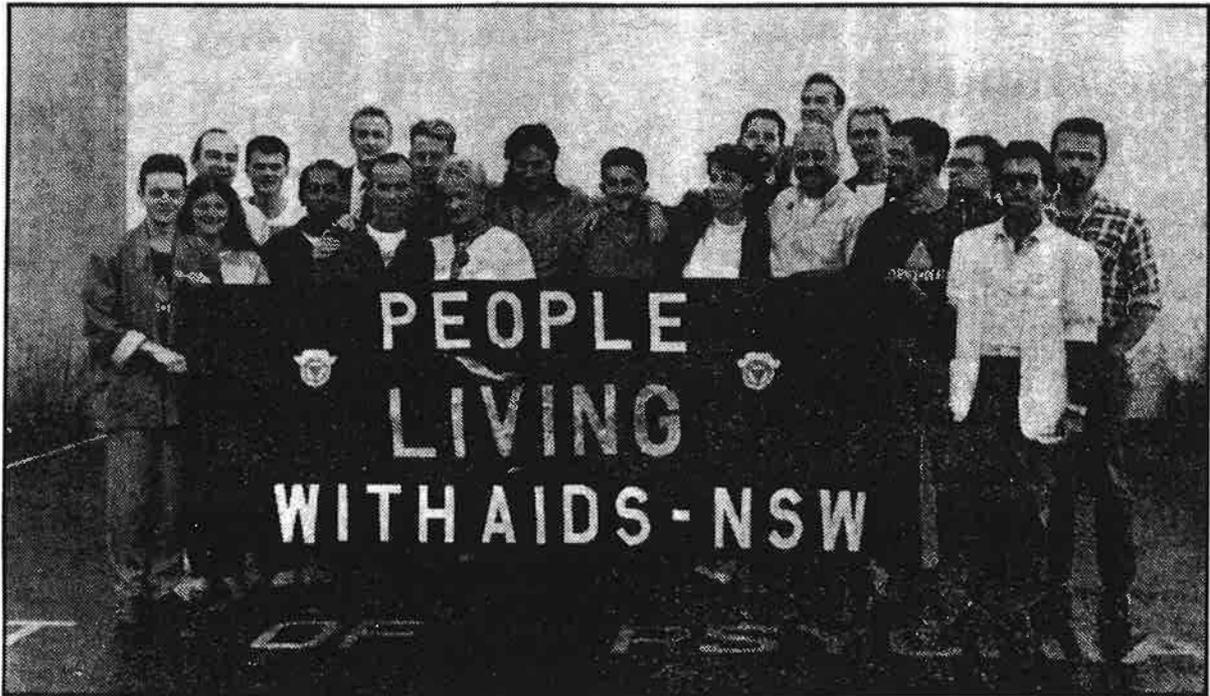


TALKABOUT

Newsletter of *People Living With AIDS (N.S.W.)*

June 1989 Issue 3, Vol.1



Terrence Bell / AIDS ADVOCATE

PLWAs confront surgeons – story, p.8

—:°INSIDE°:—

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All views expressed in *Talkabout* are the opinions of the respective authors and not necessarily those of PLWA (NSW)

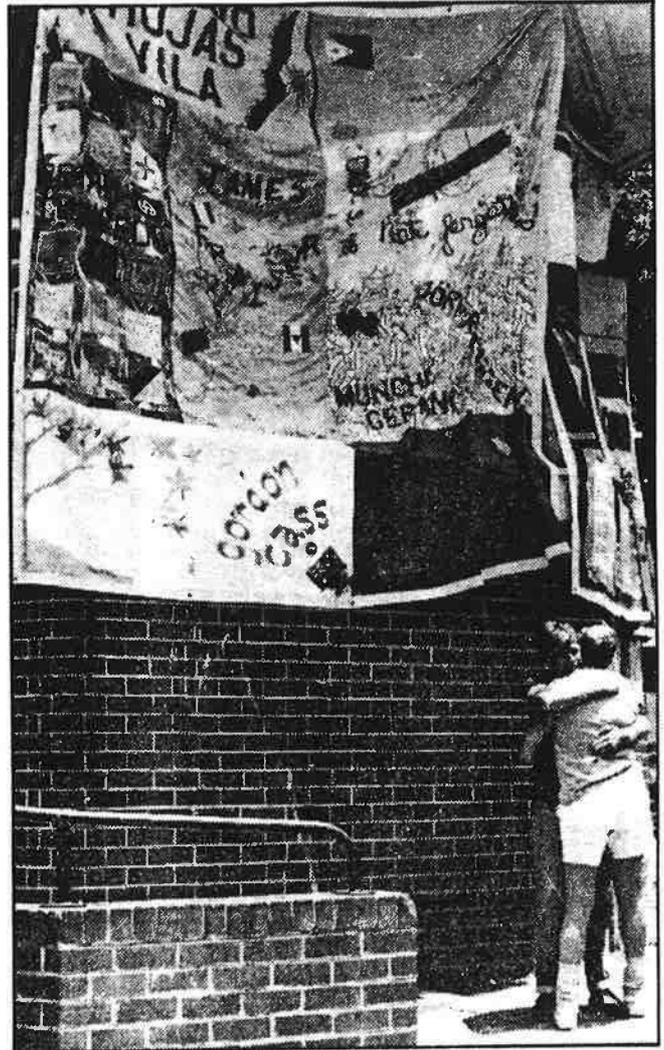
Where we speak for ourselves

LOCAL NEWS

Australian Quilt for Montreal

Most of the visitors to the Australian Quilt Project's Open Day on Saturday 29 April participated in creating a very special AIDS memorial panel. Dedicated to "All our Aussie Mates", this green and gold panel, its design dominated by the Southern Cross and an Australian flag, will be displayed during the 5th International Conference on AIDS in Montreal, Canada in early June. It will later be sewn into the massive US Names Project AIDS Memorial Quilt as a gift from Australians.

Also travelling to Montreal will be a whole "block" of eight Australian Quilt Project memorial panels. The Convenor of the project, Andrew Carter, said "Our organisation has been invited to participate in a display of AIDS memorial quilt panels from around the world to coincide with the International Conference. The special panel constructed at the Open Day will be displayed in a window of one of Montreal's major department stores. Our "block" of eight representative panels will be used firstly as a backdrop in a major press conference and then join the 3,000 panels from the US Names Project which will be visiting Montreal as part of its 1989 North American tour. This massive display will be at the Complexe des Jardins,



David James

adjacent to the venue of the AIDS Conference."

Visitors to the Open Day saw demonstrations of how the Project maintains and mends memorial panels, videos of both the US and Australian Quilts, and of course, the basic aim of the Project, how to memorialize a loved one in fabric. The Project is assisted by the AIDS Council and the Albion Street Clinic.

PLWA(NSW) withdraws from national body

In early April PLWA (NSW) announced to all AIDS Councils its withdrawal from the National People Living with AIDS Coalition. To this time the NPLWAC had consisted of a small group of self-appointed people from each Australian state and territory with little organizational framework or funding. The organization, one year after its establishment following the first Living Well conference in Melbourne, had achieved little except provide a loose structure of support to individuals attempting to establish separate PLWA organizations in each state and territory.

With this in mind, and acknowledging the importance of a viable national body representative of people infected and affected by AIDS, PLWA (NSW) sought and achieved separate affiliation with the Australian Federation of AIDS Organizations (AFAO). The result of liaison with PLWA (NSW), NPLWAC and AFAO is the setting up of a working party composed of representatives from each PLWA body and a facilitator from AFAO, funded by AFAO to assist in the establishment of viable and representative PLWA bodies in each state and territory. Over the next 6 months Keith Harbour of AFAO will visit each state and territory to assess the specific problems and needs experienced by PLWAs around Australia, and facilitate communication and cooperation between groups in order to begin to build a national PLWA body.

Friends of People With AIDS - a peer support group

In an attempt to cover all effects of AIDS in the community, there is now a peer support group for people affected, but not necessarily infected, by the virus. The group meets every Wednesday at 7.00 pm at the Albion Street Centre to coincide with the Antibody Positive Group.

The aim of the group is to give people the opportunity to vent their feelings, hurts and angers.

The group is open to anyone feeling the stress of witnessing their friends lovers or families enduring this illness. The group operates on the peer support model so that facilitators are also experiencing or have experienced many of the same problems as the other group members.

The group respects everyone's relationship to the person who is ill. Whether it be your lover, parent or friend you care for it can hurt witnessing the illness take hold. This concern is the common bond between all people in the group. The aim of the group is to give people the opportunity to vent their feelings, hurts, and angers.-

« Friends

To discuss their feelings with people who can relate to them through that common bond.

Professional, and semi-professional help will always have its place and is vital. However, this group was formed as an adjunct to these services, and can be helpful to many.

It is the responsibility of all connected with the health services to ensure that everyone receives the information and attention they require and to inform the community of services, however varied, that are available. The next time we hear a friend, lover or member of the family express difficulty in coping, we need to inform them of the existence of counsellors, Ankali, and the Friends of PWAs Peer Support Group.

Kerry Hartnett (Group Facilitator)



Meet the Committee

PLWA (NSW) will hold an informal gathering of members and friends on Sunday July 2 from 3.00 pm at 391 Riley St, Surry Hills, Sydney, the AIDS Council's Welfare Services Annex. Come along and meet your committee representatives and other members in the relaxed atmosphere of the Annex. Talk over some issues, suggest some ideas, and catch up with friends. Hope to see you there!

Transport service soon for Sydney PLWAs

ACON recently submitted to the AIDS Bureau of the NSW Department of Health an application for funding for a transport service for PLWAs. The service will be run by Community Transport, East Sydney, which is currently providing the transport service to the Day Centre.

The service will be for people living in the inner city, eastern, inner western and inner southern suburbs of Sydney and attending Prince Henry, St. Vincent's and Royal Prince Alfred Hospitals.

Geographical boundaries of the service extend from Strathfield to Bondi, Taren Point to Sydney Harbour. Referrals to the transport service will come through the Community Nurses and Social Workers at Outpatient Clinics and community agencies, and be made directly to the co-ordinator, Jan, at Community Transport.

Once funding has been approved criteria for access to the service will be:

1. Frequency of travel to clinics.
2. Income and inability to afford other transport means.
3. Living within geographical boundaries as stated.

For further information contact Anne Malcolm at ACON on 212 2728.

PLWA Youth Group formed

The PLWA Youth Group, which grew out of the youth working group at the Living Well II conference earlier this year, is now up and running. At this stage we are not being too decisive about what we offer, rather we would like to leave things flexible in order to be responsive to the needs of individuals who approach us. Broadly speaking, we are interested in providing peer support and advocacy for young people living with HIV. The group tries to avoid formalised meetings, so if you are interested in becoming involved or getting more information then call Sean or Jeffrey on 212 2728 or 211 0499, or write to us through PLWA.

Free volunteer massage for people with HIV at home and in hospital

Over a period of time the physical impact of HIV on people with the infection has been slowed through increasingly beneficial treatment interventions, both medical and alternative, and through broader lifestyle changes. This, however, results in people with HIV having to cope with new medical conditions. One condition which has been on the increase is vascular myelopathy.



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- ◆ Building Confidence
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- ◆ Trust and Friendship between Young Men.

AN ACON PROJECT

For more information contact Greg or Brent ☎ (02) 211 0499

Free massage

"HIV may directly affect the spinal cord leading to a disorder known as vascular Myelopathy. Pain, progressive weakness and lack of coordination of the legs are common. These symptoms may also occur because of inflammation of the peripheral nerves of the arms and legs" (AIDS, a Time to Care a Time to Act, p.64)

Massage can offer benefits to people with HIV who are not seriously ill by maintaining positive attitudes and stress-reduced lifestyles.

The therapeutic values of massage for the conditions described above are quite positive. A slowing down of the disease process is probable through the stimulation of the immune system and pain control.

Further benefits are derived from skin and pressure point care (a natural relaxer and relief for stress and discomfort) plus the comfort of caring human touch.

PLWA is in the process of setting up this valuable service for its members, but first we require YOUR HELP. Volunteers are needed to build a core of masseurs to provide the service. Training will include essential AIDS education as well as massage techniques, together in a supportive, friendly environment.

Anyone wanting free massage in the home, hospital or in any of our premises, please contact Richard Holland on 477 8255 (w) or 660 6392 (h)

Similarly, anyone wanting to join our volunteer masseur group contact Richard at the same, or write to PLWA (NSW) at PO Box 1359 Darlinghurst 2010.

Committee position vacant

A position is vacant on PLWA (NSW) committee for a full member. Anyone interested should contact PLWA for further information and discussions. As described in our constitution, the committee is empowered to co-opt anyone it feels would be of value to that position.

APOLOGY

Talkabout would like to extend its apologies to the people at No. 11 Jersey Rd. This address was advertised in the last edition of *Talkabout* as the location of the Day Centre. The correct address is 111 Jersey Rd, Paddington.

The disappearing tea trolley or, tea for who ?

Early on a Friday morning in early May, a young man recovering from a major AIDS related condition arrived at the new Immunology B Clinic, St Vincent's hospital. The young man asked a nurse aide for a cup of tea while he waited for his appointment. The nurse aide left, only to return shortly but empty handed, explaining "sorry, you can't have any tea because of the carpet". The young man replied in dismay, "Can I go to the kiosk to get one instead?" to which the aide replied "No, it's too far away and you'll miss your appointment".

The free tea and coffee which was available at the old Immunology B Clinic was a bright point in what was otherwise a dull routine. It was provided by BGF and Ankali workers and others who set it up and kept it topped up each week.

The tea trolley was a place where old acquaintances might be renewed or new friends made. Although only a small comfort, it is nevertheless an important one in an environment which is mostly cold and sterile.

But now our trolley has disappeared. Somehow, in the move to the new building, it got lost. Concern was expressed, questions asked, and gradually a sad story emerged.

In its wisdom, the hospital had decided that the new building was so smart,

had such nice new carpets and fresh paint, that there wasn't any need for a tea trolley.

People Living with AIDS doesn't agree. We think the tea and coffee is important and we want to tell the hospital this.

We have written to the Director of the Clinic and asked him to meet with us so we can discuss this and other concerns. If there are any other things you want us to raise regarding service in the clinic, let PLWA know, and we will take your concern to where it will be heard.



Ian Steep

Surgeons - a new "high risk" group?

A report on the storm in the surgeons' teacup

Over the last couple of months AIDS has been represented in the media in the form of a controversy over the reputed risk of HIV infection to health care workers. Media preludes to the Australian Medical Association's "Health Care Workers and AIDS Summit" included reports of HIV infected patients endangering doctors by not disclosing their HIV status accusations of the "gay lobby" hijacking rational approaches to AIDS, and the first case of infection of a health care worker in Australia, later repudiated by Dr Blewitt as a non-documented case.

Concerned about the alarmist demands of AMA doctors and their imported showcase, Dr Loraine Day, for testing of patients before treatment, PLWA (NSW) released a press statement calling for the deregistration of doctors and other health workers who discriminate against patients because of their known or suspected HIV antibody positive status.

To argue that health care workers are at high risk of HIV infection is to blatantly deny the epidemiological evidence of transmission currently available. There are only 22 cases worldwide of infection among health care workers, an extraordinarily small number given the many thousands of HIV positive patients operated on thus far in hospitals. None of those

cases has been a surgeon, and most startlingly, all cases have occurred where the status of the patient was known - a strong indication that testing will not improve the safety standards of the health care environment.

Given that gay men constitute a group which is greatly affected by the epidemic, to deny them representation and input into the fight against AIDS is undemocratic, elitist and irresponsible.

Similarly, to accuse a "gay lobby" of infiltrating and sabotaging effective and rational management of the epidemic is a total fantasy given the small gay representation on national AIDS bodies. Given that gay men constitute a group which is greatly affected by the epidemic, to deny them representation and input into the fight against AIDS is undemocratic, elitist and irresponsible. Worse, to claim HIV infected people have greater rights than the uninfected is a hysterical statement by a profession panic stricken in the face of its own growing incredibility and obvious inability to suppress its own fear and prejudice. Such comments recall often heard reactionary statements denouncing efforts to improve

the lot of women, Aborigines or migrants - comments often heard from the overprivileged in our society.

Barred from access to the Health Summit because of our lack of "expertise", PLWA attended the recording of the Peter Couchman show with Dr Lorraine Day and Dr Ken Donald - televised nationally on ABC-TV on 30 April. If people living with AIDS are denied input into so called "scientific" debates on AIDS, the media was certainly keen to hear the voices of "AIDS victims and carriers" raised against the "respectable".

So what became of this opportunity?

With an audience split between medical professionals supporting the AMA line and people living with AIDS - people with HIV infection, their carers, friends and lovers, community educators and nurses, and with Couchman himself persistently bringing the debate back to the issue of mandatory testing, little enlightened debate emerged beyond this non-issue of testing. Perhaps this is good television (so some would argue) but such debates do little to inform those in TV-land of the complexities of HIV testing and AIDS education or to facilitate the desperately needed discussion between health care workers and people living with HIV infection.

Ironically the position of the AMA seems to have softened in the wake of the summit, given that arguments for mandatory testing were strongly contested by such notables as Dr Neil Blewitt and Justice Michael Kirby. This revision of policy no

doubt deflated the debate somewhat, however we still need to be wary of those who would substitute testing for education, counselling, and non-discriminatory practices as the answer to AIDS.

The behaviour of such medical professionals will do nothing to win the confidence and cooperation of HIV infected people, a partnership necessary for humane and effective action in defeating this epidemic. At a time when testing is increasingly useful in monitoring one's own health, pressures for compulsory and uninformed testing will further discourage those at risk from seeking, in an informed and guided manner, early indications of disease progressions.

To date no democratic country in the world has instituted mandatory HIV testing, pre-operative or otherwise, for a general public.

To date no democratic country in the world has instituted mandatory HIV testing, pre-operative or otherwise, for a general public. If Australia maintains its current course it will not seriously consider this as a viable option. We can be thankful for a relatively benign and rational approach to AIDS in this country. It is unfortunate, however, that a minority of worried - well

doctors, empowered by the status of "professionalism", can capture such an extraordinary and disproportionately large amount of media space.

The surgeons debate has illustrated once again that, without planned resistance, irrational and fear driven arguments shape the way AIDS is talked about and understood in this society. An encouraging note to end on is that people living with HIV infection, themselves, are beginning to contest these persistent, sometimes subtle expressions of discrimination and oppression. Perhaps the AMA didn't lose the debate, but we gave them a run for their money. And that comment can, perhaps, be taken quite literally.

Robert Ariss

IF YOU EXPERIENCE DISCRIMINATION IN HEALTH CARE SERVICES BECAUSE OF YOUR KNOWN OR SUSPECTED HIV STATUS, WHETHER IT BE FROM DOCTORS, DENTISTS, IN HOSPITAL OR WHATEVER, LET US KNOW. FOR LEGAL ADVICE CALL JOHN GODWIN AT ACON ON 211 0499, OR THE ANTI-DISCRIMINATION BOARD. YOU CAN AND MUST DO SOMETHING ABOUT THIS GROWING PROBLEM OF DISCRIMINATION.

...such debates do little to facilitate the desperately needed discussion between health care workers and people living with HIV infection.



Monday, 10th July, 1989

The Knights of the Chameleons are kindly donating to BGF 17% of the earnings from a preview of the film -

Torch Song Trilogy

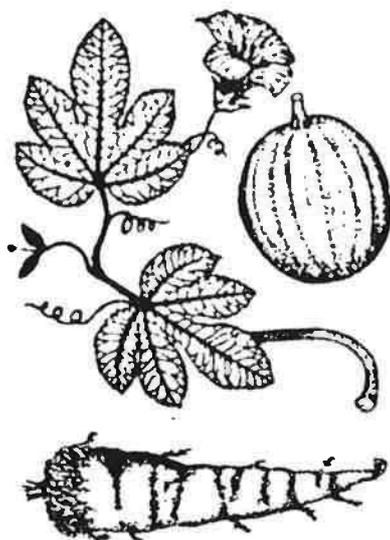
The preview will take place at the Hoyts Centre on Monday, 10th July, 1989.

Further details and bookings can be arranged through -

DON SMITH
Telephone: 264 6701

INTERNATIONAL NEWS

**The Q Factor:
cucumber root
causes excitement**



Drug is derived from root of plant, *Trichosanthes kirilowii*.

A new drug derived from the root of a variety of Chinese cucumber is creating great excitement amongst AIDS researchers at the University of California and San Francisco General Hospital.

GLQ 223, also known as Compound Q, has been used for centuries in China as a means to induce abortion. Early reports indicate the drug effectively targets and kills HIV infected macrophage cells. Unlike currently available drugs for HIV related conditions, such as AZT, Compound Q is the first substance found to actually destroy infected cells while leaving uninfected cells unharmed.

Though the substance hasn't yet been tested on humans, toxicity trials are expected to begin soon, which will then be followed by trials to determine its efficacy. Tests so far on animals suggest the drug, at least in its most pure form, has a low toxicity and induces few side effects.

AIDS activists in the states are cautioning PWAs not to be too optimistic about this, or any potential treatment before it has done the usual round of trials to determine its efficacy in humans.

[Source: Medical Science 18/4/89; AIDS Treatment News 21/4/89]

AIDS ADVOCATE

A private newsletter of AIDS commentary, news and treatment information published on an irregular basis.

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Nutrition therapy raises some ethical questions

A rapidly increasing number of people with AIDS are turning to a nutritional therapy intended to add weight to people who are wasting away. The treatment, Total Parenteral Nutrition, was invented 25 years ago as a temporary measure for people who are expected to recover from their illnesses. Its use in AIDS patients is the first time it has been used by people with a terminal prognosis.

A thousand or more PWAs received the therapy in 1988, double the previous years figure, health care providers say. This raises a troubling ethical question: can an already overtaxed health care system afford to pay for an expensive and, essentially, temporary treatment for long term patients whose prognosis is terminal.

The treatment is an intravenous feeding in which a highly concentrated solution containing all nutrients a person needs is pumped through a permanently implanted catheter into a vein that leads to the heart. Patients are normally fed for about 8 to 10 hours while they sleep. PWAs have turned to the therapy when they cannot eat because of painful sores or infections in their mouth or throat, or when they have severe diarrhoea which prevents them from absorbing food. Many readers of *Talkabout* may have experienced the scary situation of sudden drastic weight loss and its effects on their immune system or witnessed its effects on friends.

" The catheter is always there. To some people it's just such an invasion of their body. It's also the ultimate admission of disease."

The problem with total parenteral nutrition is that it can cost \$200 to \$500 per day. A private T.P.N. centre opened in San Francisco in April. The problem for PWAs is that the treatment is so expensive that it may drain their medical insurance rapidly and fears are held that it may trigger an insurance crisis. Patients need to weigh up the question of whether to take the therapy, considering the quality of life enjoyed by patients post-treatment, and the cost.

Further, PWAs do not make the decision to begin T.P.N. lightly. Larry S, volunteer co-ordinator with the N.Y.C. PWA Coalition said: "The catheter is always there. To some people it's just such an invasion of their body. It's also the ultimate admission of disease".

The bottom line seems to be, "Should anyone be allowed to starve to death simply because they cannot afford the cost of treatment?"
[source: New York Times]

AIDS health group tests U.S. Government policy

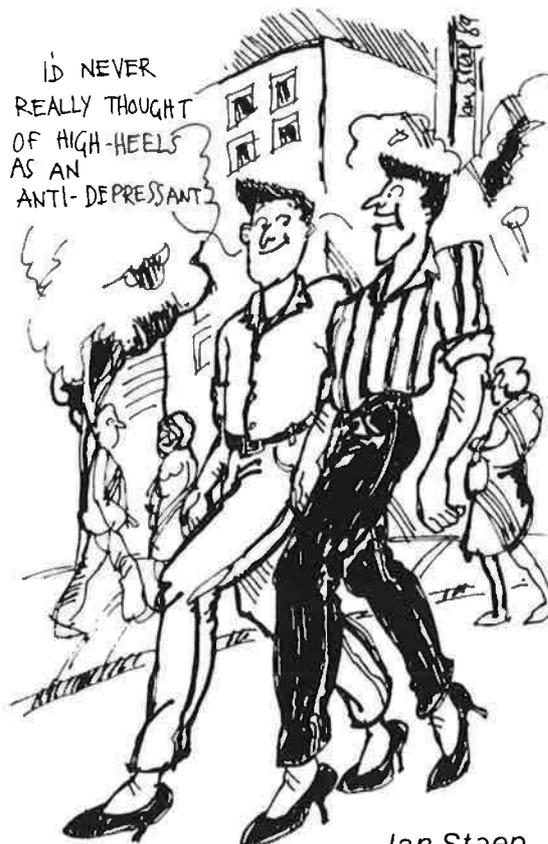
The New York "buyers club", the People with AIDS Health Group, has announced bold plans to test Food and Drug Administration (FDA) policies. The group has set up an elaborate network of contacts with doctors in other countries to import drugs unavailable in the United States, provided the client has a prescription from their doctor.

The Health Group has announced it will take advantage of FDA policy which enables people with life-threatening illnesses to import personal supplies of unapproved drugs. The New York group is the first of the buyers clubs to go beyond over-the-counter drugs. At this stage it is unknown how many people would take advantage of the program although it could be hundreds to thousands.

The FDA has greeted the scheme cautiously, stating that its responsibility was to protect Americans from harmful or useless drugs. AIDS advocates, however, point out that people with AIDS in the United States do not have time to wait for exhaustive testing and the lengthy FDA approval process to gain access to drugs already available by prescription in other countries. The group says there are at least half a dozen prescription drugs available in other countries that AIDS patients want.

Doctors and the health group agree that the drug most important to them now is Fluconazole, which is used to treat Cryptococcal Meningitis, an inflammation of the lining of the brain that afflicts between 10 - 15% of PWAs. Fluconazole, which is available in Australia under trial conditions, has far less side-effects than the previously used Amphotericin B, which can cause fever, nausea and kidney damage.

[Source: New York Times]



Ian Steep

New Zealand turns on the lights

The New Zealand People with AIDS Collective is alive and well and living across the Tasman. People affected by the virus are welcome to contact us when visiting New Zealand. Our postal address and telephone numbers are available from the PLWA (NSW) committee, as are copies of our newsletter, "Collective Thinking".

Warning on testing without consent

Dear PLWA

I am writing to warn any readers of *Talkabout* who are thinking of going to the Taylor Square Clinic or who already attend there because I thought that they may be interested to know of my recent visit there.

I had gone with the intention of receiving a vaccination for Hepatitis B. However, to my dismay and absolute horror, I was not only tested for Hepatitis, I was also tested for HIV, without my consent and without any pre- or post-test counselling.

Fortunately for me the result was negative, but this fact is totally irrelevant when one considers the process used to achieve the result.

The doctor concerned had the gall to apologise and say that we "must have had our wires crossed" when he took my blood; his understanding being that I was to be tested for Hepatitis, syphilis and HIV. When the topic of a test for HIV was broached, I had actually stated that I had never had one before, but that now I was *considering* having the test (but I had not made up my mind), a very different notion to giving my consent then and there.

As if this was not enough, I did not receive any counselling at the time, nor did I when the results came back! In fact, my post-test counselling consisted of (only after I had pointed out that I had not asked for the test), "Oh, sorry, I thought we were testing you for HIV



LETTERS

as well. Oh well, that result is negative too". I have been led to believe that this is not supposed to be allowed to happen, particularly in a clinic such as Taylor Square that has many "high risk" clients who go there regularly for testing.

Fortunately for me I am aware of what procedures are supposed to be followed in regards to testing and I am doing as much as I can about the incident, but I can imagine that someone who is not so aware could easily be led to believe that such procedures as I experienced are standard practice.

I have nothing against testing and believe that it is a decision for the individual. However, I am extremely angered to find that this practice of testing without consent and without counselling is going on in a clinic with a supposedly good reputation for looking after its clients. I really would like to urge readers who are intending to visit the Taylor Square Clinic, or any other clinic for that matter, to watch their step and attempt to prevent this sort of thing from happening to them. Heaven only knows how I would have coped had the test been positive!

Sincerely
D A

Speak for yourself!



Two songs for struggle and life

My second cousin lives in Washington DC and recently helped organize a conference of university administrators.

He wrote: "Programmed into the conference, which was attended by 3000 people, was a memorial program to our colleagues lost to AIDS. It was very moving, culminating with a display of a Quilt square complete with the association's logo. A couple of songs were presented and I have enclosed the lyrics".

Here are a few verses from two of the songs. I know you will all be touched, by both the sadness and joy of the very moving words.



The Ones Who Aren't Here

Let's pass a kiss
And a happy sad tear
And a hug the whole circle round.
For the ones who aren't here
For the hate and the fear
For laughter
For struggle
For life.

Let's have a song here
For me and for you
And the love that we cannot hide.
And let's have a song
For the ones who aren't here
And won't be coming home tonight.

(From "The Ones Who Aren't Here" J.Calvic - John's Gay Music Company)

Living With AIDS

The loss of our lovers,
Our sisters and brothers
Is a wound that cuts deep
through our history of pride
And one way to heal
All that pain that we feel
Is to stand by the living and
remain unified.

So if you've got a friend
whose condition is grim
Don't go burying him or
drawing the shades
Surrender your doubt
by reaching out
To a person who's living with
AIDS.

Living with Love, not living
in fear
Healing with hope and drawing
them near
It's a place to begin, it's a
step we can take
Empowering people whose lives
are at stake.

Living with love, not living
in fear
Embracing the light when
shadows appear
It's a place to begin, it's a
good way to start
Releasing the power we hold
in our hearts.

(From "Living With AIDS"
copyright: R. Romanovsky &
P. Phillips and dedicated to
the memory of John Peterman,
and to the future of people
with AIDS and ARC.)

Hopefully, whilst on my trip to Washington, I can find the accompanying tunes and obtain permission to arrange a performance of both pieces.

Andrew Carter.

A message from Bob

AIDS is an international epidemic of frightening proportions. Many people have died from the disease or suffered the loss of a loved one.

But great challenges seem always to bring out the best in people. As scientists strive to meet the challenge of finding a cure for AIDS others are showing the enormous human capacity for coping with great personal tragedies.

AIDS memorial quilts commemorate those who have died and acknowledge the dedication of their carers.

Through the Names Project all who have suffered are symbolically joined and I am pleased to add my support to this international affirmation of human compassion and caring.

R J L Hawke

Reprinted with the permission of the QUILT PROJECT.



IVDU Community Project swings into new phase

As reported in our last issue, IVDUs now have a community-based group set up with funding provided for NUAAs - NSW Users Advocacy Association. Phase 1 of the IVDU Community Development Project, overseen by PLWA committee member Ms Julie Bates, and under the auspices of Rankin Court and St Vincents Hospital, is now complete.

The Community Development Project now swings into Phase 2 of its operation now that NUAAs has been incorporated. Submissions for funding have been submitted to the NSW AIDS Bureau and indications so far are that the project will be supported, subject to Ministerial approval. NUAAs now seeks private, autonomous premises in the expensive Kings Cross/Darlinghurst area, away from the clinical atmosphere of Rankin Court, where a drop-in service and needle/syringe exchange facility can be operated. It is planned to hold education workshops as well as conducting both in-house and on-the-street outreach work. By setting up regional branches in major country centres, NUAAs will not only be truly representative and facilitate input from users, but will see its role continue to expand.

NUAAs held its inaugural Annual General Meeting on April 20. A constitution was adopted and the following committee members elected:

IVDU

President - Gray Sattler
Vice President -
Julie Bates
Treasurer - Robyn Jarryd
Secretary - Cecilia Gore
Committee - Steve Coady
Sue Tynan
Jamie Phillips
Delegates -

- Paul Everingham
(Injector Services)
- Alan Winchester
(Langton Clinic)

To reiterate Project Officer Julie Bates's words in our previous issue: the Advocacy Association is not supporting intravenous drug use, rather it offers, once fully operational, a risk reduction model of intervention, HIV and lifestyle education, support and possible rehabilitation. *Talkabout* wishes Julie continuing success with Phase 2 of the Community Development Project.

Paul Young

To contact NUAA
phone:331 4344



Dying with dignity

"It's not that I'm afraid of dying..."

It's just that I don't want to be there when it happens"
- Woody Allen

The one thing that all living beings have in common is the certainty of death. It is natural to hope that when the time comes we shall die peacefully, with dignity and without prolonged suffering. However, many people now endure a long drawn-out and deeply distressing process of degeneration, pain and dependence on others.

What is Voluntary Euthanasia?

The word "euthanasia" is derived from two Greek words meaning "good" and "death". Voluntary euthanasia is the inducement of a gentle, distress-free and dignified death either self-administered or assisted as the express wish of the dying person.

A distinction can be made between "passive euthanasia", which means bringing about death by withholding treatment which sustains the life of a dying person, and "active euthanasia" which is the rapid and painless inducement of death by the patient or at his/her express direction.

Unfortunately in NSW, while suicide itself is no longer a crime, aiding or abetting suicide is. This means that people who wish to have the option of active voluntary euthanasia have

difficulty in getting accurate information about how best to organize this course of action. Doctors are usually reluctant to provide a prescription for the necessary drugs. Often they are unaware of the best combination of drugs to use. Even with a prescription it may be difficult to find a pharmacy to dispense the drugs needed. It is even difficult getting medical practitioners and counsellors to calmly discuss the options for someone contemplating suicide.

The Voluntary Euthanasia Society of NSW is one source of assistance. Even though it is mainly a lobby group aimed at legal changes to make voluntary euthanasia easier, it does have a library available to members and, through informal discussions with other members of the Society, ideas about how to best organise voluntary euthanasia can be sorted out.

There are also PLWAs who have been looking into the choices for those who would like the alternative of euthanasia to be made available to them. Unfortunately legal restrictions mean that we cannot publish this information. However if you would like to pursue this matter or would like further information, the author can be contacted through *Talkabout*.

Authors name withheld on request

CSN

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About
Caring

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SUPPORT
NETWORK Inc**

INFORMATION/EMERGENCY NUMBERS

Community Support Network	(02) 212 2728
Sydney AIDS Hotline	(02) 332 4000



Lesbian and Gay Health Conference : San Francisco, April 1989

Two Sydney people gave presentations at this conference recently held in San Francisco. Paul Young explained local responses to the epidemic and recounted the development of Australian PLWA organisations. Ken Davis from ACON ran a workshop on HIV and travel/immigration restrictions around the world and the impact of the epidemic on Australia's partial recognition of gay relationships in immigration policy. They offer here some meditations on the gathering.

Sobering messages from San Francisco

With the assistance of sponsorship from the Australian Federation of AIDS Organisations (AFAO) I was recently able to attend the 11th US Lesbian and Gay Health Conference and 7th AIDS Forum in San Francisco. For me, neither an experienced traveller nor conference-goer, the trip proved a challenging and, at times, daunting experience. Please allow me to give a personal account of the conference highlights and my impressions of San Francisco.

Was I quite prepared for the impact of HIV on the world's gay mecca? I don't think so. A gay activist for 15 years, I found myself continually wondering what SFO was like ten years ago.

Browsing through the weekly gay give-away magazine, there were two pages of obituaries in each issue, and a majority of articles concerning HIV.

Everywhere are warning signs." Dial 863-AIDS", the number of the SFO AIDS Foundation. Very prominent too is a Bleachman poster campaign, Bleachman being a cartoon hero figure come to Earth to save IVDU's from HIV. The impact or success of this campaign appears minimal in the face of widespread and very visible IV drug use, especially crack/cocaine. To date only three trial needle exchange programs have begun across the whole of the US, while debate continues daily in the media. Australian legislators and health authorities have shown a commonsense approach to this issue and should be congratulated.



With AIDS-related deaths numbering in their tens of thousands and predictions that massive numbers of gay men are infected, the impact of HIV on this city has been enormous. At the same time it was most refreshing to see a PWA, with accompanying drip in tow, having a drink at a bar! At the Eagle Bar, SFO's premier leather bar, each of the contestants in the Mr Leather contest said they wanted to stop AIDS by being selected! A rough estimate is that there are approximately 80 AIDS/HIV organisations, support groups etc. in this city alone, competing for scarce funds or survival by soliciting funds from private enterprise and gay businesses. What is also strikingly evident is the greater cohesion and the role of the lesbian community in the face of the epidemic, especially as carers.

Before the Conference had begun, the media told the story of Dutch PWA and AIDS Educator, Hans Paul Verhoef, who had been gaoled on arrival in the US at Minneapolis (see Ken Davis's article below). The reason for his arrest was that he was carrying AZT and admitted to Immigration Officials (INS) that he had AIDS. This writer had nervously ticked "no" on question 35 on the visa application, the question relating to "contagious diseases". I was relieved to meet with other PWA's from Europe who had done likewise and had not been confronted like our Dutch colleague.

The detention of a PWA in these circumstances should prove an international embarrassment to US policies following the 1987 Helm

amendment to include HIV as a contagious disease. (Senator Jesse Helms of Carolina is America's Fred Nile, and has recently blocked funds for AZT in the Senate, dancing on the graves of PWAs.) Following the reactionary Reagan era, the Bush Administration with its Pro-Life stand shows no promise in re-addressing vital issues about the AIDS epidemic. The incident also carries grave implications for people with HIV wishing to travel, especially if many other countries follow the US model. With the 1990 International Conference on AIDS to be held in San Francisco, the policy must be changed, otherwise PWAs may not be able to attend a gathering which is going to directly affect their lives into the next decade. They must be able to participate in information sharing and decision making that will directly affect their quality of life.



Paul Young

PWA poverty, homelessness and discrimination remain rife in SF. By contrast, Australia's social welfare system shines. Perhaps the most chilling reminder of this is Stuart Macdonald, a PWARC who commenced a hunger strike on January 2 to protest discrimination faced by people with HIV. Now wheelchair bound, Stuart's brave stand distressed me. At ACT-UP (AIDS Coalition to Unleash Power) demonstrations outside City Hall to protest Hans Paul's detention, Stuart was one of the protesters who chained themselves to the building. Speaking with one of the other protestors, Jack Fertig, formerly the very infamous Sister Boom Boom, I asked about the many tents on the lawn outside City Hall. "Oh, that's just the PWA Vigil", he said. "They've been there for three and a half years, but it would be too political to move them". Following the recent successful peak hour blockade of the Golden Gate Bridge by AIDS activists, the meaning of a strong PWA profile assumed increased significance for me.

The Conference

Unfortunately I have little new to report in the way of PWA treatments and services. In some ways Australian PWA's are lucky i.e. you don't see homeless PWA's on the streets of Sydney. The most important message to relay is the increasingly held view that HIV is a chronic, manageable infection. A myriad of different trials are being conducted across the US, yet I detected some lack of national cohesion in the development of new trials and gathering of data,

American PWA's are tremendously fond of asking "What are you doing honey?" Meaning, "What drugs / treatments you are using". Many reported that unless they continued employment and were covered by medical insurance their AZT would cost them \$1000 per month. A very clear picture to emerge was that none believed a single treatment was effective. All took a multi-treatment approach to their infection. Most common was a low dose of AZT and Dextran Sulfate, Aerosol Pentamidine (as PCP prophylaxis), Megace (an appetite stimulant) and a wide range of vitamins. While a media war continues about the absorption properties of Dextran, many PWAs reported a better quality of life and little difficulty while using it in combination with other therapies/treatments.

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I became incredibly frustrated by the lack of options available to Australian PWAs. There are now 12 buyers clubs across the U.S. These are non-profit organizations providing a huge array of previously unavailable non-toxic substances, vitamins, etc as treatment options. I perceived a clear need for

such a group, including a massive expansion of the ACON Vitamin Co-op in Sydney.

In fact, the New York buyers club has just received F.D.A. approval to import drugs from overseas on a personal basis (see News item).



Paul Young

Close to 1500 people attended the Conference which featured over 500 presentations on a multitude of perspectives related to gay and lesbian health. A bewildering array of information on educational, medical, psycho-social, holistic and alternative care aspects of AIDS was

available. Strong emphasis was also placed on issues around lesbian health, people of color and youth. From a PWA perspective, some highlights were:

*PAWS (Pets Are Wonderful Support): This is a scheme set up in San Francisco for PWAs and PWARCs. Based on principles of trust, dependancy and friendship, it is a wonderfully simple and practical scheme to find pets for PWAs.

*AIDS and ARC Switchboard: is staffed by volunteers with AIDS and ARC who provide emotional support and information for those who feel confused, anxious or depressed, or simply want to talk to another person with HIV. A small group provides this information service 6 days a week. After visiting their office, I came away convinced that there is potential for such a scheme here with the advent of full time Day Centres.

*PWA Recreation and Support Schemes: operate successfully with substantial input of funding, concessions and volunteers from the private sector and gay businesses and establishments.

*Workshops such as "Prostitutes, Women and AIDS: resisting the virus of oppression"; "Problems of burnout"; those addressing homophobia; "Education of the Incarcerated"; and "Gay ownership of AIDS". These provided mixed amounts of new information or potential solutions on difficult topics.

*"AIDS mastery": a workshop conducted by fabulous therapist Sally Fisher was my

conference highlight
combining sychodrama and
intimacy, self-empowerment
and personal potential. I
wished it had lasted all day!

*Long term survivor Michael Callen gave an interesting paper on proposed aetiological co-factors of AIDS in the framework of a broad ranging political analysis. Michael, who inspired so many PWAs on his visit here last year, remains a source of excitement. Not only has he started a new 5 piece male accappella group, the Flirtations, but he has started a new AIDS Journal called "AIDS Forum".

The conference and the San Francisco experience left me confused and a little overpowered. The meaning of the term "epidemic" took on a new and larger dimension for me. Conference messages were abundantly clear: We need a continuing commitment to fight homophobia and calls for mandatory testing; a huge world wide struggle to fight discrimination faced by people with HIV; the battle for improved treatments and services for PWAs must be ongoing and universal; and gay men need to work more closely with the lesbian community with America as a model.

To end on an optimistic note, I feel in many respects Ausralian PWAs are far better off, despite meagre resources, in terms of Social Security benefits, Medicare benefits or housing.

Paul Young

Dutch PWA barred from U.S.

The hottest issue at the 1500-strong National Lesbian & Gay Health Conference in San Francisco had not been planned for the agenda.

As delegates arrived, news broke that a Dutch participant, Hans Paul Verhoef, had been detained on arrival in Minneapolis and gaoled in a maximum security penitentiary. Customs officers, discovering his AZT, had applied 1987 U.S. immigration regulations which bar the entry of people with AIDS, or who are even HIV antibody positive.

Faced with the option of immediate return to Europe, Hans Paul decided to tough it out, applying for a waiver of the exclusion ruling. Nic Filon, his travelling companion, continued on to San Francisco, where conference organisers began a national and international lobbying campaign.

U.S. immigration officials now claim that up to 15 travellers have been refused admission in the last year because of HIV status. In addition, regulations forbidding the entry of lesbians and gay men are infrequently used. Two Dutch travellers had been returned to the Netherlands on arrival at Minneapolis in 1988 because of their homosexuality.

The harsh action against Hans Paul electrified the conference. At the official



opening on Thursday April 6, Mervyn Silverman, President of the American Foundation for AIDS Research, derided the "acquired intelligence deficiency syndrome" of the Reagan/Bush administrations, and San Francisco Mayor, Art Agnos proclaimed Hans Paul Verhoef Day for the city.

U.S. immigration officials now claim that up to fifteen travellers have been refused admission in the last year due to HIV status.

Lunchtime that day saw conference participants join SF ACT-UP and AIDS Vigil activists in a protest rally at the United Nations Plaza. People with AIDS chained themselves across the doors to the Federal Building, successfully stopping business for one hour. "Chain up the doors, unchain Hans Paul" was the chant.

Local immigration courts ruled that Hans Paul could be released on \$10,000 bail, after signing declarations that he would abstain from all sexual activity and would not use American health services. The Immigration and Naturalisation Service (INS) appealed this ruling in Federal Courts. The failure of this appeal set Hans Paul free and set a precedent against such detentions.

On the last day of the conference, Saturday 8 April, Hans Paul arrived and gave a press conference for national and overseas media. If the United States hopes to host

the 1990 World AIDS conference in San Francisco the rules will have to be changed. "The Land of the Free" seems all too willing to obstruct the free flow of information when it concerns people with AIDS who have strategies to fight this epidemic.

There were over 500 presentations at the conference. Most featured different AIDS preventive education projects and treatment alternatives, orthodox and holistic. Candace Pert announced Peptide T as a cure for AIDS, without convincing very large numbers. Michael Callen, a New York PWA leader, reviewed the debate about HIV causes and cofactors. James Curran reported on Centres for Disease Control work. Several holistic sessions looked at "mastering AIDS", "self empowerment" and Chinese herbs. Most importantly, activists from buyers' co-ops and treatments news projects around the country met to better coordinate PWA access to therapy options.

The conference remains broader than its AIDS focus. There were dozens of 12-step program meetings such as alcoholics anonymous and narcotics anonymous through the week. There were innumerable discussions, not only on various aspects of chemical dependency, but also on being the partner or child of an addict or alcoholic.

Chronic Fatigue/Immune Dysfunction Syndrome, recognised by the Centres for Disease Control in March 1988 as a diagnosis was discussed. Its cause is officially unknown, but its relationship with Epstein-Barr Virus is

being debated.
Other issues of lesbian and gay well being were also addressed: domestic violence, breast cancer, homelessness, youth programs, the "new intimacy", midlife crises, burnout of carers and workers, and racism within our communities and services.

Ken Davis

Albion St. cancels AL721 trial : PLWA critical

On May 29 PLWA (NSW) made a strong public criticism of the unannounced decision by Albion Street to not go ahead with its long awaited trial of the egg lecithin product AL 721. Repeated approaches to the clinic's director, Dr Julian Gold failed to draw a full explanation as to why the decision was made beyond a passing comment that overseas trials indicated it was ineffective.

In the national press PLWA announced its proposal to begin negotiations with community organizations such as ACON and AFAO to establish community based drug trial initiatives on the model of those in the U.S. This is an effort to compensate for the apparent inability of institutions such as Albion St to follow through with much needed evaluations of alternative treatments. No explanation has been offered by the Clinic as to what will be done with the stockpile of AL721, spurring PLWA to call for control of the supply to distribute through community run initiatives. A decision by the clinic on what to do with the material will be delayed even further while the clinic's personnel are absent from Australia attending the Montreal International AIDS Conference.

HELP!

**Talkabout needs
contributions
from you:
articles
news
photos
cartoons
opinions
anything**

Next issue

Talkabout # 4 will feature a special section on "Women and AIDS". Submissions about this and any other issue will be welcome. Deadline for issue 4 is June 23.

Also in *Talkabout* # 4:
People living with AIDS in
Regional NSW.

BUT THIS IS NOW!

AL721 trial

PLWA envisages a system of trials which will be scientifically rigorous and appropriately monitored by private medical practitioners supervising the self-treatment of the substance. Such an initiative is seen as a step forward in broadening the search beyond the limited boundaries of current research institutions for more effective treatments for HIV infection. Further developments will be reported in the next issue of *Talkabout*.

Share Accommodation Project

The Community Services Unit of the AIDS Council of New South Wales is setting up a share accommodation register for people affected by HIV/ARC/AIDS and others seeking accommodation.

People who are seeking to share accommodation with others or who have accommodation they would like to share or rent with somebody, can contact the Community Services Unit, fill out a confidential questionnaire and hopefully be put in touch with appropriate share situations. This free service is not restricted to people infected with HIV.

For more details phone the Community Services Officer on 212 2728.

Counselling for the Wollongong AIDS Research Project

In the April edition of *Talkabout* Levinia Crooks gave some details of the aims and purposes of the Wollongong Project. As she indicated, the project has a direct charter to develop and provide counselling and support for participants as well as collecting information. Since January 1989 I have been involved as one of the two counsellors offering this counselling and support. In this article I outline some of the methods used and give some details of the support I have provided. Names have been changed to ensure confidentiality.

The project has been concerned with two groups of participants. Those who enrolled in the first stage of the project were men who were HIV antibody positive. The second stage of the project enlisted the participation of carers in the CSN training courses. There are a few participants who fall into both categories - carers who are themselves HIV antibody positive. I have worked with a number of people from both areas though the type of counselling and support has not been different for each group.

C A R E

From the outset, my approach has been one of offering support without being too intrusive. To introduce myself, I sent letters to those participants identified as my responsibility. I followed this up with a telephone call where I gave further details of the service I offered. I have kept in regular contact with these participants by mail and have also organized several informal groups for the carers I have been responsible for. I have consistently pointed out that there is no requirement that clients attend meetings or counselling sessions but that these are always available if and when needed.

My work with carers has been, by and large, concerned with dealing with specific problems when they arose. One example is Stephen. One day Stephen's client, who had experienced a very long and trying day, told Stephen that he should go back to CSN for further training. A talk with Stephen led to the realization that the client was expressing general anger in a quite specific way and that the anger was not directed particularly at Stephen himself. This reconstruing of the event allowed Stephen to deal with his own feelings of inadequacy in that situation and to resume caring with other clients.

There have been a number of such problems that have arisen with clients and in many cases I have simply been available for the carer to express his or her feelings of anger, concern, frustration, helplessness or grief.

The informal meetings, though not well attended, enabled carers to share their experiences and to provide support for each other. This was particularly useful after the death of a client who had been cared for by a number of carers. The fact that they had each been working with that client enabled them to share their grief at this loss. It was also an opportunity for carers to renew friendships that had been established during the initial training program.

The work with HIV antibody positive men has tended to be much more intense. Although only a few took up the opportunity for ongoing counselling, those who did participate appeared to gain much from the process. The fact of being HIV positive was, by and large, only the starting point in the process of considering the beliefs and feelings they had. Having the virus had often reactivated negative feelings they had about themselves and it was these that we were able to deal with. Clients were successfully assisted in looking in detail at a number of psychological self-constructs that they held, thus enabling them to begin the process of changing those constructs that prevented them from dealing with their situation. The absence of constraints such as time or money aided this process.

An example was David who, on being diagnosed two years ago, "went home and shut the door" behind him. In our talks we identified that one of his constructs was that he had to be perfect in all aspects of his life and that having the virus meant that he no longer was. Once he

realized how central these ideas had been to his feelings about himself, he was able to reconstrue this belief to the extent that he had resumed full-time work and was able to uninvite friends home. In another case, I was able to work with both my client and his lover to deal with problems they were having in their relationship.

FACE THE VIRUS

My involvement with the project concludes in early July. It has been an interesting and stimulating six months and my own counselling techniques have improved markedly as a result of my involvement. I have been pleased to work with Levinia, Larry and Robert and have learned much from them. Most importantly I have been privileged to work with my clients and to share their feelings about themselves and their experiences with those whom they care for. As a person with HIV myself, it is satisfying to feel that I have contributed in some positive way to the lives of PLWAs, infected and affected.

For further information about the project contact Levinia in Sydney on (02) 281 4404 or Vicki in Melbourne on (03) 481 5570

Robert Walmsley

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STOP PRESS

HIV SUPPORT OFFICER APPOINTED AT ACON

On 13 April, 1989, the AIDS Council of NSW appointed Terry Giblett to the new position of HIV Support Officer.

The position is designed to focus on the support and educational needs of the large number of HIV infected people who are still well.

The Living Well support groups will commence on 17 May and a new round of groups will start in the third week of each month. The groups will consist of 6-8 people and a facilitator, all of whom are HIV infected. They will run for 12 weeks with the group participants determining what they want to talk about.

A new package of pamphlets and posters will also be produced specifically for the HIV infected population.

Also, an information night and a close examination of what people infected with HIV need to know will be undertaken, and it is expected that educational programs will be set up and running by September this year.

Terry is attached to the Community Services Unit and can be contacted on 212 2728 regarding the Living Well Support Groups or any other matter relating to people infected with HIV.



INFORMATION NIGHTS
FOR HIV INFECTED PEOPLE

To be held at the ACON Resources Centre, Ground Floor, 68 Sophia Street,
Surry Hills.

1. HIV Infection and the Immune System:

Tuesday 11th July
6.30pm - 8.30pm

What the immune system is and what a virus is. How the HIV virus is spread. What the virus does in your body. How your body reacts. What is likely to happen once you are infected.

Open discussion will follow the presentations.

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2. Monitoring and Prophylaxis

Tuesday 18th July
6.30pm - 8.30pm

What does monitoring mean. What makes it worthwhile. The basics of what you need to know about monitoring. What is prophylaxis. How will it help you. What illness can be prevented by using prophylaxis. How will you know if you need it.

Open discussion will follow the presentations.

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3. Treatments and Drug Trials

Tuesday 25th July
6.30pm - 8.30pm

What are drug trials. How will they help you. The need for drug trials. What drug trials are available. The pros and cons of drug trials.

What medical and alternate treatments are available. Whose choice is it anyway?

Debate and discussion are intended as a part of this evening.

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VOLUNTEER FORM

PLWA (NSW) urgently needs volunteer assistance in a number of areas. If you are able to offer support in any way, please complete this form and return to:

PLWA (NSW)
PO Box 1359
DARLINGHURST NSW 2010

Name: _____

Contact Phone Numbers: (home) _____

(work) optional _____

I am able to help with (please circle area/s of interest):

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DAY CENTRE

HIV SUPPORT SERVICES/OTHER SERVICES*

ADMIN. ASSISTANCE/MAILLOUTS

ADVOCACY

Other areas: _____

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Name: (Please PRINT clearly) _____

Address: (for mailing) _____

Telephone No: _____

Are you willing to have any other member know your name and address? Yes / No

Are you publicly open about your membership? Yes / No

* Please note: To cover the cost of printing and postage I enclose subscription donation of \$10 for individuals, or \$20 for organisations to receive Talkabout for 12 months.

Enclosed: \$10 ... \$20 ...

I have read the rules and am eligible for membership.

Signature: _____