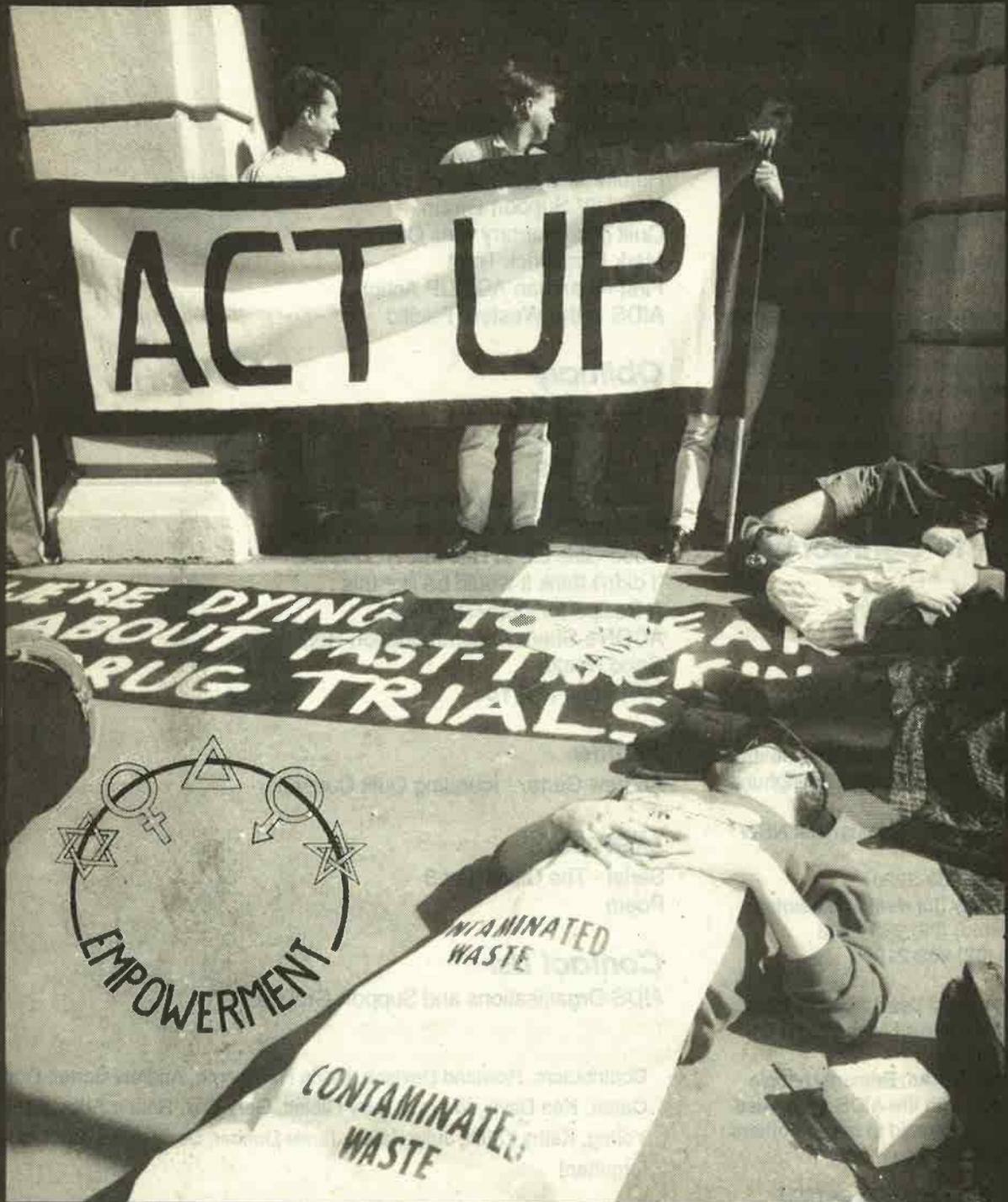


Talkabout

Newsletter of People Living With AIDS Inc. (NSW)

ISSN 1034-0866



ISSUE NUMBER EIGHT: MAY/JUNE 1990

CONTENTS

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

TALKABOUT is produced by the Newsletter Working Group of PLWA (NSW) Inc.

Copyright for all material in TALKABOUT, written and visual, resides with the respective contributors.

TALKABOUT is printed by Media Press, 7 Garners Avenue, Marrickville NSW.

TALKABOUT is made possible by readership subscriptions, donations and a grant under the State/Commonwealth AIDS Program.

TALKABOUT is also grateful for the assistance of the AIDS Council of NSW.

How to Contact Us:

PLWA Administrator:
Don Carter

TALKABOUT Co-ordinator:
Maria Hawthorne

2nd level, AIDS Resource Centre,
188 Goulburn Street, Darlinghurst
NSW 2010

PO Box 1359, Darlinghurst NSW
2010

Ph: (02) 283-3220

TTY Only (for deaf and hearing
impaired) (02) 283-2008

Fax: (02) 283-2199

Commonly Used Abbreviations:
PLWA: People Living With AIDS
(NSW) Inc.

PLWAs/PWAs: Primarily people
infected with the AIDS virus. Also
sometimes used to include others
affected by the virus.

2 Talkabout May/June 1990

Letters

Availability of AZT	3
Fear and Loathing	4

News

Albion Street to change focus	6
New Quilt Project convenor	6
Health Minister to launch IV drug user campaign	7
New HIV Support Group	8
Quilt documentary wins Oscar	8
Mark Fitzpatrick Trust	8
First Australian ACT UP Action	9
AIDS in the Western Pacific	9

Obituary

Brian McGahen	10
---------------	----

Features

Coming to a Better Understanding?	
Report of PLWA emergency meeting	12
Good Girls Go to Heaven	16
"i didn't think it would be like this . . ."	22
A Recipe for Domestic Bliss	
ACON's Share Accommodation Register	23
Good Health	
HIV, Food and You	26

Profile

Andrew Carter - founding Quilt Convenor	24
---	----

Literature

Serial - The Clinic part 3	18
Poem	21

Contact List

AIDS Organisations and Support Groups	28
---------------------------------------	----

Contributors: Rowland Davison, Maria Hawthorne, Andrew Carter, Ddn Carter, Ken Davis, Wayne, Terry Giblett, Gary Cox, Robert Ariss, Paul Young, Kathy Triffitt, Julie Bates, Jamie Dunbar. Sorry to anyone I've forgotten!

Open Letter to Don Carter, Administrative Support Officer, PLWA (NSW) Inc.

Dear Don,

In reference to our recent telephone discussion concerning the availability of AZT through local doctors.

My partner and I have lived together for three years. Eighteen months ago my partner was diagnosed as HIV positive by our local doctor.

Since that time he has monitored my partner's condition which at present is good. This I have no doubt is largely due to the positive support from our doctor.

However there will come a time

in the future when his health will deteriorate. Since at present our doctor cannot obtain AZT for his patients my partner would be required to attend Parramatta Hospital or Albion Street to obtain the drug. Therein lies the dilemma.

I know it would be impossible to persuade my partner to attend one of the clinics. Some people may think that his refusal would be an over-reaction to the situation. The decision, to him, is not. His fears of being a "guinea pig", seeing

other people with full AIDS and the "shame" of having contracted AIDS are very real to him.

Since it has been well-documented that a positive environment and support is vital in the treatment of the disease then it seems unnecessarily cruel to deny patients AZT through their local doctors.

I can only give you my wholehearted support to enable such changes to be made.

Yours faithfully,
Name withheld.

Yet another new TALKABOUT Co-ordinator!

Dear TALKABOUT Readers,

I am sad to tell you that this will be my second and last issue as TALKABOUT co-ordinator. I am leaving to take up full-time work on a western suburbs newspaper - not very glamorous, I know - and will miss working for PLWA and all the TALKABOUT readers.

As my time with PLWA has been so short I have not been able to make many of the changes I hoped to bring to the newsletter. However my successor, Jill Sergeant, should bring more fresh ideas and creativity to TALKABOUT.

Thankyou to all the contributors and volunteers who have made my time here easier, and many thanks to my co-worker Don Carter and PLWA Convenor Robert Ariss for all their patience and help. I wish TALKABOUT, PLWA, ACT UP and all PLWAs everywhere the best.

Maria Hawthorne

LETTERS

Fear and Loathing and Typical Prejudice

Dear Ed,

As a long time supporter of many minority groups and an advocate of universal civil liberties I must say something in defence of one of the more maligned and less represented groups in our society, IVDUs.

I am an addict. I'm not ashamed of that. What does bug me is the dogged stigmatisation of IVDUs, particularly among professionals and those who would seek to influence the community's views. When these attitudes emanate from other minority groups whom I have supported over the years it is at the least very disappointing and at times humiliating.

Unfortunately for all those who might choose at some time the use of narcotic or mind-altering substances, the "junkie" stereotype was constructed on the model of a very few number of users committing a large number of crimes, as well as the image of

"It would seem then that only an extraordinary amount of success can save one who uses narcotics from the description, 'junkie'."

the totally self-destructive, self-abusing addict.

While the same kind of stereotyping does not describe the entire alcohol-using community as violent alcoholics, this type of irrationalisation is used to describe all IVDUs as junkies, with one notable exception of course. We describe Brett Whitely as a national treasure despite his self-confessed addiction. It would seem then that only an extraordinary amount of success can save one who uses narcotics from the description, "junkie".

The only other alternative is to stay in your closet as much as possible and hide your personal habits from your closest friends. The worst thing you could possibly do is be blood-tested for HIV and answer the questions asked of you honestly. If you're unfortunate enough to test positive and later become ill and be diagnosed with AIDS you will regret that you ever made and honest reply to a doctor's questions.

You may find that not only are you not offered advice and medication easily available to your comrades but also the responsible flow of information between professionals may be tainted by their prejudices.

My solicitors in a civil matter have had reason to request medical reports about my illness. Apart from finding that I was being shuffled from one doctor to the next, making it almost impossible to obtain these reports, the documents that I did finally receive (one from Albion Street and one from St Vinnies) were extremely vindictive and prejudicial.

After showing the reports to mutual friends of both the authors and myself, solicitors and fellow voluntary workers in the fight against AIDS, I am convinced that I am not displaying any paranoia or being over-sensitive. Everyone has agreed that there is an underlying intent to damage my reputation or myself. This from people who should know better than most the debilitating effect of stress on a person suffering from AIDS.

Until these attitudes cease to inform and affect the quality of treatment being offered to IVDUs the war against AIDS is being lost. Those who have already openly admitted their status will be unable to honestly advise others to seek treatment and testing or modify their behaviour.

LETTERS

Instead, they will go on sharing needles and having unsafe sex rather than expose themselves to further humiliation and identification by their modified behaviour.

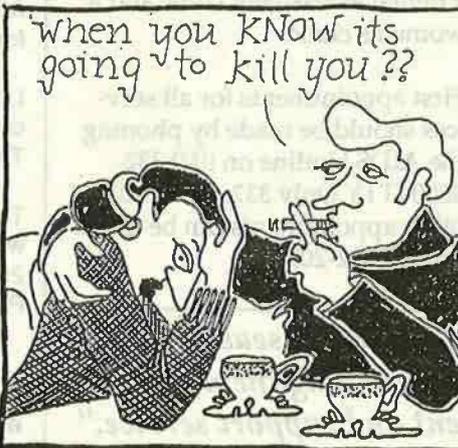
There is no place for any little Hitlers or Freddie Niles among our ranks, nor is there any justification for their divisive moral stereotyping and attitudes.

Mary Dickie of ANCA estimates that there may be up to 500,000 IVDUs in our country.

Retiring member of the Management Committee of PLWA (NSW) Inc., Rowland Davison.

"The only other alternative is to stay in your closet as much as possible and hide your personal habits from your closest friends. The worst thing you could possibly do is be blood-tested for HIV and answer the questions asked of you honestly . . ."

CAROLYN RISDALE



Reprinted courtesy Care Toad Times

LETTERS

Albion Street to change focus

After five years of providing a comprehensive HIV/AIDS testing and management service, the Albion Street (AIDS) Centre has changed focus to concentrate on its outpatient diagnostic treatment and support service.

The change follows a review of the Centre's services and the need to adapt to the current pattern of the epidemic.

Albion Street director, Dr Julian Gold, said the Centre would be concentrating on its role as an ambulatory care centre for the management of people with HIV/AIDS.

"This means we want to manage people with this disease more effectively in the community by providing them with an outpatient diagnostic treatment and support service," he said.

Development of new drugs against HIV has required the Centre to devote more time to its HIV positive patients, in addition to continued testing.

"In the past, Albion Street Centre focus was mainly on HIV testing," Dr Gold said. "However,

many of our clients who we diagnosed HIV positive years ago are now experiencing illnesses and therefore require more support from us.

"To do this, we have reduced the number of clinic hours for HIV testing. However, concentrating our limited resources in this direction should not reduce our Centre's HIV testing capacity."

People concerned with confidentiality and anonymity could continue to use the service, but should be aware that confidential free testing, including pre and post test counselling, was also available free from STD clinics attached to various public hospitals, Dr Gold said.

Aside from the HIV antibody testing clinic, the Centre also organises a medical clinic for ongoing antibody positive clients, a dental assessment clinic and a women's clinic.

First appointments for all services should be made by phoning the AIDS Hotline on (02) 332-4000 (TTY Only 332-4628). All other appointments can be made on (02) 332-2090.

"We want to manage people with this disease more effectively in the community by providing them with an outpatient diagnostic treatment and support service."

New Quilt Project Convenor

Accomplished textile artist Libby Woodhams has been appointed new Convenor of the Australian AIDS Memorial Quilt Project, following the resignation due to ill-health of the Project's founding Convenor, Andrew Carter.

"I've been lucky to have had two great years setting up the Quilt but now it's time to have a rest and spend more time looking after myself," Andrew said.

Libby has been a volunteer with the Project from its beginning and has created a number of memorial panels herself and assisted in the sewing of many others.

She has been with the Anjali Project (emotional support for PWAs) since 1987 and has co-ordinated art and craft activities at Maltraya (Day Centre for PWAs).

At present she teaches silk painting at the Sacred Heart Hospice, and with Andrew she has assisted the Long Bay AIDS Group to create memorial panels for inmates and prisoner's loved ones.

Libby graduated from the Sydney School of Divinity last year with a Bachelor of Theology.

To contact Libby, leave a message with the AIDS Council of NSW on (02) 283-3222 and she or another Quilt Project volunteer will return your call.

Turn to page 24 for an interview with retiring convenor, Andrew Carter.

NEWS

New Health Minister to launch IV drug user campaign

The Federal Government will continue to implement the National HIV/AIDS Strategy and will launch a major campaign aimed at recreational intravenous drug users and their sexual partners, the new Minister for Community Services and Health, Mr Brian Howe, has said.

Mr Howe told the audience at the AIDS Script Competition Awards Ceremony in Canberra last month that Australia had a world-recognised reputation for direct and very clear health care messages in AIDS education.

But it was time Australians accepted that the average injecting drug user looked the same as the average non-injecting Australian, and the stereotype of the "junkie" or prostitute did not fit the norm of people who casually or occasionally inject themselves with drugs.

"In New York City over 50 per cent of new infections affect IV drug users, their sexual partners or children," Mr Howe said.

"This increased rate of infection outside the homosexual commu-

nity has been called the second wave, with an estimated 80 per cent of IV drug users in New York City now being HIV positive."

Infection rates in Australia are currently estimated at between one and three per cent among IV drug users, but if overseas patterns were repeated here the figure would rise sharply over the next few years.

Mr Howe attributed the current low level of infection in part to the speed with which needle exchange and AIDS education programs were introduced in Australia.

The new testimonial-style campaign will alert users to the dangers of sharing needles and the potential of cross-infection to the wider community through unprotected sex.

Community-based organisation, particularly NUAA, Injector Services and PLWA (NSW) were involved at all levels of the campaign's production, and believe it is vital the government continues such consultation at

the "coalface" level if such campaigns are to be acceptable and successful.

"The campaign represents an excellent contribution to telling it as it is by people with HIV," Julie Bates of NUAA said.

"Participants were given the chance to speak out about their experience of living with HIV, where previously they had been silenced.

"Unfortunately, because of fear of prejudice and discrimination, the identity of speakers had to be disguised.

"Hopefully, this campaign will move the Australian society toward a more understanding and responsible attitude, once people realise HIV infection can happen to anyone," she said.

"We have to face up to two of our society's biggest taboos - sex and drugs."

Mr Howe was Minister for Social Security from 1984 and helped formulate Labor's Social Justice Strategy.

He continues to be Minister assisting the Prime Minister for Social Justice, a position he has held since August 1988.

"It's time Australians accepted that the average injecting drug user looks the same as the average non-injecting Australian . . ."

NEWS

Planned GROW AIDS/HIV Support Group

Presently work is being done to form an HIV support group within the GROW Program - the "International Community Mental Health Movement".

The group will be a special support group for anyone affected by HIV/AIDS, from persons in any stage of HIV to family members, friends, lovers, volunteers, caregivers and professionals working with people with HIV.

It will provide extra support, contacts with others and the opportunity for people to look further within, to improve one's life, to learn to live by the 12 steps of personal growth as used by GROW and to work on the physical, mental, emotional and spiritual issues of one's life.

The group will meet weekly using the GROW group meeting method. Members will be encouraged to

contact others during the week and have social nights.

GROW is a uniquely structured community mental health movement which began in Sydney in 1957 and has since spread to other countries.

GROW's program of Personal Growth, Group Method and Caring, and Sharing Community have all been developed from the findings of formal mental illness sufferers in the course of rebuilding their lives after a mental breakdown.

The person working on forming the group is Wayne W., a 24-and-a-half year old male who was diagnosed HIV-positive at the age of 19. He is also a recovering alcoholic and non-IV drug addict.

Wayne felt there was a need for some kind of support group based on the 12 Steps used by Alcoholics

Anonymous which could be used on all problems including mental health, which is very important if a person wants to live a better life with positive thinking and a lot of hope.

"I became a very sick person emotionally, mentally, spiritually and physically after finding out I was HIV," Wayne said. "Drinking did not help either. But today I can do something with my life, with the help of others in groups such as GROW, regardless of their problems because I understand much of it myself."

Wayne is presently undertaking training courses with CEIDA and plans to work with others living with HIV.

For more information on GROW or the planned HIV GROW group, contact: the Secretary, GROW, NSW Office, PO Box 64, Petersham NSW 2049. Ph: 569-5566.

Quilt Documentary wins Oscar

"Common Threads: Stories from the Quilt" has won the 1990 Best Documentary Feature Oscar.

The film, made in San Francisco, follows the stories of loved ones making memorial panels for the US Quilt.

Hopefully it will be screened soon in Australia.

Mark Fitzpatrick Trust

A trust fund to provide financial assistance to people who have acquired HIV as a result of a medical procedure has been set up.

The Federal Government provided a \$13.2 million seeding grant last November to set up the Mark Fitzpatrick Trust, named after a Tasmanian boy who died recently as a result of AIDS acquired through haemophilia treatment. The trust is run independently of the Government and is chaired by

Sir Ninian Stephen, founder of the AIDS Trust.

It will provide financial help over the next 20 years for the additional costs associated with HIV infection arising from medical procedures, including haemophilia treatment, blood transfusions, bone grafts, organ donation and artificial insemination.

For more information, contact the AIDS Policy and Programs Branch, Department of Community Services and Health, GPO Box 9848, Canberra ACT 2601. Ph: (062) 89-1555.

NEWS

First Australian ACT UP action

Over 100 men and women took part in the first Australian ACT UP demonstration, a noisy street rally, outside the Sydney offices of the federal health authorities on Friday April 27.

The ACT UP (AIDS Coalition To Unleash Power) protest was called to put pressure on a meeting that day of the Australian Drug Evaluation Committee (ADEC) to quickly approve AZT for all those with less than 500 T4 lymphocytes.

Though AZT is more widely available in Europe, North America and New Zealand, only Australians with symptoms or

less than 200 T4 cells are eligible for AZT.

Alternative drugs such as DDI are also not currently available in Australia. ADEC has no system of fast approval of drugs used overseas to treat people with life threatening illnesses, and would be likely to take two years to expand the AZT guidelines.

Street theatre during the protest depicted ADEC's denial of AZT to people with HIV through a mass "die-in".

ACT UP was formed in Sydney in early April to express the anger of people with HIV. On average one person each day in

Sydney is diagnosed with full AIDS and one person dies.

In response to extensive media coverage of the birth of ACT UP in Australia, the new Health Minister, Brian Howe, said that he would welcome information on streamlining the drug evaluation processes, and admitted that he had not realised it was a priority issue.

On average one person each day in Sydney is diagnosed with full AIDS and one person dies.

Workshop on AIDS in the Western Pacific, Organised by the League of Red Cross April 2 - 7, 1990

The League of Red Cross, operating out of Geneva, provides assistance to Red Cross societies around the world and since 1987 has been involved in AIDS prevention education in South America and Africa.

The League's work provides Australia and New Zealand with an excellent model and a basis on which to best assist our nearest neighbours, especially the poorer nations in the South Pacific. Further, the model in action proves that educational processes when used properly do have the desired impact and in a very short time produce excellent results.

My experience in Fiji demonstrated that even if given only meagre resources, with a committed approach much is actually produced and a great deal of learning can occur, despite huge differences in the

educational backgrounds of participants. (The participants ranged from people with little or no schooling to medical professionals).

I attended the conference as a person with AIDS to allow participants the opportunity to experience first hand what it is like for someone who has AIDS.

The situation in Fiji and the other island nations does look grim if the spread of AIDS is not halted now, so conferences like this that encourage community organisations such as the Red Cross to do AIDS prevention education are critical.

I learnt much about the local culture of Fiji and the other nations in the region and made some friends in the six days we were together.

The conference spent much time educating the educators about facts on AIDS; and we also talked about the appropriate way

to treat people who had become infected, as well the sorts of problems they might face.

The highlight for me was my visit to the Fijian Navy where I and some of the other conference participants spent some two hours talking to about 25 to 30 sailors about AIDS and how it is transmitted, and revealed I was a person with AIDS. Unexpectedly they were very friendly and open with lots of questions I didn't expect and I think the whole effort had a great impact on them.

The future of these Pacific nations is dependent on the AIDS epidemic being contained as much as possible, so I hope that as in this case we here in Australia can continue to give our support and encouragement, especially to their non-government agencies, in halting the spread of AIDS.

Terry Giblett

NEWS

Talkabout May/June 1990

Brian McGahen

3rd March 1952 to 2nd April 1990

*Our forces were slight. Our goal
Lay far in the distance
It was clearly visible, though I myself
Was unlikely to reach it.
So passed my time
Which had been given to me on earth.*

Bertolt Brecht

Brian McGahen died on Monday the 2nd of April 1990. He was 38 and had been suffering with HIV infection for some years. Brian took his own life.

Most of you will know of Brian, even if you didn't know him personally. He was one of the truly significant men in the Sydney gay community in the 1980s.

Brian was instrumental in forming the gay community we know today. In the Mardi Gras, he saw the opportunity to involve masses of gays in celebrating their sexuality - in a proud, open, and vibrant way.

Brian's period as Director and then President of Mardi Gras covered the crucial first five years of the 1980s. With his leadership and vision, the event became the most significant event in the calendar of our community.

On the 14th of April 1984, Brian was convincingly elected to the Sydney City Council as an Independent. Brian believed that once there was gay representation in local government, the gay community would be well on its way to becoming a recognised and legitimate part of the city.

10 Talkabout May/June 1990

Brian's career on the Council was cut short by the decision of the Unsworth Government to sack the Council in March 1987. Brian had shown himself to be a vital force in the Independent campaign to keep the City free from the property developers and the schemes of the State Government.

He was always interested in anyone's problems - whatever community they were from. Above all he had become recognised as a leader of the gay community - both by the media at large and the community itself.

Brian's last few years were less public. He was active in a number of AIDS issues - the extending of Home Care services to PLWA's, and he campaigned to have the Carer's Pension extended to "non-related" carers.

Brian described AIDS as the gay version of the Jewish Holocaust. He felt its impact heavily in the loss of his friends, political colleagues, and his business partner. Brian also recognised the devastating effect the epidemic was having on our community in terms of the loss of significant people.

Brian had fundamental principles about

people's right to control and direct their own lives with pride and dignity. This made him an activist for many years in the Communist Party and also in the Peace Movement and the Anti-Apartheid Movement.

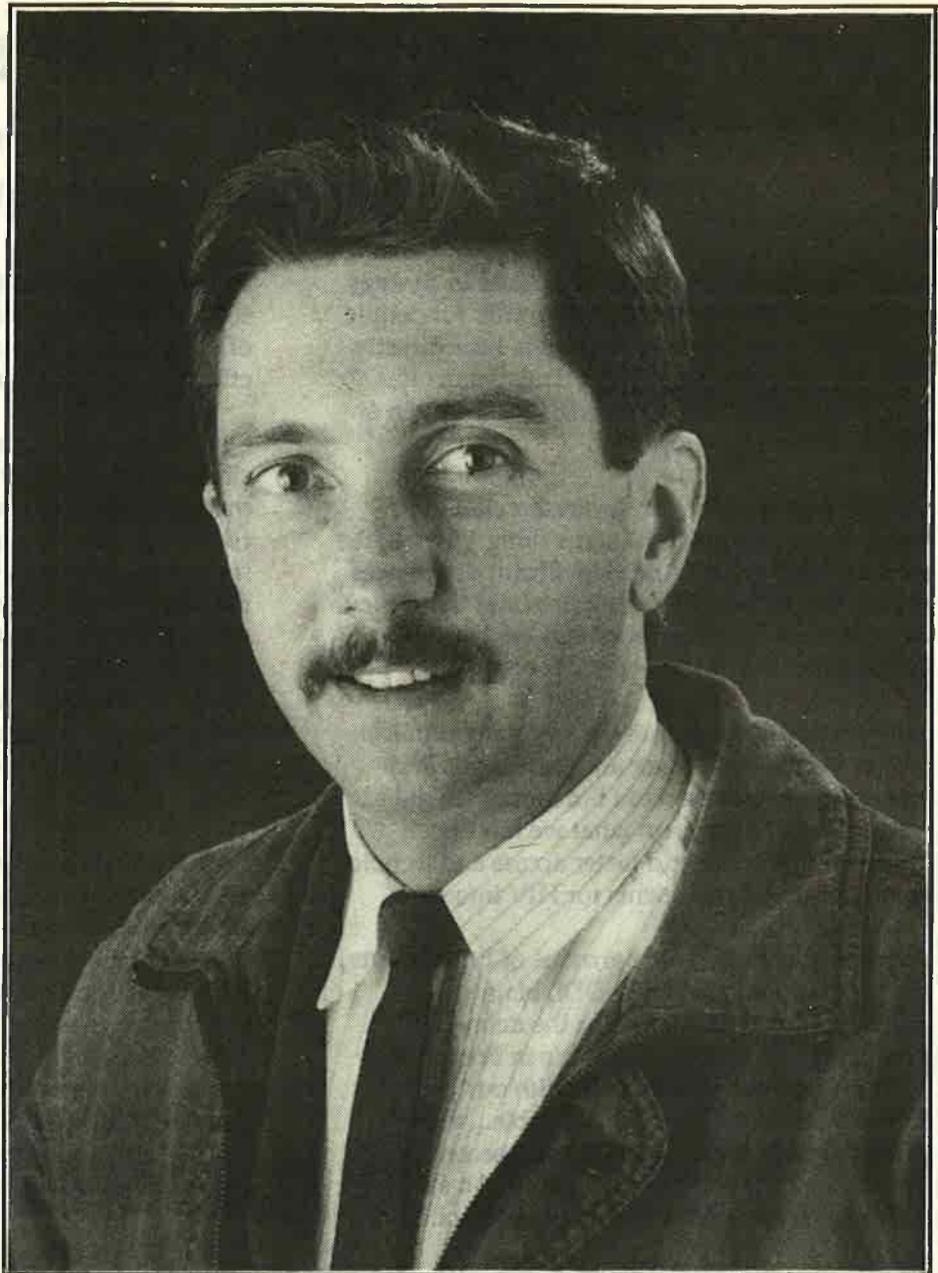
The way he lived his life inspired the way he chose to die. Brian was diagnosed with HIV a number of years ago. He was jealous of his quality of life and was insistent he did not want to endure a long drawn-out death. He did not want to tolerate a distressing process of degeneration and dependence on others.

So he died the "gentle distress-free and dignified" death he had written about, counselled people about, and talked about for two years. When he died, he had his friends around him and he was very happy and joyful.

His passing was peaceful yet with strength.

Brian was one of those amazing men that only come into your life once in a while. I will never forget his total belief in the gay community, his full commitment to social justice and liberation, and his profound integrity.

I remember with fondness the happy times we've had together, the trips to the beach, the



expeditions to the steams and the beats, the nights of dancing, the raves and the gossips.

More than anything I will remember his joy in living life to the full. He was a great party queen, our Mitzy.

GARY COX
3-5-90

Coming to a Better Understanding?

Emergency meeting highlights philosophical differences between researchers and PWAs

The PLWA Emergency Meeting held in Sydney on March 22 was a timely opportunity for people in the HIV affected communities to hear directly from the medical researchers, drug companies and government bureaucracies, their position on HIV treatment development.

Despite a comment from one researcher that "basically we all want the same thing", I think the meeting highlighted some significant differences of philosophy held by researchers and those they rely upon for drug development - us, the HIV infected.

I say researchers, because the company representatives from Bristol Myer and Burroughs Wellcome and our government bureaucracies did at least appear to agree on what we have been demanding - wider and faster access and a choice of experimental treatments for HIV infection.

For example, Robert Mongrovius of Bristol Myer, the company investigating DDI, blamed his parent company in the US for the delay of the drug trial here in Australia. "We in Bristol Myer have pressed again and again with our parent company to make the drug available... these events outside the US have taken a second priority...all the events that lead up to a study starting are not totally within our control."

The problem here appears, then, to be related to our geographical location on the periphery of a global trial network. I feel the answer must be, not

we must be or do as the Americans do (something the gay movement does perhaps a little too much of), but rather, that Australia must link more effectively into a global system.

Our old friend/enemy Burroughs Wellcome was similarly conciliatory. Pat Clear, the company's marketing manager, announced that relations between the company and the federal government improved very recently, possibly due to "some of the work that has been done by some of your organisations", after the feds agreed to view the US AZT trial results without insisting they be translated into the usual Australian format. The approval process should therefore be much quicker. He anticipated the company would submit the results within a few weeks.

We appear then to have had some success in this area in forcing the federal government to realise the slowness of their procedures and the urgency of need at the community level. Thus Peter Lehman of the Commonwealth Department of Community Services and Health could confidently report "people on ADEC are aware of the concerns of the community and the need for rapid evaluation of applications in the area of treatments for HIV...any applications that come in will be looked at with as much speed as possible".

If only it were true. We are aware now that Burroughs Wellcome have indeed submitted data for approval for AZT for people under 500 T cells. We

What we are talking about therefore are major changes in the decision-making processes in Australia over these issues. The government's will to protect the public health in this sense becomes an impediment to the pursuit of better health and a threat to the freedom of its citizens to make informed choices about their own lives.

also know that the April meeting of ADEC did not include this issue on its agenda as it may have done.

The problem appears then to be that, even if there is a will to change, there is not always a way to do it. This is largely due, as Clear pointed out, to the fact that the "Australian requirements for drug registration are amongst the most stringent in the world and it does take, no matter what the product is, an evaluation time usually much longer than most other countries".

What we are talking about therefore are major changes in the decision-making processes in Australia over these issues. The government's will to protect the public health in this sense becomes an impediment to the pursuit of better health and a threat to the freedom of its citizens to make informed choices about their own lives.

Herein lies the fundamental ethical issue highlighted at the meeting. In the same way that, say women have demanded freedom over their bodies in issues such as abortion, contraception and childbirth, people with AIDS and HIV are now experiencing an empowerment which allows us to de-

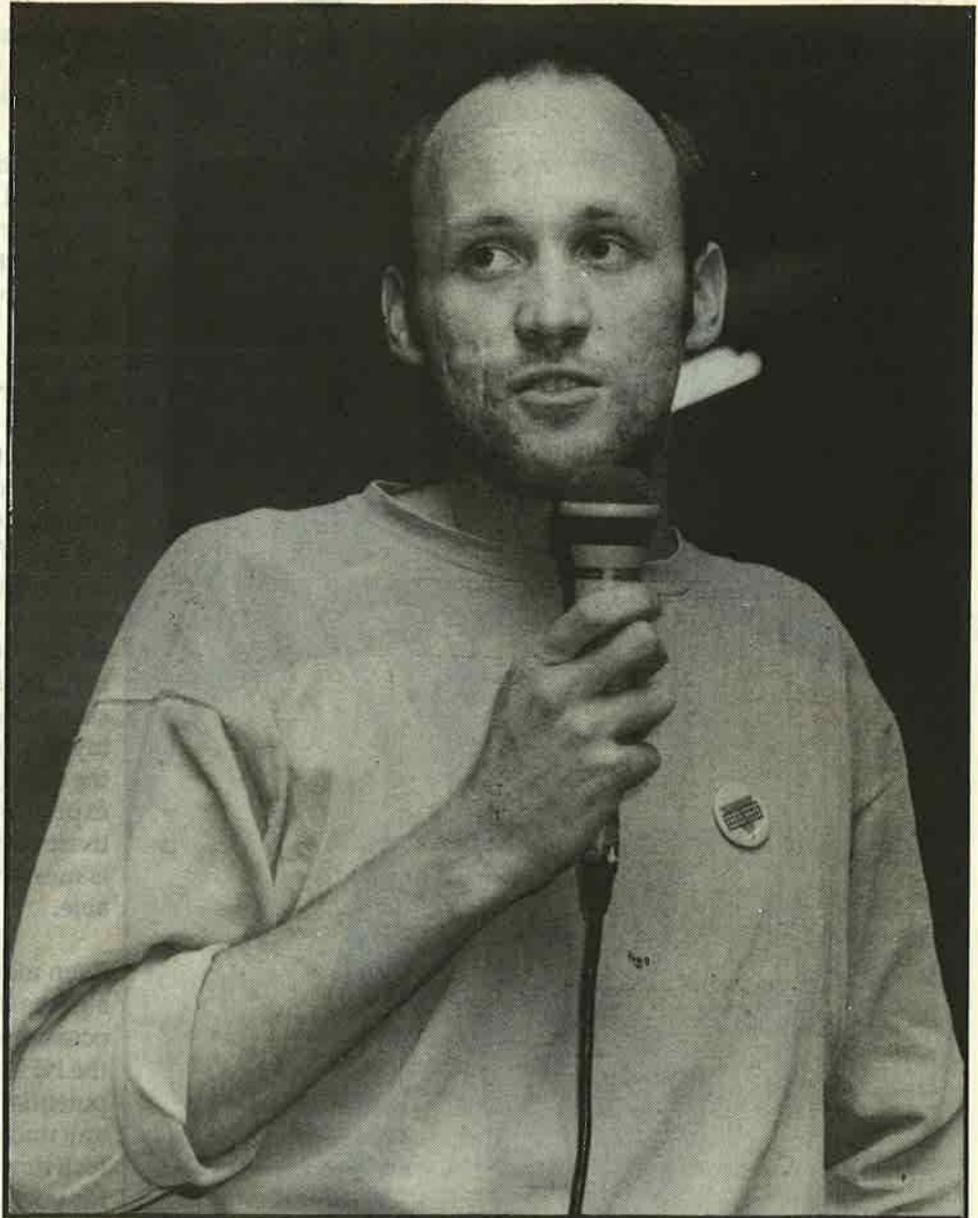


Photo: Jamie Dunbar

Terry Giblett: "I would have rather have taken the risk of taking AZT not knowing the side effects than have gone through PCP and lost over two thirds of my immune system in the process . . . I think we have to stand up and say we want the choice."

mand control over issues such as access to treatment and dignity and choice over death.

The meeting in this sense became a rehearsal of power games between the major actors - the medical research establishment, the government bureaucracies and the HIV infected.

Medical research has an apparently obstinate tradition in how it goes about testing drugs. The placebo-controlled double blind trial is the cornerstone of this tradition. Tracking the effects of drugs on people is only reliable, they maintain, if matched against a population sample not on the drug but who may think they are. This approach strikes me as an extraordinarily mystical admission to the power of the mind, not something you would expect from a tough minded positivistic science that believes nothing is meaningful unless it is measurable.

Even more astonishing are pleas, such as those heard on several occasions from Professor Cooper of the NH&MRC, that if you, as a potential subject of such trials, have any uncertainty about a drug's effectiveness, "it would be reasonable for you to be randomised to a placebo controlled study".

Unfortunately Professor Cooper's hopes are not borne out by experience overseas (and someone please explain to me why it should be any other way) where most in the UK DDI trial elect to be randomised on a low/high dose trial, and in the US where parallel track procedures are universally demanded from the community.

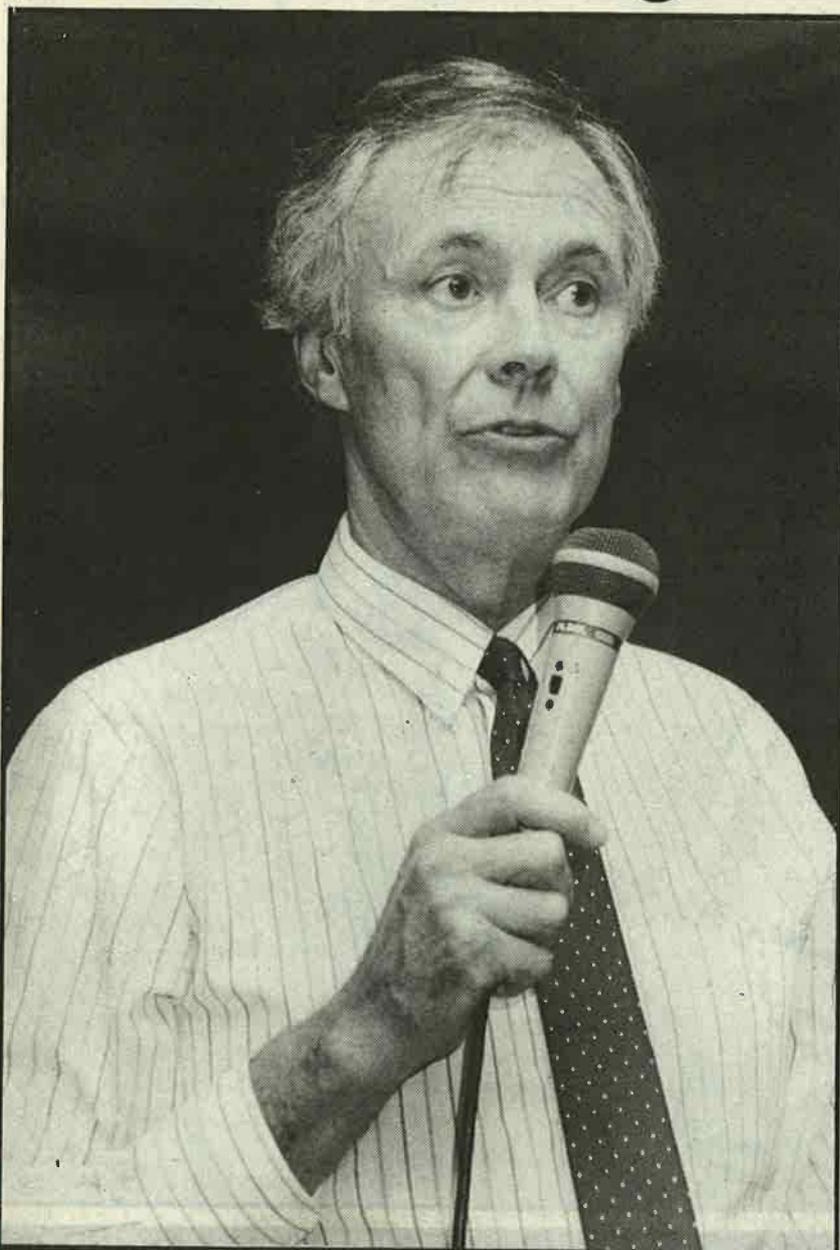


Photo: Jamie Dunbar

Pat Clear - relations between Burroughs Wellcome and the Government have improved very recently, possibly due to "some of the work that has been done by some of your organisations" . . .

When we are talking about people with AIDS at very late stage infection, described, astonishingly by Professor Cooper, as "people who are otherwise reasonably well", being expected to willingly collaborate in placebo trials, such expectations seem extremely unreasonable.

Cooper did not explain satisfactorily why but he is clearly opposed to the parallel track proposal, a system gaining currency in the US in both medical and client communities.

These differences of philosophy were perfectly summarised by Terry Giblett that evening when he described, during question time, his experience with PCP and his demand for choice in early treatment.

"Let me not recommend PCP. I've just had it, eight weeks after my diagnosis I'm still symptomatic and it's very very difficult and it hurts a lot. I would have rather have taken the risk of taking AZT not knowing the side effects than have gone through PCP and lost over two thirds of my immune system in the process...I think we have to stand up and say we want the choice."

Another problem identified at the meeting was the inequity of access to treatment. While Professor Cooper initially insisted "nobody has had to suffer in this country who has required AZT because he (sic) can't afford to pay for it", he later admitted that "we sometimes get ourselves in the false notion that everybody lives in the postcodes 2010, 2011 and 2021...I think that's probably something we have to address". We in this case being us and the governments.

CATN thereby became the final topic of contention in the debate. As I pointed out to the meeting, the CATN proposal has been here and supported by government authorities (at least in principle) for over eight months. Why has there been no progress in getting community trials off the ground?

As Rolf Petherbridge pointed out, the proposal adheres to all scientific requirements of evaluation and control and provides the best and most economic solution to expanding access to drugs

"CATN is our ultimate answer to these problems. Along with a faster, more responsive bureaucracy, we need a decentralisation of health care into the community."

like AZT beyond the already overburdened teaching hospitals. His comments were supported by Dr Basil Donovan of the Sydney STD centre.

But "some people seem to have gone cold on the idea", Rolf pointed out. The reason - "CATN is in competition with other drug trials for its infrastructure", the unwillingness to commit funds for such an infrastructure he described as "morally reprehensible" and, I would add, another clear indication of the reluctance to admonish power and decentralise the trial system into the community.

CATN, I would maintain, is our ultimate answer to these problems. Along with a faster, more responsive bureaucracy, we need a decentralisation of health care into the community.

As Professor Cooper rightly pointed out, we also carry some responsibility to inform ourselves of our options and make appropriate and informed choices with our doctors on these issues.

The Emergency Meeting was a step in the process of coming to a better understanding of researchers, drug companies and their interests, and the government. And they of us.

Perhaps we all do want the same thing, that being, I suppose, greater control over our lives and the epidemic that threatens us. We will never achieve this if the established powers, medical and governmental bureaucracies, cling to their traditions and privileges. They will continue to hear more from us, no doubt.

Robert Ariss

Talkabout May/June 1990 15

Good Girls Go to Heaven . . .

This is an interview with a transsexual living with Cat 4 AIDS and her male lover. Their names have been changed to protect their innocence and to thank her for coming forward to talk with the newsletter, bearing in mind TALKABOUT's strict confidentiality policy. Transsexuals are referred to as 'trannies' in vogue with street jargon. The interview is printed without many of the author's questions to Jesse as the flow of conversation is self-evident.

Jesse is a transsexual in her mid-twenties, and she suffered her first major HIV-related illness approximately a year ago. Her partner Jamie, her lover, is HIV positive also, but in robust health. Both are very experienced street sex workers. Both are very anti-intravenous drug use, although both have used injectable drugs (amphetamines etc) for many years for recreational purposes and lifestyle modification.

Jesse, tell me about how you cope with living with HIV and the differences it has made to your life.

The major problem after finding out 12 months ago that I had full-blown AIDS has been the boredom of being sick and not able to work. I have survived as a tranny until then. I have cross-dressed and worked as a street tranny since I was 14, originally interstate.

I knew up until 12 months ago I was HIV, but

went through a huge denial phase. I continued to survive the only way I knew how, as a sex worker. It got to the stage where all I wanted to do was cry, but that didn't help either.

HIV has made me feel powerless and depressed. A lot of other trannies - I would say at least 75 percent are HIV too but won't discuss their status because they get no support as most street workers don't stick together where gay men have a lot of support networks. At times I feel rejected by my peers.

Describe your relationship with Jamie.

Many people say I am lucky to have a lover, but I still find myself feeling isolated and getting depressed about AIDS. We have been together for more than five years and we think I gave him the virus. Since he discovered he was positive our sexual relationship has gone downhill. He says he doesn't care as long as he is with me. Now though he gets scared about lumps and spots that appear in the shower.

HIV has made me discontented about our relationship. One of the main reasons being that since we moved into public housing in the distant suburbs, we are so far from our normal familiar environment. Rather than making \$300 a night easily, now I have to try and live on a pension which makes me more depressed. At times though - I realise life without Jamie would not be worth living - he is so good to me.

What makes it harder having HIV and being transsexual?

I estimate 90 percent of working trannies are HIV but most would not admit it because there are no support systems. I told my family but they did not seem concerned. So I often wish I'd never had a test; because since I first got sick a year ago I

T

Trannies are treated by public health as outcasts - a cock in a frock. But if people want to treat me as a man, I will behave like one and punch them out.

cannot escape the fact I have AIDS because in many ways it makes me feel like a leper.

Some doctors treat me in a pathetic fashion and only a small number have been helpful. Dr Gold's assistance I describe as being like a fart in a jar. In hospital though they put me in a single room which is fine with me. Trannies are treated by public health as outcasts - a cock in a frock. But if people want to treat me as a man, I will behave like one and punch them out.

What about your present health?

I started AZT about eight months ago, but had four transfusions in three months so I've stopped it, because it kept making me sick. I don't know what happens from here. I have never received any worthwhile counselling, but get most of my support from Jamie and other people I have met in clinics. It is too late for gender surgery although I often dream about it.

What else would you like to say?

Basically to stick together, because I wouldn't wish the virus on my worst enemy. They say that tears stop but they never do. They shoot horses for having a broken leg - and living with the virus is very painful.

Now I just take life from day to day.

Paul Young
25.4.90

AIDS CONFERENCES

**AIDS in ASIA
and the PACIFIC**



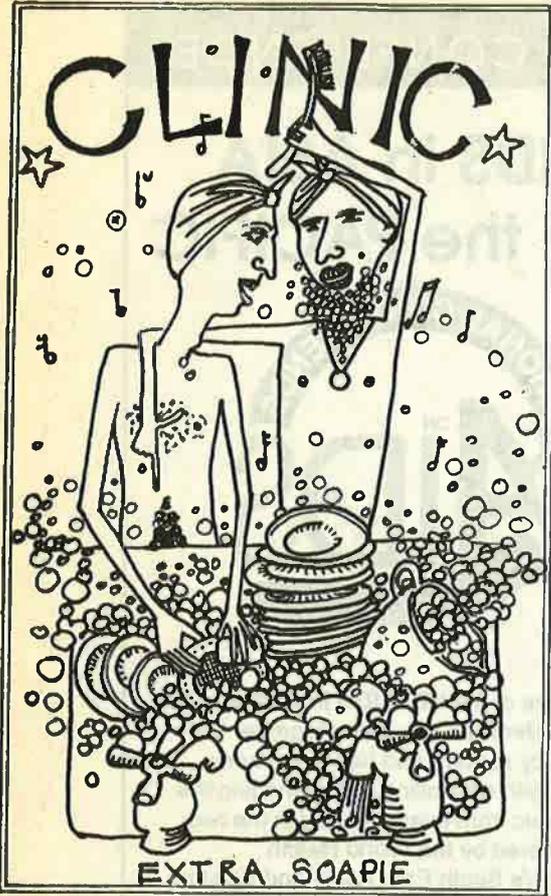
The objective of the **HIV/AIDS In Asia and the Pacific Conference** is to bring together the leading policy makers and health workers concerned with controlling and managing the HIV pandemic from every country in the two regions covered by the World Health Organisation's South East Asian and Western Pacific offices. People from government departments of health, education and welfare, clinicians and health workers from hospitals and health services and representatives of community and religious groups are all invited to attend.

The 4th National Conference on AIDS will immediately follow the AIDS in Asia and the Pacific Conference. Its aims and objectives are to bring together policy makers, professional care givers, people affected by the epidemic and other interested individuals and groups to address those issues which were highlighted in the National HIV/AIDS Strategy

For more information, please contact Conference Solutions Pty Ltd, PO Box 135, Curtin ACT 2605 Ph: (06) 285-3000; or Steering Committee Secretariat, PO Box 660, Woden ACT 2606

**5 - 11 August 1990
CANBERRA**

Talkabout May/June 1990 17



Part 3

Graphics: Rowland

"Gino, have you ever used smack?" asked Neil as they strolled together arm in arm down Darlo Road.

"Yeah, used a bit years ago when I was living on the North Shore," Gino said. "I lived in a house over Lavender Bay in some rich kid's place. The parents were on permanent vacation somewhere in the south of France. The pocket money still came in though.

"It was one big party every day. Dope came in sugar bowls, just woke up one day and it was there. Cost me nothing except a habit. Then one day Jack, whose house it was, got busted. No
18 Talkabout May/June 1990

more dope, no more nice views - C'est la vie.

"What about you, Neil? You ever put a needle in your arm?"

"Yeah, reckon that's how I caught this bloody virus," he said. "I mean, I'm not a haemophilic, haven't had a blood transfusion, couldn't have been my sex life - I didn't get lucky very often. Think someone must have been puttin' ugly pills in me coffee every morning.

"So how else would I have caught it? I've used pretty much daily for the last 15 years. Of course I've done the methadone trip and gone straight for a while, but I keep coming back to it."

"Why's ya use a dirty fit then, ya mug?"

"Well, needles haven't always been easy to get," Neil explains. "I can remember the old days, you'd have to think up a good story for the chemist then use the thing for so long you'd have to sharpen it with a matchbox and still need a hammer to get it into your veins! Things have changed, thank God - no need for stories for the chemist or borrowing off another user. You can get 'em at exchanges without hassles."

He smiled, then said angrily, "All this crap I keep reading about so-called ritual sharing gives me the shits. Who wants to wait around for your turn when the dope's there in front of

you, just so you can have a sharing experience? We just couldn't get them."

As Gino and Neil continued their stroll down Darlo Road, Neil spotted a friend.

"Hey Ann Marie, how goes it? Business picked up since those fuckin' media jerks left off? How's the dope at the moment? Heard it was knocking off a few people over Christmas."

Ann Marie looked at Gino suspiciously - a narc, perhaps?

"You holding?" Neil asked. Ann Marie pulled Neil to the side of the road?

"You fuckwit! Who's your friend?" she hissed.

"Cool it, Ann Marie - Gino's just a friend from the clinic," he told her. "How about it then?"





She thought about it. "Well, okay Neil, but I don't want to meet all your friends, ya know. How much do you want?"

Neil thought for a moment about his overdue rent and how his sickness benefits had to stretch that fortnight. "A half-weight," he said, handing her \$150.

She disappeared around the corner, calling back, "Wait for me in the Picasso coffee shop. I'll only be a minute."

In the Picasso, Neil fidgeted and played with the sugar.

"What's the story?" Gino asked. "Is she a prostitute?"

"Yeah, and a good one at that," he said with approval. "Ya know, she gives out condoms and fits on the streets to users and other workers who use."

Gino, who knew little about these things, pondered over this statement. "But I thought all prostitutes were too busy hustling making dollars to care about condoms or AIDS," he said fi-

nally.

Neil laughed. "You watch too much tele, luv! You don't believe all you see on the box, do you? Ann Marie should be paid double for her work in educating the mugs about condoms and AIDS and stuff."

"Well how long's she gonna be? I don't want to sit here all day," Gino complained.

"Just sit tight and be patient." Neil reflected on the hundreds of hours he's sat around waiting for the man.

Gino's thoughts turned to accessing a fit to use with the dope. "Where are we going to get a fit from?" he asked Neil.

"You stupid fool, Gino," Neil said. "I just finished telling you about needle exchanges. We'll go up the Cross to the exchange. Remember? Hassle free, no need to spin stories, user friendly service etc!!!"

"Oh yeah," said Gino, "but I don't want anyone to know I'm using. It's something I do just very occasionally these days."

"Be cool, Gino. Come up with me and see how it works. I'll get a couple for both of us, and you never know - the next time you get the urge I mightn't be around and you'll have to get 'em yourself."

Ann Marie slid into a chair at the table.

"What kept ya, Ann Marie?" Neil enquired.

"Got a job on the way," she said. "Can't afford to turn down a mug these days, they're getting to be as scarce as hen's teeth and a girl has to make a living. You wouldn't believe it though, he didn't want to use a condom. He reckoned french was safe. Sure, safe for him but who needs a bout of gonorrhoea of the throat? Anyway, he finally got the message - NO CONDOM, NO SEX."

Ann Marie discreetly passed the dope to Neil under the table. "Be seeing ya Neil, take good care of those T4s, won't you?"

Neil put four dollars on the table and started to leave. "Come on Gino, let's get out of here."





When Neil and Gino arrived at the exchange, the receptionist smiled at them. "Hi there," she said, recognising Neil. "How can I help you today? Thanks for bringing in all those used fits last week."

"That's okay," Neil said, "but I haven't any to return today."

"That's fine. We understand that some people dispose of their fits at other exchanges or in disposafit bins around town," she agreed. "How many would you like?"

"Just two today, thanks," Neil said, "oh, and some sterile water and swabs."

"Of course, the swabs and water go with the fits. You've got to be careful you don't get bacteria into your blood stream, and cleaning the injecting site first and using sterile water reduces that risk."

Help yourself to the condoms and lube - you never know when you'll get lucky," she said, smiling at Gino. "Can I have your exchange number and postcode?", and she dutifully noted it in a book on the desk.

"Thanks love, see ya soon," Neil said as they left. "Now that wasn't a hassle, was it, Gino?"

"Hell no!" Gino exclaimed. "I can't believe how friendly she was, didn't treat us like junkies at all. I wonder if she's used

herself in the past. But what's with the number?"

"It's just for the stats love, it doesn't identify you or anything," Neil quickly reassured him. "They get AIDS funding and have to document how many people they are seeing and how many fits they're giving out and getting back in, that's all."

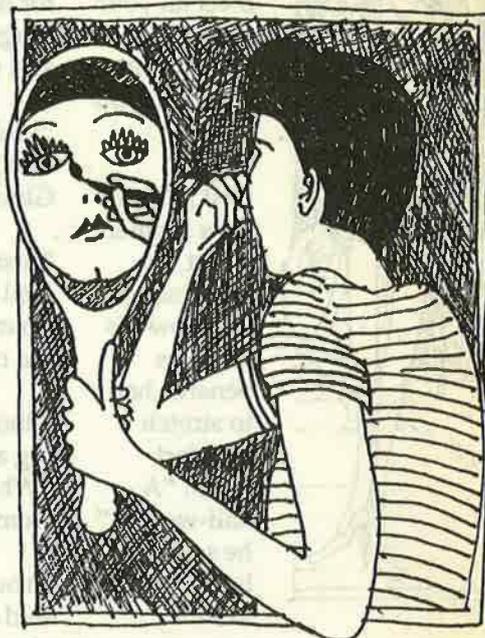
"Well, where to now?" Gino asked. "Your place or mine?"

"We can't go to my place, love," Neil laughed. "Me mum's up from Melbourne and is staying with me."

"Okay then, let's go to my place!"

Inside Gino's apartment, Neil rummaged through the kitchen draw and pulled out two spoons. "I'll get the dope ready," he said.

"Okay, I never was much good at that anyway," Gino said. "Let me know when it's ready - I'm just going to get changed."



Gino sat at her dressing table and looked in the mirror. "I wonder if her really finds me attractive..."

Clarissa Goodbodie

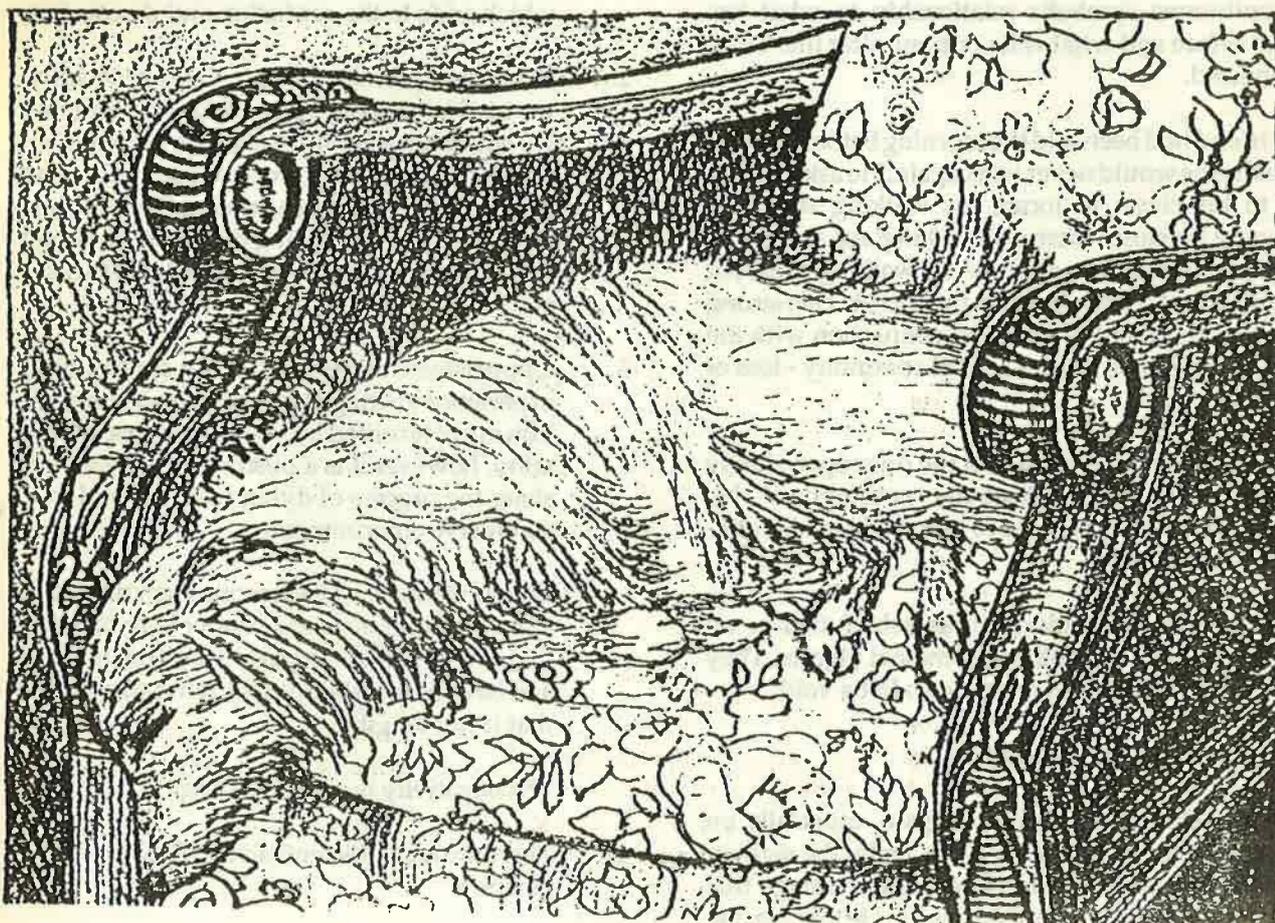
To be continued ...

(Note: each author has complete control over the characters' personalities, sexuality and gender. Therefore the "her" in the final paragraph is not an annoying typo but rather a mystifying gender change - ed.)

T

I love my dog, she's better than most
when I don't have an appetite she eats the whole roast,
My dog is a queen, she struts and she strides
she pisses in puddles oh no never inside
My dog says piff, to the cafes she passes
and ignores all the phoneys drinking coffee in glasses
They shout and they scream, keep that pooch well away,
get stuffed bloody yuppies and tourists she says
My dog is a star, she glitters and shines
and is the best little friend I could ever call mine
Oh what will she do, when the day finally comes,
that I die of AIDS and there is no one at home.

Rowland



Graphic: Rowland

"i didn't think it would be like this . . ."

"i didn't think it would be like this.
i thought it would be a pair of nice
white pyjamas and a quick injection . . ."

The writing of this article has been prompted by my experience at the Special Care Unit, Hospice located at Prince Henry Hospital.

Traditionally separation, disintegration and loss of status are death equivalents - images that relate to concerns about death whereas the experiences of connection, integrity are usually associated with a sense of vitality and symbolisations of life.

When a person is dying it is necessary to have a sense of connection, continuity and integrity. The environment, ideally, is one that encourages, nurtures these processes physically and symbolically - a continuous symbolic relationship to what has gone before and what will continue after life. To be connected.

My friend had been told the morning before I visited him that he would never walk again. He asked me to go to his closet to locate his walking stick. On opening his closet there was nothing! An absence of personal objects - no clothes - no walking stick! An empty closet. I felt a lump in my throat. This strong image is a symbol of removed connection with the past, present and future - loss of continuity - loss of control.

Not knowing what to do, I let the door open slowly so that my friend could see the "nothingness". He was confused and wanted to know where his walking stick had gone.

The nurses had decided, on his behalf, that he no longer needed his clothing, personal objects. They had taken control and in doing so left a void.

No connection, no continuity.

For the relief of psychological pain, especially on being told he would never walk again, the sight of the walking stick would have been an image that reflected positivity, control, dignity. He told me that

he wanted "to leave the hospice with some dignity", however I could feel that he was being deprived of control over his situation.

Nurses and doctors experience their own death anxiety as well as such death equivalents as fear, disintegration, separation and loss of status.

The problems that I perceive with the Hospice at Prince Henry are:

1. Lack of continuity as far as staff employment is concerned. Agency staff are often quite unprepared for what may confront them in this particular situation expressing fear, anxiety which is transferred to the clients.

There exists a lack of continuity for the client which adds to the confusion and discomfort.

2. Exhausted permanent staff. On one occasion we tried to visit our friend and were told that we could not see him due to the fact that he was too ill. In the background I could hear him calling our names. Yet again another example of a staff member making decisions on behalf of the client, taking away control. Disempowered.

3. Oppressive environment. It is a confronting experience visiting someone who is dying. You are confronted by your own sense of mortality, however it is a positive experience to share the process of dying with a friend in a conducive environment.

When entering the Hospice one pushes through a thick membrane and I cannot help feeling that I have just taken part in a difficult birth and have been pulled out into an environment that is not tangible.

The negativity is overpowering.

4. There are not sufficient kitchen facilities in the Hospice.

5. Breach of client confidentiality.

Autonomy and connection equals psychological survival equals physical survival.

A person needs a sense of history, present and future. When a person is lying in a room processing the changes that are occurring a sense of stability, status is required.

My friend died.

He didn't use his walking stick, however he did need it as psychological reassurance.

In Auschwitz it was an all important status of having a number tattooed on one's arm which meant life, however precarious.

Kathy Triffitt

A recipe for domestic bliss ACON's Share Accommodation Register

If you're looking for a house or flat to share but are daunted by the decision to either hide or reveal your HIV status to potential flatmates, ACON's free Share Accommodation Register could be what you need.

While the register is not restricted to HIV positive people - in fact, you won't even be asked for your HIV status for the purposes of accommodation - the service is aimed at people who will not be compromised if their flatmates discover their HIV status.

"What the Share Accommodation Register specifically sets out to do is to take the negotiation about HIV out of flat sharing," ACON Accommodation Officer Andrew Morgan said.

"There's still a lot of prejudice in the community against HIV - even in the gay community there's still discrimination, which is ridiculous in 1990."

Andrew said it wasn't unusual for people to be evicted once their flatmates found out about their HIV status.

"As soon as some people find out their flatmate has HIV they want them out," he said. "Often even if they know their HIV status before they move in, once the person gets sick the other flatmates get worried and decide that they have to go.

"We have a lot of people who come in and they've got sick and their flatmates have told them to leave."

Another problem faced by HIV positive people is the affordability of share housing. If a person has to leave work and live on sickness benefit, more often than not he or she will have to find somewhere cheaper to live.

"Often we can organise rent assistance," Andrew said, "but for a lot it's still not feasible to stay where they are. I mean, if you've been paying \$175 a week because you like the view of the Harbour, you're not going to be able to keep that up even with rent assistance."

Since the register was set up around a year ago, it has received 80 to 90 applications. At first the applications mostly were from people looking for somewhere to live, but currently it has more people with rooms to fill on the books.

Most people hear about it by word of mouth, but flyers are also distributed in venues and it is advertised each week in the Star Observer.

"The register is purely a contact service," Andrew stressed. "No-one is under any obligation to move in somewhere we send them to, and no-one has to take someone into their house if they

don't want to. They have to live together, after all.

"It is also only a flatmate service. If someone gets sick, we don't expect their flatmate to be their emotional or financial support. There are other services and agencies around Sydney which provide those things."

The service is not restricted to the Sydney Metropolitan area. Anyone from around the state is welcome to register.

Because of the sheer volume of applications, the register has remained a contact service only. It's up to the person looking for accommodation or a flatmate to keep ringing the Accommodation Officers for listings or to stay listed.

Andrew said the register was a valuable service.

"I would encourage a lot more people to use the service, and I would also encourage people to use the other share accommodation services around if they can afford them," he said.

For more details, please phone the Accommodation Officer on (02) 283-3222.

Maria Hawthorne

Talkabout May/June 1990 23

T

Andrew Carter - Quilt Convenor

Andrew Carter is the outgoing convenor of the Australian Quilt Project. Andrew introduced the Quilt to Australia after seeing the American project and has been involved in all areas of getting the project off the ground. He has now retired due to ill-health. Talkabout spoke to him about his involvement and his hopes.

How did you first get involved with the Quilt Project?

I saw the American Quilt in May 1988 in Atlanta, and I popped into the Names Project in San Francisco on the way home just to get some ideas to take back with me.

I came back to Australia and got some friends together and we made the first panels in Australia.

Originally they were made only to be sent back to the American project, but after we sent them we realised we'd lost something that was very special to us, that the Quilt was something important to keep close to us.

So we decided to get an Australian Quilt started. We got a committee together and aimed to have the quilt ready to launch on December 1, 1988 (World AIDS

Day). We started sewing and getting panels together. By December 1 we had about 30 panels made and about 90 volunteers involved.

What has been the most important thing to come out of the Project?

I think the most important thing is that we set ourselves three goals, three aims, and we actually are achieving them.

Our goals are: to provide a positive and creative means of expression for those whose lives have been touched by the epidemic; to illustrate the impact of the AIDS epidemic by showing the humanity behind the statistics; and to encourage support for people with AIDS and their loved ones.

We set ourselves those goals and we are continuing to achieve them.

Which panels have particularly affected or impressed you?

I couldn't say that any one panel has impressed me more than all the others. But the one that I enjoy showing to the media the most was made for Charles Frost, who was an Aboriginal. It was the first time I'd seen a panel which was three-dimensional and which brought in all those aspects of Aboriginal legend and spirituality, which added another layer to the panel.

His was the first I'd seen which had that spirituality. Then we received the Latin American panel, which had the names of around 11 Latin American people and brought in all their culture.

I was really worried that the Quilt project would become a memorial to gay white men only, but more panels like those two have come in and the Quilt is quite representative. We have over 100 panels now.

Who have the panels come from?

They've come from a mixture of friends and family, and from different states. Some are just one person remembering one person, while others are done by groups of people or to remember more than one person.

One panel that we're going to receive today was done at a dinner party. Everyone was given a sail, like off a sailboard, and wrote or drew something on it, and then one person sewed them all together. And of course while they were all doing this, they were all remembering this person and things about him.

What have some of the highlights been?

Meeting all the people involved - there's been so much love coming in this direction, and that would be the most rewarding part.

I was talking to a woman in West Australia just last week and the bond was amazing - we've never met but she was telling me about her panel and about who it was for and the love coming over the phone was so strong.

Do you encourage people to send a photo of the person and something about them with

their panel?

Yes, definitely. We want to turn this into an archival project, to keep the people's humanity alive.

An artist was memorialised recently and they sent in a program from one of his exhibitions and some poetry about him and I really liked that.

When we get a more permanent space to exhibit the Quilt we want to set it up so the panels are numbered and people can walk around the panels and then go to a corresponding number and read about the person the panel is for.

What do you think will happen with the Quilt in the future?

Unfortunately, I think it is going to continue to grow. It will continue to travel - it's very important to have it tour, especially to country cities and town.

Do you have any final messages for the people who have been involved with the Quilt or who may get involved?

No, I don't really, apart from "Get involved!". The Quilt is an example of an organisation dealing with AIDS that people can get involved in. People can get involved with PLWA but I think the Quilt Project is a bit different, maybe a bit easier to get started in. People can get involved in everything from licking envelopes to helping to sew.

I'd like to stress that while I was looking after the Quilt I had a lot of spare time because I wasn't working anywhere else, so I could put a lot of time into the project. But the people who are taking over are all working full-time, so it will be even more important for people to give them even more help and support.

Maria Hawthorne



Founding Panel Makers and Committee. (l-r) Ken Bryan, Michael Coghill, Brett Sutton, Larry Stillson, Ruth Cotton, Andrew Carter, Sara Dunn. (Kneeling l-r) Tom Collins, Libby Woodhouse, Richard Johnson.

Good Health

This is the first in a continuing series on healthy lifestyles. All readers are invited to contribute articles, tips, recipes and practices that have helped them live more healthily or peacefully.

This article has been reprinted with permission from a brochure put out by the Food Distribution Network.

HIV, Food and You

If you have ARC or AIDS, nutrition is now very important to you. It can have a positive influence on your immune system. By eating well and regularly, managing stress, and getting enough sleep, you can increase the number and functions of your lymphocytes:

Your **weight** is an important indicator of your nutritional status. If you have lost weight, and especially if you are leaner than the healthy weight for your height, then try to gain weight by eating frequently.

Don't miss meals and try eating nutritious, high energy snacks between meals. Weight loss can be caused by loss of fluid (dehy-

dration), loss of fat and muscle, or a combination of both.

Dehydration: Your body is 70 percent water. Water is continually leaving your body in the air breathed out from your lungs, in sweat, in urine, and in faeces. This loss must be replaced by fluid in the diet.

The amount we need to drink daily generally varies from about one to two litres (four to eight standard measuring cups). This can be water, soda or mineral water, fruit juice, tea and so on.

If you don't drink enough to replace your normal fluid loss or if night sweats are causing extra fluid loss, you will become de-

hydrated and lose weight.

You will lose fat and muscle if you're burning up more energy than you're eating. This will happen if:

- your appetite is poor, and you don't eat enough;

- some of the food you eat isn't being absorbed, as happens if you have diarrhoea;

- some of the food you eat is being burned up if you have a fever.

What to do if you have a fever or diarrhoea: With fever or diarrhoea you will be losing a lot of water which may make you dehydrated. If this happens your mouth will be dry, and you may have a headache. Drink, drink, drink, as much as you can.

Take a jug of water to your bedroom. Drink whatever you feel like (except alcohol or coffee). Water, diluted fruit juice, lemonade and Lucozade are all good.

You may worry that these drinks contain sugar, and sugar contains energy but no other nutrients. True, but take them: you need the energy. Try eating small, frequent meals, and eat food warm rather than very hot or cold.

T

Avoid high fibre foods such as seeds, pips and skins, nuts, raw fruit and vegetables, and whole grain breads.

With persistent diarrhoea people temporarily lose the enzyme lactase, which digests lactose, the sugar in milk. If this happens, you will be unable to digest milk and milk products and your diarrhoea will become worse.

If your sense of taste or smell is changed, try making the food look as appealing as possible. Decorate your meals with gar-

nishes such as parsley, sprigs, chives, onion rings, sliced fruit or nuts.

Cold foods are often better tolerated because they don't have a strong smell. Sandwiches, cold meats and chicken, eggs and cheese are worth trying.

If food tastes bland, you can make it more interesting with flavourings such as herbs, lemon juice, pickles, relishes and chutney.

Add sugar to tone down acids

and salty foods; add salt to tone down foods that are too sweet.

Try new taste sensations to stimulate appetite. Cream cheese with celery or apple, nuts with sultanas and dried fruit, and peanut butter with sprouts or banana on toast all have an interesting "mouth feel". The combinations are limitless.

Hunger will prolong nausea. Try to eat small frequent meals of your favourite foods. Relax before meals.

Keep up your fluid intake. Ginger ale, lemonade, soda water, mineral water and tea all keep you from becoming dehydrated.

If you live in the inner city area and are over 55, or on an invalid pension, or disabled, or on a carer's pension, then the Food Distribution Network can deliver to you fresh fruit, vegetables and meat.

At the moment there is a waiting list of around four to six weeks.

Single box of fruit and vegetables: \$5

Fruit, vegetables and meat: \$7

Fruit only: \$5

To order, phone 699-1614 by noon Wednesday.

13 Edward Street, Chippendale.

Talkabout May/June 1990 27



CONTACT LIST: AIDS ORGANISATIONS AND SUPPORT GROUPS

ACCOMMODATION:

Share Accommodation Register for people affected by HIV/AIDS and others seeking accommodation. Free, not restricted to HIV positive people. (02) 283-2222.

AFAO (AUSTRALIAN FEDERATION OF AIDS ORGANIZATIONS): Umbrella organization 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. PO Box A1242, Sydney South 2000. (02) 283-3550.

AIDS COUNCIL OF NEW SOUTH WALES (ACON): The Council provides services in education, welfare, support and advocacy in relation to HIV/AIDS to the gay and general community. AIDS Resource Centre, 188 Goulburn Street, Darlinghurst 2010. (02) 283-3222.

ACON Hunter Branch: PO Box 124 Islington 2296. (049) 29-3464.

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. Also "Just Positive" and "Being Positive" Support Groups for people with HIV. (02) 332-1090.

ANKALI PROJECT : A volunteer based project providing emotional support to people with AIDS, their partners and loved ones. Administered by the Sydney hospital. (02) 332-4000.

BOBBY GOLDSMITH FOUNDATION : A charity organization, 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) 281-1097.

COMMUNITY SUPPORT NETWORK (CSN) : Trained volunteers providing practical home/personal care. A volunteer based organization providing home care for people with AIDS. Established in 1984. (02) 283-3222.

CSN WOLLONGONG: Contact Joley Mallia. (042) 75-2609.

CSN NEWCASTLE: Contact Andrew Hope, ACON Hunter Branch. (049) 29-3464.

DAY CENTRES:

KATOOMBA (HAERE MAI): Operates every Wednesday from 10.00am – 4.00pm for meditation,

lunch, creative activity and just getting together; and on Sunday for lunch unless some other activity has been planned for that day. Contact (047) 82-1359 – Kevin or Greg, or (047) 82-2119 – Bill.

NEWCASTLE (KARUMAH): Operates every Friday from 11.00am – 4.00pm at McKillop House, Carrington. Contact John (049) 62-1140 or the Hunter Branch of the AIDS Council on (049) 29-3464.

SYDNEY (MAITRAYA) : Daytime recreation/relaxation centre for people with AIDS run partly by volunteers and funded by the NSW Department of Health. 396 Bourke Street, Surry Hills 2010. Enquiries: Irwin Diefenthaler (Co ordinator) (02) 361-0893.

DEAF COMMUNITY AIDS PROJECT: Contact Colin Allen at ACON (Sydney). (02) 283-3222, (TTY only) (02) 283-2088.

EUTHANASIA: Voluntary Euthanasia 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. Please phone to indicate attendance. Contact Nigel, Albion Street Centre, 150 Albion Street, Surry Hills 2010. (02) 332-4000 1st & 3rd Wednesday of every month. 7.30pm

HOSPITALS:

PRINCE HENRY (SPECIAL CARE UNIT):

Anzac Parade Little Bay (Sydney). (02) 694-5237 or (02) 661-0111.

PRINCE OF WALES HOSPITAL:

High Street, Randwick (Sydney). (02) 399-0111.

ROYAL NORTH SHORE HOSPITAL:

Pacific Highway St. Leonards (Sydney). (02) 438-7414/7415.

ROYAL PRINCE ALFRED HOSPITAL AIDS WARD:

Missenden Road, Camperdown (Sydney). (02) 516-8131.

ST VINCENT'S HOSPITAL 7TH FLOOR SOUTH (AIDS WARD):

Victoria Street, Darlinghurst (Sydney). (02) 361-2236/2213.

WESTMEAD CENTRE (WESTMEAD AND PARRAMATTA HOSPITALS):

(Sydney). Phone: (02) 633-6333 (Westmead); (02) 635-0333 (Parramatta). Fax: (02) 633-4984.

PARENTS' GROUP (AND RELATIVES) : A support group for the parents or relatives of people with AIDS. Please phone to indicate attendance. Lesley Painter, 2nd floor 276 Victoria Street Darlinghurst 2010. (02) 332-4000. Every 2nd Thursday 12.00 – 1.30pm.

POSITIVE WOMEN'S SUPPORT GROUP: Contact Women in AIDS Project Officer (02) 283-2222.

LIVING WELL SUPPORT GROUPS: For long term HIV positive people. Contact HIV Support Officers (02) 283-3222/2453.

METROPOLITAN COMMUNITY CHURCH (MCC) : International gay church.

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 1359, Darlinghurst NSW 2010. (02) 283-3535.

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 USERS AND AIDS ASSOCIATION (NUAA): NUAA is a community/peer based organisation concerned primarily with harm reduction, including HIV prevention and support of HIV+ people, advocacy, general support, referral and community development. Contact Julie at 24 Darlinghurst Road, Kings Cross. (02) 357-1666.

PENRITH PLWA SUPPORT GROUP: Support, information and referrals. Phone Wendy at Penrith Youth Health Centre: (047) 21 8330. Meetings are held weekly.

QUILT PROJECT : Memorial project for those who have died of AIDS consisting of fabric panels and completed by friends and lovers of those to be remembered. (02) 283-3222.

SACBE – EL CAMINO NUEVO : A group to educate the Spanish speaking community about AIDS. SACBE is also a Spanish speaking community support network. Contact Pedro Manzur (02) 283-3222.

SEX WORKERS' OUTREACH PROJECT (SWOP): 391 Riley Street, Surry Hills NSW 2010. (02) 217-2600.

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 – 6 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 Street, Parramatta. Contact Jenny: (02) 262-1764 Pam: (02) 635-0333 ext.343. Meetings are held on the last Tuesday of each month at 10.30am.

TRANSPORT SERVICE FOR PLWAs (in Sydney area): Contact CSN on (02) 283-3222.

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

SHARE ACCOMMODATION



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

This FREE service is not
restricted to people infected with HIV.

For more details please phone the
Accommodation Officer on (02) 283 3222

JOIN US IN THE FIGHT AGAINST AIDS SUBSCRIBE NOW!

PLWA Inc. (NSW) is part of a world-wide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice. Help yourself and other affected by HIV to create a positive, friendly and supportive environment in which we can all live with AIDS.

Name: _____

Postal Address: _____

_____ P'code: _____

Phone: _____

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

I wish to subscribe to TALKABOUT*: Y/N

I enclose: \$ _____

In the interests of your confidentiality:

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

I am publicly open about my membership: Y/N

Annual rates are:

Membership of PLWA Inc. (NSW) \$ 2.00

* Subscription donation to TALKABOUT: \$10.00

(Individual) (Optional for people receiving benefits)

* Subscription donation to TALKABOUT \$20.00

(Organisation)

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

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

Signature: _____

Date: _____