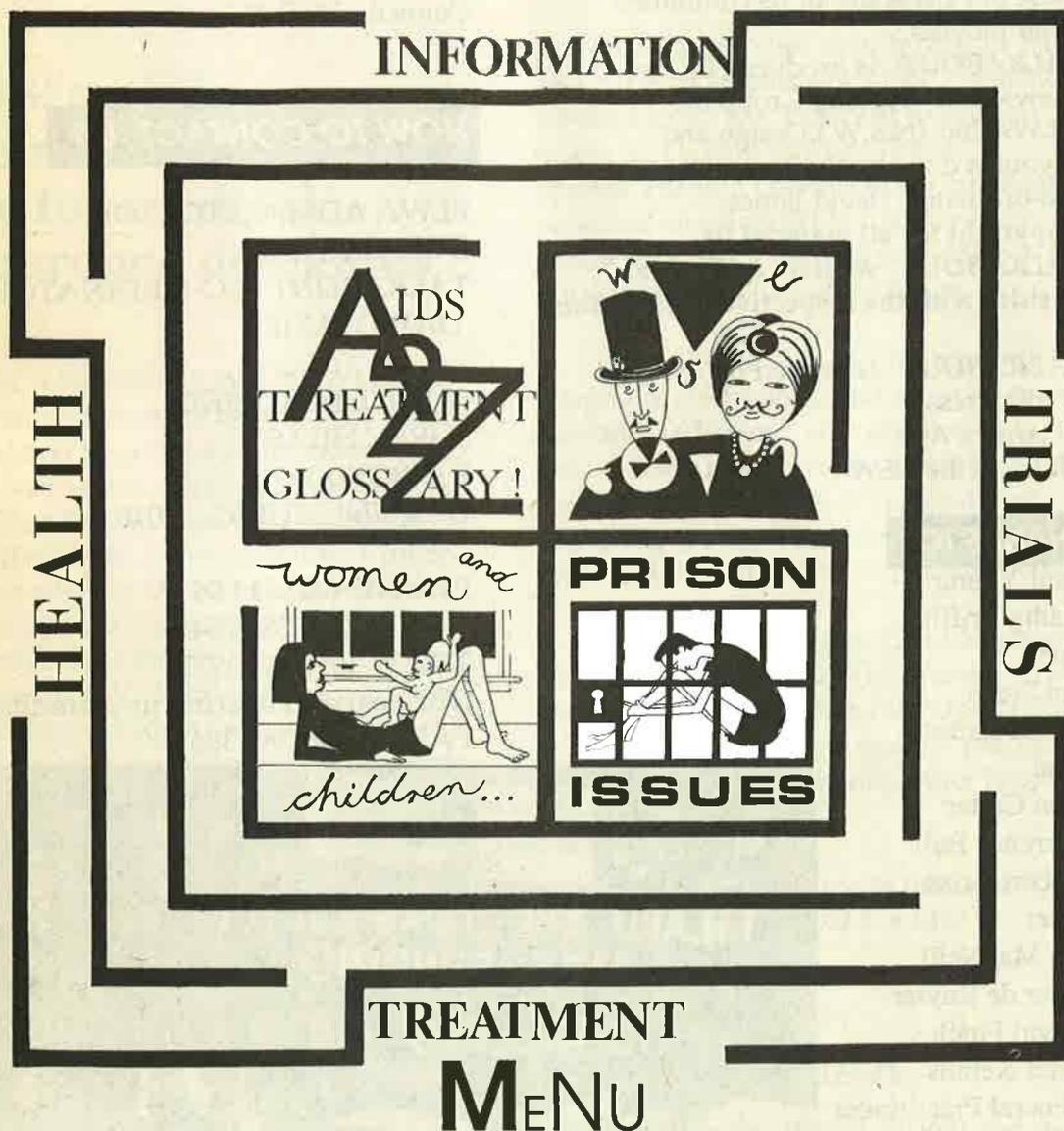


Talkabout

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Where we speak for ourselves

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AIDS activists
protesting lack
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Darling Harbour
August 30, 1989

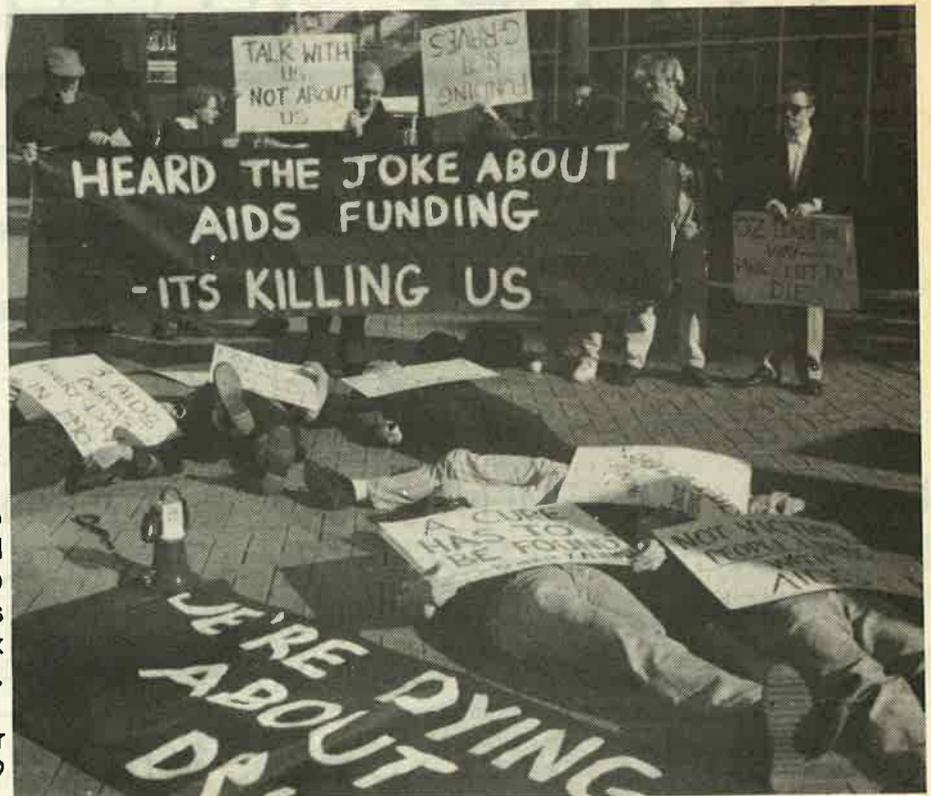
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AIDS activists anger: a testing time for medical conference delegates

On August 30, PLWA (NSW) held a demonstration outside the first Australian Medical and Scientific Conference of AIDS which was held at Darling Harbour Sydney, where Dr Neil Blewitt released the Australian White Paper on AIDS. Protesters were angered by the insufficient funds allocated for AZT in the light of evidence that early use of the drug is beneficial to people with HIV. While a large percentage of the national budget for AIDS is set aside for AZT, the increasing numbers of people wanting the drug means future supplies may not meet the demand.

Demonstrators also protested the lack of specific funding set aside for the AFAO National Treatment Information worker and the absence of a comprehensive national treatment strategy.

Conference delegate Julie Bates later reported that many of the medicos present, especially GPs, were visibly moved by the sight of "real people" who are living with AIDS expressing their concerns to such a gathering.

Protesters snuck into the conference with placards reading "We're Dying to Hear about Fast Tracking Drug Trials" and, "Heard the One About AIDS Funding? - It's Killing Us".

Prince Alfred Hospital : AIDS ward open

The hospital has been caring for HIV and AIDS inpatients since 1983. Demand for the service has increased to such an extent that a new ward has been opened. The unit consists of six inpatient beds and an extended hours Day-Stay area, where treatment will be available outside "normal" working hours.

Flexibility is seen as a high priority. A telephone information and referral service operates and clients who are known to the unit are able to go directly to the unit for assessment by nursing or medical staff. (Ed.: Why is such a service not available to all chronically ill patients in all hospitals?)

The unit is to be renovated to accommodate four single - patient rooms and a two - patient room. The unit is fully operational now and referral is by a general practitioner, immunology registrar, other hospital units or self -referral.

Enquiries should be made to the unit, Ward E10 West on (02) 516 6487 or (02) 516 6488.

Victory for PLWA & NUAA

After lobbying by PLWA (NSW) and the NSW Users and AIDS Assn., Albion St. Clinic has advised that if a patient has good intravenous access, as is necessary for the treatment, IVDU users will not be excluded from the Passive Immunotherapy Trial, as has previously been the case. The trial desperately needs donors and recipients of plasma. Call the clinic if you can donate plasma or if you think you can benefit from someone else's: 332 4000

World AIDS Day '89

World AIDS Day is a day on which to expand and strengthen the world-wide effort to stop AIDS. It means talking about infection with the human immunodeficiency virus (HIV) and AIDS, caring for people who are infected and learning about AIDS to sustain and reinforce the global effort to stop its spread.

PLWA (NSW) is organizing a picnic/ barbecue at Prince Henry Hospital on Sunday Dec. 3. THE PICNIC WILL BE HELD IN THE GARDEN NEAR THE "SPECIAL CARE UNIT", MARKS PAVILION. WE WILL BE PRODUCING A FLYER TO GIVE YOU THE FINER DETAILS.

The AIDS Council of NSW is organizing a CANDLELIGHT RALLY to be held on Monday December 4th. We will be assembling at TAYLOR SQUARE AT 7.30PM and proceeding to Hyde Park.

The fabulous SOLIDARITY CHOIR will support and entertain us.

BRING YOUR OWN CANDLES.

RALPH DEACON DIED 24.10.89.

Many people will remember Ralph as their friend, Doctor and colleague.

Ralph was intimately involved in the response to AIDS and will be sadly missed by us all.

Our thoughts at this time are extended to his lover Rolf.

DDI comes closer

On September 28, the pharmaceutical company Bristol-Myers announced that the U.S. Food and Drug Administration (FDA) had approved a Treatment IND (Investigational New Drug) protocol for the drug DDI (dideoxyinosine). The trial will make the drug available to people with AIDS and severe ARC who are intolerant to AZT and cannot participate in the formal Phase II clinical trials. The company has also promised it would make the drug available as soon as possible on a compassionate basis to those who do not qualify for either the trials or treatment IND protocol. Those eligible include those diagnosed as "clinically deteriorating after receiving a minimum of six months of AZT therapy", meaning patients who have no remaining clinical option.

The substance is taken twice a day orally in water. Results of trials to date report both antiviral and immune boosting effects, with increased T4 cell counts and decreased antigen levels in patients. Some also reported increased appetite, weight gain and increased energy. Side effects were reported by some patients, including skin rashes, seizures, headaches, light-headedness, insomnia and hyperenergy, especially in the early stages of treatment.

The move represents new hope for people with AIDS who have been taking AZT for some time and who no longer respond to the drug or cannot tolerate its toxicity.

In Australia, the company is now negotiating to have a similar trial set up early next year. Now the U.S. government has approved the protocol in that country the company can quickly move to make the drug available to Australian PWAs.

CATN - A hot tin roof?

Robert Ariss

Essential to the community trial idea is the involvement of General Practitioners in the administering, reporting and evaluation of new treatments, thus releasing patients from the tiresome, time consuming and impersonal hospital system.

On August 28 a team of researchers, doctors and community based organizations, including PLWA (NSW), held a press conference in Sydney's Darling Harbour to launch Australia's first community drug trial proposal - the Community AIDS Trial Network (CATN). The 25 page proposal is the product of consultation between the AIDS Council of NSW, the National Health and Medical Research Centre, St Vincent's Hospital, the National Venereology Council of Australia, and People Living with AIDS (NSW).

Inspired by the community drug trial system already running for a number of years in the United States, the initiative is an attempt to speed up the testing and releasing of treatments for people with HIV/AIDS. Such trials are of growing importance in the US where already one community trial has achieved success in record breaking time. The Community Research Initiative (New York) and the San Francisco County Community Consortium released data earlier this year which made aerosol pentamidine available in the US for PCP treatment. The community based

research involving general practitioners, organizations representing people with AIDS, as well as scientists and doctors, shows that this treatment could be available to PWAs at a fraction of the time and cost of regular clinical trials.

The final acknowledgment of the importance of community trials came in February this year when the US President's AIDS Commission endorsed the initiatives and granted funds for their efforts. Community trialing of promising new AIDS treatments are not so much a radical departure now, as an increasingly accepted and important arm of drug research.

Essential to the community trial idea is the involvement of General Practitioners in the administering, reporting and evaluation of new treatments, thus releasing patients from the tiresome, time consuming and impersonal hospital system. Like the US model, CATN recognises the importance of sound scientific research and guarantees this through consultation with scientific and medical advisors. The real breakthrough in such proposals, however, comes with the recognition of the importance of input from community organizations. The CATN proposal recommends trials be overviewed by an advisory body which will incorporate representatives from medical, scientific and community organizations such as the AIDS Councils and PLWA. It is possible in theory, therefore, for those most affected and in need of treatments to have a direct say in what treatments are trialled and how.

Here in Australia, and particularly in Sydney, we have seen a number of trials falter or not get off the ground at all. AL 721, for example, never made it past the starting line, and Passive Immunotherapy has not received the attention it deserves and runs the risk of failing for lack of participation and bad management. Many people with HIV are trying, or have tried,

all sorts of concoctions and remedies, from Chinese herbs, Hypericine across the counter, Dextran Sulphate and Compound Q. Unfortunately without any record keeping we cannot know, except through anecdotal reports, if these remedies are working.

On the other hand, many PWAs have expressed the fear that their reliance on AZT may well come to a deadly end at a time when no proven alternative treatments exist. Only a sluggish and irresponsible trial system is to blame for this lack of alternatives.

The question remains, therefore, will CATN solve the problem of the slow development of treatments for people with HIV? Will it improve the quality of life and life expectancy of people with HIV?

While negotiations are still underway as to the structuring and funding of CATN, it seems certain at this stage that the initiative will be a national one from the outset. Initially the trials will be restricted to the eastern states but eventually General Practitioners throughout the country will be enlisted to participate in making experimental treatments available to those who could benefit.

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For people with HIV, it is important that we have a determining say in what new treatments the trials investigate and how they go about it. In the United States the trend has been to push for not only promising antivirals to complement AZT, such as DDI, DDC or Foscarnet, but for

other treatments which work in different ways, such as immune boosting treatments like GM-CSF or Passive Immunotherapy. Trials should also look at promising new treatments for opportunistic infections and prophylactic treatments.

Perhaps the greatest improvement community trials hold for the trial system generally is to remove the necessity of placebo controlled procedures. While the scientific establishment held a stranglehold on the testing and availability of treatments for HIV, the conventional placebo controlled method reigned supreme, ie. giving half the participants a neutral substance against which to measure the effect of the real thing. The measure of success of a drug thereby becomes the development of illness or death in those who are taking the dummy substance. PWAs have been angry and distrustful of the placebo system for a long time, saying it is unresponsive and unethical in a public health emergency where many PWAs have so few options. The placebo method may, however, soon be redundant in such circumstances with the development of the idea of "parallel tracking" drugs.

Initially proposed by Dr Anthony Fauci of the US National Institute of Allergy and Infectious Diseases, the idea of parallel tracking is to do away with neutral placebos by giving people access to experimental treatments, once their safety and some evidence for efficacy is established, while matching the drugs effectiveness against those on other or no treatments at all. Thus people with HIV are given wider access to experimental treatments, while the scientific establishment is also satisfied in that good testing can still be carried out with the view to licensing effective treatments.

An additional benefit to community trials is that the numbers of people who

will be eligible for treatment will also expand. Access to experimental treatments should be guaranteed through the community trial protocols to:

- those who cannot tolerate standard treatments
- those who have conditions for which no treatment exists
- those who are failing treatment
- those who must continue with other medical treatments
- those who do not live close to trial centres and
- those already too sick to participate in existing trials.

Eligibility to enrol in a trial should thus be based essentially on a person's need as determined in consultation with their doctor. Those who have in the past been excluded for one reason or another, such as those with a history of IV drug use, women, children or young people, or those who are on other treatments, must also have access.

Though the proposal suggests CATN will be of use primarily to those in the early stages of HIV infection, potentially CATN offers people with HIV and AIDS in Australia a new hope in gaining greater access to new treatments for all stages of HIV infection. It is proposed that PLWA (NSW) has input into the running of the trials through representation on its management body. It is hoped that consultation and participation with people with HIV infection will help realize CATN's potential.

If you would like more information on the community trial initiatives, here or overseas, or if you have any suggestions as to what drugs or treatments you would like to see tested, please contact PLWA. Your ideas can go a long way to making community trials happen in the way which is best for you.

Cucumber Root - again

In late September the US community AIDS information organization Project Inform announced preliminary results of trials of the promising drug GLQ223 or Compound Q (see Talkabout #3). While researchers caution the results as only preliminary, based on information gained from a small number of patients on the treatment over very short periods, the signs are, at this stage, very encouraging.

Findings indicated the drug had both antiviral and immune boosting effects. Nine of fifteen patients showed reduced antigen levels, a measure of viral activity, of an average of 50% up to 3 months after treatment. Researchers report "Of the patients who had initially high levels of virus all had a sustained reduction averaging 68%" Especially encouraging for people with full AIDS is the fact that this result was found in patients where AZT was no longer controlling the activity of the virus.

Immune boosting effects included increased levels of T4 cells, especially those on higher doses, improved T4/T8 cell ratios, increased T-cell counts, reduced sedimentation rates and increased platelet counts - all strong indicators of improved immune system function.

The bad news is that mild toxic effects were noted in most patients, including fevers, muscle aches and pains and rashes lasting for a few days after treatment. Less common but more seriously, patients with lower T4 cell counts experienced toxicity to the central nervous system leading to mild confusion and disorientation and, in the worst cases, two deaths. The exact cause of the deaths is still not known and is under investigation.

It is because of these latter experiences

that Project Inform is exercising caution about the possibilities of the drug and does not recommend self medication. PI believes more conventional possibilities such as DDI hold safer and better alternatives with Q as a last option.

Regardless, while we wait for further results from trials, the Cucumber Factor continues to look good.

On The Parallel Track

Peter Kerans

"Parallel Track Offers the best hope to address some of the most urgent problems of the AIDS epidemic: the rapidly expanding caseload, the proliferation of

new promising treatments, the inability of traditional research institutions to test each promising therapy, the inability of most HIV infected Americans to enrol in controlled clinical trials, and the use by many patients, out of necessity or choice, of other medications."

From the consensus statement by 15 US AIDS advocacy and research organisations to the Assistant Secretary for Health, August 17, 1989.

In August, Dr. Anthony S. Fauci of the NIAID in the US announced a proposal for "parallel tracking" of promising new therapies for HIV/AIDS. The idea of parallel tracking is to allow for broad early access by PWA's/HIV to promising treatments. Previously, early access could only be obtained on a limited basis under US "compassionate use" and "treatment IND" regulations.

HOW PARALLEL TRACKING WORKS

A new treatment - treatment X - passes through early (Phase 1) clinical trials, showing safety and early promise of efficacy.

Treatment X moves into expanded clinical trials to demonstrate efficacy : Phase 2 (and later, Phase 3) trials.

Once Phase 2 trials are underway, X shown safe, but yet to be shown effective is supplied alongside (parallel) these trials to a range of people who, for some reason or other, can't get onto the trials.

Data on people getting PT access to X is collected, probably through a community based research organisation.

The anti-viral drugs ddI and Compound Q are the most obvious first candidates for parallel tracking. Details of PT are in the process of negotiation with the appropriate US government authorities.

What about early access in Australia? In this country, under a scheme called Individual Patient Usage (IPU), people can obtain treatments that aren't approved for use .

IPU treatments are obtained through a doctor. The doctor makes application to the Commonwealth Department of Community Services and Health, giving a rundown of the person's medical history and a justification for use of the unapproved drug - usually that all other available avenues of treatment have been exhausted.

Bristol-Myers, the drug company with the licence for ddI, will make the drug available for early access in Australia as soon as possible - which could mean a couple of months at the earliest. People unable to take AZT (the only approved treatment for HIV infection), or who are not benefitting from AZT therapy, should be able to get ddI free under the IPU scheme at this time, if they are not eligible for clinical trials of ddI.

Misinformation more lethal than the virus. H.I.V. = DEATH ?

Peter de Ruyter

This equation, brainwashed into our community and those who have HIV, is the basis for unforgivable amounts of needless suffering. From every major information source especially the medical scene this is just about the only message given out.

Yes, it is true that many people are dying. It is also true that many, many more people with HIV are surviving year after year, long past their doctors' doomsday prognoses. Neither this fact, nor the reason has been given adequate airing to the public.

Many people in the high risk group for being HIV positive, or those even who suspect they may be positive, are sticking their heads in the sand and not being tested. This is totally understandable, if you accept the above equation HIV= Death as the only valid reality.

If you possibly are infected and an untimely death is your ultimate end, then it makes sense on one level, to refuse to check out your status. Live while you can and deal with death when it eventuates!

Understandable, but tragic. Why? Because although that equation holds true for some people, it is my firm medical opinion based on five years of clinical experience and observation that for the majority of people this equation does not automatically hold. But there is a condition to this statement.

Recently, some more close friends became seriously ill with full AIDS. They all had suspected they were HIV positive many years ago, yet had not done anything about testing themselves, because from their perspective, what was the point? If they were going to die early in their life anyway, because everyone was supposed to die from HIV according to the "experts" then why confront all that horrible stuff any earlier than you need to?

So they ignored the early warning signs of their body, until they became so ill, that it was obvious something was seriously wrong. Now they did have to confront death, as well as deal with a disintegrating body, which no longer was able to respond so well to treatment.

The tragedy of this oft repeated scenario is manifold, but primarily it is tragic because although initially many refused to do anything about healing or supporting their body when they suspected they were infected but still well, now they desperately wanted to live and were willing to try anything to heal themselves.

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Hence the problem is that having put their heads in the sand the situation didn't go away...it only made it worse ultimately. They were still forced to face issues of death, but now with an ailing, unresponsive body. The bottom line to all this suffering is simply this. Much can be done to keep the system very much alive and well ...but you need to face reality and start early.

Orthodoxy's only real answer is symptomatic treatment and AZT. The

former is closing the stable door after the horse has bolted and the latter is extraordinarily toxic. Here in most cases, despite initial improvements in some systems, it tends to destroy and burn -out many of the vital organs and glands of the body, thus eventually more likely killing you than HIV! Yet this is the treatment that has been most publicized!

However, here in Australia over the last five to six years, plus overseas in the U.S. forever longer, Naturopathic principles and treatments have kept many people alive, year after year.

Those people who had themselves tested and then treated early on, when, despite being HIV positive their immune system was still functioning, are mostly outliving all their friends many of whom had chosen AZT as the "magic bullet" to keep them alive!

It is not that natural therapists are saying we have the cure. What we are saying is that those who took responsibility for their own health early on, and made constructive choices in how to support their body through the use of Medicinal Herbs, Acupuncture, Diet, Vitamins, Meditation and more, are generally staying well, year after year. Even those who have become ill because their immune system is now very low, can still be helped in the majority of cases. But of course, the further down the hill you fall, the longer and harder the climb back up can be.

Years ago, before all the various support groups were available, there was a point to the argument that being tested was too stressful and in itself could harm the immune system. I agree...but times have changed! So much support is available now to help people deal with issues of being found to be HIV positive.

More importantly, if you can only

realize that the HIV=DEATH formula doesn't necessarily hold for the majority of people tested early, then it takes much of the sting out of being told you are positive. And realizing so much *can* be done to keep you healthy in the long term, should give you more incentive to check your health status and make some constructive choices.

Finally, ignoring reality doesn't make HIV go away! If you are positive and you're not instigating healing changes in your life, the likelihood is that your body will - in no uncertain terms - powerfully make you confront these issues, sooner or later.

Even if you don't want to be tested, yet belong to a high risk group, then do yourself a favour and start living as if you are positive i.e. do change destructive habits such as smoking, drinking, drugging, etc.

The essence of all this discussion is simply to realize very clearly that HIV doesn't kill everyone as you are mostly being told! There ARE very successful-Natural Therapeutic ways of enhancing and maintaining your immune system and therefore your health.

The *earlier* you start, the less likely you are to go downhill. But for heavens sake, only go to someone who has had considerable experience in treating and supporting immune function. This is no time to have someone experiment on you.

So think about it; talk about it with your friends, and hopefully decide to be more realistic if you do belong to a high risk group.

If you are HIV positive, it *does not automatically mean that you have to die early-* but much of this does depend on what you decide to do. **IT IS YOUR CHOICE!**

Sue's Story : Part Two

Part One of *Sue's Story* appeared in the previous issue of *TALKABOUT*.

I start AZT next Tuesday. I just hope it fixes some of the problems the doctor thinks it will fix. I seem to get a lot of things that nobody else does. I find that very annoying. It is unpredictable. Nearly every problem I get the doctor says, "Goodness, I've never seen that before". I get a diverse mixture. I got the most terrible aches and pains and weakness mainly in my legs.

*Nearly every problem
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"Goodness, I've never
seen that before".*

It has never gone away. Six days out of seven I feel as if I've got a really bad flu. I haven't, but I feel like it. I'm not going onto AZT forever. I'm going on it for three or four months. I think my doctor is hoping it will take away these problems. Everybody I know who has been on AZT is dead. It's made their life feel absolutely, totally shocking. They have all died quite rapidly. I hope it might solve some of the problems I seem to get. I hope it will allow me to go out shopping one day and walk back to my car that might be parked a little way away. Things like that, because half the time if I go to places and I can't park right next to where I am

I suppose also I am conscious of the fact that I am a really healthy looking thirty-seven year old woman who shouldn't be healthy looking, or who nobody expects not to be feeling 100%. I feel that I have to keep that up, even for people walking down the street I have never seen before.

going I just have to go home again because I can't walk that far because of the pains and weakness in my legs. I suppose also I am conscious of the fact that I am a really healthy looking thirty-seven year old woman who shouldn't be healthy looking, or who nobody expects not to be feeling 100%. I feel that I have to keep that up, even for people walking down the street I have never seen before. Some of these elderly people, their arthritis is playing up and their heart is not good - they have wonderful built-in excuses. I haven't - I don't look sick and I shouldn't be. I feel the whole time that somebody is looking at me. I have to keep up this front.

I think we all tend to think, no matter what, you have to continue along as normal. No matter what I feel like, even if I feel as though I'm going to drop dead I must get out of bed; I must go and wash the dishes; put clothes out on the clothes line; cook the meals. I mean, nothing dramatic. Just those basic things. You have to keep things normal, however you feel. Occasionally when you can't, which happens at times, I think it makes you feel extra bad. I have made all of these incred-

ible resolutions that I am going to stick to, no matter what. Sometimes, if you didn't set such high guidelines for yourself it would probably be much easier.

THE CLINIC

I am the only female I ever see at the HIV clinic. There was a nurse there who kept telling me every time I went, "I don't know why you are at this clinic. The doctor has put you in the wrong clinic." I think that is terrible. My doctor deals with several specialist areas, like allergies. They've got different clinics for different problems. Every time I ring up to try to make an appointment in the

HIV clinic they say, "No, you can't go to that clinic, dear. Now, what is wrong with you? You will have to go to one of the other clinics because that is not the sort of clinic you want to go to." They mean that I don't sound, on the phone, like the sort of person who should go to the HIV clinic. I should be going to the allergy clinic, or the immunology clinic or something or other. They do that every time. I get it every time. I'm treated like I'm a bit silly. 'What do you really want? No, you can't go there because that is not for people like you'. In hospital I had the same problem. They thought the wrong sign was up on the door because, 'oh no, you don't look like THAT'. It is bad enough having it in the first place without having to explain to people, 'yes, that's right, I'm HIV positive'. When I walk into the HIV clinic I feel very out of place. It is hard to come to terms with, especially when people start questioning you. People who say, 'I think you've got it wrong, dear'. It just happens too often.'

EMOTIONAL SUPPORT FOR THE CHILDREN

Everybody seems to forget that when the patient dies, that's not the end of it. I think that it is almost the beginning. So much happens after that. If that family has to hide from everybody what their wife, their mother died from, it is an awful lot of strain on them. The children cannot even say what they are upset about. Nobody thinks about the children.

I have very ferocious, protective instincts towards my four year old. I also have a very vivid imagination. I can see all sorts of terrible things happening to her at kindergarten and school if people knew what was wrong with me, though there is nothing wrong with her. I don't even know what would happen. The children or, probably more likely, their parents would try to isolate their children from her. Children who wouldn't know what they were talking about being cruel to her. It is the

sort of situation, even if it is in your own imagination, you can't test it out to find out. You can't say, 'we will tell them a bit, then if it doesn't work will take it back again'. Once you have done it, you have done it. That really frightens me.

In the beginning of 1987, when my daughter started going to kindergarten, a social worker I knew in our area health centre got her into the programme. They have got a two, three, four year waiting list. She was going two days a week and that was fine. When I got sick last year I just couldn't look after her. Half the time I couldn't even talk because if I talked I couldn't breathe.

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I feel really lousy about that.*

Our community nurse got onto the child care centre and asked them if they could possibly take her. It is very hard because you have to ask them for all these favours but you can't do them the favour of telling them the truth. I feel really lousy about that. The community nurse will tell lies for me. So my daughter has been going fulltime, which is really expensive but it's the only thing we can do. She has to go there rather than the normal kindergarten because it is a long day care centre. When I am not well my husband can take her on his way to work and pick her up on his way back.

I have got a bit of money saved up,

but that is all going to go on child care fees until the end of the year. If we get into a situation where maybe my husband has to stay home we will be in a total mess. The only assistance available if I got really sick and my husband had to leave work is, I would get an invalid pension and he would get a carer's pension. I think that adds up to \$220 per week which is very difficult to live on. I think you get \$20 or \$40 extra if you have a child. My husband is earning more than that at the moment. We would have to sell the house. That's all we could do. Not have anywhere to live. I can't see that things will get better. There is nothing geared to families because according to everybody outside that window these things don't happen to families. They don't have to wait around for someone to die. I feel that at least for the next, say, ten to twelve years I just have to be there during that time because our daughter is only four. What if I can't? I think that is a very strong possibility. We are all eventually going to get sicker, we are all going to die. I don't mean tomorrow or next year but in the next five to ten years. I think we will die. Whereas a couple of years ago the medical profession said that that is a terrible, pessimistic attitude, no of course you won't and everybody will be fine. It just takes some people longer. I don't think we will be carrying around HIV for twenty years and not be affected by it.

STIGMATIZATION

Stigmatization was created by fear. I think it is just the way the whole thing came into public knowledge. It wasn't there and, all of a sudden, it was there.. It was killing off people and they didn't

know what to do about it and they still don't. Also people thinking that it was a 'gay plague'. A lot of people thought it was coming from an alien, sinful lifestyle. It is still thought of in that way because it is still incurable, untreatable. People can't cope with it. Everything you hear about it makes it worse anyway.

This feeling is reinforced by medical experiences, like going to hospital. Things are always put in a carrier and no one comes near you. All the time the media comes up with these new things and they are always negative. I really think that the

Stigmatization was created by fear. I think it is just the way the whole thing came into public knowledge. It wasn't there, and all of a sudden it was there. It was killing off people and they didn't know what to do about it, and they still don't.

public's reaction is getting worse. Every educational programme that the government might have done has failed. They have really made it worse. The Grim Reaper is an example. Every time they put that up, that horrible thing coming towards them, that is me and a lot of other people I know. People were terrified of it.

I think that probably 95% of the general public would be absolutely, totally amazed if they knew that I just got up in the morning, took my child to kindergarten, hung out the washing and did a bit of cooking. I am just a very normal, ordinary housewife, if you can use that word. I think that they would be totally astonished. If you had a photograph of one of our meetings, a photograph of these people sitting around a room, you would probably think it was a church coffee morning. They are just people. I am just like the millions of ordinary housewives that are around. I don't do anything different. I don't take precautions to protect my family. To pretend to people all of the time that there is nothing wrong, it just takes an amazing amount of energy. Some days it is totally impossible. I don't think

anybody who hasn't been in the situation can fully understand. It is very draining. I wouldn't have understood either, even when I kept thinking that myself at the beginning. It's stupid, it's not difficult not to tell people. It's difficult to pretend. It's an incredible burden not being able to tell people.

PERSONAL RELATIONSHIPS

I wouldn't say it was one of the largest problems. It is quite a major problem. When I first found out that I was HIV positive, they said female to male transmission really doesn't happen. "We don't know anybody who has, don't worry about it." So that was fine. At least there was one thing in the world we didn't have to worry about, so we thought. Then about twelve months later, the doctor went to an international AIDS conference. The minute he came back he said, 'OK, you have to use condoms all the time'. My husband had never used one in his life. We tried to explain to the doctor that if my husband came to me and said, 'I am feeling romantic but you are contaminated, so I won't touch you and I will use one of these things instead', it's the last thing I would feel like. I would feel like running around the house and screaming. The doctor said, "Yes dear, you'll get used to it." I still feel like it is more trouble. They said other people use them for other purposes. That's OK, that's their choice. They do it maybe for a limited time for contraception or whatever and that's their choice. But using one because I'm contaminated.....the doctors don't understand you. If you don't use them you will kill your husband and then your daughter will be an orphan. They started to try and get at me from that angle. My husband kept saying to them, "I am willing to take the risk."

He said, "I think that is a small risk and I am willing to take it." The doctor started telling him he will die too. Then I

get into the situation where I can't use them because they make me feel lousy. Then I don't want to anyway. If I don't use them I feel as though I tried to murder my husband even if he is a willing party to the whole thing. It is all just totally unfortunate, or totally ridiculous. It is three years and we don't have the foggiest notion as to what to do. I think that we have both independently decided that the only thing to do is stay away from each other. Then the doctors say that is not good for your relationship. Nothing else is good for it either. None of these solutions is good for it.

When you are told in the beginning, 'it is okay, don't worry about it', and then all of a sudden you are told, 'yes, you have to worry about it' and people say that it is unlikely that you will infect your husband, then you can't take the risk in case you do.

***They just keep going on
and on 'you are going
to make your daughter
an orphan'.***

***They know which
avenue to go through
to get at me best.***

They just keep going on and on 'you are going to make your daughter an orphan'. They know which avenue to go through to get at me best. I know of people who have had the virus for an awfully long time, longer than I have, who haven't infected their husbands. Seeing as they couldn't get at either of us by saying to my husband, 'you don't want to get this' he said, "Well, I really don't mind, I am just going to have a normal relationship with my wife. If it happens, it happens." He is a bit of a fatalist. Then they start getting at us through my daughter. It is bad enough for a child who is probably going to lose one parent. You don't want her to lose the

other one. If we had just left it alone, I doubt if it would have been a major issue. The way they are pushing it all the time it becomes a major issue in our lives. It is an area in your life that you take for granted, that is relatively normal. Then all of a sudden the whole thing is changed around and I am put in such a position that I can't do anything. You can't go in either direction. We just don't know what to do. My husband said for ages that he didn't care, but now he is starting to bring up the thing about the child all the time. It is really getting at him. Now he doesn't know what to do either. He is not usually like that. So, we are both in a ridiculous situation. Okay, if it was a big risk, or if it was him who was infected and not me. It would be a totally different matter. But with such a small risk! You shouldn't worry about these things. That's what they tell you, after they tell you what you've got. They say, 'Well, you've got this virus. Don't tell anybody how you got it. Don't worry because the stress isn't good for you.' That's all in the one breath. I don't know what to do about this particular issue. I don't really know what anybody could do.

The doctor said really stupid things. "My wife and I, we used (condoms) when we needed the contraception." That was alright; yes, they wanted to. It was for a couple of months. It wasn't for the next fifty years, or whatever. A different set of circumstances for using the condoms - contraception. He wasn't using them because he didn't want to touch her. I thought it was such a stupid thing to say.

The relationship with my husband is changing a lot. It is not a sexual relationship like before, it is a platonic relationship. It's changing; you've got this virus and you've been told that you don't have to worry about it, which doesn't do you any good. On the other hand you feel, that because of it, you have to stay together. I

am not saying that we do not want to stay together. There is no way that I could leave him for any reason in the world, because I couldn't cope by myself. There is no way he could leave me for any reason in the world because he would feel too guilty. A funny thing keeps you together, but it does change. I don't feel that the relationship breaks down, but it is very different. It is not the sort of relationship we would want to have. He is more for catching me when I faint in Coles or something like that. It is less of an equal sort of relationship. It is more the role of the invalid and the carer. Then again, it is not.

*He said, "Don't worry, dear.
Nobody knows."*

*I knew I was last on the list.
I just got so angry. It's my body,
no one else's.*

*Everyone was muttering around
for days, 'how do we tell her'.
I found it very annoying.*

Finally, I probably got more angry when I first found out that I was HIV positive because the doctor said, "This is what you've got, dear. Don't worry about it because nobody knows about it. Only me, my secretary, the staff at the hospital where you had your baby, the operating staff, people at the Blood Bank, the doctors at Westmead Hospital. It seems to go on and on. He said, "Don't worry, dear. Nobody knows." I knew I was last on the list. I just got so angry. It's my body, no one else's. And it's my blood. Everyone was muttering around for days, 'how do we tell her'. I found it very annoying.

Everybody gets different things, everything affects people in different ways. It would be nice if the doctors could say, 'well dear, you've got this and that. That's going to happen and then that's going to happen, and then six months later after

this happens, you will die.' I would much prefer that.

It affects so many aspects of your life, it affects every aspect of your life. It just seems strange, I think, that there is no sign of it. As though it is not there at all. This great big thing that is having such an effect. You think that somebody must be able to tell you that you have this terrible disease. It is just a great big invisible thing.

Kathy Triffit is currently working on a documentation with people who are living with AIDS. This is an abstract from an oral history as told by Sue. If other HIV positive women would like to contribute to this documentation (written or oral history) please contact Kathy on 361 3620.

General Practice

I call Jason in. The news I have for him will be a knife in his soul. Always difficult to handle this situation, but more so with this strangest of diseases. There is little point in light conversation so I straight away tell him that he is HIV positive. Silence as the message is received. I sense the darkness and disintegration that will follow, and see also the growth that may come. Slowly we talk. Paramount the need to be supported and given hope. Given. Not too much information just yet. We make an appointment for later that week.

I haven't seen Jane for some time. She tells me that her T-cells are fine and that her support group is going well. Somehow this has focussed her life and given her the energy to balance and integrate the multitude of strands that were previously disconnected. I rejoice with her.

ship. I can see that it is important for him but why the visit? He requests an "AIDS test" and I understand. We look at his past and there seems to be little risk but....I carefully explain the significance of a positive and negative result and take the blood reassuring him about confidentiality. I wonder at the new responsibility that has become a part of so many relationships.

I knock and the person from the Community Support Network lets me in. Jon is clearly dying. I examine him for the second time that week, comforting his partner that everything seems stable. I keep in contact with the hospital as I haven't much experience with this stage of the infection, and its manifestations are strange even to me.

This condition has infected medical objectivity and rationality.

The questions that must have an answer do not.

How long CAN it take for the virus to show?

What judgments am I making?

What hope is there for a vaccine or a cure?

I see a flux within the community and within medicine

This condition has infected medical objectivity and rationality. The questions that must have an answer do not. How long CAN it take for the virus to show? How many of those infected will die? Is it CERTAIN how the disease is and is not spread? How close can I be? What judgments am I making? What hope is there for a vaccine or a cure? I see a flux within the community and within medicine. There are new precautions: a needlestick after taking blood can be lethal; care must be taken when writing in the file. New regulations: confidentiality must be preserved, even on

pathology forms - fear and misunderstanding are not easily quelled once released.

Practising in the inner city there is much up to date information available to me as a general practitioner through the clinics, the hospitals and various publications and it is generously given. And much needed as the situation changes, as accurate information is one of the vital things I feel I should be able to give the people I see. For them I also perform other roles: as the one who initially diagnoses the condition; as a counsellor; and as a coordinator of services. Some use all of these, some few. It depends on our relationship and on the effectiveness of other support given. Overall, I see my own task as a general practitioner as being humane and supportive and available to people who are sometimes on a dark and lonely road.

Editor's note: This article was written by an inner Sydney General Practitioner whose name cannot be published for reasons best known to those who enforce the regulations regarding "medical ethics".

**Transport For
People Living
With AIDS**

Return transport between
your home and hospital or
clinic

Operates Monday to
Thursday
9 AM - 5 PM.

Ask your Community Nurse
or Social Worker for
information

Operated by Central Sydney Community
Transport Group Inc Ph. 3602043

HOLIDAYS AT THE BAY

Peter

Recently during my ritual morning coffee and croissant I picked up the *Herald* and read "Clash of the Long Bay V.I.P.s". I read on with a chuckle, "Who was telling the truth: the triple murderer, the double murderer, the child molester or the bomber?" Why should it be that once a person has been convicted of a crime that their honesty be in question? After all, there are plenty of people who enter guilty pleas. Should we assume that they are lying and therefore not guilty after all? I read on, "There was Ernest Wade, a 'rock spider' in prison speak because he is a convicted child molester"; and later on that "he had stabbed more than fifty inmates" and "signed his letters to his homosexual lover 'Pumpkin'". Was this a Jean Genet play? Perhaps a Harry Miller production starring Rex Jackson, Murray Farquar and Tom Domican? No, it wasn't but it served to underscore the fact that prisoners are not necessarily the stereotypical "crim", as we tend to think of them.

To be arrested and incarcerated for the duration of legal proceedings (on remand) can be a terrifying experience. It can happen to anyone for any number of reasons. In Queensland, Tasmania and Western Australia homosexuality is a crime and God help anyone unfortunate enough to run foul of the constabulary there. And it is not only the Police who are intimidating. Once they have finished with you, you are confronted by both prison officers and the inmates and never sure which is worse. Remember Jamie Partlic? He was in gaol for a few days to cut out parking fines but he was brutally bashed by two other inmates. They were both 'head sweepers' in his Wing, a position of trust and privilege within the prison sys-

tem. Most of the older and long serving inmates in NSW remember the savage reception bashings dished out at Bathurst and Goulburn Gaols before Tony Vinson changed the system which Michael Yabsley is hankering to return to and is indeed reverting to rapidly. The gaols are so full at present that periodically they can not accept prisoners from the police cells.

When I was sentenced to two years minimum in 1984 it gave me the complete horrors. I recall being assaulted by an inmate and being quite erroneously described in court by a probation officer as a transsexual. My parents were not amused and I wondered how far this strange accusation would go. Would it follow me on my files to prison and hamper my integration into the system there? Prisons are a mine-field of misinformation and prejudice. I certainly didn't want to be assaulted again!

1984 was not a well informed time as far as AIDS was concerned and in gaol it was a subject to be either ignored or spoken of in hysterical terms. Very little was known about it at all, and there was virtually no discussion of the relevant issues. A lot of people were still choosing ignorance out of a fear that informed discussion would lead to infection.

I have been an IV user on and off for many years now. Shortly after being incarcerated I found an old friend in the same Wing as myself and he invited me to visit another's cell to celebrate our reunion with a shot. What harm to share a needle once? It was Christmas and it never oc-

curred to me that there was only one needle at that time in the entire Central Industrial Prison (C.I.P.). How could I have known that? I had just arrived and I was grateful to find a friend and something to celebrate. There must have been fifty people using that fit each day, I realized later, and I never did it again. Bleach, metho or anything else useful for sterilization is banned in prison, as are condoms.

Not long after I was released from prison on May Day 1986 I had my first AIDS test. HIV positive, Antigen positive was the result. I expected as much. I had had diarrhoea constantly for the second year of incarceration and it had been acutely embarrassing being locked in a cell eighteen hours each day with a succession of cell mates who were not of my choosing.

I found an old friend in the same Wing as myself and he invited me to celebrate our reunion with a shot. What harm to share a needle once? It was Christmas and it never occurred to me that there was only one needle in the entire Central Industrial Prison. How could I have known that?

A couple of years have passed now. I take high dose AZT for category 4a AIDS Related Complex and I wonder how many others there are out there linked to me by

the use of that needle at the C.I.P., Christmas 1984. It happened in one of the "head sweepers" cells in the fine defaulters wing. (Not the same sweeper who bashed Jamie Partic to a paraplegic pulp - he never knew him. This one has a white beard and red suit and sings, "hi ho, hi ho, it's off to..." and "me - rry christmas"!

Prisons are an important issue to us all. We never know when someone dear to us may have their lives devastated by being deprived of their liberty (rightly or wrongly). And there are people living and dying with AIDS in prison right now.

Thank God I'm no longer one of them.

NIGHT SWEATS

Beside me
the water jug
my friend, the
air I breathe,
Shit, it's empty
Again.

My eyes close
and reel to reel
and again, and again
it begins, and again
My internal,
In cerebral
My video.

Go away,
I'm not in art
please go away
I'm not asleep
just piss off
fever, just
let me sleep
Eyes Open

Nasty Moon
waving through
those palms
"you who,
remember me?
you're piscean'
you must. Oh,
it's wild out here
it's hot in there.
How fabulous, Ha.
You shiver".

Nice palms,
yes, flick it
flick it Away, so now
The sky can blush
And shrill
with the bird
fanfare.

I sleep.

VIVO PARADISO

Trying to rest when you are
an artist with AIDS
is no easy matter.

In some ways,
knowledge is poison,
as even when I meditate repeating,
for example, the word "nothing",
I think of Kenneth Slessor's "Five Bells",
or Malevich's "White on White".
Numbers only lead to numerology;
forget creative imagery as fever
gives me this invariably anyway.
I finally give in accepting peace
when I'm awake rather than
the turmoil of trying to sleep.

This poem was written
when I had a fever
and yet felt perfectly conscious
with head spinning,
and the world moving
in irregular clockwork around me,
just as usual.
Maybe someone
will get a kick
out of this experience....
I send it lovingly.

VIVO PARADISO

Being HIV

Ian MacNeill

AIDS made it abundantly clear that we all have continuing responsibilities to demand better of our elected representatives, our public servants, those with voices in the media who shape public opinion, those whom we pay for their expertise.

I have not been infected with the HIV virus, though like most other members of this society, I could easily be. I've known two people who died of AIDS and many more who could. I am furious about and deeply saddened by the disease - when I think of the situation in many African countries, in New York, of haemophiliacs, of IV drug users, of gay men in NSW who had just gained some justice when this disease made its presence very, very felt. I am distressed by AIDS because it showed a lot of people up as stupid, gutless, heartless - bigoted. And yet it is better to know - it is better to know about some of the surgeons of NSW, it is better to know that the police can be lily-livered bullies, it is better to know that politicians often don't offer much of a lead, are to be scrutinised as much as respected. AIDS has shown us many aspects of reality which we might have preferred not to know about but which are better exposed: the vileness of prison wardens who actively prevented the distribution of condoms and syringes, the criminal cowardice of politicians and officials when it came to dealing with the fearful and irrational (I believe the Education Department still refuses to allow IV drug taking or anal intercourse to be discussed in AIDS education programs in schools) and the lack of professionalism

and the inhumanity of those journalists who ignored the responsibility for public education in order to provide sensational copy. They are already history, it will continue to condemn them.

AIDS made it abundantly clear that we all have continuing responsibilities to demand better of our elected representatives, our public servants, those with voices in the media who shape public opinion, those whom we pay for their expertise.

Very many people who have tested HIV positive have done much to make the world a better place, have taken the evil of AIDS and turned it to good account. They have changed the nature of medical practice and legal representation, influenced political and bureaucratic decision-making and policy implementation. The influence of their enterprises extends far beyond the area of AIDS, they have shown how to demand and get the results you want, they have demonstrated people power, they have refused to be passive victims hoping they'll be treated fairly. They have repeatedly won battles against those who have sought to discriminate against people infected with the virus. They have fought to ensure people who have tested HIV+ get a fair go. But most impressively of all, so many PWA's have lived their personal lives positively.

I have two very absurdly self-indulgent fantasies concerning this virus: one, a common one I suspect - I discover a cure (I know nothing about science); the other - I am a diva singing at a gala performance at the Metropolitan in New York. I accede to the mad applause and agree to sing an encore. I raise my hands for silence, in the hush I announce that my encore is dedicated to all my gay male friends without whom opera - nay, Culture could hardly exist. I announce the aria I am to sing, 'Sempre libre', from La Traviata by Verdi,

I (needlessly) inform. 'It means,' I say, 'simply live'.

For the purposes of my fantasy I ignore the awkward fact that SEMPRE LIBRE actually appears to mean (I've just looked it up in the libretto which came with my two record set) 'always free'. Anyway, 'always free' isn't such a bad idea either.

Ideally speaking, none of us know how long we've got to live, so we should live our best NOW, go for it NOW. The reality of being a PWA is probably very different. For them LIVE NOW is not just a toy idea from some encounter group guru but a tough proposition conditioned by many negative possibilities which have to be taken into account. Even so, everyone whom I have heard discuss their association with PWA'S says the experience has been an honour, an inspiration, that PWA'S really know how to live in order to make a good death when that comes. They know how to be real.

That's the sort of thing I admire - gutsiness.

I wanted to write this in order to be honest, to give some idea of what someone who isn't HIV+ thinks about people who

are.

As you have no doubt inferred from my second fantasy, I'm a gay man, my thoughts on the issue are influenced by that. I hope though that people who have become HIV+ for whatever reason will find something of interest in my efforts to tell it the way I feel it.

I would like those who aren't gay males to know that I've thought about the extent to which the virus has been created as gay and male and how that must be as frustrating and infuriating for them as it is for gay males.

Mostly, I don't think about people in terms of whether they're HIV+ - unless someone becomes actually ill, or behaves in a way which is destructive. When I see one of my friends is drinking, drugging, smoking too much and I know they're HIV+, I'm inclined to interpret (even though they might always have been so inclined) their behaviour as inspired by a fear of death. I think they ought to be making every effort to be healthy. Though when I think about what this means I realise I'm being unfair - I'm supposed to be, we're all supposed to be living as healthily as we can and there's always someone who condemns us for our diet, because we smoke, drink, don't do the right kind of yoga etc. We have to judge what's best for us. Whereas I might wish Jack would stop drinking Daniels, I also know that might be best for him, the best way he has at the moment of dealing with his pressures, his reality.

I have discussed excess and moderation with a friend who has tested HIV+. It wasn't easy - I was frightened that I would say the wrong things, add to his burden of fear - and I don't know if he has actually



altered his behaviour all that much as a result but I do know I did the best I could to be close to him, to show that I was trying to understand, that I care. And he does seem to be more moderate in his excesses. Of course this change might have nothing to do with what we said.

I would be a little anxious about having sex with someone whom I knew had tested HIV+, less anxious if he told me because that would indicate a desire to share responsibility for safe sex with me. And who am I to talk? I'm a hep B carrier; that involves safe sex responsibilities too. Anyway, these days don't we all have to be wary of catching herpes, warts, some other nasty? An awful lot of people have something they should warn their prospective sexual partners about. Let none of us shirk our sexual responsibilities.

And I know this doesn't make it much easier - it's hard enough as it is to really connect.

I don't think I need to go into sex and love and the whole damned thing but I do want to say I would guard my heart somewhat against someone who was HIV +, just as I would with someone who was here on holidays, married, otherwise at-

tached. It's a factor and completely hypothetical as no HIV+ person is battering at my heart at the moment, nor is anyone else and I'm getting on with my life as always. In theory, don't we all imagine we'd handle the chance for a new relationship in the unique terms that two unique individuals create? Don't we all believe we'd give it a go, see how it went? I believe I would. I believe I know relationships have to be worked at and that you just do if you want to go any further along in life with that person.

I do fear sickness, powerlessness and death - my own and those close to me. I do dread the burdens of illness. And I know that I could be the one who becomes the burden.

Yes, we have to be realistic and none of us knows what tomorrow will bring; we must be realistic but to dread unnecessarily is destructive and a waste. Yes, HIV+ people are special people but also what's so special about them? I know so many who seem to be making the best of their lives. When I'm feeling resentful of their progress through life, that is, their success, I say, yes but he has a special incentive, I ... have no excuse.

LOOSE ENDS FROM OUR LAST ISSUE

AIDS ADVOCATE

In the issue #4 of *TALKABOUT* we neglected to point out that Jeffrey Birch's article about the AIDS AND YOUTH GROUP was first published in *AIDS ADVOCATE*.

We regret this omission and thank the editor of *AIDS ADVOCATE*, Terrence Bell, for permission to reprint the article in question.

TRACEY LEE

In the caption under the photo accompanying our Sarah Dunn Profile we incorrectly referred to "the late Tracey Lee". The caption, which should have read "the late Tracey Lee Junior" referred to the person known by some as Tracey Lee Turner and previously known as Ian Pendlebury. We are pleased to advise that Tracey Lee is very much alive.

TALKABOUT apologises to both Tracey Lee and to Paul Young for the error and for any hurt caused to them.

A TRIP TO SAUDI

PAUL

I was told I was HIV positive in February, 1987. I tested because I needed to certify that I was HIV negative if I wanted to work in Saudi Arabia. I wanted to work in Saudi Arabia because my life at that time seemed more than usually uncertain, erratic, inconstant - a significant relationship in my life was changing; my work was frustrating; my emotions were labile; and my bank account was perpetually empty. Saudi Arabia would be a solution, a focus for my life. More accurately, but probably less realistically, it would be an escape.

As it turned out, Saudi Arabia was all of these things but not in the way I had expected.

It is difficult for me to recall the salient aspects of my past to give a clear picture of how I come to where I am. I want you to know that where I am is what is important. I could write of this confusion and grief I felt for months after discovering my HIV status; or of the anger which was a smouldering fire in me (anger about so many things, not just my anti-body status) and which would flare up and scorch a path through my acquaintance; or of the pessimism which was a pall over so much of what I did, thought, believed. I

SOME CHARACTERISTICS OF LONG-TERM SURVIVORS

- *A refusal to accept the fatality of the disease
- *A purpose for living.
- *The ability to express one's feelings.
- *A willingness to follow one's own guidance for healing.

could write of my sense of isolation, of how often I despaired and how infrequently I laughed. I could tell you of the weight I lost and of the rashes that spotted my body during that first winter of knowing - these not because of any particular disease process but because of my discontent, the heaviness of my spirit. When I think of that time, when I summon up a picture of myself what I see is a dejected figure trudging through a grey landscape, someone impotent and impoverished, a victim. The redeeming quality of this figure is its motion. Even trudging, the figure moves, journeys. A journey implies hope, the expectation of change, of arrival. A stationary figure is hope-less.

That journeying has brought me to where I am now. When I picture myself today I see a figure of optimism, someone powerful and content who journeys through a shining world, someone who wishes (as that faggot E.M.Forster put it) "to take the great chances of beauty and adventure that the world offers"

The transformation has occurred because of the journey and as part of it. It continues to occur. It happens through meditation, happened through therapy. It happens because I affirm life in emotional, ideological and practical terms. For instance, for me smoking negates the desire to live as well and fully as I can. Consequently I invest a fair amount of energy in learning the efficacy of life without cigarettes. Or Extasy. Or Amyl Nitrite.....

I want to affirm life and to face death with peace and equanimity as if death merely was the act of stepping through a door into another room. I do not accept that I will die from AIDS but I am coming to accept that some day I will die and that too is part of the journey.

The trip to Saudi Arabia never came off. Nevertheless I reckon I've come a long way since I didn't go there.

AIDS, TALK POSITIVE

AIDS, TALK POSITIVE is a radio series of 8 programs to help you understand how AIDS & HIV affects you. You can also ask questions. Use the talkback number listed below.

EACH program clearly explains the HIV virus, how it can cause AIDS, and how you are at risk. The programs speak plainly about how the virus is transmitted, and the steps to take so you can protect yourself and your partners from being exposed to the virus. If you don't feel happy talking about safe sex and condom use, then we give you some ways to do it. If you or your friends use needles or fits, we tell you how to use them safely.

The Adventures
of Cliff Doyle
HIV
Investigator



A detective story for people living with HIV and AIDS

Cliff Doyle - private eye is quietly nursing his head after a three month binge when a mysterious caller makes him run to his doctor. He discovers he is HIV positive. He does the only thing he knows how - he investigates. What is this disease? How did he get it? Cliff discovers that he no longer has to break down doors to get information, because there's a whole community of people ready to help him.

Cliff decides that if the pill jockeys keep on coming up with new treatments he's got a lifetime in front of him. Maybe getting his teeth kicked in each week as a private investigator is not exactly a stress-free existence!

With your reactions, call the talkback phone number listed below.

AIDS - TALK POSITIVE is a 2SER-FM project funded under the Commonwealth Government's AIDS Education Program. For further information on the project, please contact the Project Co-ordinator on (02) 2816333

**TALKBACK
PHONE
NUMBER 2111977**

**2SER
1073**

Program Date Time

A TIME FOR LIVING for partners, parents and friends of people living with HIV and AIDS	Sunday 12th November	10:00am
THE ADVENTURES OF CLIFF DOYLE HIV INVESTIGATOR for people living with HIV and AIDS	Thursday 16th November	10:00pm
NICE GIRLS GET IT TOO ! for women	Sunday 19th November	12:00noon
WE KNOW WHAT GUYS WANT for men	Thursday 23rd November	5:30pm
THE INSIDE STORY for prisoners, their lovers, relatives and friends	Friday 24th November	9:00pm Simulcast on 2RSR 88.9

TALES FROM THE AIDS WARD

PAUL YOUNG

I always recommend that if, when hospitalised, you want lots of visitors and crowded wards then St. Vincent's should be your first choice. I assume here that, despite your state of health, you won't mind lying on a trolley in Casualty in incredibly uncomfortable conditions for up to twenty-four hours while you wait for a bed on Seventh Floor South (aka "Seventh Heaven"!). A possible bonus of being hospitalised in Darlinghurst may be to wake finding cockroaches dancing across your bed. (The Franz Kafka Ward?)

Prince Henry Hospital's \$2 million Special Care Unit (no it's not an "AIDS Ward") is, on the other hand, bright, modern, and provides stunning ocean views. Television sets are provided free. Beds are generally readily available. I will never forget waking one morning as the sun rose over the ocean and seeing a large whale cruising past on its way to check out the Malabar sewage outfall. On another morning it was herd of gambolling dolphins.

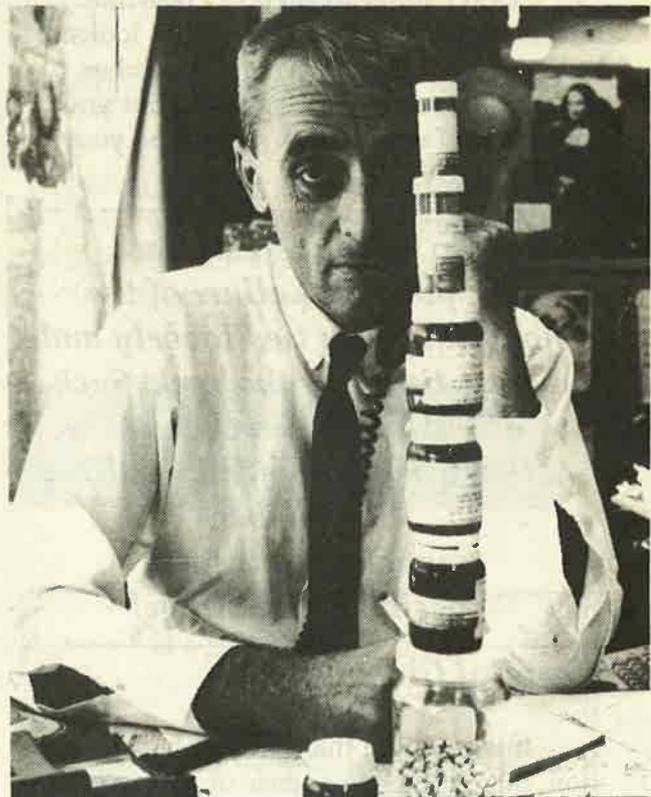
Don't be put off by Prince Henry's remote location. It can be an advantage if you like peace and quiet, as it is quite a trek by public transport and \$12 by taxi from the city. Aethetically it is far more pleasing than St Vincent's. A new walled garden should be complete in time for World AIDS Day celebrations. Food quality is very high and if you have special dietary needs arrangements are made to meet those needs. Good news for puff buffs - you won't be hassled for enjoying that quiet after dinner fag.

In both hospitals (and here I speak from the experience of four extended stays

in each) nursing and ancillary staff are incredibly competent, compassionate and talented. With many nurses being gay men the burn out factor must be high but, nevertheless, they go out of their way to LISTEN, and to take on a companion role.

Obligations To Yourself

People with HIV/ARC/AIDS are frequently very ill and freaked out by their initial visit to an AIDS Ward (or Special Care Unit!). Sudden chronic illness, radical weight loss and disorientation may mean it takes several days for you to absorb fully what is happening to you. PCP (AIDS related pneumonia) which kills 67% of PLWAs is one opportunistic infection about which many people are ignorant. Some people have had symptoms (breathlessness, chest pain, loss of appetite) for up to six weeks and not sought help. Remember, de Nile is a river in Egypt. Please seek advice before it is too late.



"Food quality is very high. If you have special dietary needs arrangements are made to meet them."

Photo: Paul Young

The Following May Assist During Hospitalisation.

* Ask the experience and qualifications (although politely) of the doctors and nurses treating you. How do they treat you? Like a number? As though you are taking up a precious bed? Are you receiving thorough information about the reasons for different tests, X-rays etc? Ask them straight out, what is the test for, how necessary is it and what will it prove or indicate? Are you being treated by an inexperienced resident doctor doing a three month stint in immunology?

* Insist on being informed of the likely side effects/toxicity of drugs you are being given. Many PLWA's are allergic to Penicillin and 50% are allergic to Bactrim (very commonly used) - ask doctors, or better still nurses as they are usually easier to relate to, when you might expect side effects such as rash to occur.

* Don't suffer in silence! Press that buzzer, no matter how many dirty looks or long sighs you may receive! Remember, the staff are usually overworked but your comfort and well being should be your main priority.

Do not underestimate the potential allure of the hospital gown tied loosely and thus temptingly at the back. Such attention to detail can often bring delightful results...

*Remember,
panache is our forte -
use it to advantage!*

Hospital Glamour

It is essential that, despite hospitalisation, one maintains a sense of glamour and style. From something as basic as taking a colourful poster and pot plant to brighten

up an often drab ward to a favourite soft toy: all these things help to lessen the boredom of a long hospital stay.

Don't forget a colourful range of hospital outfits - of course the skimpier the better; a little colour and movement will not only cheer the other patients but will also become an easy conversation starter (as in "Love yer look"!). Do not underestimate the potential allure of the hospital gown tied loosely and thus temptingly at the back. Such attention to detail can often bring delightful results especially if one is trying to attract a particular patient or staff member. **Remember, panache is our forte - use it to advantage!**

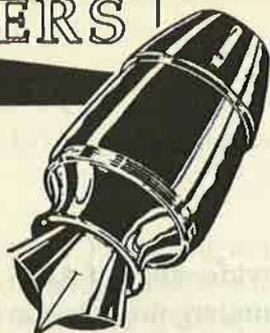
A sure sign of success is that phone number left by your bed by your favourite nurse or patient, suggesting further contact. Many a strong friendship has been struck during a hospital sojourn and the camaraderie of being a fellow patient can result in worthwhile sustained relationships.

Should you find yourself about to be admitted to hospital you may care to tear out this article from *TALKABOUT* and pop it in your handbag or wallet. I hope you find it useful.

In our next issue we will present a profile of the newly opened ward (unit?) at Royal Prince Alfred Hospital.

JEFFREY JACKSON

Jeffrey was one of the founders of Albion Street AIDS Bus. He passed away recently as a result of AIDS complications. Jeffrey's tireless efforts in AIDS education amongst street workers, IV users and the disadvantaged will not be forgotten.



Dear Friends,

I'm a 28 year old male, guest at the moment of the N.S.W. Government, here at the Malabar Assessment Unit (AIDS UNIT) in the Long Bay Complex. I knew of my H.I.V. + infection about four years ago, so I didn't have the shock of being told once in gaol. When I first came to gaol I was placed in Protection at the Remand Centre. The motive, in the words of the Superintendent, was because my life was in grave risk in the Main gaol due to my H.I.V. + status. It's hard to believe, but looks like it's true. We know about a prisoner, who knew recently of his infection, having trouble after 3 years living in the Main gaol. After 3 weeks and few complaints, I was transferred to the AIDS UNIT.

Being a Segregated Unit, time is made harder, longer (loss of remissions, having to serve the whole sentence in the Unit) and less constructive (not allowed to do most of the educational courses or work). The Unit is not too big, but because we are only a few inmates, the space is enough. In seven months I've shared the Unit with another eight prisoners. About medical care, there are no complaints. We are visited by the doctor every time we want one. The Medical Director of the Unit is a good specialist from Prince Henry Hospital who comes to visit us every two months. In case of emergency he is contacted by phone, and in case he thinks it's necessary we are transferred to some hospital outside the gaol. We also have a good team of counsellors and from time to time we are visited by people who work in AIDS in the community. In case someone wants, all kind of information is available.

Recently the N.S.W. government has approved a Non Segregation policy for H.I.V. + prisoners. We also know that compulsory testing on AIDS will be introduced at the beginning of next year. Because we would not like to suffer any kind of discrimination, we would like to see a good job done by the Corrective Services, to train inmates and prison officers in the AIDS matter.

Yours in the fight against the spread of AIDS.

M.A.U. INMATES

NOTE

PLWA (NSW) visited the HIV Unit of Long Bay Gaol in September and discussed with prisoners issues which concerned them, including segregation policy and compulsory testing. *TALKABOUT* is now regularly received in HIV units in NSW prisons.

Authorship of the above letter is unclear.

TALKABOUT welcomes letters from our readers. Though we receive a great deal of verbal feed-back about the newsletter most of our readers seem a bit shy about writing.

Don't forget to write.

STEPHEN HILL
DIED 6.8.89

Stephen was very much loved by his family and a wide circle of friends in Australia and the United States.

TREATMENT GLOSSARY

There are currently over 60 experimental drugs for a wide range of AIDS related conditions, including asymptomatic infection, awaiting or undergoing trials in the United States. Only a very limited number of similar trials are underway in Australia though an increasing number are being designed or proposed. Below is a sample of the more common and promising treatments. Some are available through trials here in Australia such as AZT, Fluconazole or Passive Immunotherapy, or are in various stages of trial in the US. and the U.K. Only AZT is an approved drug for people with late stage HIV disease.

Acyclovir (Zovirax) : Antiviral used in the treatment of CMV retinitis and herpes zoster. Often used in conjunction with AZT for ARC or AIDS patients.

AL 721 : Originally developed by Weizzman Institute in Israel. A derivative of egg lecithin thought to affect changes to the membrane of HIV leading to prevention of attachment to and penetration of target cells such as T4 cells. The Sydney Albion St AIDS Clinic recently cancelled its proposed trial on the strength of unfavourable reports from trials in the US.

AZT (Azidothymidine, Zidovudine, Retrovir) : An antiviral drug, developed by Burrough Wellcome Ltd, which blocks the conversion by HIV of RNA to DNA, thus preventing replication of the virus in the body. Available since October 1986 to people with AIDS, more recent trials have indicated AZTs efficacy as an early intervention drug for asymptomatic HIV infection and ARC. Currently available through teaching hospitals such as Sydney's St Vincents or Melbourne's Fairfield, to those with less than 200 T cells. Also available through double blind placebo trials for those with T cells between 200 and 400 or 400 T cells and antigen positive ("high risk" trial), or over 400 T cells and asymptomatic ("low risk" trial, and for haemophiliacs with more than 100 T cells and asymptomatic. More recently being trialed in conjunction with other drugs such as Dapsone or aerosole pentamidine (at Fairfield hospital, Melbourne). There are also proposals for trials in conjunction with a number of experimental drugs such as DDI, DDC, GMCSF and GLQ 223. Also to be trialed as prophylaxis for health care workers immediately after possible infection through eg. needle stick injury. A sort of "morning after" pill.

Bactrim : Not in trial as such, Bactrim is a powerful antibiotic used in the treatment and prevention of PCP. Up to 50% of users may develop allergic reactions and are better off on alternatives such as Pentamidine.

CD4 : Antiviral drug in early trial stages. May be effective in preventing HIV from infecting new cells and in killing already infected cells.

COMPOUND Q / GLQ223 / CHINESE CUCUMBER ROOT : Pure extract from a species of cucumber, long used in China to induce abortion and treat cancer. Currently in Phase I trials in the US as a treatment for HIV infection, initial results are promising in that the substance appears to target and kill HIV infected cells. Trials of Q may begin in Australia in the near future

Dextran Sulphate : Originally available from Japan for blood coagulation disorders, a trial in the US recently indicated DS was not readily absorbed into the blood and therefore ineffective

DDI/Dideoxyinosine : Promising antiviral similar to AZT. Though still in phase 1 trials in the US, early results indicate DDI is half as effective as AZT yet ten times less toxic. Could be a useful alternative for those intolerant to AZT. Trials will begin in Australia in 1990

DDC/Dideoxycytidine : Similar to DDI, also awaiting trial here in Australia.

Fansidar: Used for prevention of PCP, also allergy producing for some.

Fluconazole : Antifungal available through trial at St Vincents for oral candidiasis and cryptococcal meningitis.

Foscarnet : Antiviral under trial in the US for CMV. Possibly useful against herpes, shingles, or Epstein Barr virus. Available in Australia through the Individual Patient Usage Scheme.

GM - CSF : Experimental drug potentially useful, in conjunction with antivirals such as AZT, to reverse side effects such as anaemia

Hypericin : Available in Australia over the counter, an extract from the St John's wort said to inhibit budding of HIV from infected cells. May be good also for herpes and in conjunction with antivirals. Albion St Clinic has announced it will begin a trial in late 1989.

Interferon : Naturally or synthetically produced substance which can inhibit viral replication. Tried with little success against HIV related illness.

Isoprinosine : Investigative new drug designed to boost the functioning of the immune system. Albion St clinic is no longer enrolling subjects for its Isoprinosine trial.

Megastrol Acetate : Available through prescription for breast cancer in women, in trial in the US for use against weight loss in PWA's.

Passive Immunoneutralization/Passive Immunotherapy/PIT : The transfusion of effective p24 antibodies in blood plasma from a well HIV positive person to an unwell person with AIDS. Trials in the U.K. indicate this treatment returns patients to an antigen negative status, thus stimulating the immune function in people with AIDS. Awaiting trial at Albion Street Clinic for want of participants.

Pentamidine : Effective prophylactic and treatment for PCP taken either intravenously or by inhaling it directly into the lungs.

Next issue: Glossary of AIDS terms plus we begin a regularly updated contact list of groups and services for people affected by HIV in NSW.

CONTACT LIST

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. Nigel, Albion Street Centre, 150 Albion Street, Surry Hills 2010
332 4000 1st & 3rd Wednesday of every month. 7.30pm

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 332 4000 Every 2nd. Thursday 12.00 - 1.30pm.

TRANSFUSION RELATED AIDS: A support group for people acquiring HIV through a blood transfusion. Please phone to indicate attendance. Parramatta Hospital, Marsden Street, Parramatta. Jenny: 262 1764 Pam: 635 0333 ext. 343 Last Tuesday of each month. 10.30am

ACON: AIDS COUNCIL OF NEW SOUTH WALES: The Council provides services in education, welfare, support and advocacy in relation to HIV / AIDS to the gay and general community.
68 Sophia Street, Surry Hills 2010 Phone: (02) 211 0499

AFAO (AUSTRALIAN FEDERATION OF AIDS ORGANIZATIONS): Umbrella organization for Australian state and territory AIDS Councils.

ALBION STREET AIDS CENTRE (SYDNEY HOSPITAL AIDS CENTRE): Main Sydney clinic providing HIV testing, counselling, and support groups for people with HIV infection. Also conducts experimental AIDS treatment trials.

THE ANKALI PROJECT: A volunteer based project providing emotional support to people with AIDS, their partners and loved ones. Administered by the Sydney hospital.

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.

COMMUNITY SUPPORT NETWORK (CSN): Trained volunteers providing practical home care. A volunteer based organization in Sydney providing home care for people with AIDS. Established in 1984.

DAY CENTRE (MAITRAYA): Daytime recreation/relaxation centre for people with AIDS run partly by volunteers and funded by the NSW Department of Health.

METROPOLITAN COMMUNITY CHURCH (MCC): International gay church. The Sydney chapter of MCC originally established the CSN.

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. Phone 211 0499

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) 211 0499

SYDNEY WEST GROUP: A Parramatta based support group. Contact Pip Bowden (02) 635 4595

PLEASE ADVISE OF ANY RELEVANT CONTACTS YOU HAVE. WE WILL INCLUDE THEM IN THE NEXT TALKABOUT

NOTICES

MEETING OF PLWAs

**What do you think of
the health services
you receive?**

Any complaints?

What works well?

The AIDS Bureau (NSW Department of Health) is conducting a planning study for the development of HIV / AIDS services to meet your needs.

We want your views on what you want and on problems you currently encounter.

We are holding a half-day meeting to listen to you.

WHEN:

Wednesday December 6th.

TIME:

1.00 - 5.00pm

WHERE:

YWCA
5 Wentworth Avenue
DARLINGHURST

ENQUIRIES:

(02) 399 4655
ask for:
David, Margaret or Ian

**KARUMAH
DAY CENTRE
NEWCASTLE**

*Every Friday
11.00am - 4.00pm
The Citadel Hall
Cnr. Granger & Pearson Sts.
LANGTON*

PHONE (049) 57 2358
ASK FOR RANDY

**PLWA COMMITTEE
MEETINGS ARE HELD
ON THE FIRST THURS-
DAY OF EVERY MONTH
AT:**

**ACON BASEMENT
MEETING ROOM
68 SOPHIA STREET
SURRY HILLS
6.00pm - 8.00pm**

All members are welcome.

JON SWEENEY

Jon was a founding committee member of PLWA (NSW). He was also the first Western Beats Project Officer. He was also involved in the work of the Katoomba Day Centre. It goes without saying that we are all indebted to Jon for his work in the fight to stop AIDS.

SUBSCRIPTIONS DUE JANUARY 1

JOIN US

NAME : (please print clearly) _____

MAILING ADDRESS: _____

_____ POSTCODE _____

TELEPHONE NUMBER/S _____

DO YOU AGREE TO HAVE OTHER MEMBERS KNOW YOUR NAME AND ADDRESS: YES / NO

ARE YOU PUBLICLY OPEN ABOUT YOUR MEMBERSHIP? YES / NO

ANNUAL SUBSCRIPTION RATES ARE :

MEMBERSHIP OF PEOPLE LIVING WITH AIDS INC. (NSW) \$2.00

SUBSCRIPTION DONATION TO TALKABOUT (Individual) : \$10.00
(Optional for people receiving benefits)

SUBSCRIPTION DONATION TO TALKABOUT (organization) : \$20.00

ENCLOSED ; \$ _____

I WISH TO APPLY FOR MEMBERSHIP OF P.L.W.A. INC. (NSW)

I WISH TO SUBSCRIBE TO TALKABOUT.

SIGNATURE _____

OFFICE USE ONLY :

1. 2. 3. 4. 5. 6. 7. 8. 9.