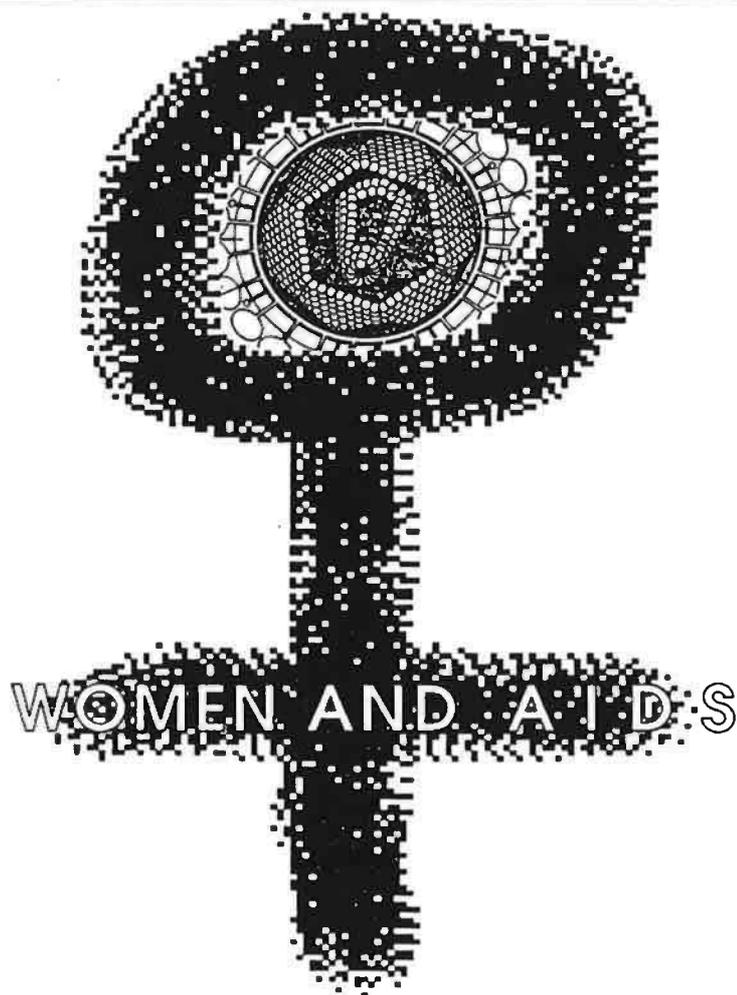


Talkabout

Newsletter of People Living With AIDS Coalition Inc. (NSW)



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Where we speak for ourselves

TALKABOUT is the newsletter of People Living With AIDS Inc. (N.S.W.) and is published every two months. All views expressed in **TALKABOUT** are the opinions of the respective authors and not necessarily those of PLWA Inc. or its committee or employees.

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PLWA COMMITTEE
MEETINGS ARE
HELD ON THE
FIRST THURSDAY
OF EVERY MONTH
AT:

ACON BASEMENT MEET-
ING ROOM
68 SOPHIA STREET
SURRY HILLS
6.00pm - 8.00pm

All members are welcome.



Sign language video launched

The auditorium of the Deaf Society at Stanmore was packed for the gala launch of the highly acclaimed 40 minute video "AIDS, not hearing aids". The video, produced by Auslan Art and Health Media with government funds, communicates messages about safe practices and HIV in Australian Sign Language. As well as the actors' signing, there are English subtitles and voice over.

The video features a bedroom discussion on HIV transmission between a deaf man and woman, cutting to explicit scenes and graphics to illustrate condom use and safe sex issues. The video also features Colin Allen, an AIDS educator at the Deaf Centre, who is running a series of workshops for different groups in the deaf community. Also included is a steambath scene where a deaf gay man negotiates safe sex with a hearing partner. Towards the end are excerpts from a general meeting about AIDS issues where deaf community leaders call for support and solidarity for any hearing impaired people with HIV or AIDS.

Neal Blewett, in launching the video, honoured the deaf community and testified to the world leadership by community groups in Australia in AIDS

T

care and education initiatives. Penny Cook, actor on television's "E Street", also spoke at the launch.

Accompanying the video is a brochure about HIV designed by Redback Graphics. The brochure uses language appropriate to the deaf community, with very explicit illustrations of sexual and injection practices.

The quality of the video and brochure are immediately evident to all and people unfamiliar with Australian Sign Language can learn much from them. They are a big step forward in making AIDS education more inclusive of diverse communities in Australia. On all counts the two products are amongst the best and most sophisticated contributions to discussion of HIV. They deserve to be a source of pride, not only for the educators and artists involved in production, but also for the deaf community as a whole.

For information about the video and brochures, or about the AIDS education project located at the Deaf Society, contact Colin Allen on 02 560 6433 (voice message or TTY), or write to PO box 432 Petersham 2049.



AIDS, Not Hearing Aids

- WHAT IS HIV? WHAT IS AIDS?
- HOW TO AVOID GETTING HIV
- HIV/AIDS SOCIAL ISSUES



Support group formed for Spanish speakers

The Spanish speaking community in Sydney has given a lead to community groups in NSW in establishing a support group for people affected by AIDS. An organization called SACBE has been founded to offer moral and economic support to people with AIDS related illnesses, as well as to their friends and families.

SACBE was initiated by Patrick Marco, a Community Health Worker, with Beatriz Copello, a psychologist. SACBE, which in the Mayan language means 'a new path', considers that it is vital to inform people in their language about the risks to everyone from AIDS as it is an illness for which neither vaccines nor effective treatments exist.

The objectives of SACBE are:

1. To offer emotional, social and financial support to people with AIDS, and their families.
2. To disseminate information about AIDS and how it affects individuals and the community.
3. To educate the community in prevention measures.
4. To maintain links and assist,

where possible, other organizations involved in the fight against AIDS.

5. To recruit and train volunteers or staff to carry out the above objectives.

6. To collect funds to financially assist people with AIDS.

SACBE invites members of the Spanish speaking community, in particular, and the community in general to participate by giving financial assistance in the way of money donations or by working as volunteers. People who wish to work as volunteers will be trained and oriented on how to assist and support people with AIDS.

SACBE in its campaign against AIDS has already conducted information seminars and offered counselling free of charge.

SACBE offers, in the Spanish language, advice, help and support to people who fear they have contracted the disease, or who are at risk of contracting it.

SACBE is managed by an executive committee and is in the process of becoming a charitable organization. The executive is formed by Pedro Manzur (President), Beatriz Copello (Secretary), Miguel Perdices (Treasurer) as well as Nelson Salas, Jorge Letter and Gilberto Diaz-Guerrero.

SACBE can be contacted through:

**ACON
P O BOX 350
DARLINGHURST 2010**

**PHONE (02)211 0499
TTY (02)281 4975**

Don't freeze! EAPA takes the worry out of being cold

Dreading that winter electricity bill? Shock! Horror! That little machine costs a lot more than you think. Under the NSW Government's Energy Accounts Payments Assistance Scheme - EAPA (previously known as Baseline), some of your problems may now be solved.

For PLWA's on pensions or benefits a large bill can be a major trauma. Assistance is in the form of \$30.00 vouchers which can be presented to further defray the cost of the bill, after the usual meagre rebates have been deducted.

People looking for EAPA assistance should take their bill to their local branch of one of the following community organisations: **St. Vincent de Paul, CAREFORCE, Sydney City Mission, Wesley Central Mission, or The Smith Family.** These organisations will assess a person's needs and issue one or more vouchers depending on their assessment. Some hints to remember:

- * go in on an off pay week- you'll seem even more broke than in a pay week
- * the bill should be in your name - take it with you
- * take rent receipts, other bills - anything you can lay your hands on to prove that

you are in financial difficulty

* residence in public housing will not alone disqualify you

* if the agency has no EAPA vouchers left shop around, as they are issued annually and, given the current rash of state government welfare cuts, the scheme could be in jeopardy!

If you want more information about EAPA contact the Energy Authority's Baseline staff on 234 4444 or ring your local agency. Remember, you can receive more than one \$30 voucher. **KEEP WARM!**

PAUL YOUNG

People living with AIDS - support group in Penrith

A group for people who are HIV positive, their friends and care givers, has been formed in Penrith. We offer general support, information, referrals and more. Meetings are held weekly in Penrith.

For venue, time and more information ring (047) 218330 and ask for Wendy.

MORE *NEWS* 

New Day Centre

The tireless efforts of Irwin and the Day Centre Committee in their quest for a new home have paid off. A long term lease has been secured for a building in Surry Hills. Extensive renovation is currently being carried out so that the new centre will be as comfortable and functional as possible. Irwin is being just a little bit coy about the exact location and opening date but if you want to know more you could try at the present centre at **111 Jersey Road, Woolahra** or phone Irwin on **360 3133**.

PWA's move to control own treatment studies

In a move which may cause raised eyebrows among the medical research establishment, a group of people with HIV has announced that it will be running its own studies.

The group, which goes under the name Community AIDS/HIV Initiative for Treatment Education (CIFTE), says it will be starting a study of what it calls "self-treatment usage experiments".

Spokesperson Terrence Bell, who is editor of the group's treatment newsletter, AIDS ADVOCATE, says that there are thousands of people in Australia with HIV who are conducting their own "experiments" in treatments for HIV.

"The only thing we're interested in, is staying alive, and if profits have to come a sorry last, then that's too bad."

Everyone is trying something different", he said, "whether it's their own combination of standard treatments, or some of the more exotic and uncommon herbal treatments.

"Many doctors and researchers aren't interested in this, except to warn how foolish and harmful it might be. We believe that in all this 'private' research something important may well be found to help people with HIV survive longer, or at least until drugs like Compound Q are proven one way or the other."

He added that if there are harmful treatments being tried the group wants to know about that too, so that people can be warned to avoid them. "What we have here", he said, "is an enormous and potentially valuable reservoir of experimental data which medical researchers are allowing to go to waste, simply because it hasn't been produced and collected according to their conventional methods.

"Our aim is to collect this information on a large scale. Then, if something looks good, we will have a powerful case for

going to research institutions and saying, 'people with HIV have been trying this and it seems to be working, so we want you to do a full scientific investigation to find out if it really is working'.

Terrence Bell also said, "Until now, most of the basic decisions about the direction of treatment research have been taken by drug companies, who are as interested in profits as much as they're interested in a cure. "The only thing we're interested in," he said, "is staying alive, and if profits have to come a sorry last, then that's too bad."

- People with HIV who want more information, or who want to contribute to the Self-treatment Usage Survey can write to **Community AIDS/HIV Initiative for Treatment Education (CIFTE)** C/- 101/112 Oxford St., Paddington, 2021, or phone 02 332 2003 (10.00am-4.00pm Mon.-Fri.)

Update on IVDU : Users Association gets funded

Well, I can say at last that NSW finally has a community organization for current and former intravenous drug users (IVDU) and those who identify with the issues of this community. It was looking a little shaky for a while, however five years of trying to gain support has paid off. With a meeting of the membership of the formerly named

NSW USERS ADVOCACY ASSOCIATION (NUAA), held on Friday June 30th, NUAA has undergone a name change and appears to have secured funding for 1989/90. At this meeting we considered a proposal for a name change. Although reluctant to delete the word advocacy from our name, it was considered necessary to alleviate concerns held by people within the Department of Health in order to ensure that we would receive funding support and Departmental recognition. Therefore, the NSW USERS ADVOCACY ASSOCIATION is now known as the **NSW USERS and AIDS ASSOCIATION (NUAA)**.

With the granting of funding until September '89 we now have the resources to expand our services, move to independent premises in the Kings Cross/Darlinghurst area and employ at least one more worker to cover our increasing workload. We are searching for shop front premises with space for offices, meeting areas and 'drop in'/day facilities.

Now that we are a viable entity we are also looking forward to expanding our membership, so please contact us on 331 4344 to talk to Julie or Celia.

BIG PRINT

IF YOU HAVE DIFFICULTY
READING TALKABOUT, OR IF
YOU KNOW SOMEONE ELSE
WHO HAS DIFFICULTY, BE-
CAUSE OF VISUAL IMPAIR-
MENT, PLEASE LET US KNOW
AND WE WILL FORWARD A
LARGE PRINT COPY TO YOU
JUST PHONE OR WRITE TO US

Share Accom- modation Register established

The Community Services Unit of the AIDS Council of N.S.W. is setting up a share accommodation register for people affected by HIV/A.R.C./AIDS or others seeking accommodation.

People who are seeking to share accommodation with others or who have accommodation they would like to share or rent with somebody, can contact the Community Services Unit, fill out a confidential questionnaire and hopefully be put in touch with appropriate share situations. This free service is not restricted to people infected with HIV. For more details phone the Community Services Officer on 212 2728.



NEW PHONE
NUMBER FOR
P L W A
281 7549

Missing quilt in Sally's ute- you beaut !

With founder and convenor of the Australian Quilt Project, Andrew Carter, on a well deserved break and at the same time raising Australian PLWA profile at the Montreal AIDS Conference, what happens? When Andrew turned his vigilant eye, nine Quilt panels disappeared!

Certain Quilt helpers lived in fear and anxiety that their convenor would find out about the disappearance. Various conspiracy theories arose: extortion attempts, a jilted or bitter and twisted lover of one panel commemoration. The Festival of Light was also mentioned. All welfare agencies were put on Red Alert in case the nine panels were offered to a charity.

A joy and a blessing - there they were in the back of a Salvation Army truck. Very sinister, indeed. The plot thickened.... why would THEY want our Quilt?

Deservedly, news of the find by overjoyed Quilt Group members received a mention in the Sydney Morning Herald, Column 8.

Clearly, funds need to be provided for security so our Quilt is never again a target for terrorism!

Message message is : hands on



As reported in our last issue a new volunteer based group offering free massage to people with HIV, ARC and AIDS has been formed and is now up and massaging. The group, calling itself "Hands On" is about to run its first training session to equip volunteers to provide basic pain relief and relaxation massage for clients in the hospital, hospice or home setting. Anyone wanting to be trained and join the team or wanting to receive massage themselves please contact **Richard Holland** on 477 8255 (h) or 660 6392 (w), or write to PLWA.



Workers start at PLWA (NSW)

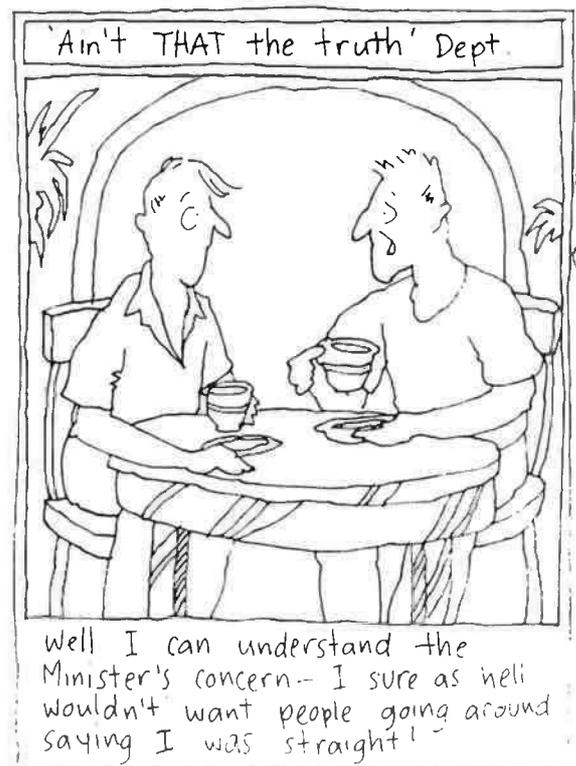
Two part time workers have now been employed by PLWA (NSW) to undertake some of the more time consuming and important work for the organization.

Eighteen year old style veteran David James has been appointed to the position of Newsletter Co-ordinator and is responsible for facilitating (i.e. extorting) contributions, trying to make them look pretty on a page, grovelling to the printer and making sure as many people as possible read *TALKABOUT*.

David is usually in the office on Tuesdays and Thursdays on (02)211 0499, or TTY (02)281 4975

Super efficient office aficionado Don Carter has been appointed to the long-ing-to-be-filled position of Administration Support Officer and is responsible for the management of PLWA internal communications and liason with other AIDS agencies. Don is available **Monday, Wednesday and Friday** on (02)211 0499, or TTY (02)281 4975.

PLWA congratulates David and Don on their appointments and wishes them all the best in making our organization a better and more successful one for all of us in the future.



Getting a second opinion - about your doctor !

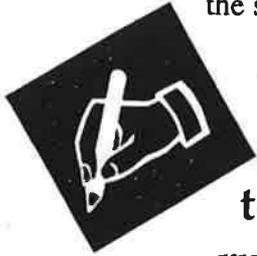
Dear *Talkabout*

I never thought I'd become the sort of person who collects doctors like a Valium freak. But I hope other PLWAs are becoming aware, like me, of the incredibly vast variety of attitudes to be found among registered General Practitioners in NSW. We should insist on certain things from the doctors we consult: care, concern, respect and honesty.

I'm sure others have had bad experiences with doctors who may not have displayed these qualities. Such a situation is an excellent reason to encourage discussion about the doctors available in the private and public sector. Too many of us are learning the hard way which doctors are to be avoided. When it comes to the crunch, most doctors will 'talk turkey', but then most of our interactions with them are for regular, routine tests - situations where they are not telling us anything new. Such a situation, which went sour for me, occurred when I was on the St. Vincent's AZT trial. On one visit, my doctor asked me where I was going for my holidays, and, when I said that I was visiting my family, suggested that I discuss my medical situation with them. This suggestion was made despite a consistently stable set of results. He did add that there was no indication that there was anything serious, but that's no comfort to someone who is feeling vulnerable. The result of his advice was the predictable gnawing anxiety, before I realized that the only person to decide when to tell my family is me. The lesson I learnt from this was



to avoid doctors who rule out the possibility of hope. If your doctor is not telling you bad news and you still leave the surgery depressed, change doctors.

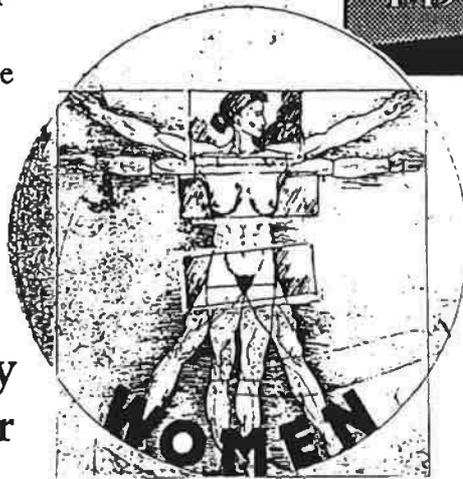


"The lesson I learnt from this was to avoid doctors who rule out the possibility of hope. If your doctor is not telling you bad news and you still leave the surgery depressed, change doctors."

At the moment I only occasionally consult a GP, for the usual aches and sore throats, and I hope this situation will continue. The only virus I've discussed with him is Herpes Simplex, for which he prescribed ample Acyclovir. For all I know, he may have secretly tested me for the virus but right now we have a relationship of trust. People who are dissatisfied with their present doctor, and are feeling daunted at having to search for a replacement, should be able to find out the opinions of other PLWAs. If enough interested people contribute their opinions, a list of doctors and their attributes or drawbacks could be compiled, to be available on request. In the continuing climate of oppression, where it becomes obvious that some doctors are not immune from media propaganda, PLWAs need such a list. If you like this idea and have information to pass on, please write to me c/o *TALKABOUT*.

Name supplied but withheld on request.

Don't forget to write.



We have a responsibility to women living with AIDS.

Until we are confronted with a loved female friend, family member, work colleague or woman acquaintance who has been diagnosed with AIDS, AIDS Related Condition(ARC) or HIV we rarely think much about infected women and the extraordinary personal and social problems they face. Women living with the epidemic are our sisters, friends, mothers and lovers. We are still only beginning to recognize some of their very particular problems. Solutions, especially, have been very short in realization.

A distinct minority within the PWA community, women experience a number of quite different issues from their

male counterparts. Current National Health and Medical Research Council figures identify 47 women out of 1388 cases nationally, 23 of whom are blood transfusion recipients, 10 from heterosexual contact, and 6 cases are under investigation.

- For too many of these women AIDS is a disease of invisibility, isolation and secrecy. They may have no one in whom to confide. How are these women coping - medically, socially and within the PWA community? Demographically, women with AIDS make up a broad spectrum of society. They do not belong to a particular class, ethnic group or community. A growing number, though, have been intravenous drug users; or their partners have been. They lack a strongly identifiable and comfortable support network to help them manage, both emotionally and in their daily lives.

Women must come to terms with many of the same problems as gay men: lack of information from their doctors, death messages from the media, having to deal with depression, working to hold on to their sobriety - all this while trying to cope with health and financial problems, job discrimination, fears of rejection and so on.

Statistically, the survival rate among infected women is half that of gay men. The reasons for this are still to be determined. Women are not being seen by their doctors at a sufficiently early stage, and are not always properly diagnosed in time. Handling their roles as carers and mothers, leaving children motherless, and deeper fears of abandonment are all major challenges which confront all women, not only HIV positive women. After testing positive, it is confusing and anxiety inducing to have to sort through one's own issues of sexuality, intimacy

and safer sex behaviours. One of the biggest challenges to infected women, and the one that causes the most anguish, centres around children and pregnancy. These are often women in their primary child bearing years. They are faced with having to tell their sexual partners that they're infected with HIV and consequently being rejected sexually. If they continue in their relationship and choose to have a baby, or if they become pregnant accidentally, they're faced with the 50/50 chance that the child will be born with AIDS.

Many of these women already have children and must deal with the prospect of preparing them emotionally for the possibility that their mother may become seriously ill and may eventually die. There are legal entanglements and questions as to who will be the child's legal guardian, who will raise the child, or children, and how they will be supported financially. The list becomes endless.

Such emotionally charged issues could throw the healthiest person into deep depression. There may be the multiple stigmas of having AIDS, being female and possibly being an ex-IV drug user. Unfortunately, some chemical dependency treatment centres and GPs are not willing to deal with AIDS as part of a treatment programme.

As a female PWA puts it, "Women absolutely need to identify their own issues and become empowered personally and as a group, *But ultimately, this is a human and global epidemic that does not respect gender. I look forward to a time when I can walk into a support group and know that I am understood and supported by all the men and women there.*"

Sue: June 7, 1989 a personal history

November, 1984.

After a very long labour I had an emergency Caesarean and had some blood transfusions about a week afterwards, when I was still in hospital...because I was there for a while. My husband brought in the paper.... 'AIDS Through Blood Transfusions'.... That was about a week after the operation. We thought, 'through blood transfusions, oh! that's interesting. So, although we never thought, 'oh, that must have happened to me', we always had that idea in our heads that it was a possibility. Whereas, for a lot we talked to, it was a dramatic shock because they didn't know that ordinary people got it. We always had that in the back of our minds.

My daughter was a few months old when I started getting quite concerned because I had a pretty rough time when she was born. I didn't feel as though I was getting any better. I just felt run down, just as though I hadn't got over the operation. I went to a lot of doctors and had all sorts of tests for all sorts of peculiar

things. They couldn't work out what it was. I asked several if I could have an AIDS anti-body test and they treated me as though I was a neurotic housewife who didn't have enough things to think about. The attitude was, 'don't be stupid'. So I didn't (have the test). Then we decided after a while, as I wasn't getting any younger, to have another child. So we started trying to have another child and after about six months, when I hadn't become pregnant, I went to see my gynaecologist. He rang me one day and said that he wanted me to have some blood tests. He thought I might be anaemic. I think that was an excuse to get me there. When I saw him he said, "Well, while you're here...I got a letter from the blood bank saying that people who had blood transfusions should be tested for AIDS anti-bodies." I had been asking for twelve months for that!

We weren't worried or anything about it. But then the secretary rang a couple of weeks later because they had done tests at the time for anaemia, it could have been those.....but just from the way she spoke, I spent a very sleepless night. The next morning I was in a state, so my husband thought he had better take the day off work to take me to the doctor, of which I was very glad. We went down. The doctor told us that, because he didn't know much about it (nobody did then, particularly gynaecologists), he had somebody there from the blood bank. She knew a lot more about it. She could talk to us because the doctor didn't want to tell me what was wrong and not be able to give me information. He had also arranged an appointment that morning with the immunologist at Westmead Hospital. We could get the whole thing in one day so that we would know exactly where we were. The woman from the blood bank took us over to Westmead Hospital to meet the doctor. My

husband and daughter were tested and then followed the worst twenty-four hours of my life. Strangely enough, I wasn't really worried about my husband. I felt that if he was positive, he would have to cope with it the same way as I did. With my daughter, she was not quite two at that stage, it was very different. I had breast fed her for about three months. At that stage I was the only person that they knew of who had breast fed their child after transfusion and who hadn't passed it on as they had expected. She hasn't got the virus, which is very good. I felt pretty horrible. It was very difficult because there wasn't....even with seeing the doctor....there wasn't that much information. At that time they were extremely positive about the whole thing. They were saying that blood transfusion people had about a 5% chance of getting full blown AIDS. I think now it is about 86%. They were very optimistic. We were told not to think about it very much.

"Apart from being told exactly what I had, that was the first thing I was told, "Don't tell anybody, and don't tell anybody how you got it."

My husband was completely devastated by the fact that we couldn't have any more children. I think that it hit him a lot more than it did me, partly because of what I went through anyway, but partly because I had realized all along that I just didn't feel well enough to look after a baby. He was quite shattered by that. I think I felt in the first few weeks that all of these people were being really nice to

me - the doctors, the hospital. Everybody was being really nice, but they weren't thinking of me as me, because they hadn't known me before. They were thinking of me as a T- Cell....as research. It wasn't me, this funny thing that I hadn't really got to know yet. The main thing I wanted to do was to talk about it to a person who I had known forever. We had known each other for an awfully long time, had been good friends even though we hadn't seen each very often. We kept in touch. I rang her and told her. She decided that her children would catch AIDS from my talking to her on the phone. She refused to talk to me. That gave me the impression that you definitely don't tell anybody, which is what I was told in the first place. Apart from being told exactly what I had, that was the first thing I was told, "Don't tell anybody, and don't tell anybody how you got it." Nearly everybody in our support group was told right at the end, "Don't tell anybody how you got it."

I was in a state of shock at the time.

That is the main common thing for all of us, not to upset people. After I told this friend (we didn't tell other friends) I tried a few more times, a few months later. Maybe she might have gotten over it, but she said, "I can't talk to you at the moment." I decided it wasn't worthwhile, worth the trouble. I still send her Christmas cards. I would like to know what she does when she gets them.

I wrote a letter to my husband's elder sister, who was a nurse; a sensible, quite practical person. I felt that his family should know about it, not so that he would get support or so that they should be concerned or anything, because I knew that they would have been. Just so I didn't have to pretend that I was feeling really terrific if I was feeling lousy.

I did have times when I was feeling pretty down.

One of the things that really upset me on the day, when we found out about it, was, about a month before I took the blood tests, I started having very bad night sweats. I knew people got AIDS and they died, but I didn't know about what happened to them. I found the night sweats very frightening because they were just so alarmingly different to anything that had happened to me before. Then when we actually got to the immunologist, and he said, "Has anything different been happening to you? How do you feel?", I said, "Not really", and then I remembered and told him. He just looked at me. He told me that that was connected with it.

Anyway, I wrote to my sister-in-law and told her about it and she told the rest of the family and that was nice. I didn't have to bother. Their attitude is that if you ignore it, it will go away. They never talk about it. It doesn't happen to people you know. I've been angry more than anything because the sole reason I told them was so that if they rang up (we don't see them very often)if my mother-in-law rang up and said, "Hello, how are you?", and I felt really terrible, I feel I have the right to say, "Well, not too good today." Not to have go into details, but just so I don't have to pretend all the time. So now when they ring up and ask, "How are you?", and I say anything different from 'I feel great, I feel fantastic', they say, "That's not good enough, just tell us you feel terrific. We are not going to leave you alone until you say you are feeling great." But I don't!' Just tell us you are feeling good.' Denial. It just makes me cross. You can't talk to them because they don't listen. It is annoying because, if I had known that they were going to be

like that, I wouldn't have bothered telling them in the first place. Anyway, we didn't tell anybody else.

My husband said to just tell him if there is anything that he could do, otherwise keep it to myself, which was fair enough because I could see his point of view. Just before Christmas, a girl I got to know very well died, leaving a husband and a two year old. I told my husband this, even though he didn't want to know that type of thing. He got quite upset and he started treating me as though I was going to drop dead any second - which is also a bit disconcerting. I think he has evened out now, but I think he is still concerned. A number of people in our support group have died in the last few months. I think he suddenly realized that this is something that is quite difficult. I sometimes think that it is more difficult for the people who haven't got it because they feel so useless and frustrated. There is nothing they can do about what is happening.

"Isolated, stigmatized....

They came into my room in gowns, masks, rubber gloves to take my pulse. They couldn't feel the pulse through the gloves. It was so silly."

I feel as though I am not normal. I don't feel like I am somebody else, I just feel that I am not me. My self esteem goes down quite a bit. It has to, just from the fact that you are trying to hide things from people all the time. When you go to hospitals they leave your dinner outside your door. It has its effect.

One of the first things I did when I found outI thought I couldn't cope with contraception as well as everything else.... so, I went and had my tubes tied. That was quite traumatic. I had it done in a private hospital. It took the doctor about a month to talk them into taking me, they eventually did. They locked me in my room. They wouldn't let me flush the toilet; they poured gallons of bleach down it all the time. They brought me a plate, a cup, a knife and a fork because I wasn't allowed to use the hospital cutlery or crockery. If anything came into my room, it stayed; nothing went out again. The plates, anything, were stuck in a bucket in neat bleach in the bathroom. Everything I ate tasted of bleach. Isolated, stigmatized....They came into my room in gowns, masks, rubber gloves to take my pulse. They couldn't feel the pulse through the gloves. This is before I had the operation. I can imagine maybe afterwards, but this is beforehand. This was the end of 1986. It was so silly. The day before (I was admitted) I had been wandering the supermarket buying some food for my husband. Walking around with everyone else. When I was in Westmead a couple of months ago, it was exactly the same. It's very hard to think that the person who is in the hospital, who they are treating like that, is the same person who is me outside of the hospital who is doing the shopping, looking after my family, cooking their meals, washing their clothes. I find it very hard. Because of the way they treat you. To think that it's all me. When you are in there it's very different and the second you go out it's just the same again. You think, 'what are they worried about?'

I AM JUST
ME.
I HAVEN'T
TURNED
INTO ANY-
THING
ELSE.
I AM ME.

I have looked after my daughter from when she was born, more or less. I did everything that mothers do for their babies, for nearly two years, not knowing what was wrong with me. Then exactly the same for the next two and a half years. They ask me things like, "Do you have a supply of plastic gloves in the house? You are doing things for the child." I am just me. I haven't turned into anything else. I am me! I don't want to turn my house into a mini hospital or something. We are just an ordinary family, with a mother and a father and a child. I am certainly not going to take

precautions when people don't catch it that way. I would love to stand out in the middle of the street and say, "I am HIV positive. I have looked after my child and my husband for four and a half years while I have had this virus, neither of them has it. Neither is worried about catching it from me. We are just another family. You think of us as people who are going to run around infecting you." If there was any chance in the world that we, people like me, were going to give it to our families, we would take every precaution in the world not to. We wouldn't risk our families. We just try to get on with things, but I find now that I am becoming not exactly political but going in the direction I really didn't want to go. Things are needed that I have to fix up if anything happens to me. There are basically only two things - if I die, get really sick or whatever, I don't want my husband and daughter, children to have to spend the rest of their lives hiding what I died of. I think public education is extremely important, especially for (the sake of) the little one. If I die in the next ten years she is still not going to be very old....having to go through life with that sort of stigma, which shouldn't be there

in the first place. I also feel if I die of this, or anything really....even now I can't contribute as much as I should be to the family....but especially if I die, I think that is very unfair if my husband and daughter are disadvantaged in any way. It would be very unfair if they are financially disadvantaged or socially disadvantaged. Not that it is dramatically important, but I think that the loss of a wife and mother is a reasonably important issue. I think that they would have had enough disadvantages without it continuing for the rest of their lives.

"I have looked after my child and my husband for four and a half years while I have had this virus, neither of them has it. Neither is worried about catching it from me. You think of us as people who are going to run around infecting you."

So I really feel that there are a lot of things I have to sort out. That's why I have to talk to as many people as I can, get quite actively involved in the support group. I would rather sit at home and relax but I really feel that I have to sort these things out, just in case. I know several people who have died. It is not that the death worries me. I think it is what comes before. The longer you are involved with support groups, the more people you see in different stages of the virus. I have seen some quite horrible things...the physical deterioration. I find that sort of thing very frightening.

What is going to happen? How do you explain it to people? How do people react? How does your family react to it?

My four year old gets very upset. Especially since I was in hospital a couple of months ago. She is not the worrying sort, she is very outgoing, aggressively outgoing, an independent little person. I don't want to lie to her if she says, 'are you going out today, where are you going?' If I am going to the hospital, I say I am going to the hospital. She gets upset. She wants to come with me because she is scared I won't get back in time to pick her up from the kindergarten. She worries about it. It is the only thing she has probably ever worried about. If you get to the stage that other people are physically now getting to, that is when it will affect your children. I couldn't see my husband leaving work to look after our child. I just introduce things like that into the conversation occasionally to see how he will react. He is getting better at talking about it. He says things like, "Oh well, if you get too sick to look after yourself, I suppose the doctor will send someone to look after you". Life is not magic like that. It doesn't work like that. I think, actually, things are improving a lot. I am very close to the community nurse. She has talked to me quite a lot about that. I think I would get a lot of help.

This is the first in a two part series. Part two will appear in the next issue of *TALKABOUT*.

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.

PLWA Women

My job as 'Women and AIDS Project Officer' at ACON came about as a result of funding by the AIDS Bureau to look at some of the issues relating to women and the HIV virus. When I applied for the job I was told that I would be dealing with the issue of "Women and AIDS and the Universe!" As the position was initially funded on a part time basis for only six months, it was really a matter of deciding where to start and what to do given the limitations. It very quickly became apparent that what was necessary was some kind of needs assessment in order to determine priorities.

Over the last four months I have concentrated on consulting with various services, organizations and individuals including women's health centres, abortion clinics, obstetric and gynaecological units of major hospitals, halfway houses for women coming out of prison, women still in prison, social workers and counsellors who have HIV positive women as clients and individual women who have contacted me wanting information or advice.

As a result of these consultations a number of issues have emerged. In relation to the needs of HIV positive women there is a pattern of isolation, fear and lack of support. Many women in this situation have the added burden of families to care for who may or may not also be infected with the virus. I heard of several cases of infected women being unable to confide in anyone apart from their caseworker or doctor. In other cases I was contacted by a relative or friend of an infected woman expressing concern

that they were the only support for that particular woman. These people complained of feeling inadequate to deal with the situation and of not knowing which way to turn for help. It became clear that it was not only the infected woman who was isolated but also, frequently, her only confidant.

The need to develop support networks for women is obvious, but it is easier said than done. The problems of geographical spread, family responsibilities and the fear of being identified all work against women getting together and developing support groups and networks. I met recently with a group of caseworkers to discuss ways of putting HIV affected women in touch with one another and, consequently, creating a support network.

As a result of this meeting a Positive Women's Group has now formed and is meeting every Thursday from 5.00pm - 7.00pm. To the time of writing the group has met only once, but that meeting was extremely encouraging and exciting and the six positive women who were present are all keen to continue. For most it was the first time that they had met other positive women and they had been wanting such a group for some time. At this meeting several important issues were raised such as need for respite care for parents or mothers who are positive, assistance as to how to explain the issues to children and how to negotiate relationships and safe sex. Any women who are HIV positive and who want to join the group can contact **Pam Blacker** at ACON, tel. 211 0499 or **Kathy Casey** at the Albion Street Clinic, tel. 332 4000.

PAM BLACKER

PROFILE: Sarah Dunn

Sarah Dunn describes herself as a 'gay activist since 1968'.

In her own words, "my name alone makes people cringe and frustrated." Undaunted and courageous, Paul Young spoke to Sarah about a variety of HIV related issues.



The caring hands of Sarah with the Late Tracey Lee

PAUL YOUNG: When did you first become involved in caring and more aware of AIDS?

SARAH DUNN: In 1984, Bobby Goldsmith was one of my oldest, best friends and I watched him get weaker and weaker. He hailed me out so many times when my kids were growing up. I was looking after my fourth friend who died around the end of 1984, beginning 1985 and Community Support Network(CSN) had just started.

PY: How did you become involved in CSN?

SD: Peter McCarthy came out to assess the needs of the guy being looked after by myself and a group of his friends, and to see if we were doing the right thing. I have been an active and consistent carer for four and a half years now. I was one of the first women carers, and have never had any regrets about being a woman carer.

PY: What role do you think women have to play as carers?

SD: The first thing to hit you is when someone you've known for a long time becomes infected, then you start to look at AIDS in a different perspective. As lesbians we always had a different attitude towards men. In that process women lost a lot of contact with men. I feel that I have always been fortunate to be in close contact with many gay brothers. I am fortunate now I am going through another stage of learning about how to live with ourselves. I've now noticed a lot more women coming out and getting involved. Sadly, it is AIDS which has made us more aware of nurturing, and how we feel. It's strange in a way. It's not as though this awareness has been great for a long time.



SD: Not just dykes but all women, all people - we all live on this planet. It's everyone's responsibility to be aware and sensitive.

PY: What do you think women's involvement in AIDS/HIV has achieved to date?

SD: With hospitals, ACON, Bobby Goldsmith Foundation etc. it was very hard because doctors couldn't give us any answers. As the first woman ACON Committee member there was never 100% agreement. On reflection, initially, too many AIDS service organisations suffered unconstructive criticism. It makes me realize how much these organisations and governments have achieved and how much PWA visibility makes me proud.

**"You are left with a wonderful richness of support between men and women. If I was in trouble I could call on them; that's what they give me through their having AIDS.
...many people are in need of emotional, not physical, support."**

PY: How do you describe yourself in terms of being a person living with AIDS?

SD: Besides being a carer, I am a PLWA because so many of my friends are. Kids I'd known at 17 or 18 on Oxford Street I've later nursed as adults. Some of my

gay male friends are like family and I have already lost many. Being a PLWA is losing people I love. That's the pain of it. Maybe that's selfish, but some days when I wake up, although I try not to think about it, it scares the shit out of me. I think I might be the only person left here and it hurts. It feels like I'm in an empty space.

PY: What do you get most from caring?

SD: I like meeting people, shape or size doesn't matter. I haven't a clue how many people I've met through caring. Over fifty? One hundred? I'm unsure. There was a time when I did two or three shifts each week, but now I do only one plus work up in the mountains. The highest point of caring is when I meet guys who get on with living with AIDS, not dying. The low point is when you lose a client you have spent eleven months, twice a week with. You have built a long term, one to one relationship which requires trust and dependency. You become part of that person's family, part of their household. I feel anger, sadness and frustration and all I can do is ROAR. You are still left with a wonderful richness of support between men and women. If I was in trouble I could call on them; that's what they give me through their having AIDS. An important thing about caring is understanding that many people are in need of emotional, not physical, support.

PY: Do you think AIDS has changed gay male sexuality in any way?

SD: Men with AIDS can now be leaders. In the process you have to be responsible, you are entitled to have sexual needs/desires/wishes. I'm frequently asked questions about my guys feeling sexual towards another PLWA. The day centre can fulfil this need, an alternative

to Oxford Street, like a 'meeting partners day', a way to meet another man. Eye contact can be magical. I say 'go for it!'

PY: What else do you think AIDS has changed?

SD: There is still room for improvement in existing services and each time you try you get a bit more - it's called achievement. I think the gay and lesbian community is a lot better, stronger. I think they themselves know they can escalate. Why stop achieving now when the struggle is never ending. They may not always put us 'up there' and pat us on the back, but they're lucky to have us. They may not like us, but they can't ignore us. For example we are now aiming towards a full time day centre in the Blue Mountains with more carers. At present the Mountains day centre operates only on Wednesdays.

PY: How important is HIV for you as a socially active lesbian?

SD: Very. Because they always say women are at lower risk and, being a cynic, I don't think enough education and support is directed towards us. I know many women who have been users. By virtue of lack of education they are still isolated and reticent about coming forward and seeking assistance.

PY: Any other highlights Sarah?

SD: I love caring. I love massaging feet and bums. Two of the most neglected areas and massage is the best way to reach people. I learn so much and my clients share so much with me. I guess that's what caring is all about: caring and sharing. Often the most simple things bring the greatest rewards. Maybe this is what AIDS has done - we listen and learn more.

HIV : infection and pregnancy

The aim of this article is to set out in clear terms the effect that HIV infection has on the outcome of pregnancy and, secondly, the effect of pregnancy on a woman who is HIV infected. I would also like to ask the question, "Is a termination the 'only solution' for a woman who is HIV positive and pregnant?"

It is well known and well documented that the major psycho-social issue facing a person who is HIV positive is that of loss - loss of life expectancy, loss of relationships, loss of health. Women who are HIV positive face another major loss - loss of the ability to bear healthy children. This can be, for some women, the largest blow because they perceive the role of mother as their most important role in life and central to their definition of "woman".

Rates of transmission

The chances of an HIV infected woman bearing an HIV infected child are, statistically, quite high. The most conservative of estimates suggest that 24% of pregnancies of HIV infected women will result in infection of the child. Latest studies suggest, however, that this figure could be as high as 65% and of these, 50% to 60% are likely to bear children who can be expected to develop AIDS within two years. Asymptomatic carriers are rare. These figures present a gloomy picture for HIV infected women who



may be considering the continuation of a pregnancy.

Modes of transmission

So, how does infection of the child occur?

Three modes have been identified:

- While the child is in utero - as a result of circulation between the mother and the foetus.
- During delivery - as the child comes into contact with the mother's secretions.
- From infected breast milk.

It is, therefore, suggested that HIV infected mothers do not breast-feed their children.

Risk to the mother

Pregnancy presents a number of risks to HIV infected women, especially women with AIDS. Suppression of the immune system occurs in normal pregnancy. It reaches its peak in the third trimester, the last three months of pregnancy, and normalises again by the third to fifth month after birth.. In women with healthy immune systems, this presents few problems. Women who are infected with HIV, however, are left open to further risk of developing opportunistic infections. Added to this is the problem that medications usually prescribed for opportunistic infections cannot be given to pregnant women. They are harmful to the foetus.

An American study completed in 1985 even suggests that pregnancy increases the risk of an HIV infected woman developing AIDS or ARC.

Termination - the only solution ?

It is obvious that pregnancy puts the HIV infected woman at great risk. HIV also places the foetus at great risk. Does this mean, then, that termination of the pregnancy is the only option for the potential mother ? The medical profession can offer her no cure and only limited assistance. Still, I would argue that it is the woman's decision. She has the right to accurate information with regard to the effects of HIV on the outcome of her pregnancy and on her prognosis. She also has the right to non-directive counselling regarding the decision to continue or discontinue her pregnancy.

Many women with a life threatening illness decide to continue with pregnancies, even though they may have a severe effect on them physically and emotionally. People who are HIV infected may already experience loss of control over their lives. Women in this situation must, therefore, be the ultimate decision makers so as not to perpetuate the experience of loss of control.

PRISCILLA McCORRISTON.

Priscilla is a member of The ACON Women and AIDS Working Group.

**WOMEN AND AIDS
WORKING GROUP
MEETINGS
ARE HELD ON THE THIRD
WEDNESDAY
EVERY MONTH
AT THE ACON BUILDING.**

Women and S/M - the ultimate safe sex?

S/M and its limitless forms of expression may be considered the ultimate in safer sex practises. As we all know, there is nothing more dangerous and exciting than one's own imagination and, as such, nothing more 'safe'.

Imagination is the key to a satisfying and inspiring S/M play. In what other arena might a young lesbian explore the inner recesses of her sexual fetishes and their outward physical manifestation? Where can a girl bring to life the spectrum of her desires in a safe, sane context but through the serious, and not so serious, play of S/M?

Within an S/M scene, traditional forms of sexual activity are no longer relevant. In fact, the sexual act need not occur throughout the entirety of play, for S/M may be considered as having its basis in mind fucking. The peripherals such as ropes, whips, costumes, etc. can be considered as the cosmetic side of S/M. These can be dispensed with, as the raw reality of a scene is the ability to negotiate powerplay through a series of actions and words independently of any props or environmental factors. The ability to take control and to relinquish it are the only necessary tools.

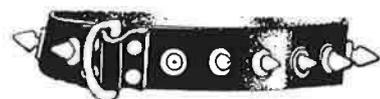
S/M 'sex' can take place anywhere and at anytime. Whispered commands can become the source of sexual excitement; the act of lowering one's eyes in

another's company, forceful fondling and a brutal kiss can constitute a sexual act. Once the mind is trained to view certain actions / words as powerfully sexual, arousal can occur in response to such actions at anytime or place. The girl who orgasms at the mercy of her leather clad lover can find the smell of leather a powerful aphrodisiac whenever it is encountered.

Thus, an exciting and safe aspect of S/M play is its ability to create and perpetuate sexual associations or what we call fetishes. If a more physical sexual act is desired within a scene, then, obviously, safer sex should be practised. S/M also has its own safer sex considerations such as the proper care and sterilization of toys, the use of condoms on all vibrators, plugs and dildos, sterilization of whips, knives etc. which have been used to draw blood, the use of disposable, sterilized needles for piercings, water soluble lubricants and gloves for any digit penetration. All these safer sex S/M practices need to be coupled with the implementation of a 'safe' word, the use of which ensures a scene is consensual and can be halted by either party at any time. Latex provides good protection and dental dams are a must for oral sex within a scene.

Rather than S/M play being viewed as a physically or emotionally dangerous activity, such play, when responsibly attempted, should be seen as a healthy, explorative and safe alternative to traditional forms of sex. What can be more safe than mind-fucking between two or more people, and what can be potentially more stimulating and adventurous than imaginative S/M play? I daresay the answer is, nothing.

FRANCINE LAYBUTT

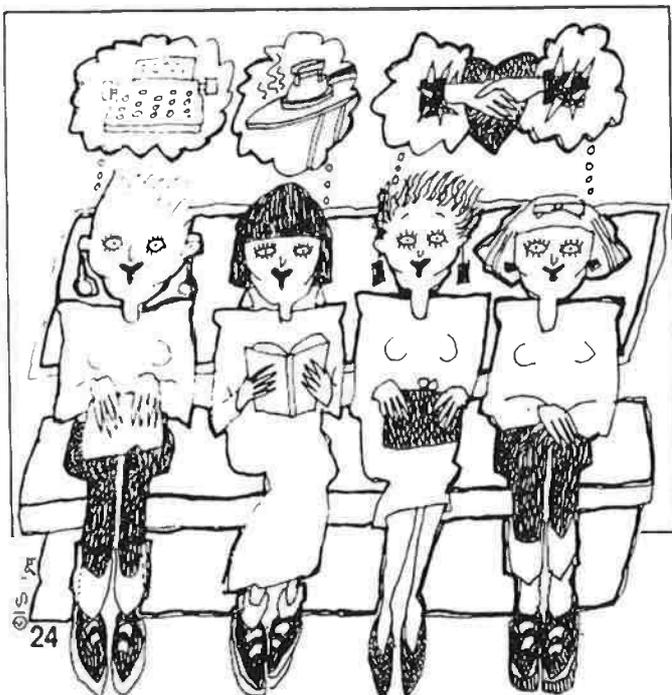


One Wicked Woman's fantasy

Scuffing round and round her seedy Darlo flat in a ratty gown and oversized-boots she spends the entire morning looking, looking for something; be it coffee pot, cigarettes or her brain. Manda chants, "I am in control, I am a control queen: sex queen. I am control." Sweet affirmations to set her on her way. She finally finds a manicure set and decides on a mega-pamper when a phone call interrupts the chaos.

Garlands of roses crash down on her head when she realizes Paris The Coolest Girl in Town is coming to escort her on a yonder voyage. Manda met Paris when Paris's ex-boyfriend snapped her space gun in half at SleazeBall '88. Paris dumped him and decided girls are nicer anyway. So much nicer.

LISA



The Netherlands

**International workshop:
promoting safer sex, prevention
of sexualtransmission of AIDS
and other STDs :
April 20-May 3,
The Netherlands**

In May this year I attended an international meeting entitled 'PROMOTING SAFER SEX', with a number of other workers in the field from various parts of Australia. The meeting was organized by the Dutch Foundation for STD Control and sponsored by the World Health Organization(WHO). The meeting was held at the Leeuwenhorst Congress Centre in the heart of the tulip fields outside Amsterdam.

The object of the meeting was to bring together the policy makers, educators, researchers and others working in the field of prevention of HIV and other STD's in the industrialized world with the aim of exchanging information and discussing obstructions and looking into new initiatives and future plans.

With approximately one hundred and fifty participants it was a small meeting compared to the large international AIDS conferences. The organizers felt that the large international conferences are often dominated by technical details

are often dominated by technical details and bio-medical issues. This often results in inadequate coverage of campaigns as well as inhibiting the exchange of ideas and research data.

W.H.O. funded some fifteen people from countries other than the Netherlands to participate in the meeting. Participants were from community organizations, STD clinics, needle exchanges, sex worker rights organizations etc. The Australian delegation was as follows:

Julie Bates (NSW)
Bernadette Hudson (NT)
Tass Mousaferiadis (Vic)
David Plummer (Vic)
Marion Watson (ACT)

The meeting opened with the usual round of introductory and welcoming addresses. These were presented by Jonathon Mann and other AIDS specialists. Although there were several keynote addresses the majority of the meeting was given over to workshops. Participants in the workshops were encouraged to make recommendations based on consensus of opinion wherever

possible. Delegates took part in workshops according to their expertise and knowledge.

In the next *Talkabout* I will write about the recommendations from the relevant workshops. In the meantime, it was the view of the Australian participants that our presence at this meeting allowed for some influence over other participants and some direction in arriving at consensus. It proved, yet again, that Australia is certainly leading the field in its initiatives in HIV prevention and support from both government and non-government sectors.

However, this was, for some of us, a difficult and tiring task - particularly when an issue thought to be of great significance was overlooked or not permitted to be addressed; the reason given was that it was not within the terms of reference of a particular workshop. This left me, at times, feeling that we were travelling over old and well worn paths. As my friend Marion Watson commented, "...a major difficulty in discussing the issues which surround any of these areas is the involvement of those working directly

Here is a list of the workshops and their Australian participants:

Men with homosexual contacts	Dr. David Plummer
IVDU	Ms. Marion Watson
Prostitutes and their clients	Ms. Julie Bates
Ethnic minority groups	Ms. Bernadette Hudson
General public	Mr. Tass Mousaferiadis

with the 'target population' in that there seems to be, these days, a tendency to work with a 'target population' instead of educating a small group from within the 'target population' and sending them out to do peer education." In one workshop the term 'peer education' appeared to some people to be some kind of radical new approach and was quickly adopted as a concept to behold!

JULIE BATES

Positive woman from Denmark speaks out

As we are devoting the majority of this issue of *TALKABOUT* to women, I would like to present the abstract from the address given by Ms. Amanda Heggs to the meeting. It was a great privilege to meet and get to know Amanda although we had only a short time together. Amanda is a woman of great determination and courage who almost single handedly is working to create an awareness of issues relevant to women living with HIV in Denmark. Amanda left the meeting on the second day as she was exhausted and quite ill. The expectations placed on her by many of the participants who felt the need to physically touch and approach her to prove that they were not frightened of her or of her illness left her drained and wondering why it is constantly necessary to educate the so called educated that positive women do exist!

In a private conversation with Amanda (which I probably shouldn't quote, although I believe Amanda would

approve as it is very relevant to the kinds of issues which affect positive women) she mused over the number of male participants standing around the bar one afternoon and wondered what kind of response she would get if she had approached some of them and intimated that she might like to sleep with them!

Abstract from the Netherlands conference

In this abstract, conference delegate Amanda Heggs, from Denmark, previews her address to the conference.

"As a woman with ARC and a student of psychology, I have for the past two years been actively involved in health education and information campaigns in connection with the prevention of HIV transmission in Denmark.

In my presentation I intend to discuss the various areas in which I have drawn upon my own experiences of living with HIV in order to contribute to this work. I will also touch upon the trials and tribulations involved in making the general public aware of the fact that seropositive women even exist.

In my speech there will be no statistics, no graphs, no overheads. It will not be a scientific presentation. I will be speaking as a woman with ARC, and not as a coming psychologist. The emphasis is on my own personal experiences, with incidental reference to the few other seropositive women with whom I have had contact. My sources of information will, therefore, be my own diary, and the conversations I have had with these women.

I have primarily been engaged in teaching secondary school children between the ages of fifteen and eighteen,

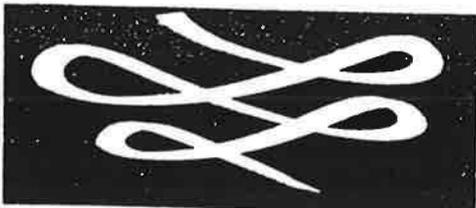
but I have also had some experience in educating teachers, who in turn are involved in introducing HIV prevention into the regular curriculum in their schools.

Part of my work has been voluntary, in the sense that is something in which I have consciously chosen to engage myself. A large part of the work, however, has to a large extent been something beyond my own volition. This part of my work concerns the spontaneous confrontations I have experienced with individuals I have met in the course of my everyday life. These include friends, school teachers, social workers and health personnel, who, in one way or another, learn that I am seropositive.

A recurring theme in my experiences with prevention work is the emotional reactions I have encountered from individuals who, usually for the first time, are confronted with a seropositive woman, and the way in which these reactions can be constructively used in prevention work.

(In my talk) I will also discuss the difficulties which have arisen when my different roles as seropositive woman, health educator and patient have converged as, for example, when I have been hospitalized. Within this perspective I will touch upon the aspects involved when individuals involved in medical treatment and welfare also, to a certain extent, become friends and colleagues. "

Amanda Heggs



Montreal

Oz Quilt convenor acts up

When I responded to enquiries, prior to my departure for Montreal, as to what I was going to do there if I wasn't actually registering for the Fifth International Conference on AIDS, I stated that I planned to attend only for social reasons! Little did I realize how busy I'd be and, most surprisingly, how rewarding 'pseudo attendance' could be. In reality, I think I wanted to be there when they announced the cure.

The six hundred dollar registration fee was way beyond my means, especially after paying my own way to Montreal. My priority was to make sure that the Australian AIDS Memorial Quilt received lots of attention and I presumed this would occupy all of my time. Of course, the Quilt received lots of well deserved attention, without too much further effort by me, so I had some spare time for socializing. The first problem of how to get past the security and into the conference hall was easily solved

I walked through the security barrier reading a large newspaper covering my lapel (where I should have been wearing the conference pass!). For the official opening I barged in with hundreds of other AIDS activists ("Activists storm AIDS conference. AIDS protesters take the stage.") and seized the podium to the cheers of conference participants. Rarely have I had the opportunity and privilege to participate in such an emotional event as the declaration of the Manifesto of Montreal.

By the second day ACTUP New York had already produced excellently forged conference passes! I loved their anarchy.

It reminded me of my student days.

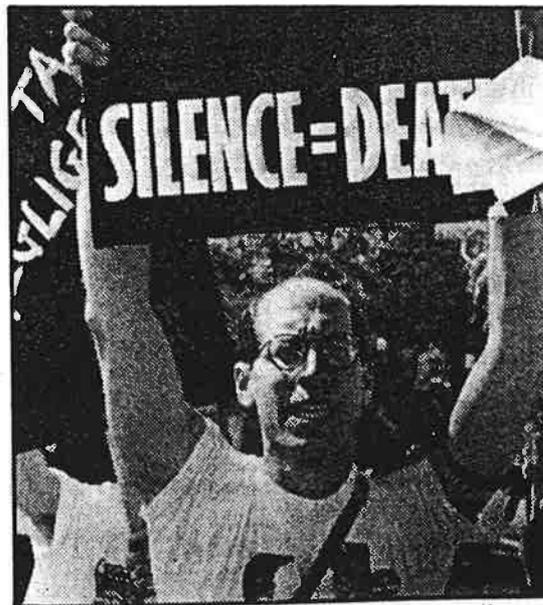
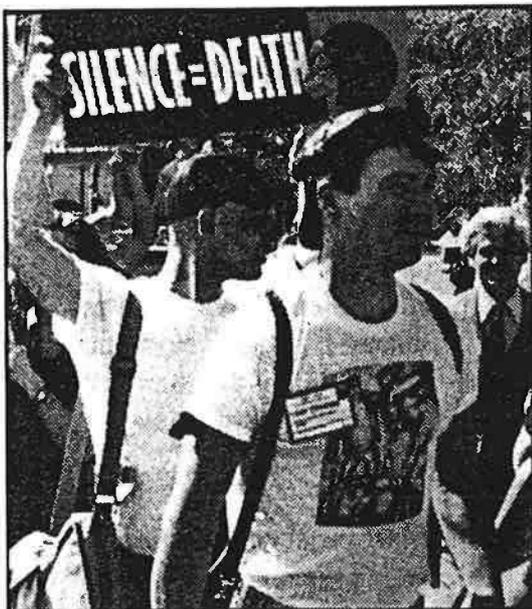
Most of the time was divided between the Names Project Information booth and the PLWA Centre, next to the conference hall. A local PLWA group, together with the local Red Cross, provided a couple of luxurious hotel suites for the use of PLWAs. Continental breakfasts, sandwiches, coffee and juices were laid on all day and it was here that the plans were made for the PWA press conference and media release (written mainly by Canadian, U.S. and New Zealand delegates). There was some concern from some European and South American PLWAs that those writing the press statement were self appointed and, therefore, not democratically representational. As I was not attending the conference as an official representative of any PLWA group in Australia, I felt that I couldn't get involved. In fact, it was a shame there was no official PLWA representative from Sydney attending. Over endless glasses of juice we shared experiences. I heard how groups had formed in countless countries, how they found funding and how they were treated by officials. We talked about access to drug treatments,

education and about life in general for PLWAs. I took a special interest in the immigration issue and discussed experiences with Hans Paul Verhoef (infamous for his arrest in Minneapolis a few months earlier after officials found AZT in his luggage). Some of us planning to travel back through the States, after the conference, were concerned that we would be turned back at the border.

My last two days were spent finalizing details for the Quilt display with Names Project staff and Montreal City Councillor Raymond Blain. I was delighted that Ruth Cotton, Bill Whittaker and Levinia Crooks helped me unfold the block of Aussie panels at the Quilt ceremony in the Olympic Velodrome and honoured to read to the thousands in attendance the letter of support from Bob Hawke which I had carried all the way to Montreal.

In one week I had participated in two very different major events of international significance and I had felt the comradeship of gathering with others with HIV. I also felt very privileged to be Australian.

ANDREW CARTER



LE MANIFESTE DE MONTREAL



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**AIDS ACTION NOW! Toronto, Canada &
ACT UP, New York, U.S.A.**
jointly issue:

LE MANIFESTE DE MONTREAL

Declaration of the Universal Rights and Needs of People Living with HIV Disease

PREAMBLE

HIV disease (infection with HIV with or without symptoms) is a worldwide epidemic affecting every country. People are infected, sick and struggling to stay alive. Their voices must be heard and their special needs met. This declaration sets forth the responsibilities of all peoples, governments, international bodies, multinational corporations, and health care providers to ensure the rights of all people living with HIV disease.

DEMANDS

1 All governments and all international and national health organizations must treat HIV disease positively and aggressively as a chronic, manageable condition. Ensuring access and availability of treatment must be part of the social and moral obligations of governments to their citizens.

2 Governments must recognize that HIV disease is not highly infectious. Casual contact presents no threat of infection, and irrational fears of transmission must be fought.

3 An international code of rights must acknowledge and preserve the humanity of people with HIV disease. This code must include:

- a) anti-discrimination legislation protecting the jobs, wages and access to services of people with HIV disease,
- b) active involvement of the affected communities of people with HIV disease in decision-making that may affect them,
- c) guaranteed access to approved and experimental drugs and treatments and quality medical care,
- d) the right to anonymous and absolutely confidential blood, urine and body fluid testing. Pre and post test counselling must be available,
- e) the right to medically appropriate housing,
- f) no restriction on the international movement and/or migration of people with HIV disease,
- g) full legal recognition of lesbian and gay relationships,
- h) no mandatory testing under any circumstances,
- i) no quarantine under any circumstances,

j) protection of the reproductive rights of women with HIV disease, including their right to freely choose the birth and spacing of their children and have the information and means to do so;

k) special attention to the unique problems and needs of intravenous drug users, including provision of substance-abuse treatment on demand;

l) special attention to the unique problems and needs of prisoners with HIV disease and guarantees that they receive the same standard of care and treatment as the general population;

m) the right to communication and all services concerning HIV disease in the language (written, signed or spoken) of his/her choice, through an interpreter if necessary;

n) the provision of reasonable accommodation in services and facilities for disabled people;

o) catastrophic/immunity rights — the guaranteed right of people faced with a life-threatening illness to choose treatments they deem beneficial for themselves.

4 A multi-national, international data bank to make available all medical information related to HIV disease must be created. This includes all data concerning drugs and treatments, especially basic bio-medical research and the initiation of any progress of clinical trials.

5 Placebo trials must be recognized as inherently unethical when they are the only means of access to particular treatments.

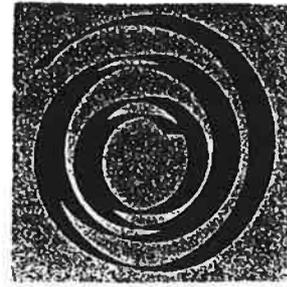
6 Criteria for the approval of drugs and treatments should be standardized on an international basis so as to facilitate worldwide access to new drugs and treatments.

7 International education programs outlining comprehensive sex information supportive of all sexual orientations in culturally sensitive ways and describing safer sex and needle use practices and other means of preventing HIV transmission must be made available.

8 The unequal social position of women affecting their access to information about HIV transmission must be recognized and also their rights to programs redressing this inequality, including respects for women's right to control their own bodies.

9 Industrialized nations must establish an international development fund to assist poor and developing countries to meet their health care responsibilities including the provision of condoms, facilities for clean blood supply and adequate supplies of sterile needles.

10 It must be recognized that in most parts of the world poverty is a critical co-factor in HIV disease. Therefore, conversion of military spending worldwide to medical health and basic social services is essential.



Song For People Living With A I D S

Oh Suzi: what a gladiator -
my inspiration - not scared
to say, "It's not FAIR".

The day before you died
you told me we were lovers
in a past life, but not this one,
yours - the only vagina I have washed.

How we laughed about zebra eyepatches
while your frail body shook and quivered;
and joked about what flavour
of mist morphine you had that day.

How hard I tried to be you,
with husband, child and TV crew,
wishing I could take your place
but then again this is maybe my own guilt.

Over those short few months
the pain of watching your pain
made us even closer than
transcendent lovers ever will be.



SIMON DE ROME

PLWA YOUTH GROUP

*We may be young but
we know what we want*

At the LIVING WELL 2 CONFERENCE, held in February, a number of specialist working groups was formed, including a Youth Working Group. It was formed by a coalition of people who thought it important to confront the issue of AIDS and Youth. It was also felt that this issue is one which all PLWAs should think about.

In that group, topics we thought to be of importance to youth were housing, medical services and money matters. But most important of all was the lack of communication between the younger and older sections of our community. It seemed to us that young people, on the whole, were not being listened to.

A simple demonstration of this lack of communication occurred a short while after LIVING WELL 2 when I attended another conference, at St. Vincent's Hospital. Its theme was Youth and AIDS, and I was one of only four young people there. The rest were either youth workers or bureaucrats. I asked if, perhaps, there should be more young people at the conference and was told, by a very petulant young woman, that she had kids running around her feet all week and, and she didn't want them here anyway. So, was this the general feeling of the conference? I think perhaps it was. I got the impression, and was told in twisted sentences, that the bureaucrats

would make the decisions and that the young people would follow without question.

The St. Vincent's conference was held at a time when the media had captured the community's attention with the issue of homeless youth. The conference was meant to deal mainly with homeless youth and HIV infection. This, although important, failed to address the issue of AIDS and youth in its entirety.

I feel that the conference did nothing to alleviate the problems of homeless youth or the problems of AIDS and youth. Its only real achievement was to give the delegates peace of mind. Young people gained nothing from the conference. It failed because it lacked the valuable input from young people, who can readily identify the real issues confronting them daily. Basically, most of the conference delegates were trying to make decisions for a section of the community with whom they are out of touch.

Things such as daily health problems, a balanced diet - simple things which most people take for granted - were not even touched upon and this is why there is need for a group such as **PLWA YOUTH**. At all future conferences we need to stand up and tell people what we want. The decisions should not be made for us. The attitude that 'we will decide what young people want', seems to be, apart from a select few, the general attitude of the community.

The main recommendations from the many developed by the Youth Group at LIVING WELL 2 were that anti-body positive self help groups should be setup in large urban centres, for young people infected and affected by the virus, and that these groups should be aligned with the PLWA Coalition in their state.

They would provide support, advocacy, information and help with problems which all youth face.

At LIVING WELL 2 the response to the Youth Group was totally opposite to that at the YOUTH AND AIDS CONFERENCE. Most people applauded the fact that the Youth Working Group had formed and that it was telling the conference what it wanted: across the board improvements in the situations which young people so often encounter in financial, housing and medical matters. And now we have an anti-body positive youth group based in Sydney. We have contacted various organizations and AIDS Councils about the group with many more to contact, such as hospitals, refuges and clinics. The going so far is tough. Being a very small group, the burden of the workload is left to one or two key people. Though the group is still small, we know it will grow.

We have the problems of people not wishing to reveal their HIV status, the fear of rejection by friends and family and the problems of loneliness and isolation. These are all real problems and it is understandable that young people would feel scared about revealing themselves and their situation to a group of other young people they don't know.

Young people living at home with their parents could find it very hard to tell them about being HIV positive when their parents tell them it's a 'gay plague' and that anybody who gets AIDS probably deserves it. In some sections of the community this still happens. The idea of 'gay plague' and the word death still come to mind for many people when they think of AIDS. Most young people I know have only a vague concept of death and dying. I myself have existed in 'immortality mode', the feeling that

no matter what happens, I will still live. The body is young and the mind reels with new experiences and strength. So, what happens when a young person finds out that he or she is not immortal at all and might die in ten years unless they take care of themselves. We see someone who is destroyed, someone lost, sad and disoriented. Although we know that death happens, it just seems so far away that it is impossible to think about.

The group, **PLWA Youth**, is forming, not to give young people back the immortality trip, but a quality of life that hopefully will last. We need to have young people standing up to the community at large and to doctors and telling them what they want in no uncertain words. Unless something is started now, there is a danger that suicide and infection among newly diagnosed anti-body positive youth will increase - all through ignorance and lack of resource materials and support. So long as the ideas and attitudes of people do not change I believe it's up to us to scream and yell until we get what we want.

I am a PLWA Coalition committee member and, although, sometimes it is hard to digest such a diverse amount of information, I am given a fair deal in the committee and treated as an equal. Sometimes I feel a little stupid, but only through lack of knowledge about some things. Acquiring knowledge takes time. For **PLWA YOUTH** to be effective it will need time. It can be done - it's just a matter of us all working at it together.

For further information about the group, write to:

Jeffrey Birch
P.O.Box 1359
Darlinghurst 2010
Phone: 211 0499

Advocacy Group makes gains for people living with AIDS

The past few months have been a whirlwind of activity and intrigue for the PLWA ADVOCACY GROUP once again.

On the hospital front a small but hard won victory has been had in St. Vincent's hospital granting access again to community groups in the Immunology Clinic to provide refreshments to patients. PLWA has approached CSN, Ankali and the Day Centre for volunteers to staff the tea trolley from Tuesday to Friday. Anyone able to help out in providing this important, additional service at the clinic please contact us.

Privacy in the treatment area of the St. Vincent's clinic seems assured in the near future following successful negotiations with PLWA. The intention is to place tinting material on the windows of the clinic to allow one-way viewing only.

The promised additional five beds on the 7th floor appear to finally be in sight. PLWA has received assurance from St. Vincent's Administration that the beds will be on line as soon as additional nursing staff have been recruited.

And on the south side of town, a successful meeting of PLWA delegates and management and staff at the AIDS ward of Prince Henry has won assurances that communications between AIDS wards will improve and access to beds assured through a system of referrals and transfers.

Members of PLWA have been outreaching to the community through a number of speaking engagements in conjunction with the AIDS Council of NSW. People with HIV have made appearances at the AIDS Bureau Ethnic Workers meeting, the Haemophilic Society, Clover Moore's electoral 'chats', and a conference of psychologists and counsellors.

Following approaches from the NSW Users and AIDS Association, PLWA and NUAA have approached the Albion St. AIDS Clinic regarding the Passive Immunotherapy trials. It appears that the protocol for the trial excludes people with a history of intravenous drug use within the last 6 months. PLWA and NUAA feel that this deliberate exclusion is a denial of access to many people in need of a promising new treatment. Albion St. claims that the reason for the exclusion is that people with an IVDU history are 'notoriously unreliable' and fail to tell the truth, thereby confounding treatment trial investigations. Our recourse has been that this attitude is not only unfounded and unethical, but the product of prejudice and fear in dealing with an increasingly affected and largely misunderstood group within the community. PLWA and NUAA feel access to trials should be assessed on an individual basis not on any assumed membership of a morally questioned 'risk group'. The fact that Albion Street has been so negligent in informing the community of its actions

has inspired PLWA to initiate its own information forum on Passive Immunotherapy (PIT) held on August 1. Similarly, the Clinic's continuing silence on its intentions with the AL 721 trial has been criticised.

On Thursday 27 July PLWA met with the director of Albion St, Dr Julian Gold and the PIT trial co-ordinator Dr Harry Michelmore to discuss our position. After several hours of hard negotiating a concession was finally won. The Clinic has agreed to recommend to the Eastern Area Ethics committee to allow people with an IVUD history onto the open trial for those under 140 Tcells and who have no other drug options, provided their "reliability" is confirmed by their private doctor. Appeal will be available through the Ethics committee if a patient is still refused.

This is a small concession from the Clinic. It demonstrates the difficulties involved in changing attitudes within Australian drug research institutions regarding the compassionate use of drug trials to access alternative treatments. However, if one considers the rapidly changing attitude amongst research institutions in the US, where community based trial programs are gaining wider recognition, it is only a matter of time and persuasion before the rigid approach to trials and treatments is changed for the better in this country.

LARRY STILLSON

Larry was a founding committee member of P.L.W.A. Inc. (N.S.W.) and president of the Day Centre Committee.

Throughout his fight against AIDS Larry never faltered in his commitment to the community. We will remember him for that commitment and for his love, integrity and good humour.

Pan and panaceas

I guess a lot of those who are happily living in or near smaller country towns and villages feel like I do now - a contentment or even a kind of joy for being where they are. There may be many reasons for this contentment, but for me, personally, the calming effects of rural and natural bush scenery come foremost.

Next, the pressures of earning a living are eased. Most of us here no longer live in flats or terraced houses if we are recent refugees from a metropolis. We now have space and often space enough to grow things. So, there is a contingent of amateur and professional horticulturalists, herbalists and organic gardeners. There are those drawing on other talents as well - painting, writing, music, pottery, sculpture, marketeering, alternative healing, naturopathy, massage, mechanics, computers. The list is pretty vast. But whatever the occupation, whether it be by way of a hobby, special interest or career, it is leisurely. The art of living can be practised and realized in these parts at a leisurely pace.

Living in the country and being surrounded by so much natural beauty, it's difficult not to become more sensitive to environmental issues. So, a leisurely existence is not necessarily a complacent one. If we are not actively involved in campaigns, at least we're helping to repair the earth in some way or other, as well as repairing our bodies and minds. There is a bond, and 'out here' it's easier to recognize and connect our lives with our own planet, suffering life threatening environmental starvation and diseases.

For the first time in my life, I've actually had time to understand myself and my environment and the potential capabilities and limitations of my body, mind and spirit. I've had time to write - poetry mostly, but I'm widening my options. Most of what I write is by way of a celebration - life, sexuality, or a yearning for wholeness, for complete love. I'm occasionally satirical. It has been a panacea for my moments of anger, fear and sadness, and maybe a bit of witchcraft or quackery to keep AIDS symptoms at bay. It is also meant to be shared - the poetry that is, and maybe exchanged. Are there any other poets and writers who can share positive feelings

through the pages of *Talkabout* ?

Many of us want to change, or have already changed our lifestyles and outlook on life quite dramatically and would have the courage to continue if they had just a few friends to give them the spiritual and moral support they need, near and far. Let's communicate beyond the clinical. I am sure all PLWAs are not articulate medicos, committee members of this and that, laboratory buddies comparing T-cell counts.

GANYMEDE

If someone you love has died of AIDS
then their name belongs on the
MEMORIAL QUILT



THE QUILT PROJECT

**For an information brochure phone
the AIDS Council of N.S.W.**

(02) 211 0499 / TTY (02) 281 4975

**IN REMEMBERING THEIR NAMES
WE REMEMBER THEIR LIVES**

T

Today is 'Arbor Day'

Today is 'Arbor Day' and I'm planting trees...
Please come by and watch with me and listen
To the sky by night and day...
The random clouds chasing birds...
Hear the singing of the Universe...
Watch all that grows from earth
And wonder at the glistening power...its worth...
Immeasurably priceless of course...

And forget that sometimes
We feel like broken straws
Blown rootless back and forth...
Dissatisfaction's ploy is to quest
For magnets in a touch...like seed to sod
Leaf to twig...nut to shell...pea to pod...

Bold mountains thrust masculine
And independent from the land...
Soon, in a million years
Their lusty height is cheap and shaken dust...
Yet it is Mother soil that gave them Royal birth!...
Mists cluster high and low...
Chirping creatures lustrous hued
Impudently socialize in pairs
Of opposite yin and yang...all imbued
With a self perpetuating passion of a kind
That's incestuous to their race...

So I need to find a beau...a friend
A complement...He'll be sent they say
In the flashing guise of love...a fellow man
To help me dig into this Universe of ours...
Hand in glove...pick with spade...a man
That's comfortable with companion man...

Today is 'Arbor Day' and in time
The trees and men will grow
Their own offspring from seeds they made...
Then the birds will fly
To a panoply of jade and emerald leaves
To sing our song and theirs
Before we die...and live
And die again...Remembered.



Readers can contact Ganymede
C/- AIDS Council of NSW
North Coast Regional Branch
113 Dawson Street
Lismore 2480
Phone: (066)221555

GANYMEDE



From All Walks of Life: The AIDS Trust

On Sunday May 21, twelve hundred people 'from all walks of life' took part in a fundraising walk to support the work of The AIDS Trust of Australia. To some it may now seem like history but, the work of The AIDS Trust goes on. *TALKABOUT* spoke to Clive Miller, National Fundraising Director of the Trust about the effectiveness of the walk.

Clive said that \$35,000 was raised from sponsored walkers and that about half of this went on various costs. The remaining proceeds will be used by the trust to assist in the fight against AIDS. The real value, however, of having walkers sponsored is that if each of the twelve hundred walkers has, say, ten sponsors then twelve thousand people have been made to think about AIDS and its effect on our community. Needless to say, these twelve thousand people are going to talk to other people about AIDS and so awareness spreads rapidly.

The success of the walk will become more apparent over the next couple of years as more fund (and consciousness) raising events are organized. The 'domino effect', mentioned above, will ensure that community scepticism (AIDS - it can't happen to me!) is overcome and that the whole community becomes concerned about AIDS.

Sept. Oct. 1989

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The AIDS Trust of Australia is a national charitable trust which distributes funds to assist in the fight against AIDS. The AIDS Trust supports activities which provide education care or research related to AIDS. Applications for funds are invited through the media twice a year. Trustees award funds to those activities which have the greatest potential to either benefit people with AIDS or to advance our understanding of the disease. Contributions for specific projects or activities are also accepted provided they have previously been submitted to, and approved by, the trustees.

The AIDS Trust reflects the need of the whole community to be aware of AIDS as the major health issue of our time. It needs the support of all of us.

Donations over \$2.00 are tax deductible.

The AIDS Trust can be contacted at:

P.O. BOX 1272
DARLINGHURST
NSW 2010
Tel. (02) 211 2161
Fax (02) 281 3867

HIV INFECTED PEOPLE WE NEED YOU TO DONATE PLASMA

If you have a **high** T-cell count then your plasma is needed for Passive Immunoneutralization trials.

If you have a **low** T-cell count you may be able to take part as a recipient. Pilot studies, so far indicate benefit to the recipient.

They are being conducted at Albion Street Centre. The doctor will ask you to attend the clinic at a mutually agreed time for approximately one and a half hours.

PHONE PLWA FOR MORE DETAILS



DONATIONS

PLWA would like to thank Peter Sawkins of Rockdale Locksmiths for his donation. Needless to say, all donations are gratefully received and put to very good use.

The Gay Liberation Quire was recently formally disbanded. Sadness and, at the same time, joy. It is now some time since the Quire last performed. We should all be grateful to all the women and men who sang in the Quire.

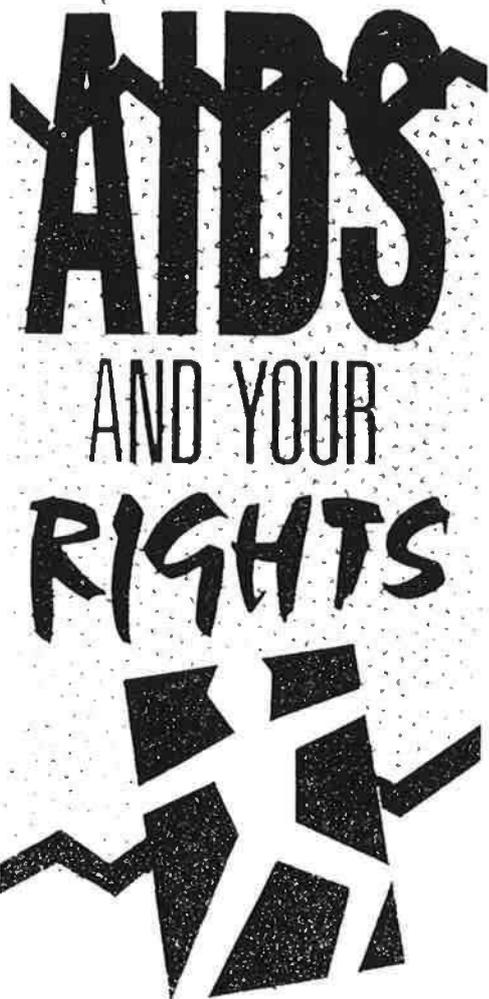
The Gay Liberation Quire was always in the vanguard of struggles for freedom, not only for lesbians and gay men but for all oppressed people. The relevance of this for PLWA is twofold. Firstly, the political and social climate in which we fight against AIDS is a much healthier one, thanks to the work of liberation organizations like The Quire.

Secondly, in a final grand gesture the Gay Liberation Quire has made a donation to PLWA. This money will be used towards publication costs of *TALK ABOUT* and also to assist in opening an Information Street Stall soon to be set up.

PLWA thanks
The Gay Liberation Quire.



A.C.O.N.
Annual General Meeting
Tuesday September 5, 7.30pm
Safe Sight Lecture Theatre
Cnr. Albion & Crown Streets
Surry Hills.



ACON has recently published a new pamphlet entitled **AIDS AND YOUR RIGHTS.** It covers a broad range of topics

- Antibody testing
- Discrimination
- Insurance
- Welfare benefits
- Medical treatment
- Wills
- Work related issues
- Custody and adoption of children
- Overseas travel and migration

INFORMATION NIGHTS FOR HIV INFECTED PEOPLE

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

1. HIV infection and the Immune System:

Tuesday September 12
 " October 10
 " November 14
 6.30pm - 8.30pm

What is the immune system? What is a virus? Find out from this presentation.

You can learn:

- * how the Human Immuno-deficiency Virus is spread
- * what the virus does in your body
- * how your body reacts
- * what is likely to happen when you are infected with the virus

Open discussion will follow the presentations.

2. Monitoring and Prophylaxis:

Tuesday September 19
 " October 17
 " November 21
 6.30pm - 8.30pm

In this presentation you can learn:

- * the meaning and basics of monitoring
- * why monitoring is worthwhile
- * about prophylaxis and how it will help you
- * what illness can be prevented by using prophylaxis
- * to recognize your need for it

Open discussion will follow the presentations.

3. Treatments and drug trials:

Tuesday September 26
 " October 24
 " November 28

What are drug trials and how will they help you?

In this presentation you can learn:

- * about the need for drug trials
- * what trials are available
- * the pros and cons of drug trials
- * what medical and alternate treatments are available
- * whose choice is it anyway?

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

P L W A
TALK
ABOUT

Please join us in our fight against AIDS by becoming a member and by subscribing to our bi-monthly newsletter *TALKABOUT*.

NAME:[please print clearly]_____

ADDRESS:[for mailing]_____

POSTCODE:_____

TELEPHONE NUMBER:_____

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

Are you publicly open about your membership? Yes / No

ANNUAL SUBSCRIPTIONS ARE:

Membership of People Living With AIDS Inc \$ 2-00

Subscription donation to 'TALKABOUT' [individual] \$10-00

(Optional for people receiving benefits)

Subscription donation to 'TALKABOUT' [organisation] \$20-00

Enclosed : \$_____

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

SIGNATURE_____

TAL

Newsletter of PLWA

NEED 6 COPIES
NOV/DEC 88

OUT

AIDS (N.S.W.)

Welcome to the first issue of Living with AIDS (NSW), the people most often affected by HIV themselves; in touch with others, asking questions; sharing relevant to us - the people

people
a voice for
affected and
getting
news;
news

This edition has been put together by a small collective for the primary purpose of introducing ourselves and advertising upcoming important events. All those on our membership list will receive a copy, together with other groups who we think will be interested. For the forthcoming issues we want YOUR contributions. Please send articles, letters or whatever you think is of interest to People Living with AIDS (NSW), P.O. Box 1359 Darlinghurst Sydney 2010. To become a member or become involved in any of our activities please fill out and return the membership applications at the back of this edition.

We hope you enjoy TALKABOUT



November/December 1988

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

Convenors' Report

The National People Living with AIDS Coalition (NPLWAC) was formed at the Third National AIDS Conference in Hobart, August 1988. The immediate aims of the Coalition were to bring together all People Living with AIDS (referred to hereafter as PLWAs) whether they have full AIDS, ARC, or are antibody positive. The Coalition aims to bring together all persons infected and affected by HIV; this includes their lovers, family, friends and primary carers.

The first committee meeting of the NPLWAC was held in Adelaide on the 18th, 19th and 20th of November, 1988. Two delegates from each state and territory attended with the main emphasis on:

- *statement of purposes of the NPLWAC
- *the aims of the NPLWAC
- *the objectives of the NPLWAC
- *the bill of rights of NPLWAC and
- *to draft a constitution for the NPLWAC

The second National Conference will be held in conjunction with the Living Well II Conference in Sydney in February, 1989.

People Living with AIDS

(NSW) was formed at a public meeting on 28 September, 1988. We were elected as interim representatives for NSW until formal constitutional matters have been resolved.

The immediate aims and objectives of PLWA (NSW) are as follows:

- *to distribute current available information related to the treatment practices of HIV infection (both medical and holistic) and management of HIV related conditions.

- *To provide an outlet for expression of HIV related experiences by HIV affected community members

- *to inform re supportive and related services

- *to educate the community at large of issues regarding HIV infection

- *to organise the "Living Well II" conference on 11 & 12 February, 1989 at the Sydney Institute of Education auditorium

- *to organise a float, in conjunction with the Maitraya Day Centre, for the 1989 Sydney Gay and Lesbian Mardi Gras to provide a high profile for PLWAs.

There are a number of working groups which we encourage our readers to participate in and commit themselves to. Some have

obvious priority:

- *Mardi Gras Working Group
- *Newsletter/Membership/Publicity Working Group
- *Conference Working Group
- *Alternative Treatment/Therapy Working Group
- *Constitutional Working Group
- *Fundraising Working Group

We encourage your participation through, for example, writing letters, working groups, contributions of money. We aim to produce the newsletter bi-monthly which will eventually be nationally distributed but based in Sydney.

The Newsletter will also eventually include a "Singles Column" recognising that People Living with AIDS have emotional and sexual needs also.

In our fight against stigmatization and isolation faced by PLWAs, our sexuality must not divide us. It is difficult enough to cope with a positive diagnosis, let alone to identify as a Person Living with AIDS, not a "victim" or a "sufferer". So come out and join us!

Paul and Irwin

People Living with Aids (NSW) announce

LIVING WELL 2 CONFERENCE

A 2-day conference for People Living With Aids, their friends, carers, family.

Saturday & Sunday, February 11th & 12th, 1989

Sydney Institute of Education Auditorium

Conference Aims:

- Provide a forum for discussion of common issues and problems
- Discuss strategies to address issues and problems
- Provide up-to-date information on Aids issues
- To assist the development and extension of support networks
- To discuss formal structures for People Living With Aids (NSW) to ensure effective pressure for response to our needs

Conference Structure:

The conference will consist of special interest workshops and several plenary sessions.

Workshops currently scheduled include:

- Current drug treatments
- Alternative therapies and treatments
- Relaxation
- Diet
- Nutrition
- Stress management
- Care services
- Empowering People Living With Aids
- Aids and your rights
- HIV positive Women
- Partners of People Living With Aids
- Parents/families of People Living With Aids

We are keen to hear from people: ● interested in facilitating one of these workshops or ● writing a brief discussion paper or ● suggestions for other workshops

Please contact the Conference Organizers through Terry Giblett at ACON (02) 211 0499

Who would we like to see there? ● Everyone and anyone affected by HIV infection.

(This conference is organized by People Living With Aids (NSW) with the assistance of the Sydney Gay & Lesbian Mardi Gras Association and the Aids Council of NSW)



WHY A CONFERENCE?

As part of the process of forming and setting up PLWA (NSW) it is important to provide a forum for discussion for as many different people as possible who are infected and affected by HIV. This will hopefully ensure that the PLWA is structured in such a way as to recognise as accurately as possible the views and issues experienced by this diverse range of people.

We hope to have representation and participation from groups as diverse as prostitutes, IVUDs, those infected from transfusions, gay men, women, youth, aborigines carers, lovers, friends and family of etc. This is not an exhaustive list and we would like to hear from these and other groups who wish to be involved.

At this stage it is envisaged the conference will consist of two main streams.

The first series of workshops will be for groups such as those above to discuss specific experiences of HIV and the issues and problems that they face as people infected or affected by AIDS. At a final plenary session these groups will present the results of

workshops to the conference. This will hopefully promote discussion on how these different groups might develop strategies to meet identified goals, individually or collectively.

It is hoped that from this a viable organizational structure and future directions for PLWA (NSW) can be decided in order to best meet the needs of all.

The second stream is aimed for people wishing to find out more information on AIDS. It is anticipated there will be a series of information and discussion sessions on issues such as: current drug treatments, trials and research; alternative therapies and treatments; stress management; diet and nutrition. At this stage we are still open to suggestions regarding possible workshop leaders and topics to be presented. If you have ideas or are willing to conduct such workshops contact Terry Giblett, conference coordinator, on 211 0499 as soon as possible.

These two streams will run concurrently.

To encourage informed

debate we would like people to present discussion papers which could be circulated prior to the conference for consideration. These papers could canvass such issues as: the emotional impact of HIV diagnosis; experiences of discrimination; impact on family; how to maintain a healthy and positive attitude to life; legal issues facing people with HIV or those identified as "high risk"; sexuality and morality.

These are only some possibilities. If you have any other issues you would like to address in a paper please do not hesitate to contact Terry Giblett or send your papers to:

PLWA (NSW)
P.O. Box 1359
Darlinghurst 2010

We look forward to seeing as many people at this conference as possible. It is hoped the result of this conference will result in greater communication, and understanding between all PLWAs, as well as the empowerment of people infected and affected by AIDS.

The needs of PLWAs must be heard.

World AIDS Day Report:

Events around World AIDS Day on 1st December 1988 were a great success for all People in NSW who are infected and affected by HIV. The most prominent and exciting event for many of us was the launch of the Australian Quilt Project. This was the first event on the calendar for World AIDS Day and thanks to the support of people like Ita Buttrose who launched it for us, the Quilt attracted lots of media interest. Further information about the Quilt can be found later in the newsletter.

Other events included the Martin Place Rally for People Living With AIDS. This rally attracted well over 500 people and considering its public location I think we can all be heartened and pleased that so many came to support us and assist us in telling the world what we've been doing about AIDS. Great speeches by Vince Lovegrove and Jim Dykes really helped set the mood and the rally ended with the release of 1 000 balloons to symbolise the now over 1 000 cases of AIDS in Australia.

But Thursday did not see the end of all the activity. We all gathered in Green Park, Darlinghurst on Saturday afternoon the 3rd and a great time was had by all. All the voluntary organisations that provide service for People with AIDS were represented and during the afternoon several hundred people turned out to see the Quilt on display around the rotunda and find out more about what other people had been doing. The day was filled with laughter as the Safe Sex Sluts competed for the crown of Safe Sex Slut 1988. Other activities included the Tug-of-War which was won by Ankali.

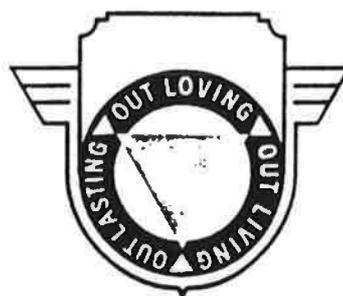
Finally the last event of the World AIDS Day activities for the community was the Carer's Party at the Australian Museum. This proved to be quite an event in itself. With speeches from Gerry Davies from Ankali thanking all the organisations for their assistance during his lover's illness and also the wonderful speech from Ruth Cotton, Manager of the AIDS Bureau who showed us all that the Bureau

does understand and support us.

All these events proved to be highly successful because People Living with AIDS were prepared to attend them. Of course I had many frustrations in organising these events, however for the most part it was great fun. Seeing the end result of People Living with AIDS standing up publicly and honestly letting the world know what this disease is really like made it for me very worthwhile. If we remember that as a community, even as a new one such as ours which we call People Living with AIDS (NSW), we can stand together and we achieve everything that we need and deserve. My many thanks go to you all who attended World AIDS Day events and now let's all look forward together and continue to show Australia how compassion, caring and understanding can indeed beat AIDS.

Thank you all.

Terry Giblett
Project Officer
World AIDS Day
14.12.88



THE
Quilt
PROJECT
AN AUSTRALIAN AIDS MEMORIAL.

A Working Group of the
AIDS Council of New South Wales Inc.
68 Sophia Street, Surry Hills
P.O. Box 350, Darlinghurst, N.S.W. 2010.
Ph. (02) 211 0499 Fax. (02) 281 3867

Inspired by the American Names Project and based on folk art traditions of quilting and sewing bees, The Quilt Project is a nationwide campaign to memorialise those we have lost in the AIDS epidemic.

The Quilt is composed of fabric panels, each bearing the name of an individual lost to AIDS, designed and completed by their friends, lovers and families. The panels will then be stitched together by volunteers to the main panel sections comprising the quilt.

The Quilt Project has three goals:

- I To provide a positive and creative means of expression for those whose lives have been touched by the epidemic.
- II To illustrate the impact of the AIDS epidemic by showing the humanity behind the statistics.
- III To encourage support for people with AIDS and their loved ones.

The Quilt Project is a memorial to those who have died of AIDS. There are no membership fees as we have found much support from many organisations who have provided us with all of the requirements we needed in order to set up the project. We envisage a periodical letter to those people contributing panels, keeping them informed of the progress and various display venues of the Quilt.

Following our experience in creating panels for the Names Project Quilt which is based in San Francisco and was displayed in Washington DC in October, we decided to create an Australian Quilt. It too will be made from individual memorial panels, each 6 feet (1.83 metres) by 3 feet (0.91 metres), bearing the name of someone who has died of AIDS or ARC. When the Quilt has reached a suitable size it will be displayed at appropriate events (Mardi Gras, Stonewall week). Details of course will be published well in advance. Hopefully it may even go on tour.

To create a panel, choose firstly a non-stretch durable fabric as the background and hem it to 6 feet by 3 feet. If you select 2 metres of any fabric, 1 metre wide, you will have more than enough to hem. Each panel **must** be hemmed so panels can be sewn together to create the Quilt, and of course if they are not all the same size problems will occur.

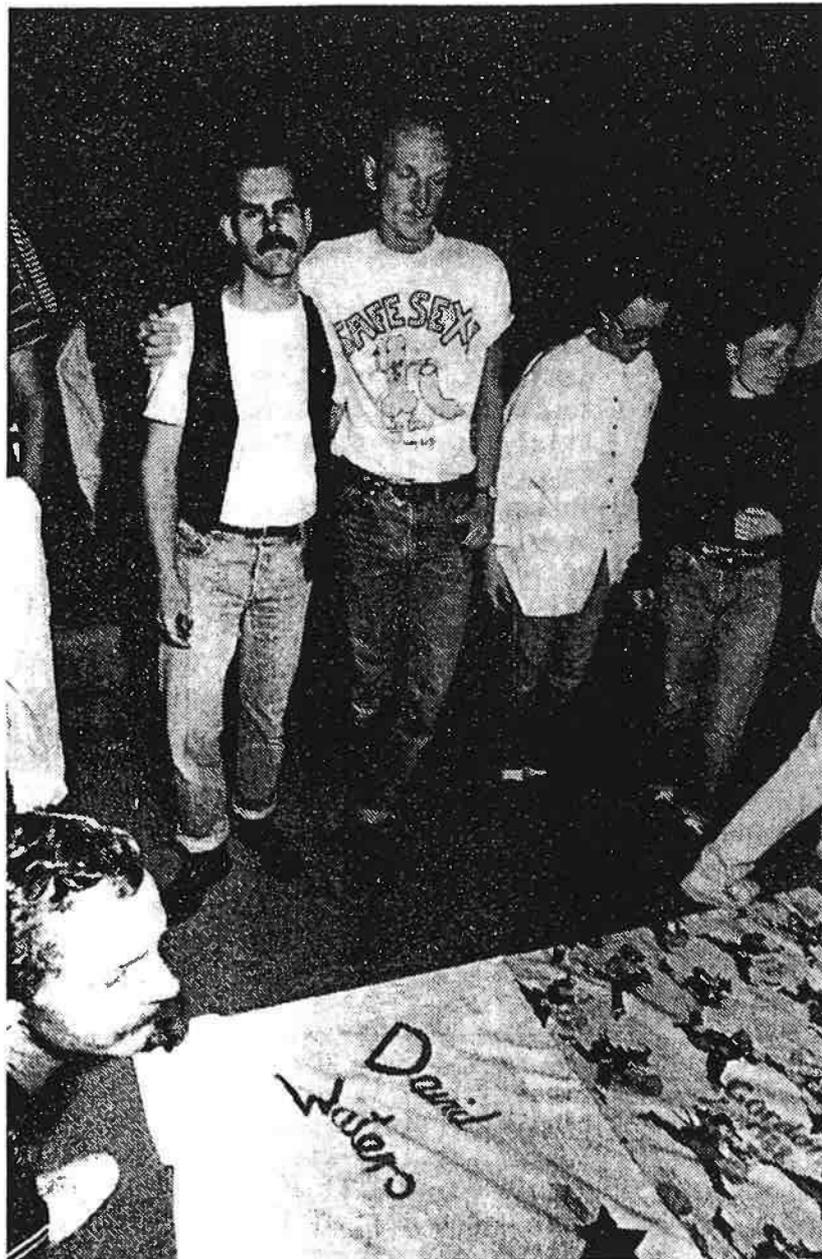
Some suggestions for your design are applique, fabric paint, stencil and collage. The Quilt will be folded and unfolded many times so remember this when you create your panel. We suggest involving families, friends and co-workers to help design and create your panel.

Also take time to write a page about the person memorialized, who they were and what they meant to you. We also hope you can enclose a photograph of the person too. When submitting your panel please enclose the following details:-

1. The name on the panel
2. Name/s of maker/s
3. Relationship
4. Address in full
5. Phone number

We are also seeking donations from individuals and businesses of unwanted fabric, haberdashery, and sewing implements and yes, even sequins.

CONTACTS: **ANDREW CARTER**
 RICHARD JOHNSON
 (02) 357 1359



THE QUILT TWIN CITY TOUR

The Quilt Project will be displayed at the Melbourne Mid Summa Festival in late January and at the Sydney Gay & Lesbian Mardi Gras in mid February.

Panels for this display are required by 15 January 1989.

AZT AND BEYOND

AZT is an antiviral that inhibits viral replication. It does not cure AIDS. The least it will do for you is to stop your T4 cell count from falling so fast. It can even sometimes cause T4 cells to rise for a time. It can extend life. Refer to ACON AIDS fact sheet "AZT for Beginners" for a good overview of this drug, including its history, the Australian experience, its chemical structure, mode of action, benefits, side effects and the alternate names of this compound (ACON October 1988).

Although AZT has side-effects, they are not as bad as dying from the lack of it. Your AIDS specialist will closely monitor your response to the drug. Most people don't have too many troubles with AZT. The earlier you take it after your T4 count falls under 200 the less the side effects, and the greater the extension to, and the quality of life.

There is a trial running currently in Sydney for people between 200 to 400 T cells. It is a double blind placebo controlled trial. Half of the subjects get real AZT, the other half a placebo. The capsules look the same as each other and have no markings. Regular AZT is a white capsule with a blue band. You need some

sort of alarm clock to remind you to take your dose at regular intervals.

As AZT is better tolerated by healthy patients, the question to be answered by this trial is: "Is it better to give early intervention with AZT, or will we exhaust the efficacy or tolerance to AZT before it is really needed?" Nobody has a crystal ball and both sides of the argument have merit. My guess is that it will show that AZT is best started when T4 cells fall below 300 instead of 200, the present elligable level (unless you already have full AIDS).

Anyway, some patients who refused AZT when first elligible, began treatment later when they got really sick but didn't do so well as they might have if they started AZT earlier.

AZT: a perspective

I meet a lot of people who are offered AZT by their AIDS specialists. Because I have been taking AZT for 18 months, they ask me all sorts of questions. I don't mind answering except that I don't want to be responsible for their decision.

Lately I have met some people who were quite afraid of even starting AZT because of the

possible side-effects.

Let me assure you of some relevant facts:

*Most people don't have any difficulty starting AZT at all.

*Those that do experience difficulty are taken off AZT immediately, to be restarted after a rest from it.

*Those people usually adjust to the drug after a few false starts.

*You will be closely monitored by your AIDS specialist, at first weekly, then fortnightly and monthly.

*If you experience any difficulty you should consult with your specialist or a GP who you have chosen for their expertise in AIDS

*Your specialist at the AZT dispensing hospital or clinic will modify the dosage given to optimise the benefits to you and minimize side-effects.

*The dosage could be reduced, or perhaps better, you could be put on "Pulsed Therapy" -

say 4 weeks on full dose, 2 weeks off; or 2 weeks on/2 weeks off; or 4 on/4 off, to allow the body to correct itself.

*The doctor who prescribes AZT is the best judge of this. It is, however, your responsibility to tell doctors exactly how you are feeling and to discuss your concerns with them.

*If your haemoglobin (red cell) count goes under 10 they will give you a transfusion and/or modify the AZT dose. A blood transfusion only takes one night in hospital and is not painful.

After my transfusion I felt like a new man - and rushed out of the hospital to find one! AZT is, of course, not a substitute for safe sex.

*You probably will tolerate continuous full-dose AZT for at least 6 months before you have to modify the dose or receive a transfusion or two.

*Even then it is worth persisting with AZT despite the inconvenience to your busy social life or the fear that the end of the world is near. It is not over yet!

I have been on AZT for 18 months. After the first 6 months continuous full-dose AZT I needed my first transfusion. Since then I required two more transfusions while my specialist adjusted my AZT dose to keep my T4 count up and the haemoglobin (red cells) up without needing any more transfusions. This was done by Pulsed Therapy of two weeks on/two weeks off. This worked much better for me than half dose continuous AZT. In fact my red cells climbed back to normal and my T4 cells stabilized. When

the T4 cells started to fall again after 28 weeks on Pulsed Therapy my doctor and I tried various on/off periods. We found that a week off AZT was not enough for my red cells to recover so 3 weeks on/1 week off was changed to 4 on/2 off. We shall see how that goes and readjust if necessary. I'm also taking Fansidar to prevent PCP as well as vitamins and minerals from the ACON vitamin co-op. I am also meditating twice daily and going to a weekly emotional support group. I'm too happy and too busy to die just yet!

The last three years haven't been entirely without anxious moments but I have enjoyed the extra time that AZT has bought me very much. I feel that AZT robs me of some of my previous energy but if I didn't take it I am quite sure I would not be alive today. I have never been brave enough to ask a doctor "How long do I have to live?". It is a silly question because doctors don't have crystal balls!

My personal case history

After finding out I was Ab positive in December 1984, I was diagnosed as full AIDS in December 1985 as I had a very aggressive Lymphoma. This was life threatening, so I was categorized as Group 4 (Category A in the old system) - full AIDS.

In December 1985 I had surgery. In March 1986 I had radiation. Aggressive chemotherapy started in October '86 to February '87. I am still in remission! Six weeks after the last chemotherapy infusion my hair, which had fallen out, started to grow back like peach fuzz and my T4 cells shot up to double what they were before chemo started. So much for the theory that chemotherapy is immunosuppressive! Temporarily it is, because when I asked, during chemo, "Doctor, what are my T cells doing?", he looked over the top of his half-frame glasses and said rather wisely, "You don't want to know!" But the chemo must have had a devastating effect on the HIV because after 6 weeks of recovering from the effects of the last dose of chemo my T4 cells went from 190 in October '86, to 386 in March '87. They then started to fall. They started me on AZT when the count got down to 300. That remained between 300 and 225 until 10 weeks ago and are now at 130. That fall is disappointing, but AZT is not guaranteed for ever.

I am now classified as a "long term survivor" (3 or more years). That is really excellent for full AIDS with a Lymphoma.

and beyond...

Well! Apart from excellent medical treatment what is the secret of my success? I'm not entirely sure. I smoke, drink, stay up late, eat whatever I like. I refuse to sacrifice pleasant foods or activities. I do, however, strongly believe that my twice daily meditations and weekly emotional support group at Albion Street clinic with Petrea King, does a lot more than just reduce my stress levels! I think that a little stress isn't bad for you. But I believe that DISTRESS is quite unhealthy. If life is too distressing you won't want to live in it, and may catch a death wish!

I have done a great deal of personal growth (courses and books) that have helped me to enjoy life more today than I ever did before AIDS. I am currently studying the top (western) new age book on attitudinal healing. (Quite a lot of long term survivors in

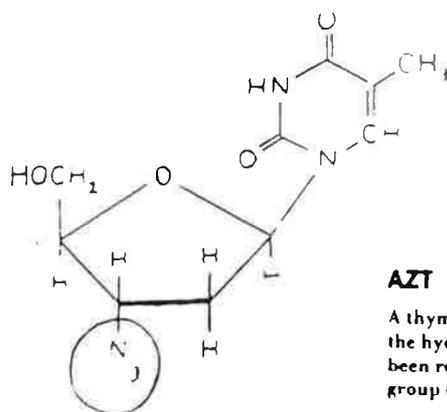
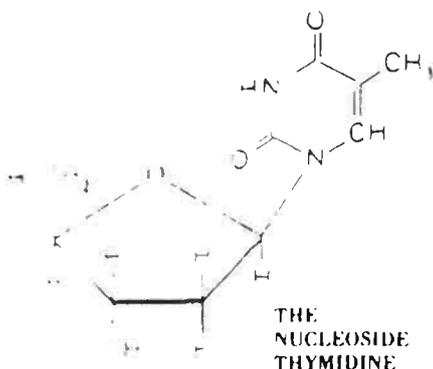
the USA are also studying "A Course in Miracles" (a miracle is a shift in perception). Easier books by Gerry Jampolsky or Louise Hay can also help you live more happily. They all teach forgiveness. I learned to deal with my fear of death and subconscious rubbish like - the wish to die, my victim consciousness, sexual and other forms of guilt and projection, all of which was like pointing the bone at myself. I discovered that I'm a good bloke after all! I had to adopt a positive but realistic attitude to death. This involved the acceptance that my body may die although I (spirit) would never die. Meantime I decided to accept life as it is here and now. I had to change the way I perceived the world. I didn't want to stay in it the way I saw it, and AIDS was my ticket out! "No one loved me!" (I didn't love myself actually). Once I started to accept and love the inner me I

discovered that lots of people had always loved me, but I had refused to accept their love. (I could only accept love from a lover - rather silly really!).

Facing the probability of death prompted me to shop around for a more realistic concept of God. The old god I was brought up with reminded me of the angry revenging poltergeist in Speilbergs movie! My research into the area of new age spirituality was quite fruitful. I had always refused to accept that I would burn in hell for being a poofter! I learned that the real God is like a "force field of love" and that this love is inside us all, even me! And God, being pure Love, does not judge, criticize, condemn or torture anyone. Even poofsters! So now I feel even more gay and happy.

May the force be with you!

Peter
December 1988



A thymidine analogue in which the hydroxyl group (OH) has been replaced by an azide group (N₃)

The Loving Touch Of Petrea King

Even as I lay on the bed dying, the doctors flitting around me, unable to do anything, I knew that if I asked God to save me and somehow I recovered, I'd have to go to church every week for the rest of my life to thank him. And that would be worse than living an eternity in hell."

I've always subscribed to the cynic's view when it comes to religion and although I can't remember who uttered this gem, I felt it expressed my feelings to the eternal question every agnostic asks themselves in a life-threatening situation. A bit like taking out an insurance policy on the after-life, and if I was right all along then no harm.

So when John kept saying he was healed, with that serene, tranquil expression that you associate with religious looneys, it seemed as if he had finally flipped. After all, John is in remission from AIDS and cancer of the lymph gland and spleen, a living cocktail of terminal conditions.

But John, (not his real name) pointed out he wasn't cured.

He had learnt to face all the fears he had of dying, so now he could appreciate life, living every moment instead of

moment-to-moment. Healing came from peace of mind.

For John, the healing process started when he attended a therapy group run by naturopath and counsellor, Petrea King.

"When I first went to Petrea I took along a bag containing about 20 pill bottles," John explained. "There were various alternative remedies that kind friends had rung me up and told me I should be doing. There was vitamin that, and this herb and that herb. I use to rattle.

"I told her what was wrong and that I was taking all these pills, she said how could I help you? I unzipped the bag and emptied all the pills on to the floor between us. And I just burst into tears.

"It was like people were being very supportive, and all these pills were supposed to work, but it just wasn't working. It was very very frightening.

"I've cried many times in this disease, and I'm here to tell you that real men probably don't cry but men who are real do cry. I think I've become more real. I've become more in touch with who I am."

Petrea explains this healing process as peace

of mind, discovering how to be more alive rather than looking for ways to die gracefully.

"When we know how to live in the fullness of life, then we die extremely gracefully. This creates the perfect environment for the healing process to take place, because healing is peace of mind.

"Many of the people I nurse through their dying are healed. Because all the old bitterness or resentments or angers or frustrations are melted, and there is just peace there."

Petrea King is one of those magical people who have learnt from their own harsh experiences and apply that knowledge to help others.

Five years ago, Petrea was diagnosed with myeloid leukaemia and told she had less than ten weeks to live. When she started to ask herself what it meant to die, she felt part of herself hadn't lived, the part that contained all her feelings. So rather than thinking her way through life, Petrea began to explore her feelings.

With love and help from her family, Petrea began the difficult path to remission from the leukaemia.

Rather than rely on conventional religions, Petrea shuns them and the beliefs that are attached to them.

"If I built a life that had no pain in it," she explains, "it didn't have a great deal of joy either. By being willing to have my own pain - from whatever source that might come - has allowed me to be alive alot more. So I feel alot more pain now in having people die".

"Yes it is tragic and sad but there is also someting very high and very right about it as well".

An important part of Petrea's living therapy

is physical contact, through touch, holding or massage. A young man who had contracted AIDS began crying when Petrea massaged him for the first time, explaining that no-one had ever touched him before unless they wanted something.

"Touching provides a tremendous amount of emotional support".

"You cannot walk in on someone and say hi, how do you feel about dying, but you can always ask them if they would like a foot rub or a back rub or massage. This creates the right enviroment so that the person can talk about what is closest to their heart."

Petrea King holds weekly therapy groups at the Albion Street Clinic and has written a book on her treatments called "Quest for Life". and is available through most bookstores.

She also holds weekend-long therapy sesions at Goulburn.

Petra can be contacted trough the Albion Street Clinic (ph 3324000).

author: Malcolm Jones is a freelance journalist who has gratefully contributed this article to our first newsletter.

DO IT IN A CONDOM



Aids Council of New South Wales.

OZONE

Until very recently we were told ozone is a protective layer of the Earth's atmosphere that gets destroyed by the rising fluoro-carbons from our deodorant and Fabulon spray cans. Now, it seems, a group of researchers have found a positive use for ozone for people with AIDS. At a public seminar in Sydney in October this year, Dr Michael Carpendale, principal investigator at the San Francisco Veterans Administration Medical Center, presented data on the treatment of PWAs and PWARC, and experiments in vitro, of ozone (O3).

Ozone is an established purifying agent for water and sewerage and has been used by some therapists in Germany against cancer. A Dr Kief is reported as "curing AIDS victims" by ozone treatment, and now the technique has been taken up by an organization in the US called Medizone. The group received a US patent approval by the US Food and Drug Administration in 1987 to experiment with ozone therapy on human subjects.

The theory of ozone treatment appears simple. Dangerous foreign organisms like HIV are anaerobic, meaning they have a low tolerance of high levels of oxygen in the hosts blood. By introducing tolerable, non-toxic levels of ozone into the blood, "hyperoxygenating" it, all

lipid enveloped viruses such as HIV are destroyed while leaving the blood cells unharmed. Ozone is not usually injected directly into the bloodstream. Rather the blood is extracted first, infused with ozone and then returned to the body. Alternately ozone can be administered anally, the preferred method for the treatment of chronic diarrhoea.

By this method a Dr Preuss in Germany has claimed to "cure" 10 people with AIDS conditions by actually removing the virus from the patients blood altogether. Dr Kief's claims, although not so extravagant, appear encouraging in that he reports a treatment of ozone administered 2 - 3 times a week for a 6 - 8 week period resulted in increased T4 cell counts in patients. Similarly, Carpendale claims increased T4 cell counts and reduction of diarrhoea in 2 patients with AIDS/ARC.

Ozone therapy is now available in Sydney at a cost of around \$35 - \$50 per treatment and a number of PWAs that I spoke to who receive the treatment reported increased energy and feelings of well being for a period after treatment. While ozone therapy may be administered by a practitioner, it is also possible to purchase portable ozone making machines for self (anal) administration at a cost

of approximately \$5000 from practitioners in Germany. A few of Carpendale's clients in the US are reported to be self-administering and doing well by it.

While these results appear encouraging in an atmosphere where the medical establishment offers very few alternatives, a few cautionary notes may be in order.

Firstly, ozone therapy has not yet been reported for scientific scrutiny in any medical peer review journal, the conventional channel for sounding out new treatments. Because of this, and the very anecdotal reports available to date, it is impossible to evaluate ozone therapy in a manner satisfactory to the scientific establishment. One may argue that placebo controlled testing of new procedures may not be ethical for patients with little therapeutic alternatives, but this does not preclude practitioners from administering treatment in a more rigorous manner, for example with larger patient samples, and reporting their results in an accountable fashion.

Secondly, many patients, both here and in the US, report being on other treatments or health regimes whilst undergoing ozone therapy. It is

therefore impossible to determine if ozone is the causative agent, a co-factor to improved health, or of no benefit at all.

The claims of removing virus from clients blood should be treated with caution. While free virus may not be present in the blood, no tests have been done on patients to determine if tissue was free of virus. It is also incorrect to interpret a reading of antibody negativity as meaning a virus free condition. It

is simply an anti-body free condition, extremely improbable in a patient who had produced antibodies in the presence of a foreign virus, except when near death.

Finally, of course, is cost. For those who are incapacitated by illness the potential costs of a treatment whose effectiveness is unknown is a difficult decision. For the convinced, a full years continued treatment program could entail from \$2 - 3000 in expenses.

These notes are offered as an introduction to the alternative treatment of HIV infection with ozone. Because of the paucity of information available it is difficult to make judgments as to its efficacy at this time. Ultimately it is the decision of the individual who must judge the costs, doubts and possible benefits of such alternatives.

Robert Ariss

DEXTRAN SULPHATE

This drug definitely works as an anti-viral against HIV in vitro (in glass) but is unproven as an anti-viral in humans. Trials are currently underway in vivo (in humans) in the USA at the San Francisco Hospital.

Where this drug was once thought to be effective by itself it is now suspected it would be better used in conjunction with AZT. Though trials are still underway in the US to determine its effectiveness used this way, at this stage it looks like it will in fact be ineffective primarily because the drug may not readily be absorbed into the blood. Hence the drug will not be effective taken in pill form. There is also conflicting data

on T4 cell response and P24 antigen response (Antigen is part of the virus detectable in the blood).

Usual recommended dosage is 300 mg pills 6-18 times a day, ie. 1800 to 5400 mg/day. Higher doses sometimes cause diarrhoea but this may cease upon withdrawal of treatment of over 3 000 mg/day, resting, then redosing at less than 3 000 mg/day. No other side effects have been reported despite warnings that platelets should fall. Because they do not, this is an indication that there is no absorption into the blood.

Price is about \$300 per 1000 pills from Japan or \$400 per 1000 pills from local

agents

This buys a supply good for 18 weeks at 8 pills/day for 80 kg body weight

If you go out of your way to get this drug, get your GP to monitor you. Don't drop your AZT dose or other medications. It isn't worth the risk of following the half dose recommendation from the US on this writers experience. However, it is possible it would have some beneficial effect at a high dose with full AZT.

If any readers have experience with this drug, good or bad, with or without AZT, could you please contact us. Few people have managed to get this drug so we are keen to hear the Australian experience.

AL721

This drug still sounds promising even after 4 years of inadequate research overseas. It is not a cure but a mild antiviral. The anti-viral theory sounds plausible. Some good results have been received in trials in the US, Israel and France, proving effectiveness in reducing P 24 antigen in trials of less than 20 people. More than 60% of subjects responded well. One patient is reported to have experienced clearing of KS lesions. Some good anecdotal reports have also filtered through from overseas.

Being a food, AL721 is completely non-toxic with no side effects experienced. Only taste is reported to be unpleasant. AL 721 requires refrigerated storage. The US recommended dose is 20

gm/day. It can be taken as a food, for example in orange juice or on toast, but no oil, fat or milk can be ingested for at least 1 hour after.

A trial will start in Sydney in 1989 through the Albion St clinic. Participants will be 15 HIV positive people with T4 cell counts between 200 - 400 and who are P24 antigen positive. People on AZT or participating in any other drug trials are disqualified. There will be no placebos administered in this experiment. It is hoped that the substance will produce a drop in P24 antigen levels.

If you qualify make sure you get in on this trial. It is possible this stuff could work, at least for a while, and if it doesn't, it can't hurt you! It's better than doing

nothing, especially if you are P24 antigen positive (as well as antibody positive). Follow instructions to the letter please - we need clear answers from this trial. If there isn't enough AL721 to fit you into the 15 places of the trial, then contact us and bitch about it. It is these kind of trials that should be encouraged however trials limited to 15 tend to yield inconclusive evidence and merely confuse the issue. Samples of at least 30 are desirable.

FOR FURTHER INFORMATION REFER TO:

AIDS Council of NSW
("AZT for Beginners")
Albion St library
St. Vincents fact sheets
Project Inform
literature ("AIDS
Treatment News", USA)
AIDS Hospital
specialists

ASK

HIV HOUSING

During the past four years, I assisted more than 500 people at the Department of Social Security with H.I.V. related problems. It is not unreasonable to estimate that close to 90% of those people faced housing difficulties.

90% of P.W.A.'s are gay men. In a couple situation, high disposable incomes, no kids - they are seen as highly desirable tenants by landlords and agents. They can afford exorbitant inner city rents but what happens when they fall ill?

Following a positive HIV result or sudden chronic AIDS related illness, many experience severe lifestyle disruption and readjustment; relationship, friendship, familial breakdown or crisis to eviction. HIV completely changes their lives and naturally their attitude and outlook can be drastically altered. A positive attitude may result in no change to a small percentage, they continue to work and maintain their previous lifestyle.

What does Social Security offer? A paltry \$15 a week rent assistance for invalid pensioners, \$10 a

week for sickness benefit recipients after a 6 month waiting period? With average Sydney rents nudging close to the \$100 a week mark for a single person, D.S.S. offers little.

There are enormous links between stress and immune-deficiency. Following a positive result or sudden illness, enormous pressure exists to continue to work to meet heavy rental or mortgage commitments? A sudden onslaught of gas, Telecom and other bills, whilst leading a hand to mouth existence on D.S.S. payments frequently results in health deterioration.

What is available?

The overall situation is grim, however we do have:

Bobby Goldsmith Foundation

Through the Foundation Housing Project it offers 7 beds on a medium/long-term basis for gay men only. These are currently fully occupied.

AIDS COUNCIL

At the end of January 1989, 6 permanent single units will be available paying market rental and

a further 6 semi-furnished single units (on a temporary basis) for PWA's awaiting priority housing.

DEPARTMENT OF HOUSING

Application by PWA's must be made for priority housing on grounds of disability or medical condition. A recent consultative mechanism was set-up by ACON's Welfare Officer, Anne Malcolm, comprising Department of Housing officials, CSN, PWA's and community-based agency representatives working in the HIV area. Department of Housing Disability Unit officials (shortly to have their positions abolished) stated the maximum waiting time for priority housing (20% of fortnightly benefit or pension) was 4 months. In my experience, up to 6 month waiting period is not uncommon.

Applications are considered on an individual basis at committee level twice weekly. At present, there are 78 people in the 4 areas of Sydney awaiting priority housing. A list of phone numbers and addresses for Dept. of Housing Area Teams is provided later.

When applying, ensure your application is specific. Identify your specific needs i.e. mobility, access to medical services. Your application must be accompanied by a letter from an AIDS Social Worker (contact Anne or Ms Lesley Goulburn at St Vincents) or other professionals. Address your application to the "Team Leader", allow a maximum of 2 weeks. Ensure you ask for their name and direct line. Personal contact is the best way to assist your application. The Department will also subsidise private rental whilst awaiting priority housing.

Private Rental:

Department of Housing can assist anyone able to manage in the private market with bond, relocation costs and two to four weeks rental subsidy.

Supported Housing Program:

A minimum of 2 people is

required; although few 3 or 4 room dwellings come up and single parents are naturally considered priority given this fact. You will be issued with separate leases, so your own rental remains at 20% of your fortnightly income. If one lessee moves out, you have 6 weeks to find a new person, otherwise the Department chooses someone from their waiting list.

Supported Accommodation Assistance Program:

There is an urgent need for this type of accommodation for HIV-related dementia. Recently 4 patients were using palliative care beds at Prince Henry Hospital. A submission for such a project is to be written in the near future as it is seen as priority that such people receive supported accommodation.

Mortgage Relief:

The Housing Department provides short-term financial assistance (unspecified) to persons

suffering serious difficulties related to 'unforeseen events' and your gross "household" income must be less than \$44 000pa.

118: AIDS Related Hostel

Ph: 360 1489
Short term accommodation only providing accommodation, emotional support, food and "security".

It is envisaged the ongoing consultative mechanism with the Department of Housing and other agencies will continue, to minimise some of the great difficulties faced by People Living with AIDS and housing.

Authors:

Ms Lin Broadfield and Paul Young

Lin Broadfield was employed until recently at the Tenants Union until its abolition by the Griener Government.

Paul Young formerly worked at D.S.S. Bondi.

Department of Housing Area Teams.

Team 1. (City, Redfern, Alexandria, Darlinghurst, Woolloomooloo, Kings X)

Phone: 2827266.

Team 2: (Eastern Suburbs)

Phone: 3896900.

Team 3: (St George, Sutherland, Cronulla)

Phone: 2827233.

Team 4: (Inner West - south of Parramatta Rd)

Phone: 2827244.

Team 5: (Inner West - north of Parramatta Rd and North Shore)

Phone: 2827255.

For Parramatta, Mt Druitt, Penrith and Lidcombe/Auburn areas, call
Parramatta office: 6354122.

For Bankstown, Fairfield, Liverpool and Campbelltown areas call Liverpool
office: 8216111.

PEOPLE LIVING WITH AIDS (NSW)

APPLICATION FOR MEMBERSHIP

ELIGIBILITY FOR MEMBERSHIP:

The following persons shall be eligible to be admitted to membership by direction of the Steering Committee:

- (a) All persons who identify as being infected with the Human-Immuno Deficiency Virus, either as positive to the antibodies to the virus, or as being diagnosed as having AIDS or an AIDS-related condition, and
- (b) All persons who identify as living as partners, lovers or spouses of people infected with HIV.
- (c) All persons who identify as close family, or as close personal friends who care about a person infected with HIV.
- (d) All persons who identify as having been eligible for membership under the above clauses with respect to a person who has died as a consequence of an AIDS-related illness.
- (e) Other persons may be admitted to membership by resolution of a Forum meeting of the organisation in acknowledgement of their identification with people living with AIDS and their voluntary contribution to the well-being of the organisation and of People Living with AIDS.

I have read the above rules and am eligible for membership.

Signature: _____

Name: (Please PRINT clearly): _____

Address (for Mailing): _____

Postcode: _____

Telephone No: _____

Are you willing to have any other member know your name and address? YES/NO

Are you publicly open about your membership? YES/NO

Please return to:

P.L.W.A. (NSW)
PO Box 1359
Darlinghurst NSW 2010

JOIN

TODAY

Talkabout

PEOPLE LIVING WITH AIDS (NSW)

VOLUNTEER / TASK GROUP MEMBERSHIP

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

P.L.W.A. (NSW)
PO Box 1359
Darlinghurst NSW 2010

NAME: _____

CONTACT PHONE NUMBERS: _____ (WORK)

_____ (HOME)

I am able to help with:

NEWSLETTER

FUNDRAISING

DAY CENTRE

ACON SUPPORT SERVICES/OTHER SERVICES
(We will provide information on request)

ADMIN ASSISTANCE/MAILOUTS

LIVING WELL II CONFERENCE
FEB. (We need lots of help!)

Other skills / interests I have which may be of assistance are:

