

# Talkabout

Newsletter of People Living With AIDS Inc. (NSW)

*Where we speak for ourselves*

ISSN 1034 0866

## COMING OUT!

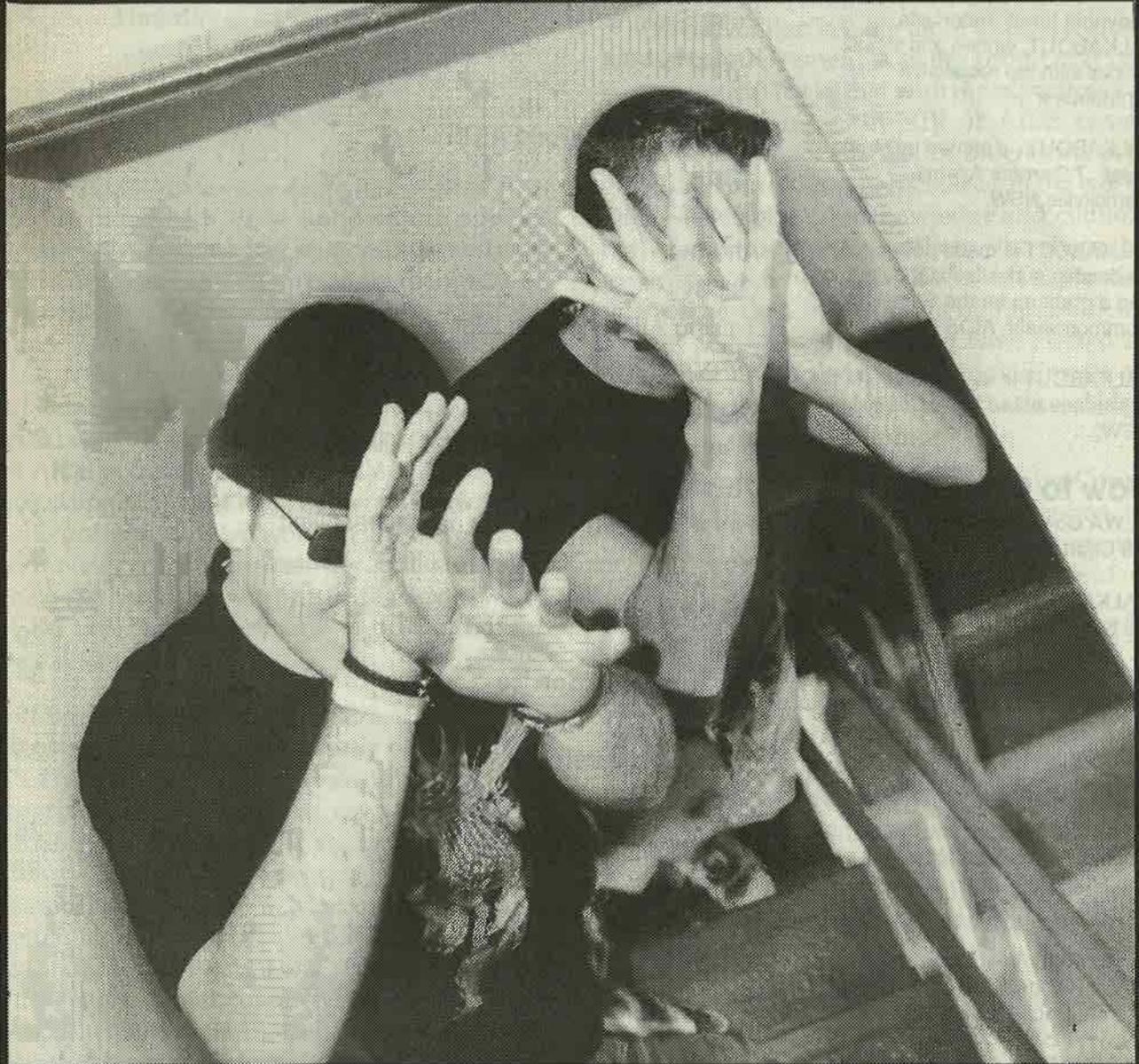


Photo: Jamie Dunbar

## ON WORLD AIDS DAY

Vol. 2, No. 4 NOVEMBER/DECEMBER 1991

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

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

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

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

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## Commonly Used Abbreviations:

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

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## *The challenge is living. Today.*

In this edition of *Talkabout*, PLWA (NSW) responds to this year's World AIDS Day theme - "Sharing the Challenge". Where do people with HIV/AIDS fit within a World Health Organisation (WHO) global education program which singles out one day of the year to highlight AIDS as an important health issue? What is the situation of people with HIV and AIDS on a global scale? What does "Sharing the Challenge" really mean to us?

WHO estimates one and a half million people are living with AIDS worldwide, a number equally divided amongst men, women and children. A staggering 9-11 million are thought to be HIV infected. But the figures only tell half the story. The distribution of HIV infection across cultures reproduces the brutal inequalities of the contemporary world. While developed countries begin to recognise the extent of the problem of AIDS in their societies and allocate resources accordingly, increasing numbers of new infections occur in the third world. It is projected that, as developed countries slowly gain control of their epidemics, by the turn of the next century AIDS will become primarily a problem of the world's poor.

But from this devastating scenario some hope emerges. We may be thrilled by a story from a PLWA member who, while visiting the African continent recently, came across a complete collection of *Talkabout* in the shelves of a Kenyan library. Sharing the challenge for us in this case means finding ways, such as through this newsletter, of linking people with HIV/AIDS across boundaries of distance and culture. The recent fifth international conference for people with AIDS, which some Australians were fortunate to attend, again confirmed this growing global link. The hope and strength of people with AIDS from countries such as Uganda and South Africa

is inspiration to us all. Their stories convince us that the most important work we can do is to continue to build on these links, locally, nationally, and internationally, sharing our knowledge and experience of living with HIV.

Eleven million is a big club! The basic message of our movement is as important and relevant as ever. That is, that with the expertise that comes with living with HIV or AIDS comes empowerment. All the health brochures, programs and bureaucratic efficiencies in the world will never replace the knowledge and comfort that comes from meeting others who share the experience of living with HIV or AIDS. It is for this reason that, in this issue of *Talkabout*, we feature people with HIV who have elected to 'come out' about their status, providing us all with encouragement and hope in the knowledge that we are indeed a community.

The recent decision by the Legislative Council's Inquiry to recommend compensation to those with medically acquired AIDS is an unwelcome development, therefore, to those of us who take the policy of "sharing the challenge" as a necessary principle. Sharing the challenges of living with HIV assumes an equality amongst us. There are, it is certain, differences between gays and straights, men and women, adults and children. But the means of acquiring this virus pale into insignificance when faced with the far more important challenges of getting on with the business of living with it. In this issue, different people living with HIV talk about some of the challenges in their lives. We must listen to each other, and learn.

People living with HIV/AIDS do not need a special day to be reminded about AIDS. Living with HIV/AIDS is an everyday challenge. Many of us wish for a day when we celebrate a world free of AIDS.

## The breast decision

I was glad to read *Positively Pregnant* in your latest issue of *Talkabout*. Not often is it recognised that women face additional problems when they are infected with HIV. When these issues do get raised, for the sake of these women, the information should be up-to-date and accurate.

It is correct that the recommendation of the World Health Organisation (WHO) still stands that only where artificial feeding does not present a safe alternative, breastfeeding should continue irrespective of the presence of HIV. This recommendation was given in 1987 and since then further research into this area has been conducted. Until today, breastfeeding is assumed to be a mode of transmission of HIV from an infected mother to her uninfected baby.

Breastfeeding in general has two advantages for both babies and mothers, regardless of whether they come from a high or low socio-economic background. These advantages include: the provision of important antibodies until the infant's own immune system is established, the prevention of gastrointestinal and respiratory illness, infections, and certain

immunologic disorders. Breastfeeding appears to reduce the risk of some chronic diseases (like Insulin dependent diabetes mellitus 92).

How the mother may feel about breastfeeding is as good a basis for decision making as any other - but her feelings are related to her knowledge base.

It is important that the woman makes an informed choice and that each case gets assessed individually. Advice against breastfeeding could be justified if:

1. there was a known risk of transmission (transmission is likely in rare cases); and
2. The risk of HIV transmission is greater than the risk of causing harm by using substitutes.

In the European Collaborative Study (1991), of the 154 bottle-fed babies with maternal antibodies to HIV, 36 turned out to be actually infected themselves, while of the 15 breast-fed babies four remained antibody positive.

This is no concrete evidence of an increased risk, though numbers are still small. The transmission of HIV via breastmilk is considered to be rare, although it is possible to detect HIV antibodies in breastmilk of infected women.

Public policies cannot be based

on these rarities but only on a well calculated risk assessment.

We cannot justify real or highly probable harm to HIV infected babies by withholding the advantages of breastfeeding on the grounds that this might perhaps prevent infection of a single baby.

"Investigators in Italy have recently presented data which suggested that children with perinatally acquired HIV-1 infection who were breastfed progressed to AIDS more slowly and live longer than similarly infected children who were not breastfed".

And again, we cannot justify exposing an uninfected baby to the risk of HIV infection simply to protect the health of uninfected babies.

The main concern is the health of individual babies. Kennedy suggests that breastfeeding should be discouraged in a seropositive woman who is in an advanced stage of the disease or in the rare case of a woman seroconverting after birth. He goes on saying that if breastfeeding is discouraged only in such specific cases, the life-giving benefits of breastfeeding could be maintained for the remaining cases.

Ulricke Radtke  
Clinical Nurse Specialist.

References for this letter available from PLWA office, ph: 283 3220.

## LETTERS

## Uganda positive

The situation of AIDS in Uganda is actually worse. Burials are the order of the day. A person can at least attend two burials in a day. When you are burying this one here another one is in a critical condition or another one has just passed away, so we have no peace in Uganda as far as AIDS disease is concerned.

The government and private hospitals, villages, homes, many clients have already died or are at the death's door. Most of our families are afraid of AIDS, there is worry about the future of the young ones in Uganda.

When I was in Kampala, the capital city of Uganda, I joined the AIDS Support Organisation (TASO), a support group which has been successful in Uganda. Going to TASO, I met other Positives who were in the process of forming the Uganda Body positive Association (UBOPASSO). My involvement was welcome. Seeing that I was under-used by TASO, I left to my home district to start the Good Samaritan Project. This was a strategy to mobilise other PWA in the district to fight for our rights.

To start off, I was helped by a priest for accommodation and food with some little money, then another priest introduced me to another board run by the same priests. They supported us with \$US3,000. The money I have been using to pay hospital bills for those who can't afford even buying foods. Now we are

remaining with \$US352. So the next step we don't know where to go. I have written several letters requesting for funds but they reply saying we remind them next year. On this same money, it's where I get a little money to support me for my daily living. I no longer get funds from a priest.

Please help, if you have any ideas how to support us. Even the office we are in is being assisted by the Diocese. In fact we need our offices if we get funds.

Here, a condom is something very private in our culture. You know we live up country. People up country still believe that AIDS is a problem for those in big cities and towns. This fact is false, that's why AIDS is finishing us. We also lack proper knowledge of using condoms, eg. a younger man puts on a condom when he is going to meet a girlfriend two kilometres away. By the time he reaches the girl, the condom is already in pieces. This is because you don't want your friend to know, because she will mistake you to have AIDS.

There are some traditional healers who claim that they can heal AIDS. Many have finished people's money. There are some, I have heard they are trying but I haven't got a chance to meet one who has been there. One was using soil. So many people flock there but she was silenced by the government.

I think that is all for now and God bless.

Januarius Rodgers.

## Five more phrases you hate...

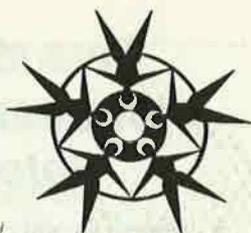
1. Where did you get AIDS from?
2. Women are not supposed to get it! Are they?
3. You really look 'positive' today.
4. You had better get rid of your pot plants you may get germs from the dirt.
5. You don't look as though you have AIDS.

- Kerry.

Talkabout readers are invited to write in and add to this list



Graphic: Allison Wiseman



## Tribute to Megan Mkwanzani

*Megan Mkwanzani died at home early on October 7th. Megan had recently completed phase 1 of the National Resource Package for HIV+ women that was funded by CAPE. The women in Victoria working on phase 2 of the package will be grateful for Megan's clear and comprehensive work. Phase 1 was not originally intended to stand alone, but Megan did such good work that it will be published as a separate paper.*

*The following is a tribute to Megan given by Amelia Tyler, on behalf of Positive Women, at Megan's funeral.*

In June '89 a few women met in Surry Hills. We identified as women and we were HIV+. That group became known as Positive Women - an emotional support group for women with HIV/AIDS. Megan Mkwanzani was a founding member.

In the past two and a bit years we, as a group, have experienced many losses - the loss of lovers, friends, sexuality, health. Also the loss of fear, shame and isolation. Now we are experiencing the loss of a group member - our friend Megan.

So what has Megan been to us?

Well, she was a stroppy bitch! She certainly wasn't afraid of having an unpopular opinion. She had a quiet voice that had a steely determination. She had an uncanny insight into reality, that wasn't to be sidetracked.

Each of us, as individuals and as a group, have been touched by her genuine care and concern. Even through shaky periods in the group's development Megan kept things together by being there - literally - with the key to the building!

As a feminist, Megan's belief in the strength of women working together was a gift to the group.

It was always very hard to know what to do for Megan; she had such clear boundaries - she could cope and we never stepped over the line! We might have wanted to but it was hard to know when and how to do it.

There was no 'let up' with Megan, even when the cost of that determination, in her work, was her health.

On that score, she has left us with a typically caring message: to let up on ourselves; to get the support; to take the rest and not to forget our own needs.

She knew how to give and always did but found it difficult to ask and receive. It was even cheeky' to ask for a meal to be made for her when she couldn't cook for herself!

We will remember you, Megan, in many different ways:

Those reassuring glances, on the couch, when talking about lesbian issues.

The proud mother; the private woman, the angry widow!

That particular humour....

Bagging Richard about numerous annoyances.

Needing everything to be in order - where was that pink slip?

Your encouragement and hopefulness.

Your quiet dignity that commanded such great respect.

The vulnerability that emerged when you leapt from the security of the group into the big bad world of ACON.

The look that you and I created there - your sound politics and my silk shirts!! Your 'pasta shell' jewellery designed by Vuli and Bheki and that tacky plastic rose that meant so much!

Megan we love you and we'll miss you.  
(And I send you a very big hug).

## *Tribute to Peter Steinheuer*

Dr Peter Steinheuer, who was appointed AFAO's first National Treatments Information Officer in June 1990, died of an AIDS related lymphoma on September 30th at the Sacred Heart Hospice.

Peter worked in all sorts of areas during his 35 years, combining work in radio, television and print journalism with his work as a doctor in general practice and with the Australian Army. He always seemed to be working on two or three things simultaneously, as though any one thing alone was not sufficient to feed his extraordinary intellect.

He loved the machinations of the media in all its forms and always had stacks of unread newspapers (and videoed TV programs) awaiting his attention - and look out if whilst cleaning up you should, accidentally or otherwise, throw away anything unread! He was fascinated with the way the media portrayed things and could manipulate public attitudes.

He loved journalism and was absolutely thrilled when he got the Treatments Information job because he saw it as a way to combine this interest in journalism with his large and always growing knowledge of HIV. He did this to great effect whilst working for AFAO, particularly with his pet project the HIV Herald. This project was peppered with Peter's unique and somewhat black sense of humour. He would search high and low for the best "cure of the month" for each issue, each 'cure' being an exposé of some bullshit AIDS cure.

Peter, who had known of his own HIV infection since 1986, was a tireless, intelligent and powerful advocate for PLWAs. He spoke at conferences, broadcasted and wrote about HIV with knowledge, sensitivity and humour. It was his reporting, as Dr Peter, with JJJ's monthly AIDS update, which led to JJJ winning the 1990 AFAO award for Best AIDS Reporting -

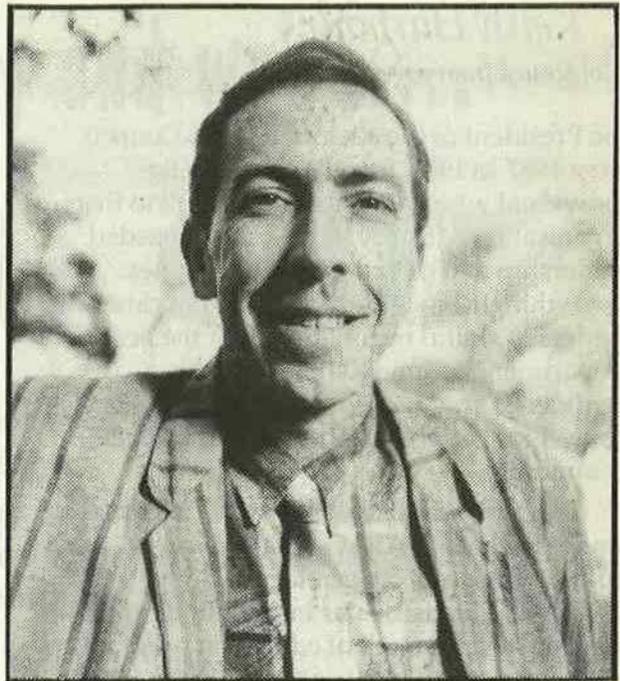


Photo: Jamie Dunbar

something he was very proud of.

Peter is survived by his lover of nearly ten years, Keith, whose love and support, together with that of his family and a legion of friends and colleagues, maintained Peter through his most fearful and difficult times.

Farewell and thank you Dr Peter, you remain an inspiration to us all.

Graeme Bray

## *Tribute to Keith Harbour*

The AIDS movement in Australia lost a prime mover with the death of Keith Harbour at Fairfield Hospital on 25 August.

Keith was involved in the early days of establishing the Victorian AIDS Council, became Convenor of the Support program in 1986 and

## Keith Harbour

(Continued from page 7)

the President of the Victorian AIDS Council from 1987 to 1989. there is probably no individual who has contributed more to that organisation's history, giving much needed leadership and direction at crucial times. Everything from midnight calls from care team leaders to skilful negotiation with the health Department became Keith's brief: his confidence and perseverance building a real respect for the organisation with the general community.

His activism extended beyond Victoria. He was a delegate to AFAO for a number of years, holding the posts of Secretary and Vice President. His particular interest in recent times was the development of education programs for HIV+ people but it is fair to say that in most aspects of AIDS politics Keith had some involvement: giving a considered opinion, lobbying and canvassing the issues. And he was one of the most active members of ACT UP, being arrested (the charge was later dismissed), after a demo in Melbourne.

In June this year in the Queen's Birthday Honours he became a member of the order of Australia for his services to people living with HIV/AIDS. The governor of Victoria, Dr Davis McCaughey, made a special visit to Keith's bedside at fairfield to invest the medal a month before he died.

We at PLWA (Vic) still mourn Keith's loss and will for a long time to come: he was our mentor, our strategist, our deep thinker who knew how to channel the anger and frustration we felt, and a loyal friend who was enormous fun to be around. Keith used to laugh it off when people called him "an elder statesperson of the AIDS movement", but he was (and is) one of our greats. Good on you Keith. You made people sit up and take notice. We love you for it.

David Menadue.

### PLWA STRATEGIC PLANNING DAY

Saturday 9 November

10 - 4pm

first floor, 74-78 Oxford St.

Lunchtime launch of the World AIDS Day issue of *Talkabout* (lunch provided)

This is your chance to have your say in PLWA

### Office shuffle

We are sad to announce the resignation of Gerald Lawrence as co-ordinator. Pinch-hitting for PLWA is Titi Chartay, who has temporarily stepped down from her co-convenor role. The co-ordinator's position will be readvertised in January when PLWA's funding for 1992 is confirmed.

### Working with your doctor

a workshop on your relationship with your doctor

See Page 37 for details

The Final deadline for January/February issue of *Talkabout* is

**December 6**

Send Contributions to: PO Box 1359 Darlinghurst 2010 or ph:

(02)283 3220

It's World AIDS Day and we're....

# COMING OUT!

*One of the big challenges faced by people living with HIV/AIDS is that of overcoming the stigma of AIDS. Jill Sergeant spoke to several people with HIV/AIDS about 'going public'. They also talked about what "Sharing the Challenge" means to them.*

## BLAIR

*Blair Silverlock is a residential support officer at Badlands and a volunteer facilitator with ACON's HIV Support Project. He is also now a familiar face as one of the men featured in a recent advertising campaign about HIV.*

**Why did you decide to come out as HIV+?**

I think it was from doing a lot of support groups - the topic that often comes up there is how for gay men having HIV is almost like a second coming out, a second wave of stigma and rejection and marginalisation. One of the main reasons, I think, was to shake off that stigma.

About two years ago I was a lot more 'in'. I hadn't spoken to my family about it and I was working at a teaching hospital where I didn't tell any of my work colleagues. But I was becoming more isolated, more distant from my family, be-

cause I suppose to me it seemed all very false. I wasn't acknowledging a really important aspect of my life.

I had my diagnosis in 1986 and I came out to my family early '89.

**Has it been a good thing to do?**

Yes. Personally it's been a really good thing for me, because now I feel that I've come out and I don't have anything to be ashamed of and I don't have anything that I need to hide.

Coming out at work's been a really good experience. Family has been interesting. My family's reaction has been supportive and positive, but when I did the Burroughs Wellcome advertisement it was like, oh gosh, these things are all very well as long as you keep things within the family. That's the second level of stigma, I suppose, that my parents and family are feeling that even though they can be supportive of me, they don't want to seek support elsewhere.

Living in Sydney, and the sort of community around here - it's becoming more conducive to

coming out. I think that's something that's happened in the last few years. There's a few more people who've stood up as well, and said they've got HIV.

### Why did you do the Burroughs Wellcome advertisements?

I think it was a lot of the issues around the stigma. I saw the ad as being a chance to get quite a wide coverage, and that it was going to get a bit more into the general community too, in terms of putting HIV in that context of just being a virus, and putting a face to it.

### Have people reacted to seeing your face in print?

Yes, a lot of people have actually said to me they think it's really good, and it was a really brave thing that I've done. Some people have said they're really proud of me for doing it and things like that. That's been quite nice, I've had a lot of encouragement.

### Do you think more people should be coming out HIV+?

I do. I think for people's own sanity or security they should. Of course I can't speak for everyone's situation, but I know, especially when I told my family, I thought: "they're going to reject me". I had all those fears, and I was pleasantly surprised. I'd like to see people testing the limits, because it is in a sense shaking off internalised oppression too. If you're not being out and sharing that with *important* people in your life, then you're denying yourself. And as an individual coming out you're giving a political message as well.

### Why are you working in the HIV/AIDS field?

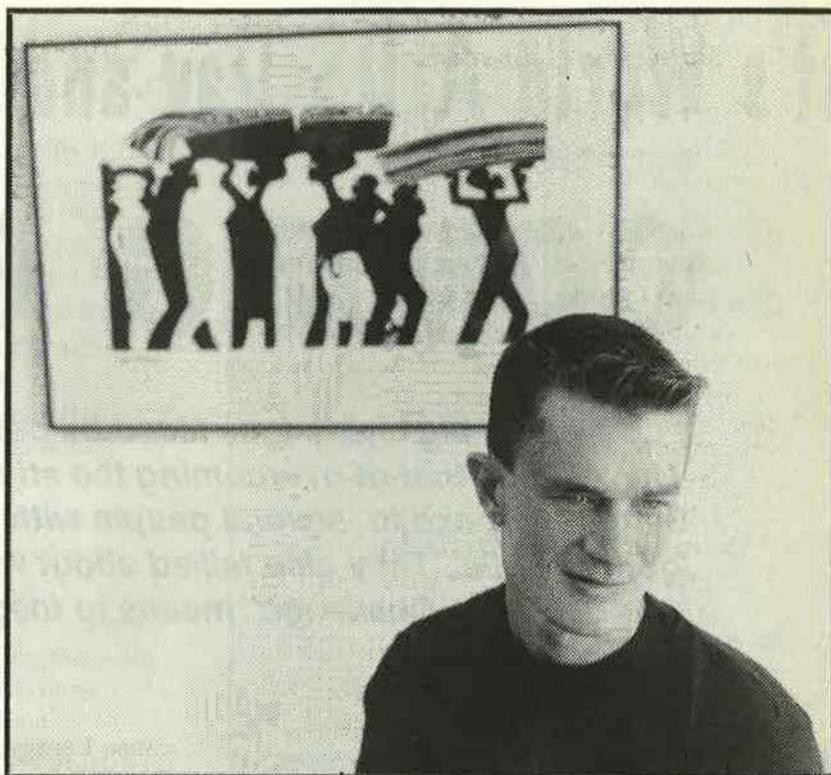


Photo: Jamie Dunbar

I suppose because it involves so much of my life. I came from a health/welfare background, so it was a natural progression for me, it wasn't a major leap sideways. I thought I had something to contribute in terms of my knowledge of HIV. Having had the virus for so many years I've become very well informed about it.

Working at Badlands there's a bit of a dilemma because I suppose I'm portraying myself as being really together and not really being exposed to that stigma. Also being HIV+ you're inclined to work as a role model to other HIV+ people working in the field and HIV+ clients. But I am living with a life threatening illness and I am confronting my own mortality and sometimes I think I need to remind my work colleagues and clients of that. At the same time I have to acknowledge that it's easy for me to put up that facade, because I have a supportive family and so on. I have experienced the stigma and I can appreciate that some people really have a battle getting over that.

## How do you interpret the World AIDS Day theme: Sharing the Challenge?

Sharing the challenge is standing up and saying, we're here, we're part of this society. This is a major epidemic.

Also, as an individual, you need to be aware of your own unwillingness to share what's going on with you - and I think that is the first step. I think it's a brave thing to do and it's not an easy thing to do and I don't expect everyone with HIV has got the resources to undertake that.

Thinking on a global level I suppose part of sharing the challenge is looking at our neighbours - Thailand, the Philippines and Africa - in terms of things like treatments and education and support issues for HIV+ people. Maybe we've got a bit of expertise in the area of education that we should be sharing.

Also just being aware that it's an economic burden on the whole of the community. In the recent budget there was such a kaffuffle about the \$3.50 for a GP visit, but there was really nothing in the health budget about AIDS. But it's obvious to people like me with HIV that there's going to be a need for more money from somewhere, and I haven't heard any politicians talk about how they're going to come up with that. It's basic economics, the community's got to share some of the responsibility.

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***Sharing the challenge is standing up and saying, we're here, we're part of this society.***

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I really do think the whole idea behind sharing the challenge is breaking down any stigma or barriers about the virus and simply acknowledging that it's a disease and people don't deserve to die whether they're from a poor country in Africa, or whether they're gay, or IV drug users. Those sort of values or judgements against people just need to be forgotten.

## SKYE

***Skye is an eight year old girl with AIDS She was one of the children who went public about their HIV infection at World AIDS Day 1990.***

### How did you tell people that you have HIV?

Some of the kids in my school know, and I have been on the radio and on tellie and in the newspapers.

### Why did you talk to people on the radio?

So they can tell everyone about HIV.

### Did you like talking to them?

Yes.

### How did you feel when you saw your picture in New Idea?

I felt pretty good, because they told everyone about AIDS, and it really helps for people to know. Then they know that you can't catch it by touching and stuff like that.

### What about the kids and teachers at your school?

All the teachers know, and my class knows, and sort of all the school knows. My Mum and Trish and Pam\* told them at a meeting.

### What were they like after they were told?

They reacted a bit. A boy who lives near here, I think it was one day after that, he come over and I said "do you want to play with me?" He said, "No I can't, because you've got HIV", even though his mother and father went to the meeting. They didn't believe that you can't get it from touching. I was

pretty down, I went and told Mummy. She said just to ignore it.

**Is he still like that?**

No. His parents have changed their mind too.

**Why do you think they changed their minds?**

I think because they saw friends coming here to play.

**What about your friends, do they talk to you about it?**

Oh yeah, they're all right. I don't really tell them a lot - unless they can keep a secret. I can hardly even keep it a secret myself. It's hard for me not to tell people.

**Do you feel better now that people know?**

Yeah. And when people torment me and they try and ask me what's wrong, like if I have my tube in, I just say the truth.

**Do you think it's important to tell people, to go on radio and talk to magazines and newspapers?**

Yes. Did you know, on some show a couple of months ago they were showing people having AIDS and dying and other stuff, to make people learn about it more.

**What do you think about World AIDS Day?**

I think that it's very good because you raise money for the AIDS children. Last time, I was the only one who turned up, and I was the one who had all the fun. It was three days, every day was like an adventure, and on the third day I went to Home & Away.

*\* Trish Langdon, Pam Palasanthiran and Marilyn Cruickshank from the Paediatric AIDS Unit, Prince of Wales Children's Hospital,*



Photo: Jamie Dunbar

## SHARON

**Skyl's Mum.**

**Why did you decide to go public about Skyl having AIDS?**

We decided to go public as far as the school goes because I felt it was the right thing to do by the people concerned. We were only going to tell the

staff initially, and then when we moved to Brisbane two years ago we decided that we would tell the whole school body and parents. It's always been a situation where you're damned if you do, and damned if you don't. If people keep being quiet about being infected then the general public are not going to realise that there are a lot of people who are infected, and that whether they're children or mothers or gay men, they're all just human beings and like anyone else with any other disease.

We also told the parents to help with the situation of misinformation. To say: we've lived with Skye for X amount of years without knowing and we're not infected and it's really hard to become infected.

#### What sort of reactions did you get?

We didn't have any negative reactions at all in Brisbane. But when we told the school here there were a couple of parents who ranted and raved a bit. They were informed at an information night, so we had professionals telling people that there was no problem, but these people just had it in their mind that they were at risk and their children were at risk and nothing anyone could say or do could change their minds. One set of parents actually pulled their kids out of the school. Out of the school population it was just three families that reacted in a bad way.

#### What about CounterAid and the media?

That's all been really positive stuff. Apparently they had a lot of feedback and it helped a lot with fundraising and public awareness.

The most positive thing for us about going public was that we didn't have the stress of trying to keep a secret. It's a really destructive thing I think, trying to lie to people and conceal your life. I would not go out or talk to people very much because if they would ask me what was wrong I would feel really bad about lying to them, so I just avoided people. Now we don't have that drama. Gary was the same, he was really stressed out, he used to get migraines. and since he's been able to

be open about it our quality of life's a lot better. It's been good for the kids too. Skye's happy because she doesn't have to try and conceal things.

#### What do think about the theme of World AIDS Day: Sharing the Challenge?

I think if people would pull together instead of pulling apart things would be a lot better. There's always been all these splinter groups. Everyone's obviously affected by different things, but if everyone could get together on most issues it would achieve a lot more I think.

#### The media gives the impression that there's a lot of conflict between all those different groups. Do you think that's really the case, or is there more sympathy?

There's a fair bit of sympathy I think, but the fight for the AIDS dollar is definitely there. It's a real pity but that's because of funding and I think the government doesn't help much. Everyone's fighting to get their portion of money. Apart from that, I think most people really feel for other people's situations.

## ANDREW

**Andrew Knox is twenty. He is a haemophiliac with HIV.**

#### How long have you known you're HIV+?

January '84. We were all taken into an office at Sydney University. The doctor just quietly lent over and said, "You're HIV+, by the way". And I said, oh, what does that mean? And they told us and that was it. I didn't really know much about it in those days.

#### Did you tell people straight away?

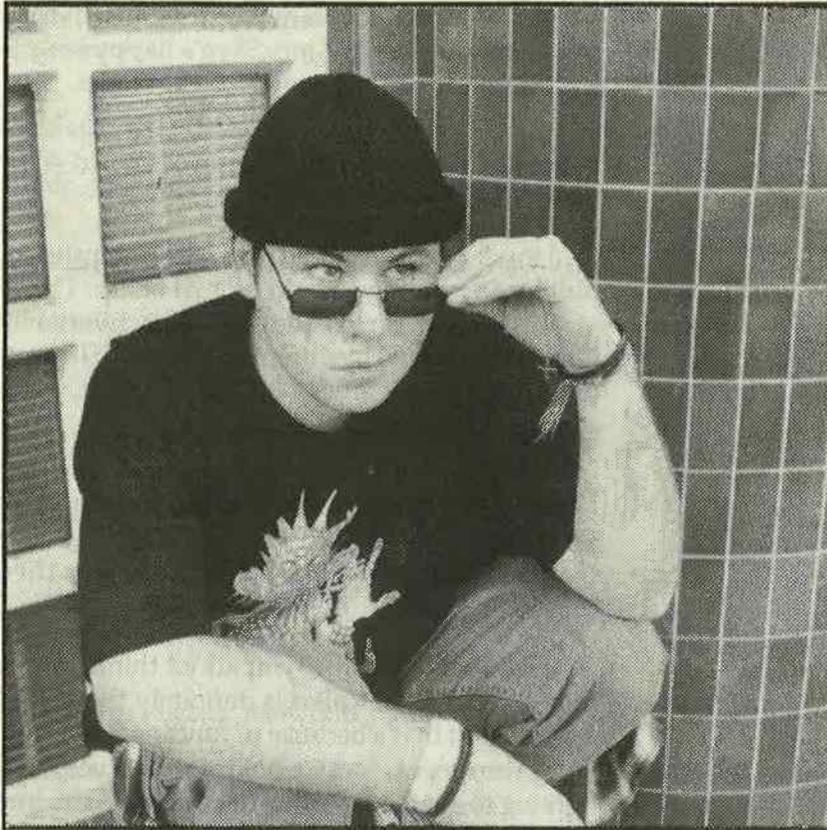


Photo: Jamie Dunbar

I told a few close friends and that was it. Most of them were fairly positive, most of them stuck by me, only two or three kind of drifted away. It was slow gradual kind of stuff.

**What about now? Are people happy to talk about it with you?**

Most people aren't. My father's one, he's just not happy about talking about it at all. I spoke to him yesterday and he hung up on me after I told him I'd stopped taking the pills. That's just him, I've accepted him like that.

**What sort of things do people say to you?**

Most will give you sympathy. I had a few male friends, not close friends, who look at you like, "oh, you must be gay or you must be a bisexual" or something like that and you've just got to tell them

how it is. Usually they come around, but sometimes they just fade away and close the door on you.

**Has anyone ever told you that you couldn't tell people?**

A social worker did, but I didn't really take much notice of that. I've always told people straight out.

I know a few people who've got the bug who wouldn't tell anybody about it - probably because of their families and stuff like that.

**Has it been easy for you?**

It's always been easy for me. I suppose because I've always been single - or single on, single off.

**Was it ever scary for you? Did girls reject you when you told them?**

No-one ever really rejected me. They'd say things like, "you don't mind if we don't have sex" and stuff like that, and I'd say, "no I don't mind". Or they'd say, "you wouldn't give it to me, would you?" and I'd say, "well no, fingers crossed, but I might". They'd say, "oh, what the heck" and I haven't infected anyone - fingers crossed.

**Do you think the fact that you're a lot younger than a lot of other people with HIV makes any difference?**

I think it does. I suppose people who are more established in their lifestyle are a bit more afraid of it. When I first got it I was young and active. As you get older, you might not have so much to fall back on. I'm not as fixed in my habits - like rolling on a condom is no problem to me.

**How have you felt when you've seen other people with HIV on TV and in the papers?**

I'm not sure if I'd go so far as to go on TV and say, hey world, I'm HIV+. I don't know what their reasons are. Why would they go out and say it? If it makes them happy it makes me happy, but I don't understand why they want to tell the whole world about it. Because that would bring a whole lot of stigma upon them - people closing doors, they might lose their job...

**What do you think about the World AIDS Day theme: Sharing the Challenge?**

Sounds good. We - the HIV people - didn't bring this upon ourselves but we've got to get together and help each other out.

**And do you think that happens now?**

No, it doesn't.

**How do you feel about the other groups in the community who have HIV?**

People that got it through sexual practices, I don't have as much compassion for. I have compassion for them but not as much as for someone who got it through a transfusion to save his or her life or pain. I'm for all of us getting compensation, but I'm not sure whether we all should get it or whether people who got HIV through blood products should get all the money.

**Do you feel that you've got a stronger case for compensation than those who acquired it sexually?**

Yes I do. I think we should get it and get it soon. Compensation would make a lot of difference to us.

**A lot of other people with HIV would strongly disagree with you. Is it easy to "share the challenge" with other people who are HIV +**

**when you have that strong a conflict about how you got the virus?**

It is I suppose, yeah. It's rather hard to put it into the same basket.

**As people who all have HIV in common, what is it that you should be fighting for?**

Care and support, for us, and for family and friends.

If the government wants to give us all money, they should make it a huge amount.

**What's next on your list, after compensation?**

Remaining well. I'm basically well now.

My mother hasn't got the virus you know, she's fine and fit, but she's always so depressed and moping around. And I've got the bug and I'm not taking any pills, and I'm fine! I'm basically groovy....

## GABBY

***Gabby McCarthy is Chairperson of the Maitraya Day centre. She is also involved with the Positive Women's group.***

**How long have you been open about being HIV+?**

It's been a gradual process since I was diagnosed, starting with significant people and just taking one step at a time getting more and more open.

**When you were first diagnosed, did you feel like you could tell people?**

I did, but it was quite scary. A lot of the gay



Photo: Jamie Dunbar

guys I know talk about feeling like they were back in the closet. Well I'd never been in a closet, and it was one of the most horrifying aspects. You have to re-evaluate your relationships with your friends and family and you think, can I tell them this? Or are they going to run screaming?

My mother was great, she was the first one I told, then friends.

After I told my close friends I went through a process of throwing it at social friends just to see how they'd react, to test them to see whether they were 'true friends' or not, and I've never really had anyone run screaming, which has probably helped the process along.

#### **How do you feel about it now?**

It's really easy. I don't have to watch what I'm saying about where I've been or what I'm doing. I don't have to think about who knows and who

doesn't and what I can and can't say in front of people.

#### **What have people's reactions been like?**

Quite a lot of surprise, but generally supportive.

#### **A lot of women are very closeted about being HIV+. Do you think they should come out?**

Of all the women that I know, I know and understand their individual reasons for not being public or for not telling many people in their lives at all, and they're quite valid reasons. But as an overall concept it frustrates me because I think there's a lack of service provision and a whole lot more discrimination happening to positive women. If there were a few

more women prepared to be vocal and stand up and be counted, it would change things for women. The more of us who do it the easier it is because then we just start to blend in with the crowd. But it has to be a personal choice.

#### **Why do you think it's been easier for you?**

I was single at the time, I don't have children, I have a really supportive family and supportive friends. I think the most valid reason for a lot of women is that if they go public with their status it's going to affect their children. How can you possibly send a ten year old girl to school, if you've been on the news the night before, knowing that she's going to cop flak from other kids at school?

#### **You're involved with Maitraya now - what's the connection between being HIV+ and working in that field?**

I guess it's because - there's lots of things that might help, but there's nothing I can concretely do to heal myself. So I think there was a level of frustration from that, and a desire to want to do something. The other feeling that I have is that it's now that I've got the time the energy and the health to do these things. I'd like these services to be here when I really need them.

Going to the Day Centre was probably the biggest risk I'd taken at that point. It was funny because I was really nervous, I thought, I'm going to walk in there and everyone in the place is going to know I've got IT. And everyone thought I was a social worker or a counsellor who'd popped in - they were the only women at that point who were coming in. I spent the day *telling* people I was HIV+.

In the past year more women have been coming in. One Friday I sat down to lunch with five other women - none of them were doctors, social workers or counsellors. It's really nice to see those barriers being broken down.

**What do you think about World AIDS Day and the theme: Sharing the Challenge?**

It's a big government wank. Last year was 'Women and AIDS'. Big deal, nothing's changed. There's still the stigma, the lack of treatments, all this stuff that I have to deal with every day of the year that makes me angry every day of the year, and I just get angrier on World AIDS Day.

**If this theme was really taken seriously, what do you think it means?**

That moral judgements on people with HIV should be completely canned. The media and the Fred Niles of this world shouldn't be allowed to get away with it. We should see the government ac-

tively breaking down those barriers and doing something real.

Something that I've been aware of is that my story's been quite effective: I was in a two year relationship and that's how I got the virus. When I go out and do workshops and talk to people about being HIV+ I haven't had a single bad reaction and a lot of the comments have been that people are relieved to meet someone with the virus, that they don't have the same fears about HIV or AIDS after meeting me.

A lot more of that should be done. I only do it if I'm being paid, on the principal that I'm not going to spend my entire life running around volunteering to do something that the government should be paying for.

**Do you feel like there's a lot of division among all the different people with HIV?**

There's this expectation that because we all have this virus in our system that we'll be this nice homogeneous group that will all get on together and have the same needs. The reality is that we're all individuals and our needs are different. There are all sorts of issues, but I think the bottom line is that we've all got to go in and fight for each other.

I feel really strongly that there should be a baseline service that's provided to everybody, but also on top of that provides specialist things - like Albion Street provides pap smears now.

*Thanks to Loretta Rosicky at the Haemophilia Unit, Royal Prince Alfred Hospital and Trish Langdon at the Paediatric AIDS Unit, Prince of Wales Hospital, for their assistance.*

# Talking AIDS

**Britain's primo AIDS cultural activist, Simon Watney, discusses with Robert Ariss the language they use to talk about us. And how to fight back.**

**Simon:** One of the things that strikes me immediately in Australia is that the PLWA groups are constituted quite differently to those in Europe and America. In those countries there seems, historically, to be a much more crude distinction between groups that work on behalf of people with HIV on the one hand, and people with AIDS on the other hand.

**Robert: Is that a good or bad distinction do you think?**

I think it's an inevitable distinction. But I think it's a distinction which may damage or lead to limited perceptions of need. In Britain there was a network of support groups for people with HIV from '85 onwards - Body Positive, which has done very good work around the country. But the PWA groups are much smaller and they've been much less efficient at getting funding by and large. I'm not attacking them, obviously. Just the situation's different. Because Body Positive groups offer one of the few reliable support networks for people with HIV, the larger issue of treatment drugs for people with AIDS has tended not to be in the foreground.

**In terms of the representations of AIDS, how do you see the situation that people with HIV have been put in. And how may that situation change given the development of consumer groups?**

Well, the sort of work I've done now for

quite a few years is to try to unpack what seems to always be the intense homophobia, sexism and racism - most images of the epidemic actually - in the press and on television. Practically, we've got to try and improve the reality of the situation in which people with HIV find themselves.

Now, to some extent that reality's going to be changed by housing policies, by discrimination policies and many other things. But those aren't going to affect at all the way bigoted or ignorant journalists write, or television producers who commission programs. And it's those agendas which need to be targeted and thought about and taken apart. By and large, given the obvious priorities, often those cultural issues come in a very poor third to prevention and health care. Whereas I see the cultural issues as inseparable in both safe sex and in actual care.

On the one hand the perception of the "meaning" of HIV and AIDS determines all sorts of questions of funding for safer sex and safer drug works, as well as for bio-research. At the same time, that perception also determines how next door neighbours and families respond to friends, acquaintances, loved ones, parents, children, uncles and aunts with HIV and AIDS.

For many years there's been astoundingly little criticism from the liberal middle ground of our societies, and none from the left, of what has been one of the most ferocious campaigns and cruel misrepresentations in the history of journalism - at least on a par with the worst excesses of the German press of the 1930s. And yet it sounds preposterous to say that! It only takes 10 minutes reading of the Australian papers this week to find out

**"If people with AIDS around the world have agreed that they do not want to be seen as "victims", then that has to be respected."**

*Simon Watney  
(at right)*

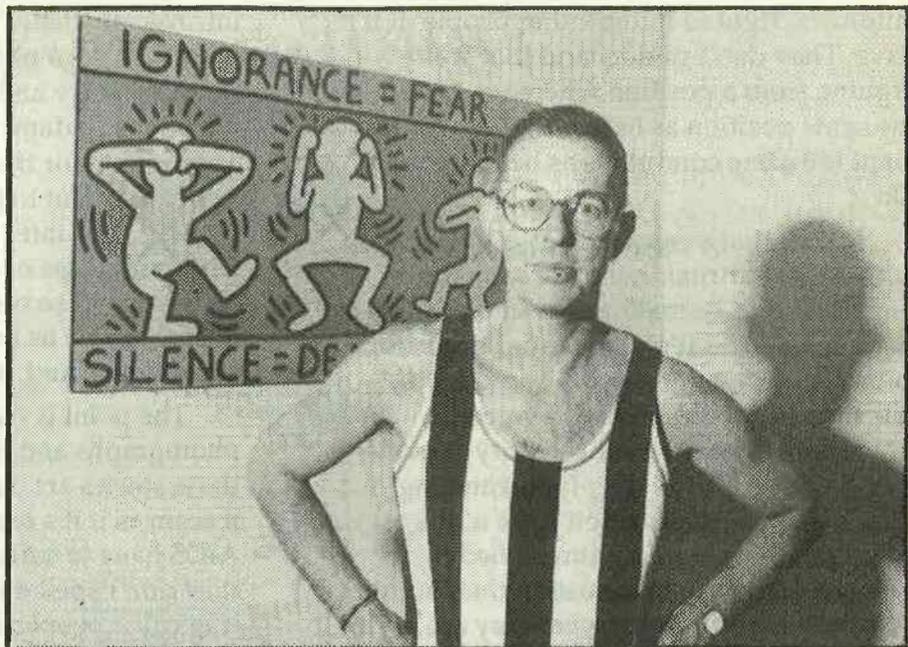


Photo: Jamie Dunbar

how grossly mis-managed the coverage is in relation to the question of gay culture or Mardi Gras. In the Sydney Morning Herald, wherever you look, it's patronising, insulting, glib, homophobic journalism. It's maybe not quite as confident and aggressive as British quality journalism, but the attitude's the same, it seems to me. More and more it tends to be dressed up as being multi-cultural and almost progressive. But the only reason I can write like that about Mardi Gras is so people can laugh at it! Those things have to be aggressively attacked. It's absolutely fundamental to gay men, whether they are HIV or not.

**It's been difficult for PLWA to address the media because they're always demanding...**

"give us a person with AIDS!", with their head on a plate basically.

**Exactly, and in some respects that's what we want. But we want to direct it. And we found more often than not that we are manipulated to**

**their ends. So what do you think we can do to grapple with this, to wrest some control?**

There are immediate practical things. One is the question of having media spokespeople who regularly and dependently can be at press conference where the journalists are. I know press releases sometimes seem to disappear into fax machines and go nowhere. And sometimes those faxes seem to be endlessly labour intensive and pointless. The real thing is to have a face that journalists will recognise and know. Someone who they recognise genuinely knows much better than the political and bio-medical experts around them. That, I think, is one factor. The other thing, in terms of the ways we can be misrepresented, is to reduce one's points down to very short soundbites. Try and speak in very short sentences. And they can't render that into some contrary meaning to what you intended.

For example, in Britain, when one talks about "gay rights", a lot of people think that by "gay rights" we mean gay men having an

automatic right to things other people don't have. They don't understand that we're arguing from a position where we *don't* have the same position as heterosexuals. We just want the same conditions as heterosexuals have.

I think that's especially affecting people with AIDS in Britain who are sometimes understood to be making *special* pleadings or arguments. And it's very hard, I think, for journalists to understand the amount of discrimination experienced by people with HIV and AIDS. The very category "people living with AIDS" is deeply threatening. That's why journalists don't use it. It's as simple as that. They are threatened by it. They have to be able to sustain their authority as journalists to control what they are saying about the world. And that means calling people "victims". People with AIDS *are* victims of discrimination, people with AIDS *are* victims of all sorts of unpleasant forces. But that's not to say that people with AIDS should be described by journalists as "victims" as their primary identity. And if people with AIDS around the world have agreed that they do not want to be seen primarily in their identity as "victims", then that has to be respected. And any journalist who doesn't do that is deliberately flying in the face of what people with AIDS have insisted on

**And as for us, as generators of information and images and ideas also, what kind of images do you think we could successfully use to counter that?**

I don't think I can say. I can't tell you what you can best produce in Australia. All I can say is that to do justice to the achievements of people with HIV one needs to do a pretty good canvass, and not to be worried about ever pushing one particular style or one particular technology as being

intrinsically better than the others. You don't try and make a phone call with a hair dryer nor do you try and dry your hair with a telephone. It depends on what's most appropriate for the task in hand. I think it's very important to try and produce, just as you say, a counter practice to the more familiar images of endless death and loss and isolation and so on. But not to challenge those in such a way as to pretend that those aren't actually real and, sadly, common experiences.

The point is that the way in which those photographs and narratives are constructed, those stories are constructed, endlessly make it seem as if it's inevitable that people with AIDS have to suffer in particular ways. What they don't spell out is that the suffering that, tragically, people *do* have to endure is actually inflicted upon them by the decisions of anonymous bureaucrats and civil servants and governments and directors of research programs all around the world. It's not an intrinsic aspect of HIV. It's not part of the natural history of HIV. It *is*, however, part of the *political* history of HIV. We haven't set that up or chosen that political history. The terrain has been decided by obstinate governments and homophobic scientists and teachers and journalists. And the counter-practice is simply this - quietly and rapidly building wit around this furphy, to expose their double standards and their hypocrisy and their cynicism.

And I think the most important thing, as we know from experience, is that people with AIDS know a great deal. And that costs people a great deal too. Maybe one's tended to trust human nature too much in the past. Which is why we're so endlessly disappointed with the responses to this epidemic! But I think any series of representations which try and be accessible and truthful and not try and over simplify with any kind of populism is very important.

# Anguish in

## BOHEMIA



### Part 5

#### By Dara Toad

*The story so far.... Nigel has realised that the girl upstairs (Nancy)- a past lover- has HIV. Nancy went with him to get the results of his HIV test - positive. Brad, still recovering from a stab wound, received a diagnosis of KS and failed to trick with the doctor. Robbie has met a mysterious man in leather at an ACT UP demo.*

#### The KS Party

After Brad's diagnosis with Kaposi's Sarcoma he went into a deep dark depression for two days. On the third day, he arose again from the dead.

'This queen', Brad thought, 'is going to do this with style'. He was going to let everyone know he was going to keep living. 'A party' he thought. 'Yes, a KS party - totally tasteless - but how else am I going to face this thing'.

The invitations were sent out to everyone he knew, the decorations purple and spotty. His mother politely refused because she thought KS stood for Karma Sutra and that she was being invited to an Indian love orgy.

The scene was set, the guests had arrived, the party was in full swing.

#### Nancy Spits The Dummy

"Brad, who's that leather man with Robbie!" Nancy shrieked. "Are you responsible for this?"

"Nancy, stop being hysterical. Robbie met him at the ACT UP demo. I'm sure it's just friendship."

"Brad, I'm not an ignorant heterosexual you know. Find out what's going on and make sure Robbie's OK - anyway, does he know about leather and all that stuff?"

"Oh Nance, your ignorance is showing. OK, I'll check out the leather queen for you - why don't you worry about yourself - there's a gorgeous man over there ogling you and I think he's straight."

#### Brad Checks Out The Leather Man

Robbie had gone to the loo - now was Brad's chance. Brad made his way across to where the leather man was sitting.

"Hi, there big boy!"

The look returned said it all - "Who IS this queen?"

"I'm Brad, this is my apartment - you've met Robbie have you?"

"Yes, how do you know him?"

"I'm a good friend of his sister Nance who's busily freaking out at the sight of her innocent young country brother in the clutches of a leather man!"

The leather man laughed. "Oh, well, we'll have to encourage her paranoia then."

Brad reported to Nance a couple of minutes later that the man's intentions were purely platonic.

### **Nancy gives Nigel the brush off**

"Can't we just go somewhere quiet and talk?" Nigel wasn't enjoying the party.

"Oh, Nigel come on. These people are really friendly. Just try chatting a bit." Nancy was trying to enjoy the party.

"That guy over there keeps ogling you." I'd like to break his face.

"No, he's not." What guy? Where is he?

"Yeah, look at him flexing his biceps and giving you the old 'I'm a blond, blue-eye hunk' look." The slimey bastard.

"Come off it, Nigel. At Brad's party? You don't mean that guy over thereeeeeerrrrrr? Oh, golly!" The ice in Nancy's drink started making chinking sounds.

"Jesus, you women are all the same! Little Miss Perfect nearly drops her drink at the mere glimpse of a body fascist. He's probably a real moron."

"Nigel, the way you're behaving doesn't indicate to me that you're far off brain dead yourself. Lighten up will you."

Nigel scowled at Nancy. His bottom lip was well and truly out.

"I can't stand here and talk to you anymore, I'm going to circulate a bit."

"Nance, please don't leave me."

"Nigel, get over it."

"Bitch!"

"Moron!"

### **Brad gives Robbie The Third Degree**

"Robbie, who's the new man in your life?"

"What are you talking about?"

"The tall dark handsome butch one you arrived with and have been with for the last two hours"

"Oh, I just met him at the ACT UP demo"

"Are you sure you know what you're up to?"

"You old queens, think you've been everywhere, done everything - let me tell you, you're not my mother and I am quite capable of looking after myself so you just keep your eyes away from my friend"

Robbie stormed off. Brad reported to Nance a couple of minutes later that the leather queen used to be Robbie's teacher in the country and that there was nothing happening.

### **Sound advice for Nancy**

"Enjoying the party, hon?"

"Oh, Melanie, talk to me. Give me all the dirt you've got. Make me laugh."

"Dear, oh dear, Nance, you're not a happy little vegemite. What's up? This is a party, remember."

"Nigel is giving me the shits. I can't go anywhere or do anything without him needing to be there too. I'm his friend not his nurse maid."

"Darling, Nigel's in a pretty bad space at the moment but he has to work through some of his stuff by himself. He can't expect you to fix it all



Graphic: Ian Barbour

for him. You've not exactly got a worry-free life yourself. You have needs too - and what you need right now is some full-on attention. I think my friend Jack would be interested.

"Jack. Who's Jack?"

"The tall blond hunk who's been keeping an eye on you ever since he arrived."

"You're kidding! He's a friend of yours?"

"Yep, and I brought him along to the party just for you!"

"Melanie you're fabulous! But how does a dedicated dyke like you know a heterosexual hunk like him - he is straight isn't he?"

"Don't ask me, darling, go and ask him!"

Nancy didn't need any more encouragement. Pulling out her best smile, she went over to Jack and introduced herself. His smile said it all. They were going to have a great party!

### Robbie & Nancy get their bit

"I've got to go now", said Wayne, as he finished his gin and tonic.

"Oh." Robbie summoned a look of disappointment. Wayne smiled and rubbed his shoulder. He glanced across the room to find Brad watching him - again. Bugger that queen, he thought.

To Robbie: "Listen, why don't you come back to my place?" Our young hero from the country was taken aback by the suggestion. "I ... er ... umm ..."

Wayne grabbed him by the hand. His assertiveness was overwhelming. "Come on. You'll enjoy it, I promise." before Robbie could say another word, he was being whisked out the door.

Brad, watching Wayne and Robbie depart, turned to look for Nancy to report this latest update. Too late, he saw her heading for the door after Robbie. But she wasn't chasing him. Oblivious to her brother's adventure, Nancy was escorting the blond hunk.

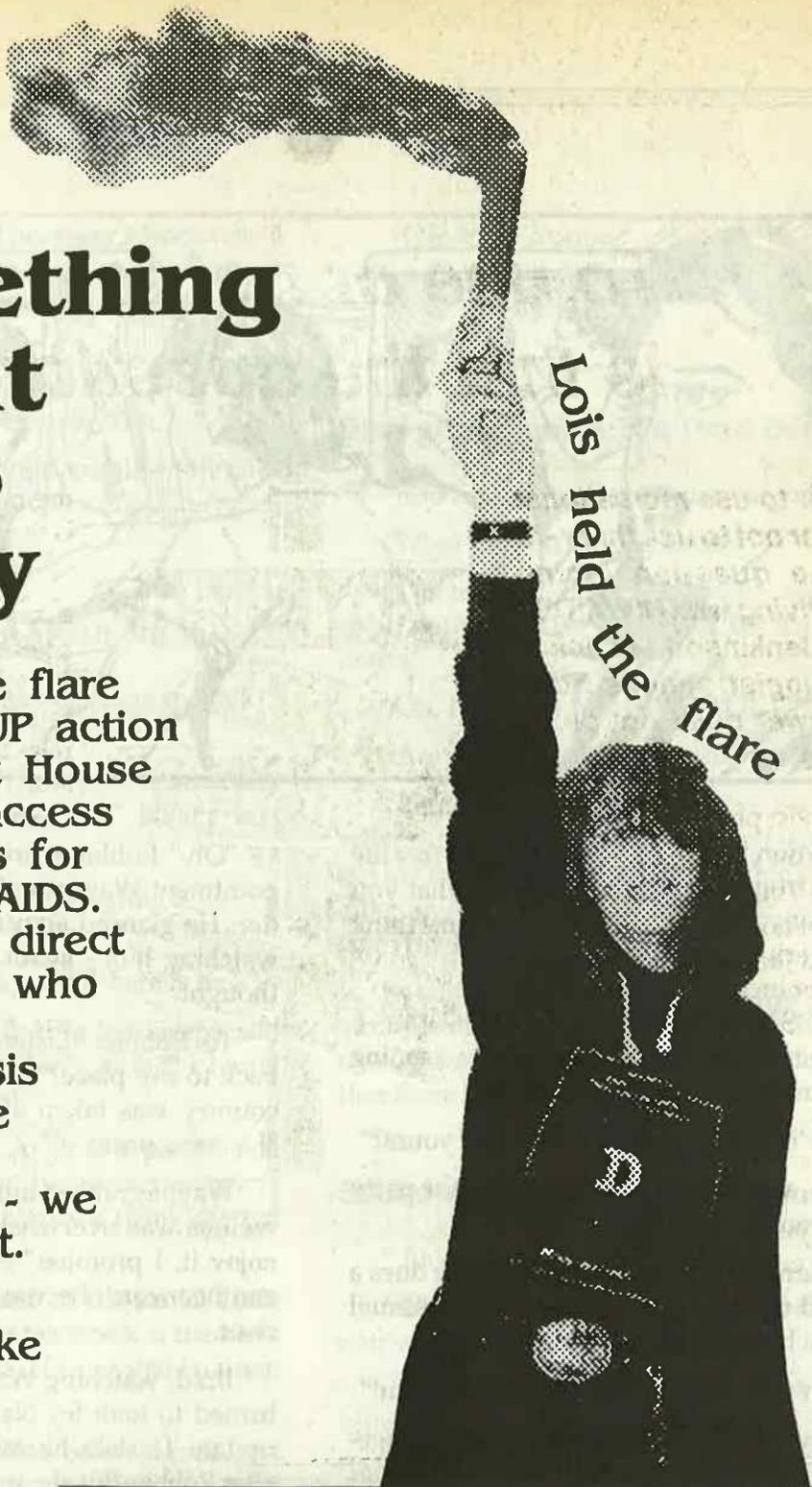
"Yes", she was saying, "I've got a lovely collection in my flat, it's just this way..."

*To be continued...*

# Lois did something about AIDS today

Lois held the flare at the ACT UP action at Parliament House to demand access to treatments for People with AIDS. ACT UP is a direct action group who believe that the AIDS crisis CAN end. We protest and demonstrate - we are not silent.

It doesn't take much to do something about AIDS today : ring us and plan to come along to the next ACT UP meeting.



Lois held the flare

**AIDS Coalition To Unleash Power**

Meets Tuesdays 7pm  
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Phone 281 0362  
for more information.

**ACT UP**  
SYDNEY

## To use or not to use Is that the question?

**Whether to use recreational drugs, or not to use them - is that the question facing people living with HIV/AIDS? Simon Jenkinson, a clinical psychologist, suggests that the answer need not be so hardline.**

For most people, a more realistic question is rather: "how am I to use drugs?" If 'drug' is defined as any *psychoactive*, that is, mind-altering, substance, then most of us, including people with HIV/AIDS, use at least one of: tobacco, caffeine, alcohol, marijuana, amyl nitrate (poppers), tranquillisers (such as valium), sedatives (such as mogadon), heroin, amphetamines (speed, crystal), cocaine, designer drugs (MDA, ecstasy). The judgement as to *how* to use a particular substance is essentially an individual, personal judgement - dependent on a person's specific situation, in a social context.

For example, how should I use **alcohol**, when I love the taste and the 'buzz' that it gives me - and I also have some hepatitis-related liver damage?

How should I use **tobacco**, when I find it relaxes me in social situations - and I've just had a bout of PCP?

How should I use **marijuana**, when I enjoy it without the depressing hangover alcohol gives



me, but I'm unemployed...pot is so expensive!?

The decision in each case is a balancing of the *benefits* against the *costs*. Benefits include physical sensations like taste, feeling 'high', muscular relaxation; psychological benefits, like heightened enjoyment and sense of humour; social benefits, like feeling part of a group who all enjoy the same drug. The costs are sometimes harder to see. They may be, literally, financial costs - just the sheer expense of some drugs. They may be physical costs, especially for those whose physical condition is already compromised. They may even be psychological - a too

heavy reliance on a particular drug to confer a sort of artificial self confidence. For each of us, the challenge is to balance the benefits against the costs, with perception, with self-awareness, with insight.

### A holistic solution

In seeking an answer to the question, "How am I to use a particular drug?", the person with HIV/AIDS may find a *holistic* solution to be most helpful. Answering the question holistically means taking into account the interaction between the drug and the whole person, not just the pharmacological effects of the drug.



Graphic: Allison Wiseman

disinhibitors. For people living with HIV/AIDS the whole issue of drugs and sexual disinhibition is a complex one. It raises the question of the person's responsibility to his/her own health status, which may be compromised by unsafe sex, as well as his/her responsibility to the sexual partner's health status.

The old line - "I was so pissed/stoned I didn't know what I was doing" sounds rather feeble, in current circumstances.

The whole person is multi-faceted...

### Physical

Some parts of the human body are evidently more vulnerable to damage by certain drugs, eg. the respiratory system by tobacco. So a tobacco smoker with HIV who is considering taking up a new fitness program with aerobic exercise might want to consider how his/her lungs will handle the extra strain. The decision may be to quit smoking, or to limit it.

### Social

Certain drugs, especially alcohol, are so much a part of our social interaction. If a gay man with AIDS, for example, feels really at home in the bar scene, but doesn't want the feeling of being 'out of control', he may decide to use alcohol, but use less than he did before he was diagnosed.

### Sexual

"Sherry, my dear? Why yes  
But two at the very most  
Because three puts me under the table  
And four puts me under my host."

Alcohol, as well as many 'party drugs', such as ecstasy, have the reputation of being sexual

### Emotional

The effects on one's emotional state is a key consideration. After all, isn't the fact that drugs are *mood altering* substances the main reason why we use them? There are times when we really want to change our emotional state. Speed (amphetamine) is a good example. Speed can be used to brighten, enliven, energise. Ironically, speed can, in certain circumstances, be an emotional 'downer'. If used excessively, or for a prolonged period, it can induce anxiety, paranoia, and a 'rebound' depression.

A person with HIV/AIDS, who may be feeling lethargic and run down, can choose to use speed in a way that acknowledges the potentially negative emotional kickback. This might mean choosing to use occasionally, rather than every week, for instance; it might mean choosing an alternative method of energising oneself - perhaps by doing some jogging or swimming.

We are physical, social, sexual, emotional beings. Respecting the *whole* person in making decisions about drug use makes sense for a person with HIV/AIDS - rather like respecting oneself as a person far more complex, more gifted, than merely 'someone with a virus'.

## HIV in the sun: PLWA goes to the North Coast of NSW

In June/July this year Nicholas van Schalkwyk, co-convenor of the PLWA committee, visited the far North Coast of NSW. The goal of this visit, which was funded by the NSW Department of Health, was to undertake research into the needs and experiences of PLWHIV/AIDS in rural NSW, and establish how best PLWA can help meet these needs. The following is an edited extract from Nicholaas' report to the PLWA committee.

The Centres visited were Lismore, Byron Bay, Murwillumbah and Grafton. In each of these centres a small group discussion and some telephone and face-to-face interviews were conducted with PLWAs. In total 21 PLWAs were interviewed and meetings with health care and other service providers were attended in Lismore and Mullumbimby.

The Sexual Health/AIDS Service and ACON estimate that there are currently 60 PLWA's in the Lismore area and a further 40 in the Byron Bay area. This does not include Murwillumbah, Grafton and other isolated areas. Without exceptions, the representative from PLWA (NSW) was very warmly received and time and time again PLWAs expressed their appreciation for this opportunity to discuss issues, problems and needs.

The problem most frequently mentioned by PLWAs was isolation. People often live in isolated locations - sometimes even without telephone contact. In most instances this is the preference of the individual who often has left the city to "get away from it all". This very much entails "getting away from AIDS" as well. On several occasions PLWAs expressed the opinion that many of their peers are in serious denial. These individuals

adopt a low stress, healthy lifestyle and believe these changes in itself will take care of their HIV infection.

In most instances this geographical and consequent psychological isolation is fine while the individual's health remains relatively unimpaired. With the first signs of progression (often a fairly serious opportunistic infection) the loneliness, lack of care facilities and other drawbacks of isolation soon become dramatically apparent.

Isolation is also experienced by PLWAs in less geographically isolated areas. This appears to be the result of having to be "closeted" about HIV status for fear of reactions in these small communities. For example, PLWAs in Byron Bay, (perceived to be a relatively "liberal" community), may not fear discrimination as such, but still prefer the privacy of not being open about their health status. Some interviewees felt that while perhaps empathetic, the local communities are not likely to reach out and actively support PLWAs. This perception is based on the pervasive local attitude of "live and let live", yet "without involving oneself with another person's problems".

### HEALTH SERVICES

The provision of satisfactory health services varies significantly across the geographical area covered during this visit. Lismore, with its newly re-organised Sexual Health/AIDS Service under the directorship of Dr. Kieran Mutimer (previously from Taylor Square Medical Clinic), appears to be well set up. While there has been no significant pressure on the health service to date, with only small numbers of people acutely sick, service providers expect the needs to increase significantly in the near future as current clients progress to more acute stages of illness, more HIV positive people move into the area (apparently

noticeably happening) and more people are diagnosed. It is anticipated that the large intravenous drug using community may contribute significantly to the newly diagnosed figure. However, with a regional AIDS co-ordinator in place, the State Health Department appears to be gearing up to manage the anticipated demand.

No other centre I visited has nearly adequate health services. Neither Murwillumbah nor Grafton currently have a medical practitioner authorised to prescribe AZT. In Grafton there is no doctor sympathetic to HIV/AIDS issues and local dentists will not service HIV patients.

Murwillumbah, Mullumbimby and Byron Bay each have at least one doctor available to PLWAs. When these doctors are not authorised to prescribe drugs clients must travel for up to two hours to obtain medication in Lismore.

Localised services clearly still require significant development. Suggestions to improve local services included negotiating with Nimbin Hospital to provide a "step-down" facility, approaching the Catholic church to provide palliative care for final stage PLWAs, and to approach some private nursing homes to provide facilities. More generally, though, it appears as if a significant effort still needs to be directed at changing local doctors, dentists and other medical staff's attitudes toward HIV and PLWAs.

A number of PLWAs indicated a preference for alternative therapies as part of, or as their only health management program. There is a clear need for more information in this regard, as well as for a comprehensive referral list of practitioners in the area.

## HIV SUPPORT

Currently there is one support group, the Positive Time Group, functioning on the far North Coast. This group had not met for some months at the time of this visit. Instead of organised support groups, there appear to be one or two individuals, often in the same household, who provide support in each area. This service is very much on an

ad hoc basis and often results in the individuals involved experiencing feelings of inadequacy due to lack of formal skills and proper facilities. Some of these support givers currently expressed being "burnt out".

There was a strong perception that ACON's Lismore branch does not adequately service PLWAs. The general perception is that ACON's priority has been "prevention" before the well being of the already infected. Serious doubts were also expressed about the counselling skills available at ACON and about confidentiality issues. Interviewees outside the Lismore area, for obvious reasons, also perceived the branch to be inappropriately located, resulting in expensive travelling when requiring service.

In Byron Bay a strong need was expressed for a house that could provide accommodation and support for PLWAs arriving in the area for the first time. This would allow new arrivals to familiarise themselves with the area, to make up their minds as to whether they want to stay and to link into a local social network.

In Lismore the need for accommodation was also raised in relation to the need for a "halfway house" to accommodate geographically isolated people who may require short term care.

PLWAs in Murwillumbah, in response to a recent care crisis with a PLWA who became acutely ill and died within a short period of time, have had a first meeting to establish a support/organising group (PLWA North Coast in embryo?). They are closely working with Steve Codey, AIDS Educator from the Department of Health.

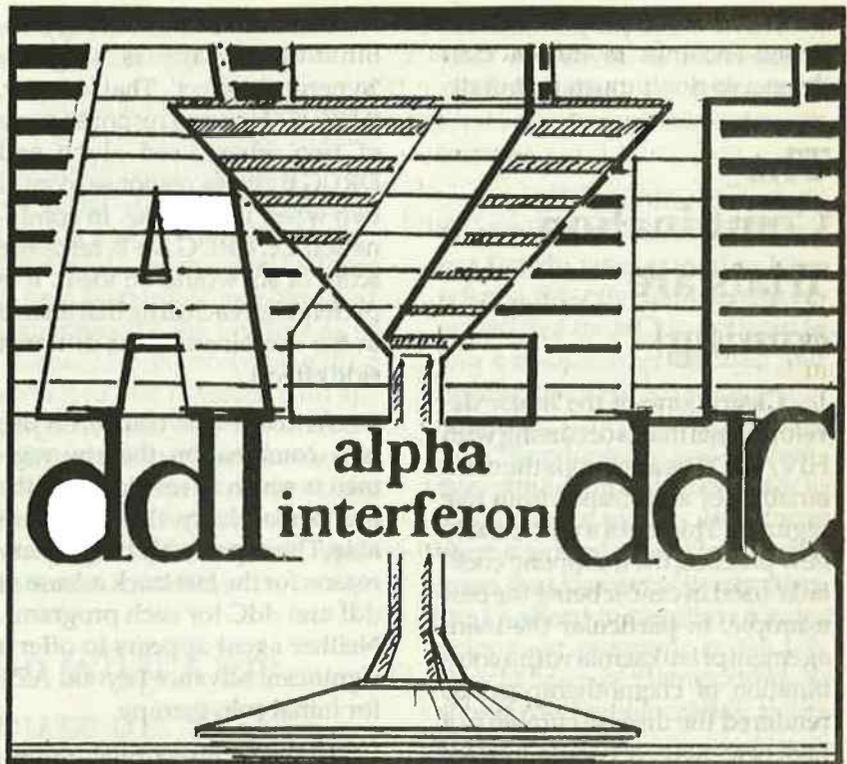
Finally, PLWAs I spoke to suggested the following issues which are priorities for them: financial support for travel expenses; a fund to reimburse carers for travel expenses; accommodation facilities in Byron Bay and Lismore (apparently a submission in this regard has already been prepared by ACON's Lismore branch); developing a comprehensive referral index of alternative/complimentary practitioners in the area; and training of volunteer PLWAs in co-counselling skills.

## The National Treatments Project...

The Treatments Project would like to introduce you to a new member of staff. The new 'kid' in town is Ian Mcknight... that's me! I come to the project after an 18 year career in the pharmaceutical industry in Australia...and was I glad to get OUT! Prior to that I did time at Sydney Uni. where, between parties, and being a tramp, I studied pharmacology.

I hope that I can bring some of that experience (not the tramp bit) to the Project, so that Ross Duffin and I can provide the community with one of the most comprehensive and up to date HIV/AIDS treatments advisory services in the world. So please feel free to contact us at any time with any questions that you may have and we will do our best to assist. There are also a number of planned developments for the project so stay tuned for the news!

We can't do it all from the Sydney office. The project is a national one and therefore it is going to be vital that we empower people to assist the Project in all states. In some states this is already under way with Treatments Officers in place; in others it is yet to be developed.



## ddC goes Californian ...UH HUH! SURE!

The previously discussed changes of supply of ddC have occurred and it is now available through the Staying Alive Buyers Club ...in Los Angeles. This will have a number of benefits to us in Australia, the most important being that it will be considerably cheaper than supplies from NYC. (New York) It's around the \$90 mark for 400 capsules, but talk with Lyle Chan at the ACON Buy-

er's Club for prices. The first shipment has now arrived, not without some minor teething problems, but they seem to be solved. A further benefit to the user is the simplification of the paperwork that is needed ...yes we can save a few more trees! Unfortunately, the downside to the change is that the Staying Alive organisation does not accept credit cards, (A Californian HERETIC!).

Lyle informs me that there are a number of new things going on in the club including a Newsletter, the creation of a support group for ddC users and fundraising

# TREATMENT NEWS

events to assist people with reduced incomes to obtain their drugs...so don't touch that dial!

## The Combination Trials are coming!

Clearly one of the major developments that is occurring with HIV/AIDS treatments is the combination of antivirals within one regimen. This is not a particularly new practice, the treatment 'cocktails' used in cancer being the best example. In particular the management of leukaemia with a combination of chemotherapies has rendered the disease curable in a high percentage of people. Indeed, HIV/AIDS treatment agencies such as Project Inform in San Francisco have been advocating the use of multiple therapies in combination since 1985.

There are a number of objectives for the use of combination treatments, and these include:

- \*To increase the effectiveness of the treatment at any one point in time.
- \*To extend the duration of time that any one treatment is effective in the individual.
- \*To diminish or eliminate the development of resistant strains of virus.
- \*To reduce the level of side effects of any one drug.
- \*To provide greater flexibility to the individual.

The overall aim of using combination therapy is to get a 'synergistic effect'. That is to say, if DRUG A gives a response score of two when used alone and DRUG B gives a response score of two when used alone. In combination, i.e. DRUG A + B, response score of six would be ideal. It is preferable if each drug that is used in the combination has different side effects.

At this time, of course, the use of a combination therapy regimen is severely restricted by the number of drugs that are available. This is probably the primary reason for the fast track release of ddI and ddC for such programs. Neither agent appears to offer a significant advance beyond AZT for initial solo therapy.

I will now give a quick 'thumb nail' sketch of the current thinking about specific cocktails of antivirals that are being used in HIV/AIDS overseas and soon, we hope, in Australia.

There appear to be three favourites around:

- \* AZT in combination with ddC
- \* AZT in combination with ddI
- \* AZT in combination with alpha interferon

The most promising data so far presented is for the combination of ddC and AZT. One study of 56 patients has indicated that where doses of 300 and 600mg AZT were combined with doses of 0.03 mg/kg ddC, there were significant increases in the T cell levels, and they remained at a higher level for as long as a year. In a larger ongoing study, (ACTG155), the focus is on adding ddC to the regimen when AZT has already been taken for six months or more.

There is good sense in combining AZT with alpha interferon as each drug interferes with a different stage in the life cycle of the virus. The most optimistic results to date come from a study in which 23 patients with more than 200 T-cells and p24 antigen levels over 70 received AZT alone or AZT + alpha interferon over six months. The end result was that the combination treatment demonstrated greater suppressive effect on viral replication than AZT alone. In fact there appeared to be evidence of a greater effect than the two drugs' individual responses combined. Unfortunately there were also a number of toxicity problems reported in the study. A study in the Netherlands has also shown a greater depression of the viral activity in patients with both

### ***Help me if you can I'm feeling down!***

As a final word, we are always looking for volunteer assistance with tasks such as typing and also the distribution of the HIV Herald. This is scheduled to occur within the first week of each month, and that is when we need some help. If you have an interest in this area and you want to help please feel free to call me at any time. Ta eversol lan

treatments. However, the responses were short lived, there being no difference between the single treatment and the combined treatment at six months. In addition toxicity was again reported as a significant problem. These results are almost identical to the experiences in yet another trial that has been conducted in Paris. Therefore alpha interferon may be valuable in short term use of the combination, particularly if KS is present.

Finally the combination of ddI and AZT is being considered in a couple of trials. A study by Dr. Ann Collier has demonstrated T4 cell increases to be better with the combination of AZT and ddI than when AZT is used alone. Again, there was some decay by the end of the six month period, but the drugs were well tolerated when taken together.

These results suggest that combination therapy may well be the way of the future for anti-viral therapy. Larger trials are clearly needed to compare the combination possibilities in greater detail and in particular to determine which options and dosages are best.

## ddI out of the closet!

The good news is that ddI has been approved for use by the FDA and the Canadian Health Authorities as of the 11th of October. It is indicated for use in adults and children who are intolerant or unresponsive to AZT. We are currently in the process of obtaining the precise conditions of use and

we will put them in the next *Herald* and *Talkabout*..

DDI is about to be considered by the Australian Drug Evaluation Committee (December). Thus the registration of the drug in Canada and the US should provide the needed pressure for there to be a favourable response and registration of the product as of February 1st. We of course will be adding to that pressure with appropriate lobbying of the committee and also of Squibb who are the manufacturers of the drug. There really is no reason why this product should be refused registration in Australia.

## So what's the buzz on SP-PG as a treatment for KS?

This compound was first developed by Dr. Robert Gallo of the National Cancer Institute (NCI) in the United States as far back as 1987. The initial studies conducted on immunodeficient mice provided excellent evidence of SP-PG's ability to induce remission of KS lesions. The drug prevents the development of capillaries within the tumour, thus preventing blood supply to the tumour cells, which are starved and die.

The Japanese company, Daiichi Pharmaceuticals, which holds the manufacturing rights to SP-PG has reported a number of problems since taking it on. They have reported that they could not find a way to synthesise and

manufacture the agent on a large scale and that there are considerable problems with obtaining a level of purity suitable for use in humans.

The NCI has offered to assist the company with these problems, but Daiichi are reported to have refused this offer. It is further reported that the NCI has offered to join a co-operative research and development agreement with the company, which would facilitate rapid development and registration of the drug in the US - Daiichi again refused to sign. It has now been reported that Daiichi has given the US office of its company the go ahead to negotiate for development programs in the US. Daiichi has now claimed to have solved the manufacturing problems.

There is still a need to certify this manufacturing process with the FDA and reproduce the Gallo research responses with the manufactured forms and submit toxicity data etc. At the very minimum this will take at least six to twelve months to complete. They may then be able to commence in human trial work. Daiichi was scheduled to meet with the FDA in July of this year to discuss these issues ...we await the outcome. I will keep you posted in future issues of *Talkabout*.

## Vaccination Day on the way?

There is a lot of confusion about vaccines. In particular the 'if and when' a vaccine that will prevent HIV infection will be available and the question of the

usefulness of vaccines to individuals who are already HIV+.

The development of a vaccine that will prevent infection appears to still be a long way off and I guess the best estimates are in the order of ten years or more. However a far more exciting prospect is the use of vaccines as immune boosters for people who are already HIV+. It is currently estimated that there will be initial trials under way with this group within the next two years. Some of the initial screening studies indicated that there is a significant retardation of disease progression if vaccines are introduced at a relatively early stage. There is also

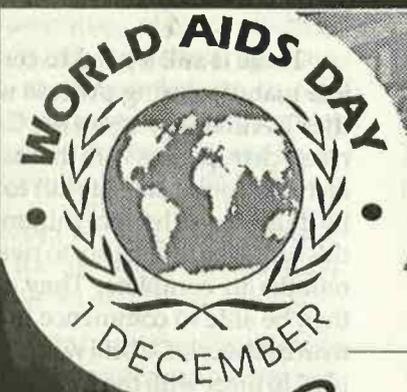
some initial evidence to suggest that they are able to reduce the quantity of virus in the body. This may have a particular significance for HIV+ women who are pregnant as it may prevent infection of the baby, particularly at birth.

The results are early but at the Florence Conference in June there was evidence that the T cell levels were stabilised, there was a significant fall in the incidence of opportunistic infections, increased average weight levels and an increase in survival.

It makes good sense therefore to use the vaccine in conjunction with the anti viral agents such as

AZT, since anti virals stop the reproduction of the virus, while the vaccine removes it from the infected cells.

Marcus Conant, one of the leading practitioners in San Francisco, has predicted that he will start using vaccines before the end of next year. Let us hope and work for having a similar early entry into Australia, provided of course that the safety data etc. is o.k. While not the solution to HIV it certainly can be considered as a significant addition to the process of preventing disease progression. Once again you will be kept informed of any developments in this area.



# SOCIAL SECURITY

## - Sharing the CHALLENGE !

S

haring and facing challenges isn't new to Social Security. We do it every day, helping our clients with the challenges they must face.

For people living with HIV/AIDS Social Security will be holding an information seminar to explain how: Disability Support Pension, Sickness Allowance, Carer's Pension and Child Disability Allowance can provide practical help and support.

Privacy and confidentiality will be other important issues discussed at the seminar.

*The seminar will be held at the AIDS Council of NSW on Tuesday 26/11/91 between 6:30pm and 8:30pm.*



# YOU talk back!

Thanks to all who answered the *Talkabout* Survey, published in the July/August issue of *Talkabout*. By now you must be wondering if you're ever going to hear feedback on it. Well here it is:

Seventy nine people answered the survey, of whom 32 identified as people with HIV/AIDS. Eight people identified themselves only as the friend/partner or relative of a PWHIV/AIDS; twenty identified only as a community based HIV/AIDS worker or health professional; five described themselves only as volunteer workers and three only as persons with an interest in HIV/AIDS. Most people described themselves as fitting into several of these categories - illustrating the extent of their involvement with HIV/AIDS.

Forty six men and 29 women and 1 transsexual replied to the survey (and a few of unspecified gender). Of these, 3 women and 29 men were HIV+. All the HIV+ men were gay, one of the women was a lesbian and the other women were heterosexual.

Most respondents lived in Sydney (45, of whom 22 were HIV+), 13 were from NSW outside Sydney (4 HIV+), 15 from interstate and 4 from overseas.

The survey indicated that you really pass your copy of *Talkabout* around. Only 17 people kept *Talkabout* to themselves, 24 people said that 2 people read their copy, 36 people said 3 or more people read their copy. We have averaged this

out to a total of 229 readers for 77 copies of the newsletter (3 readers per copy).

Several people complained that *Talkabout* was too infrequent. Thirty five thought it should be a monthly, 33 thought it should remain bi-monthly. Twenty HIV+ people, 1 health worker and 5 community-based HIV/AIDS workers thought it should go monthly. Ten HIV+ people, 11 Health workers and 11 community based workers thought it should remain bi-monthly. Family members, partners, friends and volunteers were about equally divided on the issue.

When it comes to the content and style of *Talkabout*, most respondents were favourable. Typical comments were that *Talkabout* is: "user friendly and punchy"; "a good balance of the rational and the radical"; "it encourages HIV+ individuals to feel good about their lives".

Some of the things people liked most about *Talkabout* were the contributions by PLWAs: "the realisation that other people with HIV feel similar things to me"; "real life writing". Other comments were that it's: "easy to read"; "positive and informative". People liked the special theme issues (particularly the Positive Sex issue) but argued that they shouldn't be too frequent: "waiting two months for an issue to find it weighted heavily on one theme is a let down." Point taken.

It's harder to generalise about

the things people disliked - except for the Soap Opera, *Anguish in Bohemia*, which was easily the most controversial feature. Some of you loved it, others hated it. Layout, and design - "the T (for Toxo?) on each page" - also came in for some critical comments, but 70 respondents said they did like the layout and design of *Talkabout*.

Several people suggested we use recycled paper - as we have to keep within the costing levels allowed by our grant, this is subject to the expense. We'll be looking into it.

Some HIV/AIDS workers made such comments as: "would be more useable with a wider public if it contained less explicit images". Some specific articles also came in for criticism.

People suggested many topics or special themes they thought should be covered in *Talkabout* - treatments and alternative health issues were clearly the biggest priority, followed by sex and relationships. Some HIV/AIDS workers wanted feedback from PLWAs on their services - so write in with your comments and we'll publish.

On the whole *Talkabout* fulfils respondents' expectations that a newsletter for PLWAs "be at once practical and cover general issues"; that it discusses "openly and in a non-moralist way all the things PLWA/HIV are thinking";

*Continued next page*

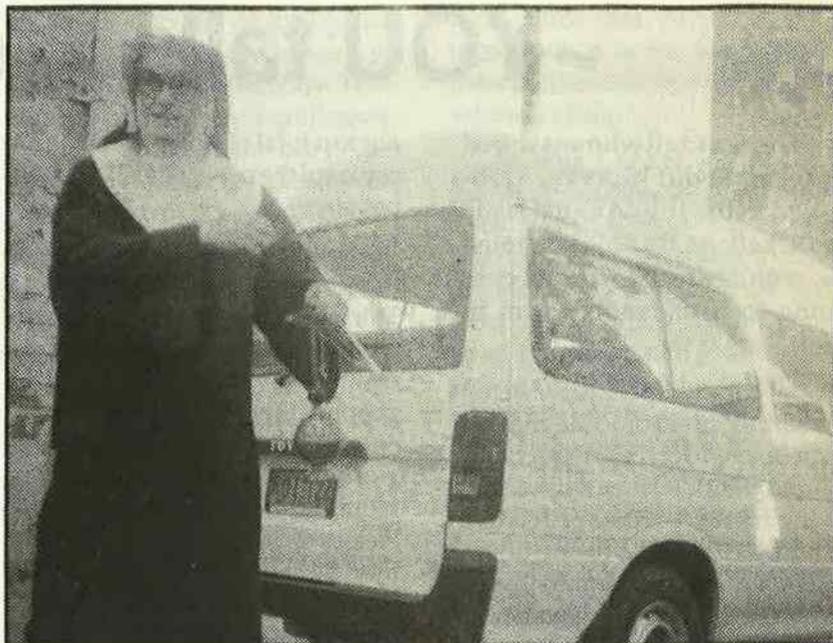
## Expansion of HIV transport service

An increased need for transport to and from hospital appointments by PLWAs, which has become increasingly evident over the past year, has now been met by the expansion of the Central Sydney Community Transport Group.

The HIV Transport Service, which has been operating since 1989, will now be known as Tiffy's Transport Service in memory of Terry Giblett. It will operate from Monday to Friday from 7.30am to 8.30pm. The expansion has been made possible through funding from the AIDS Bureau.

Co-ordinator Rob Lake said that the expanded hours were an acknowledgement of the differing treatment needs of people living with AIDS, as well as the increasing need for the service.

The Transport Service uses two vehicles, one leased through ACON, the other, the 'Lady Suzie' bus, was bequeathed to the Bobby Goldsmith Foundation for the medical transport needs of PLWAs. It has also been used by community organisations such as the Maitraya Day Centre.



*Sister Paula, of the Order of Perpetual Indulgence, blesses the new addition to the HIV Transport Service.*

## You Talk (continued)

that it be accurate, supportive and informative.

We are beginning to make some changes in response to your comments. *Treatments News*, for example, has already expanded and we'll be looking at how we can improve it further. We'll also be taking up your suggestions for articles or special issues you'd like to see - just be patient, it takes a long time for a bi-monthly to get around to everything!

Many people (27) indicated they would like to get involved with *Talkabout* in some way. Don't wait for a personal invitation! (We don't know who you are.) If you would like to write something, or have any ideas, either send it in, or ring up and have a chat about it with Jill, the newsletter co-ordinator.

There will be more feedback on the survey at a *Talkabout* lunch-launch at PLWA's Strategic Planning Day on Saturday, November 9 and a complete report should be available by early December.

Thanks for all your support and encouragement.

# NEWS

## For Our Children

Mickey and Minnie were out in force - to the delight of the kids - at the launch of a new CD on October 8.

The CD, *For Our Children*, is a compilation of children's songs by 22 major vocalists including Ziggy Marley, Pat Benatar, Paula Abdul, Paul McCartney, Bette Midler and Bob Dylan, with a memorable version of "Itsy Bitsy Spider" by Little Richard. It was originally produced by Walt Disney as

a fund raiser for the Paediatric AIDS Foundation in the USA. Sony Music are distributing it in Australia. 75% of the proceeds will go the Foundation and 25% to the Kids With AIDS Project in Australia.

The AIDS Trust hosted the launch of the CD by Ita Buttrose, Vince Lovegrove and Professor Brent Waters.

*For Our Children* is available from all major record stores.

## Darwin rap

Actor/writer/director John Paul Jobling is currently working as a writer-in-community for the Darwin Gay and Lesbian Society (DGALS) with funding from the Literature Board of the Australia Council and the Community Cultural Development Unit. The project was an initiative of DGALS who were seeking to strengthen the 'scene' in Darwin after a spate of media poofter bashing by the *NT News*, Darwin's only daily paper.

HIV+ and gay, Jobling is leading regular Masterclass Theatre Workshops at Brown's Mart Community Theatre, who are administering the grant for DGALS. There is an HIV group, a men's group, a women's group and a mixed group. The products created by the series of workshops include short performance pieces, radio plays, poetry, prose and rap.

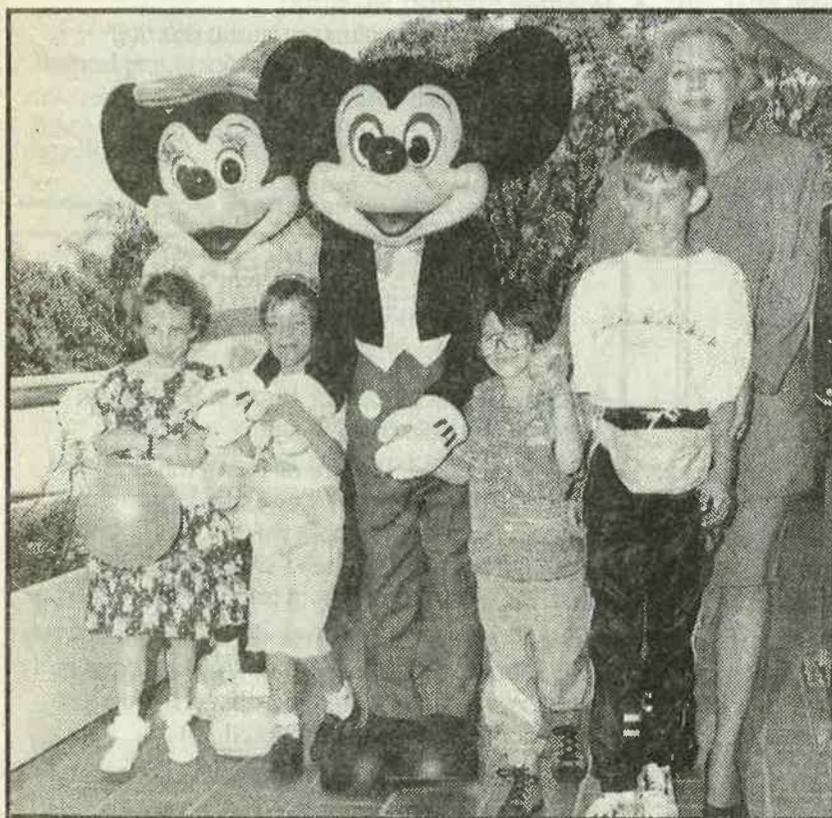


Photo: Jamie Dunbar

Eve, Skye, Troy and Ross with Minnie, Mickey and Ita at the launch of *For Our Children*.

### Part time work for HIV pensioners

Be social, have a good time and make some extra cash.

Choose your hours.

Interested?

Ph: 660 4190

10am - 4pm

7 days

# TALKABOUT DIARY

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

## NUAA

NSW USERS & AIDS ASSOC INC

### INFORMATION NIGHTS

**On the third Monday of every month at 6.00pm**

**at 16 Leswell St Bondi Junction**

These nights provide an ideal opportunity for injecting drug users (current and ex), members and any other interested individual to come and share ideas as they relate to injecting drug use.

**November 18**

**Heroin: then and Now**

**Speaker: Timothy Capelhorn**, Council member, NUAA.

Tim will give a historical perspective on narcotic prohibition.

For further info ring NUAA on 369 3455, or drop in to the office.

### HIV support/Action group

#### HUNTER AREA

Is held on the last Tuesday of every month. The group meets at 6.30pm at:

**ACON, level One, 6 Bolton St, Newcastle.**

A welcome is extended to all HIV+ people to attend.

If you would like to attend the group or require further information please contact ACON on (049)29 3464

### CENTRAL COAST SERVICES

#### Sexual Health Service:

HIV clinic (treatments, monitoring, counselling)

Strictly confidential/anonymous service

Tuesday, Wednesday, Thursday appts.

(043)20 2114

#### Support Groups:

HIV+ Support Group

HIV Carers Support Group

Lovers & partners Support Group

For info contact Pauline (043)20 2241

#### Positive Support Network:

Community based volunteer group offering emotional and practical support (including home care) for PWA HIV/AIDS.

For info contact Peter (043)23 7115 or Paul (043) 20 3399.

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

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

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

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

#### November/December dates

**6 November 20 November**

**4 December 18 December**



**EVENTS**

**Exhibition:**

**23 November - 1 December** at Art Gallery of NSW. Australian and foreign posters and videos on HIV/AIDS. There will be other regional gallery exhibitions.

**Memorial Quilt display:**

**25-29 November** display of panels in retail outlets in central Sydney.

**30 November - 1 December** - entire Quilt display at Stage 1 Gallery, 84 Mary Ann St, Ultimo, Saturday 10-am - 9pm, *Unfolding ceremony* 6pm

Sunday 10am - 5pm.

**Saturday, 30 November** - *CounterAID* fundraising event for the AIDS Trust. More than 150 celebrities will be serving behind the counter at Grace Bros, David Jones, HMV, Skygarden and Virgin. Community AIDS organisations will have stalls in the Pitt St Mall, and more than 50 chefs from Sydney's leading restaurants will be cooking in the David Jones Food Hall. Last year CounterAID raised \$140,000, this year's target is \$200,000.

*Summer party* Alexandria Stadium, \$35 only from Aussie Boys - \$10 from each ticket goes to the AIDS Trust. DJs Brett Nichols & Craig Truslove, special appearance by Kate Ceberano.

**Sunday 1 December**

*Reflective event* to occur in afternoon in central Sydney. Location to be advised.

*Play "Not me mate"* by Free Wheels Theatre. Site and time to be confirmed.

**Monday, 2 December**

"Working with your doctor", a workshop organised by PLWA on your doctor-patient relationship. 7 - 10pm, Heffron Hall, Palmer St, Darlinghurst

**Penpal wanted**

Glen Rogers is an inmate of Cooma Gaol and has just completed the four day Prison Peer Education course. He would like a pen pal who is HIV+ and maybe who is lonely. Glen is learning to write and does not get many letters so he thinks this would help him while helping others.

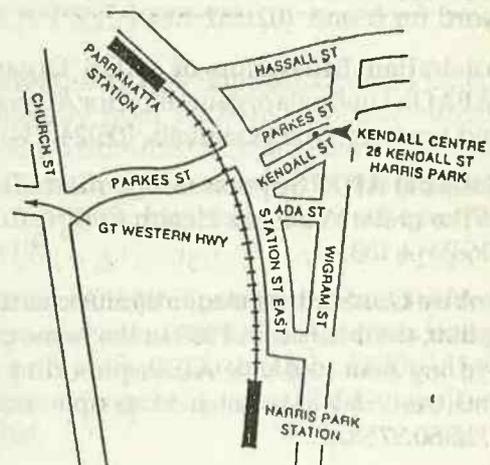
You can write to him at  
**PO Box 7, Cooma 2630**

**SERVICING THE WESTERN SUBURBS**  
the  
**KENDALL CENTRE**

aids information & support services

- |                 |                            |
|-----------------|----------------------------|
| Needle exchange | <b>26 Kendall Street</b>   |
| condoms         | <b>Harris Park 2150</b>    |
| Education       | <b>Tel: 893 9522</b>       |
| Counselling     | <b>Mobile: 018 251 888</b> |
| Referral        | <b>Fax: 891 2087</b>       |
| Outreach        |                            |
| Support Groups  |                            |

*A unit of the Western Sydney Area Health Service*



# CONTACT LIST

## **AIDS ORGANISATIONS AND SUPPORT GROUPS**

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

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

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

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

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

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

**Ankali:** Provides emotional support to people with AIDS, their partners, family members and friends. Volunteers are trained to provide one-to-one non-judgemental and confidential support to any person affected with AIDS. Ankali is an Aboriginal word for friend. (02)332 1090.

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

**Bathurst AIDS Support Group** meets Tuesdays 7 - 9pm at the Women's Health Centre. Contact Vi, (063)314 133.

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

**Civil Rehabilitation Committee Family Support**

Centre. HIV education & support to families of ex-prisoners and ex-offenders. Call Pam Simpson (02)289.2670.

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

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

**CSN North Coast:** Contact Nora Vidler-Blanksby (066)29 5048 or ACON (066) 22 1555.

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

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

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

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

**Legal Project (AFAO):** Legal advice and advocacy on HIV/AIDS related problems. Contact Michael Alexander (02)283 3222.

**Lismore Sexual health/AIDS Service:** a free, confidential service for all STD and AIDS testing and treatment. For further information or medical appointment ring (066)23 1495.

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

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

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

**National People Living With AIDS Coalition (NPLWAC):** PO Box 164 Canberra ACT 2601, Ph:

(06)257 4985, Fax:(06)257 4838

**Newcastle Gay friendship network:** Peer support, workshops and activities for gay men under 26. Contact ACON Hunter Branch, (049)29 3464.

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

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

**NSW Users and AIDS Association (NUAA):** NUAA is a community/peer based organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free forums/information nights 6pm, 3rd Monday of each month. Ph: (02)369 3455

**Parents' Group (and relatives):** A support group for the parents or relatives of people with AIDS. Please phone to indicate attendance. Aileen Goss, 2nd Floor 276 Victoria St Darlinghurst 2010. (02)332.4000. Every 2nd Thursday 12.00 - 1.30pm.

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

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

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

**Quilt Project:** Memorial project for those who have died of AIDS consisting of fabric panels and completed by friends and lovers of those to be

remembered. (02)283.3222.

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

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

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

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

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

**Transfusion Related AIDS:** A support group for people acquiring HIV through a blood transfusion. Please phone to indicate attendance. Parramatta Hospital, Marsden St Parramatta. Meetings are held on the last Tuesday of each month at 10.00am. Contact Pam or Claire (02)635.0333 EXT. 343. **Red Cross BTS:** Contact Jenny (02)262.1764.

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

## DAY CENTRES

**Blue Mountains PLWA Support Centre -** Operates Wednesday from 11.00am - 2.30pm - lunch served. Fridays from 6.30 - 9.30pm - dinner served. Tuesdays from 10am/noon for individual or group counselling. For further information Ph: (047)82.2119.

**Newcastle (Karumah):** Upstairs 101 Scott St Newcastle, Opposite Newcastle Railway station. Every Thursday from 11.00am. Contact John (049)62.1140 or the Hunter Branch of the AIDS Council on (049)29.3464.

**Sydney (Maitraya):** Daytime recreation/relaxation centre for people with AIDS. 396 Bourke St, Surry Hills 2010. Enquiries: (02)361.0893.

## HOSPITALS

**Prince Henry (Special Care Unit):** Anzac Parade Little Bay (Sydney) (02)694.5237 or (02)661.0111.

**Prince of Wales:** High St, Randwick (02)399.0111.

**Royal Newcastle Hospital (Immunology Unit):** Pacific St. Newcastle, (049)266 870.

**Royal North Shore:** Pacific Highway, St Leonards (Sydney) (02)438.7414/7415.

**Royal Prince Alfred Hospital AIDS Ward:** Missendon Rd, Camperdown (Sydney) (02)516.6437.

**St George Hospital:** Belgrave St. Kogarah. Inpatient/Outpatient & Day Treatment Centres and STD Clinic. Contact Stuart Linnet (02)0350 2742/43

**St Vincent's Hospital 17th Floor South (AIDS Ward):** Victoria St, Darlinghurst (Sydney) (02)361.2236/2213.

**Sydney Sydney Sexual Health Centre,** Sydney Hospital, Maquarie St, Sydney. Appointments Ph: (02)223.7066.

**Westmead Centre (Westmead and Parramatta Hospitals):** (Sydney) Phone (02)633.6333 (Westmead); (02)635.0333 (Parramatta). Fax (02)633.4984.

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

**JOIN US IN THE FIGHT AGAINST AIDS - SUBSCRIBE NOW!**

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

First name: \_\_\_\_\_

Last name \_\_\_\_\_

Postal Address \_\_\_\_\_

P'code: \_\_\_\_\_

Phone: \_\_\_\_\_

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

I wish to subscribe to TALKABOUT\*: Y/N

I wish to make a donation of: \$ \_\_\_\_\_

I enclose: \$ \_\_\_\_\_

**In the interests of your confidentiality:**

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

Y/N

I am publicly open about my membership:

Y/N

**Annual rates are:**

Membership of PLWA Inc. (NSW) \$2.00

\* Subscription donation to TALKABOUT: (Individual) (Optional for people receiving benefits) \$10.00

\* Subscription donation to TALKABOUT (Organisation) \$20.00

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

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

Signature: \_\_\_\_\_

Date: \_\_\_\_\_