

# Talkabout

Newsletter of People Living With AIDS Inc.(NSW)

Where we speak for ourselves

ISSN 1034-0866

Vol. 2, No.6 MARCH 1992

## HIV LIVING at mardi gras

Preparing for the big day: HIV Support Project workers and volunteers pictured with their spectacular Mardi Gras creation. The giant puppet led the parade.



Photo: Jamie Dunbar

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

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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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## Talkabout goes monthly!

the April issue of Talkabout will be  
launched at the PLWA

Annual General Meeting on

9 April

at 7pm

Deadline for this issue is 16 March

## Albion St and ddC

There has been a great deal of excitement in the PLWA community about the availability of ddC in Australia, first through the buyer's club and more recently in a Roche-sponsored program. With this excitement there has also been a degree of confusion about the known value of ddC as an anti-HIV treatment.

ddC is, like zidovudine, a nucleoside analogue with a similar mechanism of action but with distinctly different side effects. ddC has been tested in far fewer people than zidovudine and we are still learning how to best use it. In a direct comparison of ddC with zidovudine in people who had never had an anti-HIV drug, (ACTG 114), zidovudine was clearly a superior drug with fewer progressions in those who received this treatment.

In a second study, again comparing the two drugs (ACTG 119) in those who had been on zidovudine for more than one year, one half of the group continued with zidovudine, the others were treated with ddC. ddC was associated with the development fewer opportunistic infections and cancers.

The superiority of ddC in this context may have been because of the development of HIV strains resistant to this drug. The conclusion of this study is that as first line

## Secret Miracle Cure Tested at Mardi Gras Fair

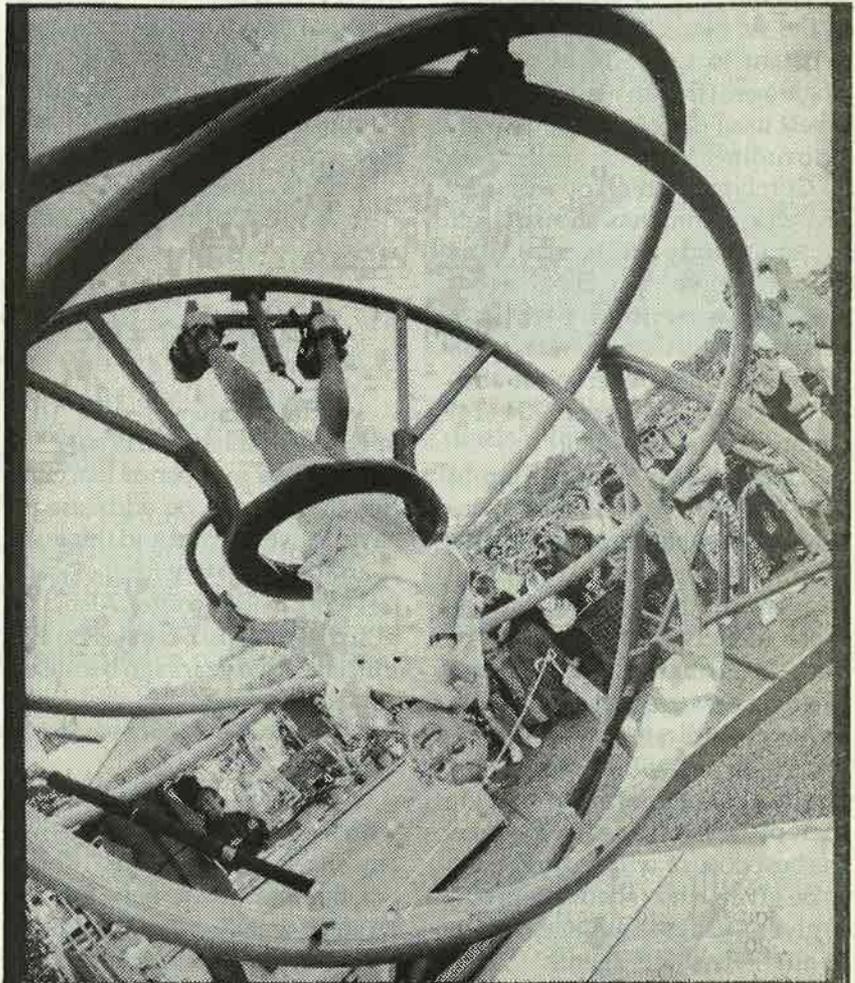


Photo: Jamie Dunbar

Joost Moos goes for a spin at Fair Day

therapy zidovudine must remain the first choice.

A further benefit of zidovudine therapy is its ability to penetrate into the brain. Because of this

property it can be used to treat and possibly prevent the development of HIV encephalopathy ("AIDS dementia"). Significant drug penetration into the brain is not a property

## LETTERS

of ddC and because of this it has an unknown (but possibly poor) ability to treat or prevent HIV encephalopathy.

For this reason the medical staff at the Albion Street Centre are reluctant to recommend ddC as single agent therapy but feel that it is best used in a combination with zidovudine.

Combination therapy with ddC and zidovudine has shown itself in a small study (ACTG 106), to be more effective than either agent alone. However it must be remembered that this study was of 48 people, who had never had an anti-HIV therapy and whose CD4 (T4) count was less than 200.

This is a very select group of PLWAs and it is impossible to conclude that what happens in this group of people is also going to happen in other groups, such as those already on zidovudine or with CD4 counts higher than 200. There is however theoretical evidence to indicate that combinations of drugs will be more effective in the long term than single therapy. What we need to learn is the best dose of which drugs need to be given, and whether it is best to give all drugs simultaneously or to alternate single agents.

The present Roche sponsored ddC trial is a comparison of two different doses of ddC (1.125 vs 2.25 g/day) in those with AIDS or ARC and less than 200 CD4 cells, who have proved unable to continue with zidovudine, or who have had immune deterioration despite continuing with zidovudine. It is hoped that this trial will give up information about the best dose of ddC required to limit progression of HIV disease. This trial makes available a drug which may have a

valuable role in the fight against HIV.

At present, entry to this trial is limited to recognised hospital based HIV management units, so for those PLWAs who would prefer to be managed by their own general practitioner, access to ddC is limited to the buyer's club supply.

**Dr. Julian Gold, Director  
Albion Street Centre**

## ACTing UP

I write to answer ACT UP's update in January/February '92 which has a number of inaccuracies that should be addressed. I have no axe to grind and this is not as an advertisement for the hospital I work in (St George). Also, I am a PLWA who 'fled' the system at St Vincent's two years ago because it was so appalling.

To answer the inaccuracies, as I see them,

1. "...any person can present with AIDS at any hospital in Sydney and get quality care." This is not the aim of the new funding arrangements. Certain hospitals ie. St. Vincent's, Westmead, Prince Alfred, St. George, North Shore, Prince Henry and Concord have been funded to have specialised 'beds' and 'services'. This means that anyone may present at any hospital but will probably be transferred to a hospital with specialised doctors, nurses, social workers etc. These area hospitals do provide quality services.

2. "...and does this plan take into account the fact that over 40% of people with HIV in the country live right around St. Vincent's

Hospital." This fact is well known in allocating funds. It means, for example, that my area, which has around 5% of people with HIV, gets less than 5% of funding.

PLWAs should, I feel, try services in their area if they don't live around St Vincent's hospital. If they aren't providing a good enough service, then return to St. Vincent's hospital and demand its expansion and improvement.

**Stuart Linnet.**

### 5 more comments we hate

"Doctor, my bones ache, I have this rash, there's this buzzing..."

1. *It's the virus.*
2. **many people decide not to have sex.**
3. *It's just a blood test.*
4. **This won't hurt**  
and from an AIDS Council Worker:
5. *I've never had HIV.*



Thanks to Robert Runaway for this month's five comments. Readers are invited to contribute to the list.

## An HIV ministry

I would like to let all people affected in some way by HIV/AIDS know that while I was in San Francisco I was ordained to the Sacred Order of Deacon on the 29th of November 1991 and ordained to the Priesthood on the 30th of November 1991 by Most reverend Bishop Paul A. Diederich, SGS, of Boston. Paul is a bishop within the Western Orthodox Church in America (WOCA).

Bishop Paul already knew that I was a person openly living with AIDS related conditions (ARC), and that I was diagnosed HIV antibody positive in 1985. Paul accepted my whole background and accepted me the way I was which I believe is a small positive step for any bishop or church, to be willing to ordain to the priesthood any gay man openly living with ARC.

WOCA is a traditional independent church within the growing independent Catholic movement. WOCA bishops trace their lines of Apostolic succession through both Bishop Aftimios Ofiesh of the Russian Orthodox Church and Bishop Carlos Duarte Costa (a former Roman Catholic bishop).

All my services will be free to all people regardless of background, sexuality, present position and creed etc. I plan to keep my ministry small but I hope to be able to serve all people. Anyone interested in coming along to my home masses, or who would like to use my ministry, can contact me at PO Box 936 Darlinghurst NSW 2010.

Many thanks,  
Rev Father Wayne Wright, SGS.

## Tribute

### Brian Hobday

Our community lost a jewel on February 5 with the death of Brian Hobday. In death as in life, Brian remained in control, displaying his usual independence, courage and concern for others. It was these qualities tempered with a whimsical sense of humour and forceful dignity that made Brian such a tireless worker for the community.

His commitment was unequivocal and from the time he arrived in Sydney in 1979 from Inverell, he threw himself into the politics of the community with as much gusto as his love affairs.

Brian's involvement included being a member of Brian McGahen's election team, a founding member of the Bobby Goldsmith foundation, Mardi Gras member and parade co-ordinator from 1983 to 1985, PLWA committee member in 1991 and resolute ACT UP activist.

What is remarkable about all this energy Brian gave to the community was his relative youth. Brian was only 31 when he died but he handled everything in his life with uncommon maturity and

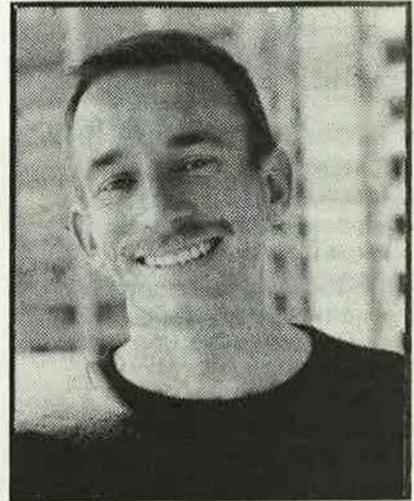


Photo: Jamie Dunbar

uncompromising purposefulness. He was happy to eschew the limelight and do the 'shit work' that really makes an organisation viable and did so with patience and humour.

Adoring travel, Brian realised a dream and took a first class trip around the world. He also revisited a favourite city, San Francisco, for last year's Mr Drummer final. Right to the last moment of his life, Brian lived to the fullest with a zest that was magical. He was also very proud of his parents, Dot and Don, who were not only supportive of his sexuality and antibody status but themselves are now committing energy to a parents group.

Brian's loss hurts but his memory and inspiration will continue to fire on in all those who knew him.

-Titi Chartay

## Tribute

### Nicolaas van Schalkwyk

I first met Nicolaas in late 1987 when he was then working as volunteer co-ordinator and telephone counsellor for ACON. Nicolaas was perfect for the job. His rich, mellow voice and gentle manner soothed the most distraught of the worried well, and reassured the victims of media and medical hysteria and misinformation.

Nicolaas's energy and creativity were responsible for some wonderful HIV education efforts, including ACON's "Love Him Safely Everytime" poster, which introduced the issue of multi-racial relations to safe sex education; the huge AIDS contingent of the 1989 Mardi Gras parade; assisting in the organisation of the Living Well III conference in Adelaide; and more recently, an outreach study for PLWA to the north coast of New South Wales, documenting the situation and needs of people with HIV in that region.

Nicolaas lived with HIV to the time of his peaceful death with the help of a practical belief in exploring

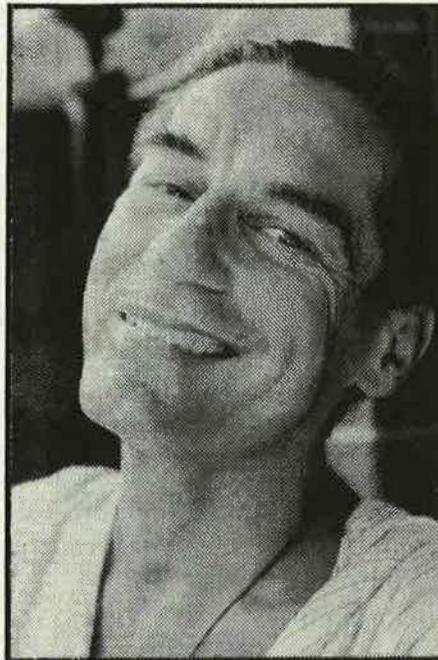


Photo: William Yang

health and treatment options. While he favoured alternative and natural remedies for his ailments, he accepted the value of conventional medical treatments when they proved of help. His faith in the value of such options gave Nicolaas control over his own body and mind.

And when treatment was no longer helpful, Nicolaas

surrendered his body, peacefully and without complication. His last message to us leaves us, as did his friendship, with a strength of spirit.

"I leave full of love and excitement, for at last I will have complete wisdom"

- Robert Ariss

"I discarded this body on the twelfth of February 1992 as it is now too worn for the times we live in.

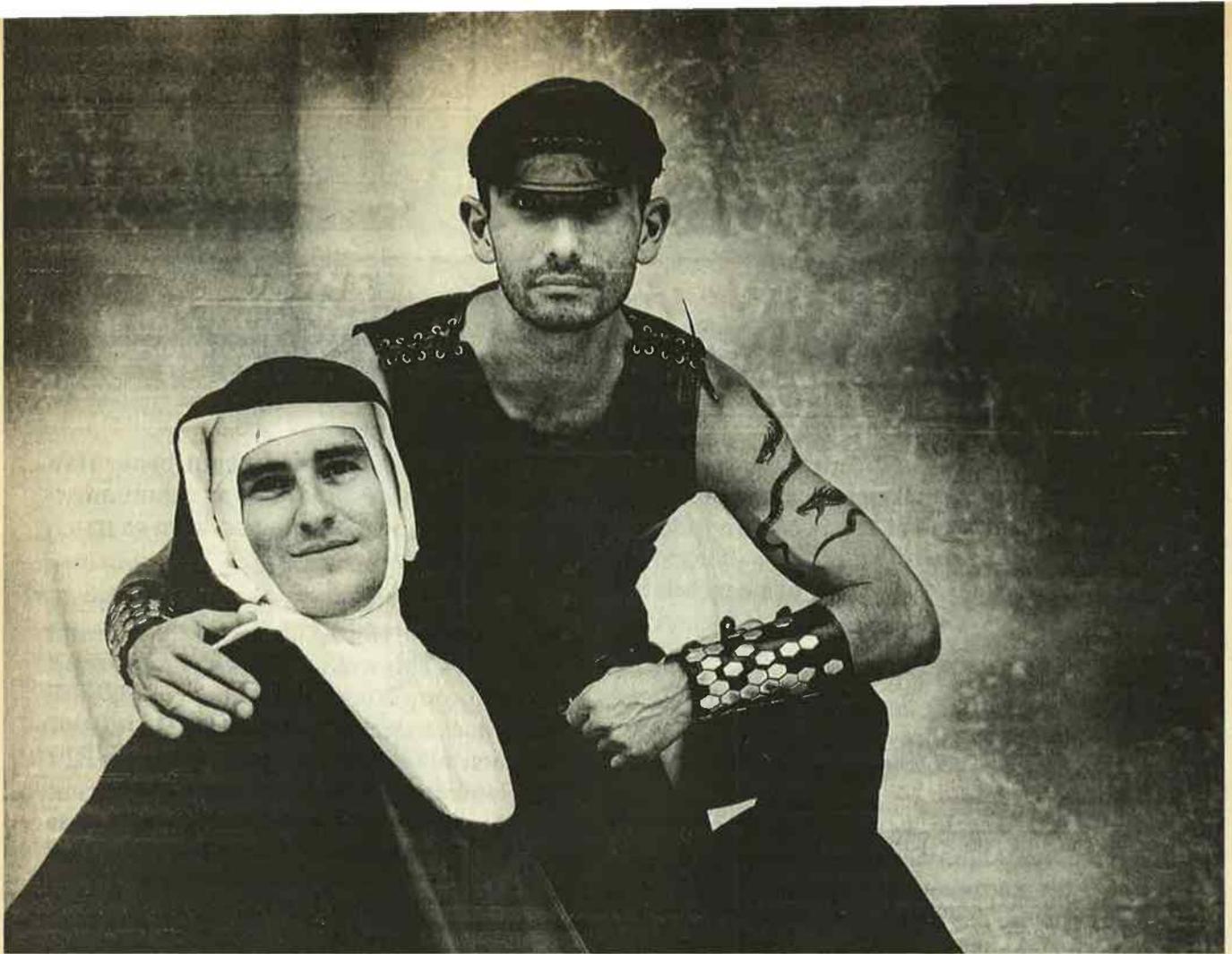
At the beginning of a new day, without ceremony or ritual, my ashes will be thrown over a cliff in the Blue Mountains into a valley of serene beauty and eternal peace.

I leave full of love and excitement, for at last I will have complete wisdom."

**Nicolaas van Schalkwyk**

#### Nicolaas van Schalkwyk

The Committee and staff of ACON are saddened by the death of Nicolaas van Schalkwyk, our friend and colleague. Nicolaas worked at ACON as an educator and counsellor from 1987-91 and his contribution to our community's work in fighting this epidemic will be greatly missed.



Our community is diverse. Some of us are into frocks, some of us are into muscle, some like leather, others live to shop, some of us are just into other men.

We all share being gay and we share the effects that HIV has on our community, our friends, our partners, ourselves.

**Our love ~ gay love ~ will help us survive. Our community is stronger than ever.**  
.....

Fight aids. Always have safe sex. Always inject with new or clean syringes. Support our friends: those with HIV and those without.



a gay men's community message from the aids council of nsw. more info 02 283 3222 tty for the deaf 02 283.2088

## POINT OF VIEW

# HIV+ *and* Queer

It was 1981, I was all of 16 and had a staunch view that my individuality was the most valuable asset I had in my entire life. As an individual I was no longer able to keep up a charade of trying not to mention sexuality or steer clear of speaking about who I was attracted to, and the concept of pretending was just not me. So I decided to "come out" as being gay and to start dealing with the views of peers, friends and family about my wanting to love and fuck with men.

So, there I was: 16, gay and thinking that there were more than one of me in the world, but not really knowing. It was a time of great confusion for me, knowing I was gay but not knowing if I was ever going to be able to live as a gay person.

Then one night I was listening to the radio and heard a program called "Gaywaves". I almost immediately joined the co-operative that managed the program, just to meet people who were in the same brain space as I was. I then met more people, found bars, bookshops, cafes, restaurants, and a lifestyle which while it did not fit my ideas of who I was or who I wanted to be completely, was supportive of me as an individual and encouraged me to be as free as I wanted about my sexuality and lifestyle.

In 1987, at the age of 22 I discovered that I was HIV positive, after having been infected since 1982. After dealing with my feeling of being dirty and unable to live in the community, never mind my fears of death and dying, I started to wonder why it was so hard for me to "come out" about being HIV positive. After all wasn't this the community that helped me crowbar myself out of the closet and advocated for a free and non-discriminatory society? How could

it be that I felt intimidated about being HIV positive? Why was there no "gay community" support for me, when there had been so much for me being gay?

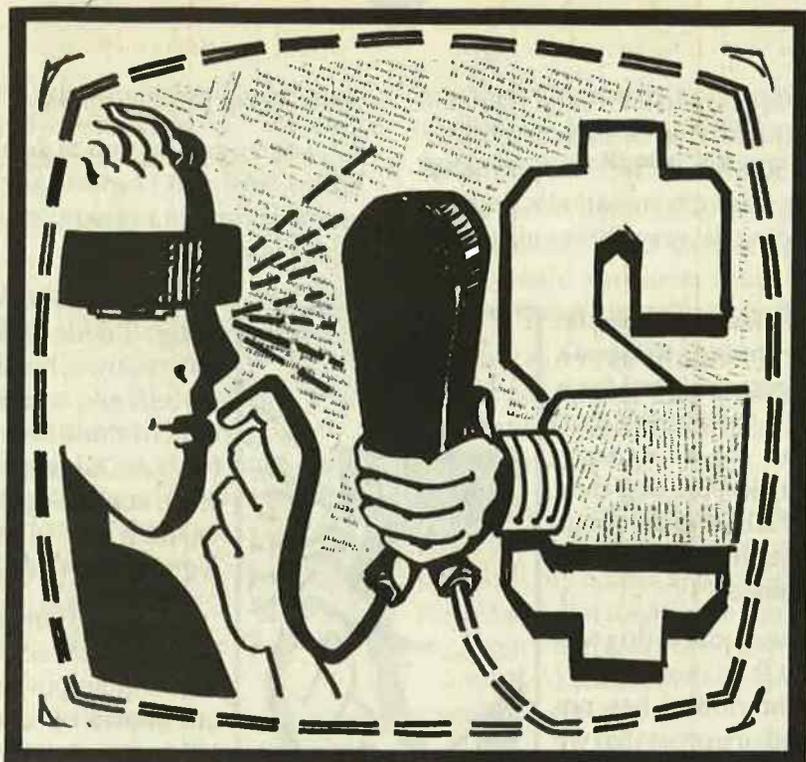
It was difficult for me to attach pride to being HIV positive, but I found it was easy to be proud of who I was. This was reinforced when I found a support group where I met other people with HIV. It was exactly the reason I joined Gaywaves. Then when talking more publicly about my HIV status, I found that I was having as much trouble with peers, friends and family as I was having with being gay, and the shocking thing was that the worst reactions were from gay men and lesbians. So yet again I was struggling with having to come from the fringe and deal with acceptance all over again.

While you could easily call the AIDS movement a "gay-owned" franchise, I feel that the gay movement itself has been overshadowed by AIDS. The urgency and seriousness has meant that many gay activists have moved to work in AIDS or have died from AIDS, and the "gay community", who are simply people grouped together because they fuck with people of the same sex, have become complacent to the point that they criticise the very activists that are fighting to improve our quality of life.

By far my major concern is the lack of acceptance the "gay community" shows to people with HIV and AIDS. Are we becoming the bigots that discriminate against us on the grounds of homosexuality? Gay people need to take stock of the lifestyle they have, and if it is not to be eroded they need to start to respect difference especially that of people with HIV and AIDS.

Lloyd Grosse

# HOT TIPS



Graphic: Ruth Samuels

## For Your 15 Minutes Of Fame

**Something PLWHIV/AIDS are constantly being asked to do is talk to the media. Many have done it - with the most altruistic motivations - and been burnt by the experience. But, for the sake of fighting stigma and discrimination, it's a job worth doing. Jill Sergeant picked the brains of several seasoned HIV+ interviewees for tips on how to get the most out of an interview situation.**

**1. Don't be afraid of it, but approach with caution. Being a media star takes some getting used to. If you're thinking about talking to the media some time in the future, try and get some experience in public speaking - perhaps do a course with the ACON Speakers' Bureau. It's important to educate yourself about how the media operates - read up on it. If you know how it works, there's less chance you'll be manipulated.**

**Bruce:** An article was printed in the *Independent* where the reporter had spent hours with me with a tape recorder, speaking about ACT UP and ACT Up's role in treatment access, and when the article actually came out, I was totally misquoted and the article had nothing to do with what we'd been talking about. That's a frequent experience for activists and anyone who works in HIV....

The media has its own agenda, and don't think the reporter is going to announce what that agenda is when he or she starts talking to you.

**Amelia:** They changed the story around somewhat, and it was badly written. We were lead to believe, when that story was first suggested, that it was about women and treatments. It ended up being a story about her...

**Jill:** "The most tragic AIDS family in Australia"

That's right, which isn't about treatments at all. And that's why Megan had originally agreed to do it, because she was a woman that had a bad expe-

rience with being intolerant to AZT, and then not being able to get onto a ddi trial because of red tape and bureaucracy.... So even though the journalist who wrote that story was very empathetic, I realise that her understanding is very different, of the whole situation.

**Bruce:** We need to learn to use the media to our advantage, to speak through the media, because I start from the premise that it is their obligation, their duty, to report the news accurately. We need to make sure that they do that, and one way is that we have our own agenda, which is very strong, and we promote that agenda.

I do not expect the media to do good stories. I believe that they should, and I believe that our community has not raised nearly the kind of uproar that we need to raise about, first of all, the way gay people are treated, which is slowly starting to change, ....but also about the way AIDS is portrayed....

Simon Watney wrote a very eloquent piece in summation of all of this and said, if you see repeatedly that a person who has the means to tell the truth is continually lying, the only logical conclusion is that they don't want to tell the truth, and I think that's what we have to assume. It's not that there's not enough good will; there's deliberate ill will and misrepresentation.

**Gabby:** The media is constantly looking for something that's going to be new, interesting, different, something that people are going to want to read about, because that boosts circulation, or increases ratings, which means that you can charge more for your advertising, which is what pays your wages... There's lots of information around about how the media operates, and if you're really serious about doing it, it's a good idea to give yourself that background, rather than waste a precious opportunity to get information across and change people's perceptions, which I think is the motivation for all of us. If you let yourself be misrepresented then you may be giving rise to the

next crop of misconceptions.

**2. If someone asks you to do an interview at short notice, you don't have to do it right away. Give yourself time to prepare, whether you need five minutes or a day.**



**Gerald:** I suddenly forgot all of the things I'd done before, like writing things down, having pointers there for myself, and had fallen into a pattern which I think is very much there in the HIV/AIDS area, which is, we get asked to do something and we jump in and we do it, we don't actually plan what we're going to do.

**Bruce:** I think most of the mistakes happen because the media wield such tremendous power.... A television camera shows up and everyone goes to jelly, goes "oh my god, they want to talk to us". Well you don't have to do that. If they want a story they'll be persistent.

Look at how many politicians have been caught out, making remarks that they were very sorry later they'd made, because it was an off the cuff remark and they were caught unprepared.

**3. Look at work the journalist's already done. Watch or listen to the program. Check them out. Can you trust them to do the right thing by you? Don't assume she/he knows anything about HIV/AIDS.**

**Amelia:** Because it had come through Petrea and Jennifer at the Quest for Life Foundation, I presumed - which you should never do - that [the journalist] had been checked out and she was okay.... When she came in here... I realised that she didn't know anything, she'd done no research, her language around HIV was just appalling. She was using "AIDS victims, sufferers", all that, and she didn't know the difference between being HIV+ and having AIDS - I mean, basic stuff. As a journalist I felt it was her responsibility to have done a little bit of background work....

That was actually just before Jean died... I think

I got the transcript about a week or so after he died. And it was appalling. It was badly written, she had squiffed all the facts because she hadn't understood it, so she interpreted. I actually didn't want to see anything at that point in time about myself or my partner in print. I had said to her beforehand, "my lover's very sick and I don't know how I'm going to feel about that".... I actually rang her and said "I want anything that refers to me or my relationship with my lover to be taken out." She didn't want to do that. I explained the reasons why, and said I was under a lot of stress and very distressed by the whole thing and I didn't want to see it in print.... the way she treated me was quite appalling. She wasn't listening to anything I had to say, she said the public had a right to know, and I asked her why, but she couldn't give me a good reason....

I pushed the point.... eventually she had to bow down to that, but in the meantime she was quite abusive to everybody.... It was really very distressing..... I couldn't understand her motivation, and even now, and this is over ten months ago, I still can't see it. It was sensationalism.

I think a lot of journalists don't actually know what they're asking people to do, they don't understand the risks people are taking and the amount of emotional vulnerability they're setting themselves up for. It is very personal, it can make me feel very vulnerable, exposing myself like that.

**Bruce:** Except for a very few people with a hell of a lot of integrity out there, I just think journalists in general here are just basically incompetent. Even if you wrote a story with an unfavourable slant, where you had a very strong personal opinion, getting the facts is simply a matter of craft.... They're not very good journalists, because they get so many things wrong. It isn't just a slip of the pen to deliberately make up a quote that someone's said.

**4. You could try and negotiate some sort of contract with the program or publication which gives**

**you the right of veto. You are, however, extremely unlikely to get it. It's better to make sure you don't say things you'll later regret.**

**5. If you've done other interviews in the print media, send them copies (the ones you were happy with) and some information about yourself, so that they are prepared.**

**6. Think carefully about whether or not you wish to be anonymous, and what level of anonymity you want. If you choose to go completely public, support is crucial.**

**Gabby:** I really still would hesitate to go on television full face, just because it means - the people at my corner shop might know - not that I really have that many problems about them knowing, but it's that loss of privacy.... I don't know that I'm ready to walk down the street and be a recognisable person with HIV....

I felt really misrepresented when I saw the documentary I'd done on Channel Ten, yet the next day I was down at the Day Centre, and nobody knew that that was me, and they were all talking about this fabulous woman who'd been on, and she wasn't homophobic and she wasn't this and she wasn't that, and the guys who'd seen it were all raving about it.

**Gerald:** I've chosen not to in the past and would still choose not to be anonymous, because I think there's a power that comes out of having real images up there, that is confronting to the people that are looking at it, and also, in a way, confronting to yourself.

**Amelia:** In an ideal world, I would like to be able to turn around and say yes, I'm Amelia Tyler and I live at so and so, and this is my family and this is where I work and this is who I am - but it's too scary. So you give bits about yourself. I don't have to give my name, but give certain information about myself and people can identify me anyway. So you don't give those bits about you either, and normally the bits that are strongly identifiable are major parts of your personality, so then it can get



very distorted, because they haven't got the individual's major personality to work with, I suppose.

**Bruce:** In 1992, I think it would be better not to do the interview than remain anonymous. I think that's very important, because that's another media image in AIDS which we want to fight, which is the nameless, faceless HIV+ person who can't reveal their face and has to be shadowed out .... I think this is an image we have to fight tooth and nail. Certainly I'm not denying the majority of HIV+ people in this country cannot walk the streets proclaiming that they're HIV+. I know that, I'm not naive in that area, I'm not uncaring. However we have to start changing that...

If your little two paragraphs is in a whole article about positive people's feelings and they're all going by a pseudonym or a first name, that's fine, but if you are a major sort of feature article about HIV+ people appearing in the *Australian*, and you can't use your name, I would say forget it. I would tell them to get somebody who could .... I'm not saying, gee this is easy, why don't you do it, I understand the difficulties... But my god, nobody ever said it would be easy to have HIV or AIDS... we've never won any ground in an easy way. The people who have come out and fought have had to live in very difficult situations.

**7. Talk with friends/colleagues/your group about what you want to get out of the interview. You can write a list of things to say and/or things to avoid to take with you as a reminder. Be clear about what you do and don't want to say, and don't let yourself be distracted.**

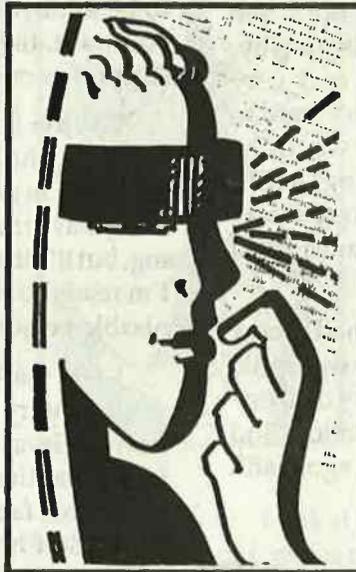
**Bruce:** You'll show up at a demonstration on hospital beds and the first question they'll ask you is about people getting drugs, or health insurance, or mandatory testing... many people are misled on that, into talking about issues that they're usually not very informed about, not prepared to talk about, and [which] have very little relevance. This

is a part of the media's general approach, which is to turn AIDS into this totally non-understandable monstrosity, which has so many facts and angles which are confusing that no-one could possibly understand it, and that comes from a refusal to actually do their homework and report responsibly on the issues.

**8. Remember, you're doing them a favour - it's not the other way around.**

**Amelia:** Journalists could do so much better, and they could actually get an awful lot more information out of us if they did the right thing.

**Bruce:** An activist needs to learn to use the media. You learn to speak through the media, and you make them a mouthpiece for your actions and your words. You do not start with the fact that the media has a right to its opinion or that they are being somehow very gracious by spending their time on you... On the contrary, I feel we, particularly as out positive people, are doing them the favour by making their job easier.



**9. Don't let them bully you into saying things you'd rather not.**

**Amelia:** It's quite easy to get off the track, and if they get into your little vulnerable bit, they'll go right into that, and maybe all the other important stuff that you've wanted to raise just gets lost, because they've found the sensationalist bit, the "oh the sorrow and the depression and the gut wrenching..." all that sort of stuff.

**Bruce:** It's not a matter of being polite, they're very aggressive that way, they often play devil's advocate, and if necessary, you just look straight at them and start talking about something completely different. You don't answer the question. You're not under obligation to.

**10. Make sure you're not alone afterwards - even if the interview went well, you'll probably want to be able to talk about it to someone you know. Also make sure you're not on your own when you**

watch or listen to the program, or pick up the newspaper that's got your interview.

**Gerald:** Even though I knew that there were lots of people out there that I could have rung up and said "I'd really like to watch Channel 10 news with you tonight", or "I'd really like to read the paper with you and talk about it", I didn't do it. I think I didn't do it because I didn't arrange that beforehand.

I was in [at ACON] the next day [after the Herald interview] and I felt it very hard to ask for or get feedback. There was one person who spoke to me about doing the interview.... he took me aside and said, "I saw the stuff in the media, how do you feel, that must have been really hard to do". And I found I sort of just melted, and I thought, thank god, somebody's said something. I had feelings of not being sure that I'd done the right thing, or - just not being able to really debrief about it, on what the outcomes were. I felt very ill at ease about it.

**11. Being photographed:** probably the most useful thing to bear in mind is that if the photographer likes you, they're more likely to print the best shots of you for their editors. You have virtually no control over which photograph will be selected for publication, how it will be cropped, or what the caption will be. Even the photographer doesn't have complete control over the editorial process, so your best bet is to try and get them on side, even if it means being friendly to someone you don't like much.

Talk to the photographer about what kind of image you'd like to project - she/he may be glad of this input and take pictures you'll like.

**Bruce:** I had a long argument, a real fight, with the photographer, who was wanting me to pose for the picture.... I had some really whacky sunglasses and he wanted me to pose with the sunglasses on.... at first I thought it was only the sort of 'big bad activist' look with the black leather jacket, but then I realised it was more than that - it was this

traditional media image that a positive person cannot show their face, and I took the glasses off and put them away. He got very angry with me, really aggressive with me and insisted that he had to have the sunglasses or there would be no photo, and I said, "that's fine, forget it, ...I'm not afraid to show my face and if you take a picture of me you've got to show my face".

**Jill:** And did he, in the end?

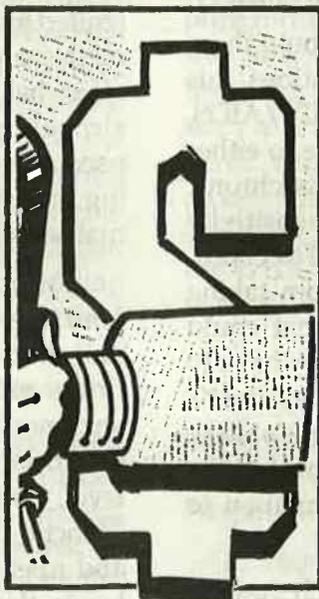
He did, yes.

**Amelia:** I was going to do a story for the 'no idea', and then I saw how they'd done Megan's story, and how in fact they didn't do the right thing by Megan at all.... They'd agreed to a certain photograph, and then they actually showed a photograph of me and Megan, and of me putting my arm around her. The photograph she'd agreed to was her standing by herself - it was about her being a very lone person, and having to struggle because her husband had died, and they missed that. They reinterpreted the whole thing, and no-one could challenge that because she was dead... The fact that they'd put me in there, and I hadn't agreed to that - the photographer had taken some shots of us while she was too frail and she needed to sit down, she was freezing cold and I was rubbing her back to get her warm. They put that photograph in which made her look very dependent - which she wasn't, she wasn't a dependent woman at all.

**Gerald:** When it finally came out, I was quite happy with it, apart from the fact that they'd printed the most depressed looking photo out of the 25 odd photos that they'd taken.

**12. If you feel really shaky about it, even if it's right at the last minute, remember: you don't have to do it.**

*Thanks to Bruce Brown, Gerald Lawrence, Gabby McCarthy and Amelia Tyler for interview tips, and to Jamie Dunbar for tips on being photographed.*



# L♥ving Your Liver

## **Vic Hernández, of New York, introduces Thioctic Acid, a liver protective nutrient.**

One afternoon while purging my medicine cabinet of out dated medicines, I came across a bottle of Thioctic (pronounced Thi-oc-tic), also known as Lipoic acid or 'pyruvate oxidation factor'. My physician had suggested I take Thioctic along with the medication he had prescribed for intestinal parasites. He told me that thioctic would protect my liver from the toxic substances in the medication. It was a precautionary measure since I had had no previous liver damage. I had no side effects from Thioctic or the medication. And the parasites are history.

As I looked at the bottle now, some three years later, I pondered the implications this would have for friends of mine with HIV/AIDS. Many of them have liver damage due to either substance abuse, previous medications, chronic and aggressive hepatitis, chemical sensitivity and other chronic disease of the liver. The condition of their liver prevents them from taking antiviral therapies or medications that could fight an opportunistic infection. If they have to take the medications, regardless of their liver's condition, they risk further liver damage or liver failure. I believe Thioctic can help to protect the liver and here is some further information to support this.

Thioctic is a micronutrient which has recently been used in cases of chemical hypersensitivity syndrome and residual liver damage. The principal physiological function of thioctic appears to be its action as a coenzyme in different metabolic reactions and pathways. It acts as a component to support the action, and not as the direct action.

Nutritional biochemists have incorporated Thioctic as a member of the B vitamin family as it is essential to many bacteria, protozoa and animals (humans included). Thioctic is a catalyst for which recognised enzymatic function and nutritional requirements have been established. Like vitamin B12, biotin and the folic acid group, it is biologically active in extremely minute amounts. This compound plays a pivotal position in the metabolic activities of both plants and animals.

While Thioctic exerts profound pharmacological effects, it is a non-toxic nutrient. A strong anti-toxic action of Thioctic has been demonstrated for acute and chronic poisoning by heavy metals and other toxins. A similar beneficial effect has been reported in liver damage from alcohol and narcotics. Thioctic has also been used successfully against phosphorous poisoning and stethogenic diets where it acts to normalise the fat content of the liver.

The action in the liver is as follows: imagine your liver as a huge waste management system. The more waste (toxins such as medications, drugs etc) you subject your liver to, the more enzymes your liver has to produce to manage the onslaught. Your liver reaches a high toxicity level, resulting in elevated liver enzymes. What Thioctic does is render these toxins harmless and open pathways to accommodate toxicity levels, thus lowering enzyme levels and reducing the strain on the liver that can jeopardise its function.

Physicians specialising in the treatment of alcoholics have used Thioctic widely as a liver protective agent. Primary care physicians are using Thioctic for patients with idiopathic liver

enzyme elevation, in addition to case of viral hepatitis and residual drug-induced liver injury.

Research indicates significant effectiveness of Thioctic for chemical hypersensitivity syndrome, diabetic neuropathy, peripheral neuropathy, heavy metal toxicity and elevated liver enzymes.

For those persons living with HIV/AIDS the implication of the nutrient is important. For the liver compromised person, Thioctic can serve to ease the toxicity bombardment of the liver brought on by the many toxic medications that most HIV+ persons take. Thioctic serves to lower elevated liver enzyme levels. It is important that you discuss the use of thioctic with your physician. Unfortunately, some physicians use elevated liver toxicity (enzyme tests: SGOT or SGPT) to determine dose range or the maximum amount of the drug your liver can take. This is poor medical procedure, but some physicians do it, so it is important that you tell your physician or health care team about Thioctic. If not, and you are taking Thioctic, this may be the scenario: your physician does the liver enzyme tests to determine dosage; your liver enzyme levels are low because of Thioctic; the physician gives you a high dose of the medication thinking your liver can take it; you can end up with a fatal overdose of your medication. Thioctic itself is harmless but communication is very important.

For persons who are immune compromised with a strong liver, an ounce of prevention could serve you well. Research indicates that Thioctic is effective for those suffering from diabetic or peripheral neuropathy. There is no data on the effect of Thioctic on HIV related neuropathy but the implications of the above information would seem to indicate a strong effectiveness. We need to encourage further investigation and research to determine the effect of Thioctic on HIV related neuropathy.

Thioctic is one of the more recently recog-

Thioctic acid is not available in Australia.

For further information you can contact:

Asta-Werke AG, Chenische Fabrik  
Artur-Ladebeck-Strasse 128  
Postfach; 14 01 29,  
4800 Bielfeld 14, Germany

(trade name is Thioctacid)

or

**Ecological formulas**  
1061-B Shary Circle  
Concord, CA. 94518  
Ph (510)827.2636

The contact person is Suzanne Sutton.

nised biocatalysts that has been synthesised in pure form. One of the most nutritionally effective forms of Thioctic is in combination with thiamine, preferably the fat soluble derivative such as the Allithiamines naturally present in garlic. This molecular conjugate appears to have an essential role in the break down of alpha-keto acids and in the transference of pruvic acid into the krebs cycle (the utilisation of energy out of matter).

Thioctic is available in two forms.

1. Prophylactic dose: Lipothiamine ( a functional form of Thioctic acid and thiamine). Each tablet contains 10mg of fat soluble thiamine and 7mg of thioctic acid.

2. Therapeutic dose: Thioctic. Each capsule contains 100mg of thioctic acid. Thioctic should be stored in a cool, dark place.

Good luck and stay healthy.

*References for this article are available from the PLWA office.*

# Anguish in

## BOHEMIA

### Chapter 7

By Rod Adams\*

*The story so far: Nigel, rebuffed by Nancy at Brad's KS party, retreats into angst until his \$30,000 compensation cheers him up. Robbie is perplexed by Nigel's lack of a political conscience. Brad and Nancy choke with rage over Nigel's outrageous claim, on a Current Unfair, to be an innocent AIDS victim....*

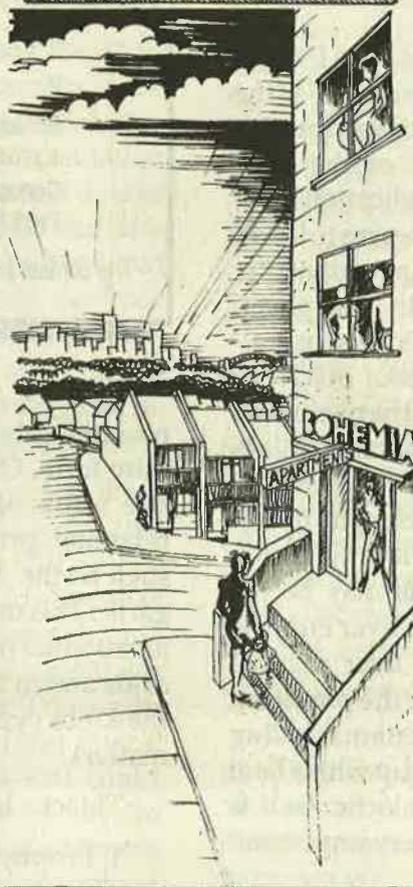
#### Nancy repots a plant

Evening nestled around the inner Eastern suburbs of Sydney. The neons across the street fluttered on, casting shadows under the portico of the Bohemia apartments.

Upstairs, in her kitchen, Nancy calmly swept up the pieces of broken china; earlier her temper had completely got the better of her.

The more she had thought of Nigel's \$30,000 "medically acquired" compo pay-out, the more she had wanted to break something heavy. She'd always hated that salad bowl (it'd been a gift from her AIDS-phobic mother).

Then she'd remember Nana Bent's pained expression while interviewing that little worm on national TV. Nigel had told the world he'd slept with half the men in Sydney, stuck dirty needles in his arms and had sex with "women";



that she'd refrained from breaking every glass in the apartment was a minor miracle.

There was a knock on the door. Opening the door, she froze. "Nigel!" she spat.

"Ummm..." he stammered, "I'm going south for a bit and I was wondering if you'd look after my maidenhair fern - just water it daily with tepid water and spray the leaves... oh and it really likes broken egg shells every now and then..."

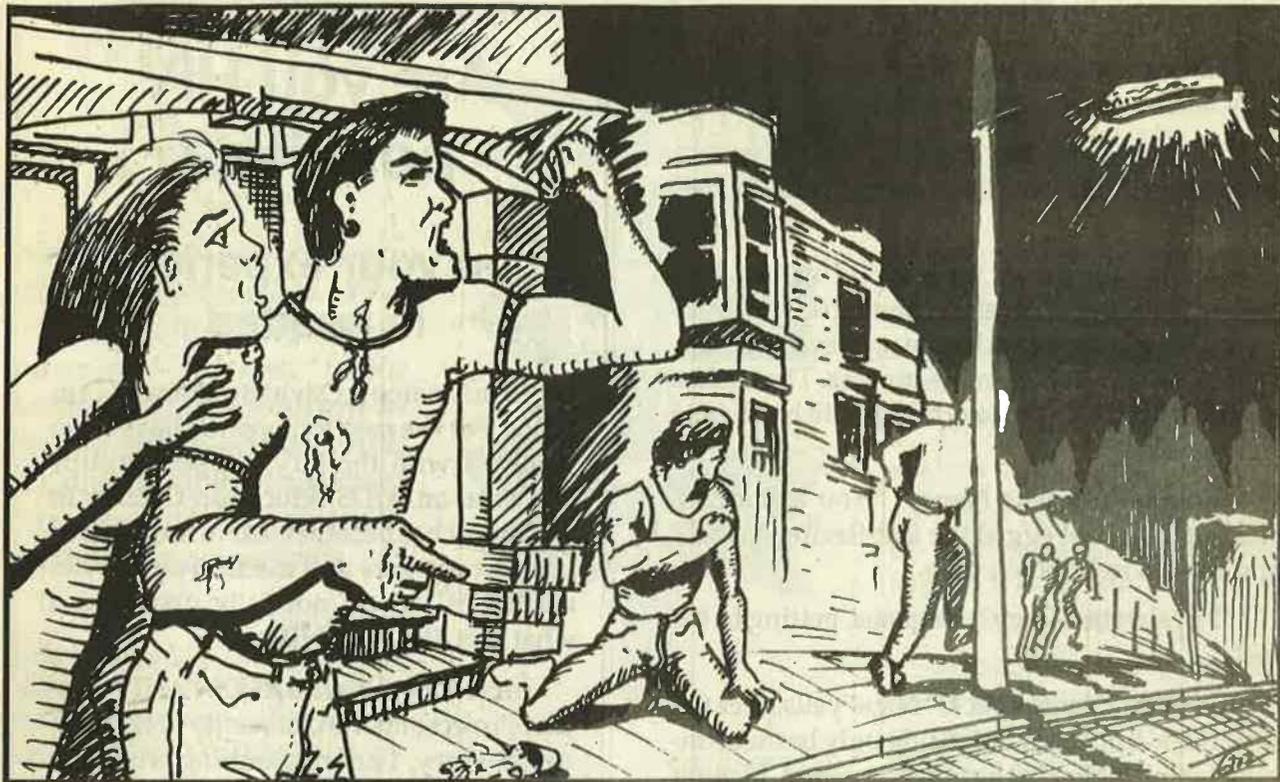
"Water it! I'll repot it for you!" Nancy grabbed the fern and hurled it down the stairwell. Nigel, dumbstruck, turned and hurtled down after it.

"Hang on, I'll get you some eggs for it!" she screamed.

#### Brad cabs it

Brad was feeling so much better. He loved late night shopping. The first pair of 501s he'd tried on fitted perfectly. The two T-shirts, pair of shoes, serviette rings, fabulous new lampshade and cushion covers now weighed heavily in his bulging shopping bags.

The cab meter ticked on. The lights changed. In a few minutes he'd be home, sipping a Manhattan.



Graphic: Ian Barbour

### Safe place?

"Well Robbie, here we are," Wayne said as they pulled up opposite the Bohemia Apartments, and reaching over gave Robbie a kiss. "Thanks for a nice day babe. Give me a call later tonight, okay?"

Robbie nodded and opened the door. "Did you really think I wouldn't?" They smiled at each other and Robbie leaned over for another kiss. He got out of the car and watched as Wayne drove off.

It wasn't until he was standing alone that he noticed three boys standing across the street. They were watching him. He suddenly felt uncomfortable.

Robbie fumbled for his keys as he walked towards the apartments. His fingers tightened around the whistle on his key ring.

"Hey look guys," the uglier of the three boys called out, "the little poof just kissed his boyfriend good bye!"

Despite his fear, Robbie crossed the street. He pushed the ugly boy out of his way, bawling out "lay off, dickhead!" as he climbed the stairs to the entrance.

The boy grabbed Robbie's t-shirt. At the same time the other boys closed in behind.

Robbie tried to lift his whistle to his mouth, but the bashers behind him grabbed his arms, knocking it to the ground. Before he could yell out, a fist landed in his stomach and he reeled backwards.

"You little AIDS carrier," the ugly basher hissed.

Suddenly, the front doors of the apartments burst open and Nigel stumbled into their midst

shouting "you're freaking crazy Nancy!"

An egg whistled past his left ear and hit the ugly basher smack between the eyes.

"You little worm Nigel!", Nancy yelled, launching another misdirected egg into the melee.

Robbie slumps to the ground as the two bashers holding him release their grip and start to flee. Nigel ankle-tackles the ugly basher, grazing his right knuckles in the process. The basher turns his head only to have his lip split by Nigel's right hook.

"Robbie!" shrieks Nancy. "You bastards!" She hurls her last egg at the fast-fleeing bashers and rushes to Robbie's side.

"I'm alright Nancy", he gasps, getting to his feet.

"And don't come back!" Nigel yells after the now thick-lipped and bleeding ugly basher running helter skelter in the other direction. Licking his own bleeding knuckles, Nigel mutters under his breath: "You may have taken on one 'AIDS carrier' too many this time."

Brad's cab pulls up. Leaping from the back seat he surveys the scene. "Is this private carnage, or can anyone join in?"

"Oh Brad", Nancy sighs, "I think they call this HIV living!"

"Come on, everyone," Brad says as he shuts them all inside, "I'll show you HIV living. The Manhattans are on me."

*To be continued....*

*\* Sadly, we bid farewell to talented authoress Dara Toad in this episode. Dara has decided to retire and make way for the new creative energies of Rod Adams. Welcome aboard Rod!*

## Are you HIV positive?

### then your experience is needed

Hi, my name is David Bunker and I am HIV+. For the past four years I have been involved with the HIV support groups and been an AIDS Education Officer. In this time it has become clear to me that our support workers and medical staff (who are not HIV+) do not fully understand what it is like to be HIV+.

In conjunction with ACON's HIV Support Project and the University of technology, Sydney, I am researching what it is like to be HIV+. This I have chosen as part of my Bachelor of Adult Education.

What I am asking for is no more than an hour of your time. In this period I will conduct a confidential recorded interview. (No names will be mentioned during the interview).

The aim of the research is to produce a booklet for those who work with people who are HIV+. Also for those who have just found out they are HIV+, so they see that they are not the only ones who feel the way they do.

If you are able to give some of your time and are willing to be interviewed, could you please contact me on 319 6577 (or leave a message on the answering machine - I will be discreet when calling back). I look forward to meeting you and to your help in this matter.

## Weight Gain

*Weight loss can be very distressing if we are HIV+. It's a visible sign that people notice. It's something we confront in the mirror everyday. And it's not healthy either. Neal Fitzgerald offers a diet plan for putting on weight.*

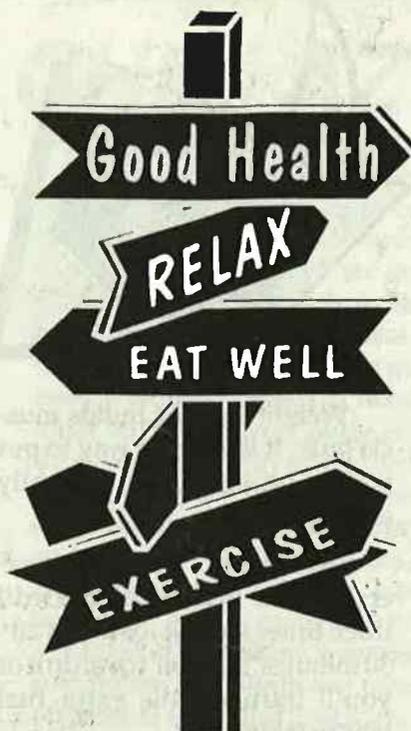
There's more to putting on weight than just eating enough of the right kinds of food, and in the right proportions to meet our needs. Often our bodies don't digest food properly - our digestive enzymes aren't being effective, or there's not enough of them. We may not absorb what gets digested because our gut wall is inflamed. Stress can cause our digestive system to shut down.

### Take your time

Try to eat in a relaxed environment, take your time over dinner and give it time to digest. Good company will relax you and usually means you will eat more slowly.

A glass of wine over dinner stimulates digestion.

Chew your food well, especially whole grains. Chewing breaks the food into smaller particles, so there is more surface



area for digestive enzymes to attack.

Get up half an hour earlier in the morning so that you can have a more leisurely breakfast.

### Make it tempting

The smell, taste, sight, and even the thought of food stimulate the production of digestive juices, so it's important to learn to cook meals that look good, smell good and taste good. Try using herbs and experiment with contrasting textures, flavours and colours in your meals.

### Getting interested

Keep your meals regular and don't skip any.

Mid morning and mid afternoon snacks or drinks help put

## No Pain

on weight as long as they don't dull your appetite for the following meal. Nutritious soups and vegetable juices are easily digested.

Try a light bedtime snack of yoghurt or wholemeal toast.

If you don't feel like eating try some pawpaw or pineapple half an hour before the meal to get the juices going.

Swedish bitters (from the health food store) or a strong cup of roasted dandelion coffee may stimulate appetite.

If you feel nauseous, ginger root tea before the meal will make you feel better. Use ginger in vegetable juices.

A glass of sherry before the meal may also help nausea. Stay away from oranges if you have this problem.

Slippery elm powder added to drinks or porridge can help calm an upset tummy.

### The main course

Make sure that you have a balanced diet of fresh, whole, good quality (and if possible organic) foods.

Heavy protein foods can strain the kidneys.

Sugary or fatty diets will put

on weight - but in the wrong places!

Aim to have 15% fats (from cold pressed oils, nuts and seeds), 15% protein (fish, eggs, tofu, beans, yogurt) and 70% unrefined carbohydrates (vegetables, whole grains, brown rice, dry baked potatoes, whole meal bread and pastas).

Fish or free range chicken (without the skin) five or six times a week plus tofu or beans for lunch and an egg or two in drinks or for breakfast will give you plenty of protein even if you're weight training.

Have lots of green leafy, yellow and white vegies and at least two serves of fresh fruit each day.

Raw vegies and sprouts supply enzymes, vitamins and minerals, so keep up the salads.

### Side dishes

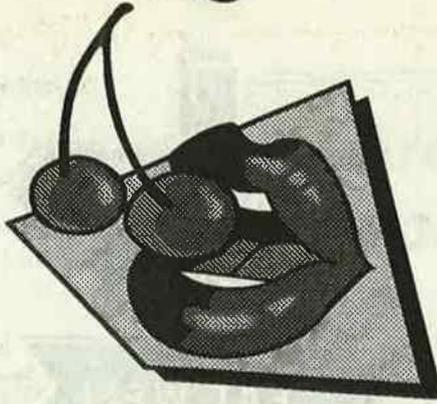
A multi-vitamin and mineral formula can be taken for a while to kick start your enzyme system.

If you are on chemotherapy or have a very poor digestive system, digestive enzyme replacement may also help. You can stop taking these supplements when your own enzymes get moving.

Live culture yoghurt or acidophilus supplements increase the health of your gut wall and improve the absorption of food.

### Extras

If you are susceptible to thrush or candida, steroid hormones can make it worse. It's best to avoid these.



Weight training builds muscle bulk. It is the best way to put weight on efficiently, healthily and attractively.

Do some form of aerobic exercise (that makes you puffed!) three times a week for about 20-30 minutes, but don't overdo it or you'll burn off the extra fuel you're taking in!

If you are anxious and stressed, you can do some form of relaxation or meditation. It's a good time to eat just after meditating.

Try not to panic. Resist the temptation to put on weight at all costs.

Eat a balanced diet, enjoy your food, reduce your stress levels, get lots of rest, fresh air and exercise.

If you experience rapid weight loss or are severely under-weight, see your health practitioner.

Even if you don't put on a lot of weight, these measures will make you look better and be healthier.

Next month we'll publish some weight gain recipes - so stay tuned.

## On the buses

Tiffany's Transport Service is a treatment related transport service for PLWAs. It operates from Monday to Friday, between 7.30am and 8.30pm. Tiffany's aim is to provide transport from home to treatment or appointments at St Vincents, Royal Prince Alfred, Prince Henry and Prince of Wales hospitals, and to the Albion Street Centre.

People unable to use public transport and/or unable to afford taxis or private transport, are encouraged to use the service. Our priority is to provide transport to people needing frequent treatments as transport can be both expensive and difficult to organise in these circumstances.

There is a charge of \$1.00 per day. The drivers have undergone first aid training. People needing constant attention, or who are seriously ill, should use an ambulance.

Bookings for Tiffany's are made through an answering service: 361 0958. Leave your name, appointment time and place, address and phone number, and we will call back to confirm that transport is available.

For inquiries about the service, phone the office on 360 2043. Drivers' rosters are prepared Thursday or Friday of the week before, so please call us with your appointment details as soon as possible. The service is operated by Central Sydney Community Transport Group, and funded by ACON.

Rob Lake

# Personal Strategies

## - CHI + AZT -

I am one of those "invisible" HIV+ lesbians who has found little support from western medicine in dealing with this virus. Information and research specific to women, let alone lesbians, is extremely limited.

I sero-converted in mid-1985 and spent the next four or so years drinking and using and basically in denial about my HIV status. So, when I began looking at alternative treatments my liver was already pretty shot from many years of alcohol and drug abuse and my state of mind was negative and often depressed.

Acupuncture was recommended to me as a way of restoring some harmony and balance in my body and mind. The Chinese theory behind acupuncture is that there is a life force in all of us called Chi energy and that when we are ill, this life force is not flowing properly.

The acupuncturists I have seen have examined me and taken diagnoses in a much more holistic way than western doctors ever have. My lifestyle, physical symptoms (however trivial), childhood history, prevailing stresses, predominant emotions etc are all taken into account.

I find this approach refreshing and supportive. The *person* is treated and not the disease. I have become more conscious of the state of particular vital organs in my body and the effect they have on me and less focussed on the virus itself.

Two years ago, I combined Chinese herbs with the acupuncture. The two therapies complement one another and I see my Chinese herbalist every two weeks or so. She checks all six pulses - three on each wrist. The deeper energy of major organs is monitored on the left wrist pulse and the superficial energy on the right. The herbalist can feel the Chi energy in the body from these pulses and in the healthy individual, these energies should balance. Also taken into consideration are the condition of the tongue, eyes and complexion along with any other physical or emotional problems.

The herbalist then writes and makes up a 'script' of different Chinese herbs: leaves, roots, pieces of bark etc, which contain the appropriate healing qualities for my condition. I then boil these herbs up in a clay pot at home and drink the liquid twice daily.

It takes a while to gain the effect from taking the herbs since Chinese herbalism works from the internal organs outwards, this is in contrast to western medicine which concentrates on symptoms exhibited from the invading virus.

I have come to greatly respect Chinese medicine which was in existence 300 years BC - about 2,000 years before the evolution of western medicine.

For me, the most valuable part is that I have been listened to, believed and given explanations by these practitioners of Chinese medicine and that *all* aspects of my

health are taken into consideration in their diagnoses.

Since HIV+ women are in a minority in Australia, we have needed to rely on our own anecdotal information about our HIV symptoms and drug side effects. We have had to document this information ourselves since it is not formally recorded. I have therefore found it helpful to see my body and mind from a different, Chinese perspective, where I do fit in.

Although I am an obvious advocate of Chinese medicine, I have not ignored western drug treatments. I take AZT as well and have done so for two years of the six and a half that I have been infected with HIV.

I have not had any opportunistic infections and believe that my personal combination of sobriety, Chinese treatments, AZT, meditation, yoga, swimming, laughter and the support of friends and other positive women helps me to maintain an optimistic attitude and healthy body.

My practitioners:

Deni Sevenoaks  
(acupuncture) 399 3216

Lily Liu (herbalist) 360  
1656

*Name withheld by request.*

*This is the second in our new series where readers write in about their personal HIV health strategies. Contributions are welcome.*

## Wellcome set for a bonanza.... But at whose expense?

Wellcome, the manufacturers of zidovudine (AZT/Retrovir) and acyclovir (Zovirax), two prominent drugs used in the treatment of HIV/AIDS, is set for a world wide marketing bonanza.

Early press statements have indicated that these two agents may have more benefits in slowing the progress of HIV than had been previously recognised. However, this is where the problem begins, as neither of these agents can currently be obtained without an exorbitantly high cost to the patient.

To understand the problem, there is a need to review the results from these trials. The first study was looking at the effects of acyclovir and zidovudine on the incidence of the opportunistic illness cytomegalovirus (CMV), in people with CD4 (T cell) counts of 150 or less. The study was terminated when it was observed that the individuals within the combination treatment arm of the study, (i.e. acyclovir and zidovudine together) were surviving twice as long as the people who were receiving zidovudine alone. However there was no dif-

ference in the number of cases of CMV being reported within the two groups.

The study was also able to show that after a six month period of treatment, the CD4 count in the group taking the combination treatment remained at a higher level than in the group taking zidovudine alone.

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*Acyclovir is not, at present, a realistic treatment option for an individual in advanced stage of HIV/AIDS, unless they are exceptionally wealthy.*

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The conclusion drawn is that when these drugs are used together, there is a direct effect on the replication activity of the virus, and that this effect is significantly greater than when zidovudine is used alone. These results are also a reproduction of a previous trial which looked at similar issues. It can therefore be assumed that these responses are real and that there may well be a

beneficial treatment option to consider for people who are at the lower end of the CD4 cell range.

While acyclovir is listed on the Pharmaceutical Benefits Scheme (PBS), the government reimbursement scheme, it is accessible only to a small number of people whose clinical profile falls within the approved indications for the drug. In the case of the 400mg tablet of acyclovir, the requirements are that it be for the treatment of non-ocular herpes zoster with severe pain the patient must be greater than 60 years of age, with the duration of the rash being less than 72 hours.

Clearly, this is very remote from HIV/AIDS, and aciclovir is not available to treat this condition unless the individual is willing to pay for a private script. The dose recommended from the trial is 3200 mg / day (i.e. 8 x 400 mg tablets per day). Consequently a script for 70x 400 mg tablets will only last for a little more than 8 days. This then works out to 42 scripts per year at an annual cost to the patient of \$17,566.50 plus the cost imposed by the pharmacy to dispense the script.

Even if a clinician was pre-

TREATMENT NEWS



look at the effect of zidovudine in reducing the progression of HIV disease among people who do not have any symptoms of HIV infection and who have a CD4 cell count that is greater than 400. The trial had two arms, with one group receiving 500 mg of zidovudine a day and the other receiving only placebo capsules. This study has been running since December 1988 and had enrolled near on 1,000 volunteers. The specific factors that were looked for were the progression to category IV (AIDS) and or a fall in CD4 count to 350 or below. All patients who completed three years within the study were then offered zidovudine unconditionally.

The preliminary results show that at the point where all participants had been in the study for two years, the likelihood of the placebo group progressing to category IV AIDS or a T cell level below 350 was twice as high as those people who had been taking zidovudine. This effect was seen to occur at all levels of T cells.

The other interesting fact that came out of the study was that the reported side effects were no different in the treated group to those seen in the placebo group. This suggests that the use of zidovudine at an earlier stage, i.e. when the immune system and the body is fully functional, may lower the risk of side effects.

The implications are enormous as these results strongly support the theory that *all* indi-

viduals who are HIV antibody positive should consider starting zidovudine, no matter their CD4 level.

The potential market size increase for Wellcome as a result of this trial is staggering. In Australia alone the potential number of individuals who could benefit would be in the order of 15,000 - 20,000 which is, at a conservative estimate, about eight to ten times higher than the current number using it.

However this is small time when compared to the potential within countries such as the United States, where the figures range into the millions.

In Australia the official indication for use of zidovudine is for people who have a CD4 count below 500. In theory this poses a problem for individuals who have higher T cell levels, in terms of

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**The implications are that *all* individuals who are HIV antibody positive should consider starting zidovudine, no matter their CD4 level.**

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obtaining the drug through the reimbursement scheme. We would suggest that, in the light of these fairly conclusive results, that there should be some changes in the availability of zidovudine.

With the substantial increase in the volume of drug that will be used on a world basis, we would

suggest that Wellcome again review the price downward.

In Australia it currently costs about \$4,000-\$5,000 per year to keep an individual on zidovudine. If this were to fall to around the \$3,000 mark, then it might be listed on the PBS. There are a number of products within this cost bracket currently listed, setting a precedent for the inclusion of zidovudine (and also ddI).

A listing on the PBS will provide a further advantage as it will then allow the person's primary care physician (i.e. the GP) to prescribe the drug. It is still an unacceptable fact that New South Wales is the only state where zidovudine can be prescribed in this way. Even then the prescription has to be taken to the "designated" hospital pharmacy for it to be filled. If listed on the PBS the script can be filled through the normal retail chemist. This would have a substantial impact on people who live outside the immediate vicinity of a hospital or in rural areas.

If Australia is to continue to provide a publicly funded health care scheme that prides itself on being equitable to all the community, it is important that there be free access to treatments that provide significantly improved life quality and survival time to members of the community. This of course does not confine itself to HIV/AIDS, although these principles are currently being strongly tested within this area.

by Ian McKnight  
AFAO Treatments Project

# AIDS BEDS NOW!

The ACT UP demonstration outside the private residence of the NSW Health Minister John Hannaford demanded more AIDS beds in Sydney hospitals.

This demonstration was ACT UP's last resort, after attempting to negotiate with the NSW Health Department, the AIDS Bureau and the various hospitals - to no avail. The street theatre ('The Hannaford AIDS Ward') shown in the picture was preceded by a string of stories, told by people with AIDS, about the ghastly bed shortages - being left in casualty ward, having to lie down on trolleys instead, having to stay in corridors because there was no space in a suitable ward. Pictured on the stretcher is Brian Hobday, who died of AIDS eight days later.

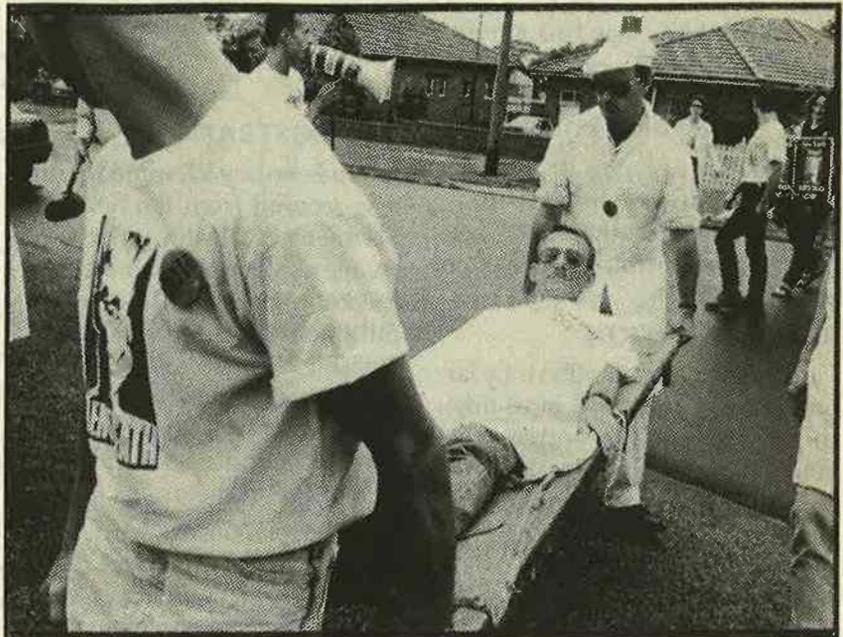


Photo: Jamie Dunbar

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## New women's group at St George

A new women's group has started at the AIDS Day Treatment Centre of the St George Hospital.

It is for women who are HIV negative. The women are either the partners of, or care for, men who have any stage of HIV infection.

Although this is the only common point of the group, the women involved have found it

very helpful and supportive. They find they are able to break down their feelings of isolation and discuss their own concerns.

The group meets every second Thursday evening and is totally confidential. If anyone is interested in joining please call Stuart Linnet on 350 1111.

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## OUR LOVE

**OUR LOVE - GAY LOVE** - is the central theme for the 1992 ACON annual campaign, which was launched in February by Betty Hounslow.

OUR LOVE celebrates the diversity within the gay community and reinforces the comm-

onality: a shared identity and a united stand against HIV.

Probably, by now, you will have seen OUR LOVE images or participated in OUR LOVE activities. The campaign includes poster/ads, badges, t-shirts, a valentine's day card, shows, displays and a film advertisement. The posters and cards feature positive messages about living with HIV, safe sex and safe injecting drug use.

The annual campaign is funded by the NSW Department of Health through the AIDS Bureau, but this year funding has been supplemented by generous donations from Darlinghurst businesses, both gay and non-gay, and the work of many dedicated volunteers.

# Committee news

As the term of the current committee draws to a close, it is a good time to reflect on our major achievements over the last year.

PLWA NSW has had a busy and hectic year, a year where the committee and the organisation have undergone quite a few changes.

Following are a list of various activities and areas that PLWA has been involved in this year, on your behalf:

## REPRESENTATION

PLWA representation is by far one of the committee's most time consuming jobs. We represent the voice of people living with HIV and AIDS on a great many bodies, some one-off and others ongoing. Listed below are some of the major representations we have made in the last 12 months:

The NSW Ministerial Advisory Committee on AIDS Strategy, the body setting state policy for the NSW Health Minister, (Stuart Linnert for the first half of the year and now Lloyd Grosse). The Australian National Council on AIDS, (Robert Ariss). The Anti-Discrimination Board's Consultative Group on HIV/AIDS Discrimination, (Guenter Plum, Claude Fabian, Titi Chartay and Lloyd Grosse). The Central Sydney Area Health Service's AIDS Policy Committee, (Gerald Lawrence). Albion Street AIDS Centre Committee, (Peter Base). The AIDS Council of NSW, (Claude Fabian and Lloyd Grosse). The National People Living With AIDS Coalition, (Claude Fabian). The Badlands Committee, (Michael Staiff, now also the Secretary of the Committee of Badlands). The AIDS Treatment Action Coalition, (Claude Fabian, Guenter Plum and

Lloyd Grosse). The HIV/AIDS Discrimination Project (Commonwealth Department of Health), (Guenter Plum). The HIV Briefs Editorial Committee, (Guenter Plum).

## ADMINISTRATION

In February 92, more funding was secured from the NSW Department of Health, which will enable us to employ our Newsletter Co-ordinator, Jill Sergeant, on a full time basis to produce a monthly *Talkabout*. We were also funded for the upgrading of our Administrative Support Officer to a more pro-active and responsible position of Co-ordinator.

Our relationship with ACON has been an issue of much discussion, and with the ACON Organisational Review completed there will be new talks about where PLWA fits in the ACON structure and how the dynamics of the two organisations will continue to work.

## SERVICES AND PROJECTS

**Referral and Advocacy:** PLWA continues to advocate on behalf of individuals with hospitals, Doctors, Government and AIDS Services of all kinds. We continually respond to requests for information and referral.

**Doctors Forum:** PLWA held a forum to air some of the problems around HIV/AIDS and general practise. Our thanks to Peter Hornby for co-ordinating this forum.

**Public Relations:** We have been placing more emphasis on getting heard in the media and have endeavoured to increase both PLWA NSW and people liv-

ing with HIV/AIDS' media profile.

**Joint Committee on Fundraising:** PLWA has recently brought the AIDS fundraising bodies together to see if there are better ways to handle the issue of fundraising in NSW. Some of the participating groups are the Bobby Goldsmith Foundation, the AIDS Trust of Australia and the AIDS Council of NSW. Our hope is that these groups will harness fundraising more effectively so that people living with HIV and AIDS will get the greatest benefit from the variety of fundraising which is happening in NSW.

**Regional Outreach Program:** PLWA was funded by the Department of Health under their non government Organisation Funding Program to undertake outreach work in non-metropolitan areas in NSW. Nicolaas van Schalkwyk visited the far North Coast of NSW in June/July 1991.

**Planning Days:** We have had two successful planning days where we were able to get together as a group and discuss the issues of PLWA for a whole day. These days have proved very useful.

**PLWA  
ANNUAL GENERAL  
MEETING  
and Launch of Monthly  
*Talkabout*  
Thursday, April 9,  
7.00pm  
ground floor, 188  
Goulburn St  
Darlinghurst**

# 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.

## HIV Support/Action group HUNTER AREA

Is held at 6.30pm on the 4th Wednesday of every month 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



## HIV RELAXATION SESSIONS

Would you like to learn various easy healing, strengthening, relaxing techniques to help in HIV?

Open to people with HIV,  
Carers, Partners, Family

at NO financial cost

Come along Wednesday Evenings  
between 6-7pm

Newtown Neighbourhood Centre  
Cnr Australia & King Streets  
Newtown

## ACON meditation group

**Where?** In the Training Room, ground floor, ACON, 188 Goulburn St. Darlinghurst

**When?** Tuesday and Thursday mornings, 9 - 10.00am.

**Cost?** Free: social security/unwaged  
\$2 suggested donation for waged (towards purchase of meditation cushions)

Open to all people living with HIV/AIDS, their friends, lovers, supporters, carers, health workers etc. All welcome

### About meditation:

Meditation can be useful as a means to reduce stress, energise the body and increase clear thinking. There are many techniques and traditions of meditation, some of which are specifically beneficial in the healing process. Meditation does not have to have any particular spiritual context or implication to be effective. Material on, and some assistance with different techniques will be available for beginners.

Try to wear loose fitting clothing if you can, and, if you have one, bring a meditation cushion.



## 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 PW HIV/AIDS.  
For info contact Peter (043)23 7115 or Paul (043) 20 3399.

## NUAA 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 individuals to come and share ideas as they relate to injecting drug use.

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

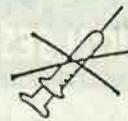
## SERVICING THE WESTERN SUBURBS the KENDALL CENTRE

aids information & support services

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

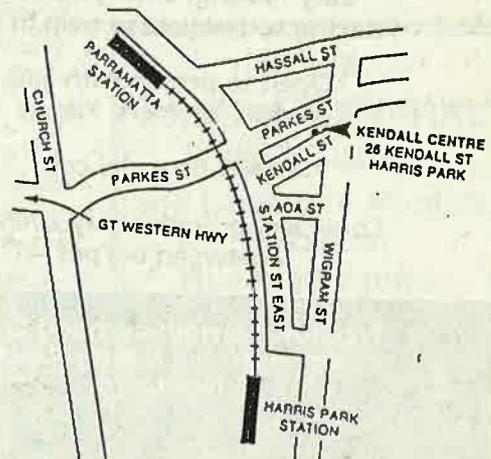
A unit of the Western Sydney Area Health Service

Don't share  
needles &  
syringes



ANYONE CAN GET AIDS

Always use  
condoms



## New England Region Needle Exchange Program

For locations of outlets and outreach services  
067-66 2626 message, 018-66 8382 mobile  
A free and confidential service  
Providing fits, swabs, water, condoms, lube,  
information and education

## Western Sydney Area Health Service

### Before Clinic Education for HIV+ people

Tuesdays at 1.30pm, clinic B,  
Westmead Hospital

**April: Nutrition and You**

Tuesday 7, 14, 28

**May: Participating in Clinical Trials**

Tuesday 5, 12, 19, 26

For more information please contact Judith  
Townsend-Stahre 635-0333 ext 327

# 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)281 0362 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 Rosemary Bristow, 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):** GPO Box 164, Canberra ACT 2601. Contact Matt Bradshaw: (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 "Positive Time" group:** a support and social group for PLWAs in the North Coast region. Contact ACON North Coast Branch (066)22.1555.

**North Coast - Wollumbin CARES:** Community AIDS Resources and Support. Contact Simon (075)36 8842.

**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)318.5400. 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. Every 2nd Wednesday, at 12.30. 5th floor, Notre Dame bldg, Burton St Darlinghurst. Ph Linda Barr 339.111 page 248 or Marie Pettitt Page 256 to indicate attendance.

**Partner's group:** A support group mainly for partners of people who are in/outpatients at St Vincents. Every 2nd Tuesday, 6 - 8pm. Please phone Chris Connole on 339 1111 (page 345) if you're interested in attending, or Leslie Goulburn, (page 255).

**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. Phone (02)754 2237.

**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

**John Hunter Hospital (Clinical Immunology Ward):** Lookout Rd, New Lambton, Newcastle (049)21.4766.

**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 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)350 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).**

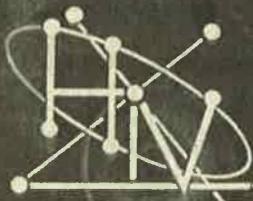
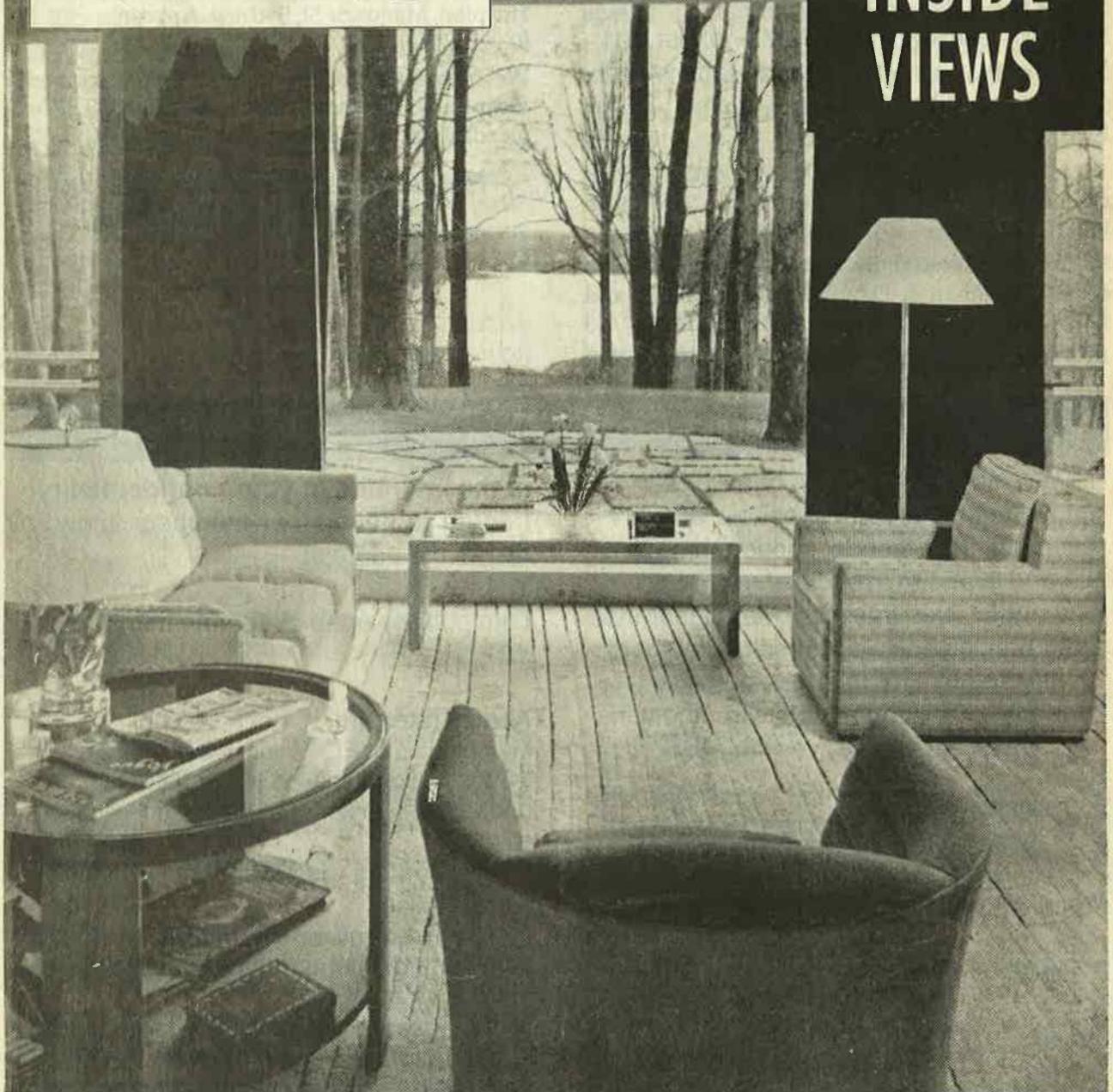
**Please forward this completed form with all subscriptions/memberships to PLWA Inc. (NSW), PO Box 1359, Darlinghurst NSW 2010.**

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

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

# HIV *living*

## INSIDE VIEWS



Those of us living with HIV have inside views. We have a lot to gain from sharing these with each other. And a support group is the place to do it. Call us to find out more about joining one.

• **SUPPORT PROJECT (02) 283 3222 or 283 2453**

AN INITIATIVE OF THE AIDS COUNCIL OF NEW SOUTH WALES INC. (ACON)