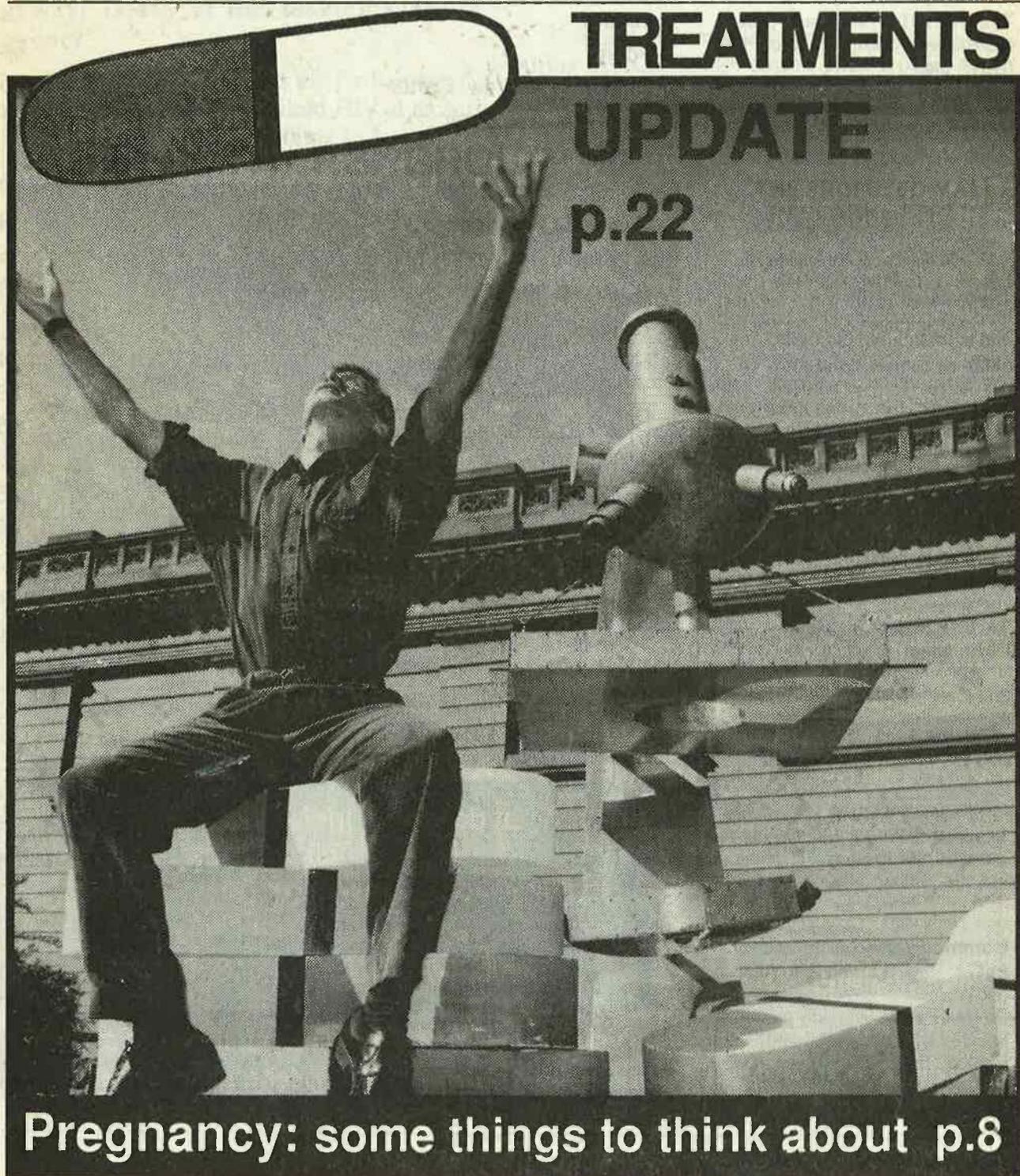


Talkabout

Newsletter of People Living With AIDS Inc.(NSW)

Where we speak for ourselves

ISSN 1034-0866



TREATMENTS

UPDATE

p.22

Pregnancy: some things to think about p.8

Photo: Jamie Dunbar

Vol. 2, No.3 SEPTEMBER/OCTOBER 1991

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Commonly Used Abbreviations:

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 Final deadline for November /December
issue of Talkabout is
October 8

Send contributions to PO Box 1359, Darlinghurst
2010.

Call Jill on 283 3220 to find out the date and time
of the next Newsletter Working group meeting

Update on ACT UP Update on ACT UP

Innocent victims. Naughty guilty victims. Naughty Franca Arena. Medically acquired HIV. O-U-T-I-N-G-!!! Crossover membership?! Who is Queer Nation anyway? Is any of this making sense to anyone?

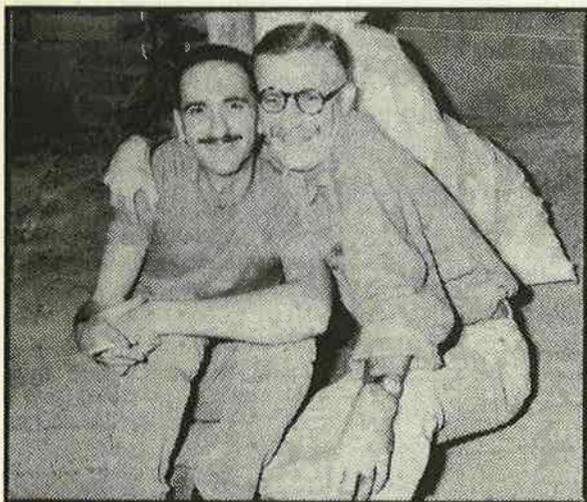
When ACT UP protested the Parliamentary Inquiry into Medically-Acquired HIV at its August 8 hearing, there was nothing to foretell the now-infamous Franca Arena Affair. ACTUP had organized a simple zap, where we would put up our FRANCA ARENA:HOMOPHOBE posters (not outing posters, mind you!), distribute non-discriminatory terms of reference as formulated by ACT UP for the Committee to adopt, and demand that Franca Arena apologize for the outrageous statements she made about how people who got AIDS through a "lifestyle" should have known better and so should be treated differently from people who got it from hospitals.

After all this was done Parliament security was called and escorted ACTUP from Parliament House. We thought that would be the end of the matter. But, no. Franca Arena holds a press con-

ference saying that minutes before the protest, she received a threatening phone call telling her to beware of AIDS infected needles, and also that John Stapleton of the *Sydney Morning Herald* told her that her sons were to be outed.

Franca Arena and the media attributed this outing to ACT UP. Of course they would. Any radical action in Sydney to do with poofers has got to be ACT UP, right? Remember *One In Seven's* red paint and how ACT UP got asked time and time again why we did it? This cost ACT UP much precious energy doing an obscene amount of media appearances denying involvement in the outing of Franca Arena's sons (who were outed by Franca Arena herself at her own press conference!). Energy that could have been much better spent on AIDS activism.

But the bottom line is: the ACT UP protest worked. The issue of the inquiry into medically-acquired HIV is being discussed extensively, in and out of the media. And it looks like the right opinions are being formed. The *Sydney Morning Herald* (John McClelland) and the *Telegraph Mirror* (Sue Quinn) were amongst media that ran stories saying how despicable ACT UP's actions were, but that their reasons were valid. Remember, ACT UP is an in-your-face organization. It isn't here to be stroked or praised. It's here to end to the AIDS crisis.



Photos: Jamie Dunbar

Scenes from ACT UP's fundraising party QUEER see, there's more to ACT UP than placards and die-ins.



Maitraya meals

Dear friends,

On behalf of the Maitraya day Centre Foundation Inc, I would like to express our thanks for your kind donation to the Foundation Inc. of \$1,000.

As suggested, this amount has been dedicated to providing an additional meal service on Wednesdays.

The Wednesday meal has been trialled for the last six weeks, with 15 - 20 people being served each week. Our clients are very grateful for the additional meal and have commented that it certainly does help them. The Maitraya Day Centre Foundation Inc. is very pleased to advise that this additional meal will be continued in the future.

Matthew Kanters,
Secretary.

(This donation was raised from sales of PLWA T-shirts. - JS.)

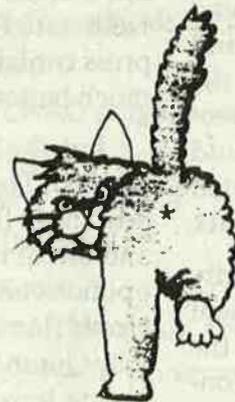
Request

Hi, my name is David Bunker and I am HIV+. I am seeking HIV+ people to interview for a research project which will result in a booklet for use by support & health care workers who work with HIV+ clients. If you are able to give some of your time and are willing to be interviewed, please call me on (02)319 6577.

Seven phrases that turn our stomachs worse than AZT

1. You look really good. Really
2. Does your mother know?
3. Are you sure you're all right?
4. You need to look for the deeper meaning in all this.
5. Gee, I thought you were dead!
6. Avoid cat faeces.
7. Straight acting GWM, HIV-, seeks same.

(from a list by Patrick McGrath)



If you would like to add to this list with your own most hated HIV/AIDS remarks, send them in and we'll publish them in the next issue

PO Box 1359 Darlinghurst
2010

Time mine

Time stand still, be still like the trees
Let me inhale the clear wind
and hold onto it inside myself
Expelling it only when I see fit.
I challenge you - time
I hold you in my fists caught
You cannot move on until
the breeze whispers softly
through my hair
until the crow cries with its
brilliant familiarity
or until I open my fist
and I set you free.

by Manny Papadopoulos

Andrew Carter

5.7.54 - 20.6.91

I learned of Drew's death whilst on my way to Norway and the Arctic circle. This is the unfinished trip Drew and I planned last year.

It was Drew who got me hooked on overseas travel and we had four trips together. It started with a 'rescue me' weekend after Drew had gathered me up after I had found myself a little glum following the end of a seven year relationship.... but I'll go back to the 1950's for some background.

We started out as womb-mates and in that confined environment got on surprisingly well. I remember a little rough-housing and that special feeling of not being alone. When Mum went into labour we had our first D & M and Drew's logic won out over my chaos theoretics and it was decided he would go first, but I could break the sac.

Through our infancy we shared our cribs, through our childhood we shared prams and bedrooms and from adolescence we shared girlfriends, bongs, then boyfriends. The occasional fight would merely be over material things like Mum's satin party frocks or Nanna's old stellites.

Drew did well at high school and moved on to teachers col-



Photo: Jamie Dunbar

Andrew (Scarlet) Carter (centre) with co-founder of the Australian AIDS Memorial Quilt, Terry Giblett (left) and Mike Smith, co-founder of the American Names Project

lege we led quite different lives around this time but did cross paths at sordid parties. Our characters were laid down over this period - Drew and his smart yellow sports car and me on some filthy Triumph or BSA. He had his first trip to Europe and was hooked. Then I moved to Sydney, Drew to Canada. He returned to Australia after a year and moved into my house in Darlo.

As gay men we loved Sydney. The friends, lovers, parties and especially the community. We continued to travel extensively with his turf being overseas and mine being the Australian bush.

It was when I was living in Victoria that I learned through his letters of the gay related immune disorder and how it

was affecting his mates in SF, LA and NY. Then came his own positive result. I needed to be closer again and came back to Sydney.

His job in travel was his life. Always on the drawing board there was an elaborate vacation planned. I think at last count he'd been to 48 of the US states. We went to the Gay Games in '86 together and as proud reps in the Australian cheerleading squad, he showed me his haunts in the Castro and West Hollywood. We drove through the Rockies and danced through the bars and he was the best travel companion.

Drew meticulously recorded the progression of his HIV illness. Aside from his involvement in policy and service provision for fellow PLWAs he

planned for his own future. By now, Drew had lost most of his close friends to AIDS. Gordon, his lover of five or six was dead. So was Brian, Grace, Paul from New York and others.

The Australian Quilt was born from him making panels for his mates with US contacts - and sending the panels to the Names Project in San Francisco. He always reported to me on treatments he was trying and potions that sounded promising. The constant sweats, shits and skin complaints had to be made comfortable and he wanted others to learn of his experience.

Then last year he spoke of the one big special overseas trip. He didn't speak of it as his last, but he wanted it to top all the others. We planned it for a few months. Railpasses throughout the UK and Europe, especially around the Baltic to Leningrad. Of course, as an avid royalist he called it St Petersburg.

Drew was a sick man by this time and although there was the need for him to not travel alone, he so much wanted to, and did, show me the places he so much loved. He dragged me around the alleys of Venice, I could barely keep up. ... And the highlight, when he had those 'boy in the sweet shop' eyes, was Berne, city of bears. Bear fountains, statues, shops, shirts, hats and

pens. Bear everything. Here Drew O-D'd on his arctophilia.

Berne was also where he had to make a hard decision. It had been a long holiday for a sick man. Afternoon naps were getting longer and when you travel with an illness there is the feeling of maybe being trapped. We beelined it to Amsterdam where we assumed there would be user-friendly services. I called my mates at ACT UP/Amsterdam and we were in a clinic first thing next morning. Drew was poorly and he had to decide between stopping still for at least a month, or to head home. He chose the latter, insisting I continue on with the tickets we had. He was hospitalised in Sydney and the run of transfusions began.

Over the next eight months Drew's physical health declined at a steady rate and throughout he was clear and concise, tho' sometimes through a morphine haze. We cried and cried, and laughed. We joked with each other and our mates. We knew

the realities. Those close to him felt an immense, radical change. What was he up to. The news of the great Teddy Bear Cull swept Betty Bay and environs. Drew had decided where he wanted to be. He wanted to return to Perth.

That special thing Drew and I had as twins would often have people asking "What's it like being a twin?" Of course the answer is "We don't know. What's it like not being a twin?" I believe it's the love or closeness we all feel. On June 14th I wrote to Drew and Anne, and in a footnote to Anne said "Annie, I'm scared. I can't feel Scarly anymore!" He had a week to go and the pain and the morph was now serious stuff. I can't put into writing what that week felt like, but I know we all would have felt it.

Thank you all for loving Drew. Thank you for your participation.

Don Carter

IT'S NOT TOO LATE

to fill in the *Talkabout* Survey

(which was published in the July/August *Talkabout*)

The survey is not just an exercise in PR - your opinion is worth a lot to us. If you think *Talkabout* is important, if you think we could be doing it better, if you have ideas for its future, tell us about it. Have your say.

If you don't have a copy of the survey, give us a call on 283 3220. Send completed surveys to: **Reply Paid 595, PO Box 1359, Darlingurst 2010.**

Results & feedback will be published in the next issue.

Fighting for my people

My name is Michelle. I have HIV disease. I work as a women's educator in the AIDS field. These last two factors caused considerable conflict recently when I attended the 1st National HIV Positive Women's Conference and, upon returning to Canberra, writing a report about the way I viewed the conference. Because of others' opinions I found myself attempting to separate 'the worker from the positive woman'. After much inner searching around this issue I have come to the conclusion that for me they are one and the same. I work with HIV/AIDS because it is my life and therefore the two cannot be separated.

Approximately 50 positive women from around Australia and New Zealand attended the conference although unfortunately numbers tended to dwindle to around twenty women on the last day.

For many the conference was extremely confronting, due, in my opinion, to the diversity of the women attending. They ranged from upper middle class to women who had done the drugs, prostitution and jail trip. Time since diagnosis ranged from seven years to a couple of months and knowledge of the virus from none to "as much as anyone can know". Some women work in the AIDS field, some attended positive women's support groups, some were still intent on 'hiding' their HIV status and some had not come to terms with their status and were going through various stages of denial. Some had never met another positive woman.

The main issues highlighted for me were those of discrimination, the lack of knowledge of HIV/AIDS and the disinterest in 'AIDS politics'. Many of the women have little or no knowledge of the virus or of current medical treatments for HIV. Their primary care givers in some cases were equally non-informed, particularly where women are geographically isolated. In a few cases cited, medical practitioners were unwilling to access even basic information as they considered it a waste of time when perhaps only treating this one person with HIV.

Discrimination and rejection because of HIV has caused enormous damage to the self esteem of many of the women. Unfortunately, rather than being openly angry about this, these women have taken to 'hiding' their HIV status instead.

Women with HIV are discriminated against daily

and in many instances are unaware that it is discrimination. They accept this treatment as part and parcel of living with HIV/AIDS. I heard many instances of discrimination at the conference and yes, it made me angry.

Women are now a priority in the AIDS epidemic. ACT UP's slogan has been SILENCE = DEATH ACTION = LIFE. Both of these have proved true. How many deaths do women have to see before we begin to fight for our own? I have lost many friends and acquaintances since the beginning of the epidemic and it makes me sick thinking of the many more I have yet to lose. I am tired of listening to excuses from women about why they can't get involved. I am tired of saying I understand their reasons for remaining silent. I will no longer apologise for not understanding. People are dying, women are dying, people, including women, are being discriminated against daily in the most horrific ways and this will continue.

We will never have specific women and AIDS services unless women come out and demand them. Discrimination will not stop unless we fight to stop it. Women do not have to have a positive status, they do not have to disclose, to be vocal about the wrongs that are done to us as PLWHIV/AIDS. Gay men have been fighting for their own since the beginning of this epidemic, they have fought for women when necessary. But they don't have to and we should stop expecting them to, they have enough on their hands.

There is nothing to stop women joining groups such as ACT UP or PLWA and fighting for the rights of all positive women with them. Unless positive women come out of hiding nothing is going to change for us and women have no right to complain when they are doing nothing to make changes. These are some of the comments that I made at the conference.

I have been told many times and again at the conference that it is my choice to be public and vocal about living with HIV. I question the word choice. I could not live knowing that my life depended upon doctors and governments 'doing the right thing'. If I want to live, if I want 'my people' to live, then I don't have a choice.

**Michelle Morrison, HIV+ woman
Women's Officer, AIDS Action Council of the ACT.**

T

POSITIVELY PREGNANT

Watch any TV soap opera, read any popular magazine and you'll get the message: Women with HIV can't have children. Can't? HIV doesn't cause infertility. The not-so-hidden assumption behind this statement is that women with HIV should not have children - even that they no longer have a right to do so. At the very least, there's an assumption that HIV+ women no longer want to have children.

The reality is rather different. Women with HIV do want children and they get pregnant. Some find out they are antibody positive when they're already pregnant, some decide to become pregnant, some have failed contraception. Generally, they really want that baby and believe that they do have a *right* to have it. So may their partners. And you can't force women not to get pregnant or to have abortions, without a severe infringement of their civil liberties.

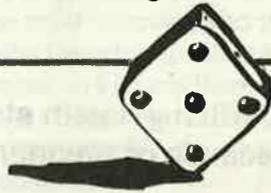
Pregnancy for HIV+ women should not mean an immediate termination, but it does mean some tough decision making. You'll need to consider some difficult ethical issues - such as your right to have a child versus a child's right to be born without a life-threatening infection. The risk of having an HIV+ child may be as low as 13% - is that an acceptable risk for you? Or maybe the possibility of an infected baby is a lesser evil than termination. Ultimately, the ethical dilemmas are yours to resolve. The main



thing is not to rush into a decision that you may later regret - whether because it was the wrong decision or because it was made in too much haste. This section of *Talkabout* aims to help you make that decision.

Positively Pregnant was compiled with the assistance of the Paediatric AIDS Unit at Sydney's Prince of Wales Children's Hospital. The Unit provides a range of

services to HIV infected children and their families. If you would like information or counselling about pregnancy call Trish Langdon (Social Worker) on (02)399 2772, Dr John Ziegler (Paediatric Immunologist) on 399 4537, or Marilyn Cruickshank, (Clinical Nurse Consultant) on (02)399 2774 .

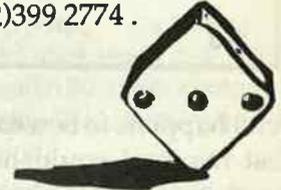


1. Will my baby be born with HIV or AIDS?

All babies born to women who are infected with HIV will have maternal antibodies to HIV. This does not mean all babies will be infected with HIV, but the baby is at risk and a number of studies show that there is a 13 - 30% probability the baby will be infected. Studies have shown that if a woman is symptomatic or viremic (ie, where the virus is actively replicating itself; this can only be diagnosed by blood tests), she is more likely to transmit the virus to her infant than if she remains asymptomatic and has normal tests.

Maternal antibodies remain in the baby for 12 or even up to 18 months, making a definite early diagnosis difficult. Doctors will attempt to isolate the virus to speed the diagnosis process, but often a baby can only be diagnosed with the onset of symptoms, such as oral thrush, failure to thrive, bacterial infections, diarrhoea etc. It is very important the baby be checked regularly (at least once every six- twelve weeks) so as to maximise the possibility of early diagnosis and hence the prompt use of appropriate treatment.

Babies, if found to have reduced T-cells, may be put on AZT and/or bactrim.



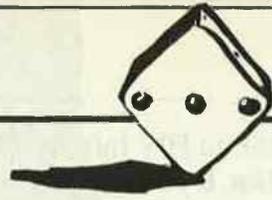
I was married in March, discovered I was pregnant in May, it should have been what a newly married couple hoped, instead...I was devastated. I had been diagnosed, when donating blood, as being HIV+ two years earlier and having children wasn't something I should do.

One of my first thoughts when I was told I was HIV+ was that I would never have children. I told my immunologist I was pregnant and expected him to say "You must have a termination", but he didn't. My husband and I had to make the decision.

It was so hard to know where to turn, where to find information to help us make a decision, to know if we really had a choice. There were so many questions and so much to consider.

If the worst happened, how would you tell your child you infected them? The guilt of being the cause of a child's suffering. Was I being selfish and irresponsible if I went ahead with the pregnancy? Was I being selfish if I terminated? Also knowing how the hospital system works and that having a baby is not a very private matter I was worried everyone would discover I was HIV+ if I had the baby. I imagined people coming to see me in hospital would notice the unusual care being given. (I didn't tell my nursing friends until after the baby was born, in case they discovered I was infected. Such secrecy is sad.)

It was not until I contacted a great friend,



2. Is there a safe test before birth which would indicate whether my unborn baby will be infected?

No.

who happens to be a social worker, that I realised just maybe I could have this baby. The social worker started searching for information and statistics on infected women having children and the effects of AZT on the foetus. We spoke to different medical people who seemed more positive than I had expected.

Emotionally, trying to decide either to terminate or continue the pregnancy was harder than coping with being diagnosed HIV+. I remember wishing someone would tell me what to do, wishing I could see into the future. My husband didn't pressure me, but I knew he was hoping we could go ahead with the pregnancy.

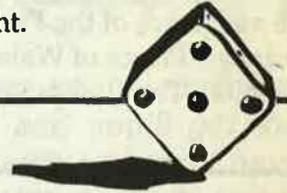
The decision to have my baby wasn't made at a decisive, exact moment. I just stayed pregnant and eventually knew I couldn't terminate. I had the feeling what is meant to be, is meant to be.

My beautiful baby girl turned seven months today and we had a day of waiting for test results. We still don't know if this story has a happy ending. I have days when I fear the worst and I wouldn't cope if she is infected, but in between those fears there are some wonderful times and looking at my daughter, I know I made the right decision.

My husband's thoughts

I knew before marriage that my wife was HIV+, but love and support took its course, just like her pregnancy, and so we have become a HIV conscious family. Earlier it was day by day with not a lot of talk about the future, but a family must

have a future and strength. We have been lucky to have great support and trust from family and friends. We have not been treated like lepers but real people with a small hiccup in life. We cope well but inside I hope for a trouble free, long life with my new family. I can see a light at the end of the tunnel and I hope doctors and researchers strive for a brighter light.



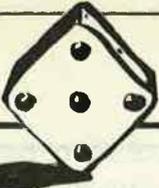
3. Will my health status change because of pregnancy?

No. Recent studies confirm that pregnancy does not hasten the progression of HIV in pregnant women or adversely affect their health. However there may be a slight, but not necessarily permanent, deterioration of their immune system in the post partum period.

When I received my HIV+ diagnosis, just over two years ago, I believed I would not be alive for much longer, so for me to even consider having children was out of the question. I was very distressed; I had always seen myself, one day, being a mother. My partner had often expressed his deep desire to have children, we had even gone so far as to have lengthy discussions about who would stay home to care for the babes and who would go out to work.

I searched for all the available information on HIV and pregnancy; there wasn't that much around and much of it was very contradictory. I spoke to a couple of doctors, who both seemed to think that sterilization was my best option! I rang my mother, feeling fairly desperate about it all. She suggested that sterilization seemed rather radical and perhaps I should seek a third opinion - thank you Mum!

I did seek a third opinion and what I got was information and support, but no judgements. It



4. Should AZT be taken during pregnancy?

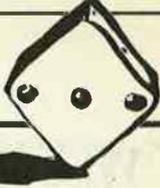
AZT has not been shown to cause any congenital deformities in the small sample studied. However, some of the side effects of AZT, such as anaemia and nausea, may present problems to the foetus. AZT does not prevent transmission of HIV from mother to child. Women who are already taking AZT at the time of conception are recommended to keep taking it unless there are other clinical indicators. If a woman becomes pregnant and is not already on AZT she should delay starting it until after delivery.

was only then that I could clearly start to make a decision. I had found that while I was being told "You can't", I strongly felt "Well I want to" but once I was told "You can" I felt I had time to think it through - I had the control!

Why did I really want a child? The obvious reply was because I was very much in love with my partner and it seemed like a natural way for us to extend our relationship, to create something special together..BUT....

What if I did pass the virus to my child - however low the odds, if the child is positive that is 100% positive - could I live with my emotions? What if the child is negative - would it possibly have to see both parents die a not too attractive death? What if we became too unwell to work, where would the financial support come from? What if we were too unwell to look after the child, would anyone else want the responsibility, especially if it too was HIV+?

There are so many "what if's" in life without throwing HIV in. I believe having a child is an enormous responsibility, regardless of your health status, and, possibly, I wasn't aware of how enormous until I was faced with such a hard decision.



5. How about other medication/ drugs?

DDI and ddC: no information so far.

Co-trimoxazole (Septrim, Bactrim): prophylactic doses should start when the T4 count drops below 300 (bactrim is usually started only when T4 count falls below 200). Bactrim has no major effect on the foetus.

Methadone: HIV+ women who start methadone often find that the functioning of their immune system improves. HIV+ opiate users are advised consider methadone treatment during pregnancy, as methadone is probably safer for both woman and baby. Like heroin, methadone crosses the placenta and can affect the baby in the first days of life. However, there is no known increase in the risk of transmission of HIV from mother to child as a result of methadone use.

There are no conclusive studies on the interaction between methadone and AZT, let alone on their interaction with HIV+ pregnant women.

Alcohol, nicotine, marijuana and cocaine: None are recommended during pregnancy. All precipitate immune depression and are associated with lower birth rate, prematurity and increased risk of congenital birth defects. The HIV+ pregnant woman may be at much greater risk from the effects of these drugs.

It took about six months for me to feel comfortable with my decision not to have any children. It still saddens me but I look at my situation and know I've made the right decision for me. My partner died four months ago, my worst nightmare came true.

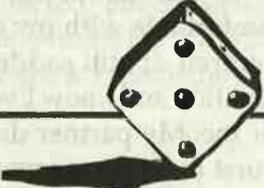
I have still got about ten years of childbearing time left for me, and who knows what may happen? New drugs, new information, perhaps even a cure! Then I could go ahead and have a baby, though finding a suitable father might pose a problem or two!

When I first became aware that my pregnancy test was positive, I was overwhelmed by the daunting thoughts of having to have a termination, an experience which I never wanted to go through. Nevertheless it was what I thought I had to do because that is what I had been told.

During the early days of knowing I was HIV+ I had a meeting with my doctor and he had told me that I could have "no children for the moment". Upon reflection I think I interpreted this as meaning if I were to become pregnant I would be ordered to have a termination. I was very confused therefore when my new doctor insisted that I discuss the matter with a social worker. I couldn't see the point and felt rather upset by this ordeal being drawn out even further.

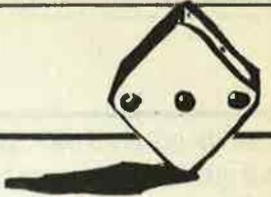
Not long after my meeting with the social worker I was referred to Dr. Ziegler at the Prince of Wales Children's Hospital in Randwick and it was there that I learned the facts, as they are understood to be, on HIV and babies. It soon became clear that I could have this baby that I so wanted to keep and that there was a fair chance of it being healthy and unaffected by the virus I carried.

Obviously the decision was extremely difficult and one which I struggled over for many days: I wanted this baby but was this a good reason? Was it a selfish decision? I considered all this but the fact was I needed this baby. I



6. Is there anything unusual about HIV+ pregnancies?

HIV+ women appear to have a higher than normal incidence of twins.



7. Should I have a vaginal or a caesarean delivery?

The delivery should proceed according to general obstetric indicators. Studies to date have indicated no preference for either mode of delivery: caesarean births do not appear to prevent babies being infected, neither does a vaginal birth appear to increase the chance of infection. It is possible for transmission to occur during either delivery. Invasive procedures involving instruments and equipment should be avoided so as to minimise lesions and abrasions.

wanted to fulfil my maternal craving and I didn't want an abortion.

My pregnancy was great, with no problems and little discomfort. I had regular check ups and was treated with the same care and attention as any other would be mother.

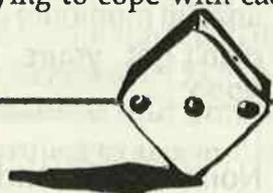
The birth of my baby was one of the most exciting and happiest moments of my life and one which any woman should be allowed to have. My experience being a happy one was aided by the help and understanding of the hospital staff who supported me no end and to whom I am very grateful. There were a couple of incidents which alienated me from the other mothers and were upsetting. One was a very judgemental doctor who asked me many questions on whether I would have more children. Was this one planned? - but all asked in a very disapproving manner and very upsetting for me, especially just after giving birth. Another was being unable to get my bed linen changed by the staff in charge of that duty. Once or twice it was done but once she told me off for bleeding onto my sheets so I decided to do it myself.

Despite this, I got through most of the inci-

dents without too many questions from curious relatives and friends and soon had my beautiful new baby at home. But this wonderful sense of security was short-lived as almost immediately I had to start all the hospital visits, the blood tests and the anguish of whether my child was infected by HIV.

It was after about the second or third visit that I was told that all the evidence pointed to my baby being HIV+. The news was devastating and my heart and stomach sank to new lows as the realisation dawned on me that something that had been a one in four chance was now reality. It had not mattered how much I had tried to prepare myself for the event I was still overcome by shock, sadness, guilt, so many emotions that all I wanted to do was get out of the hospital and cry, which is exactly what I did.

This period of time was very, very upsetting for both myself and the father but he was very supportive and helped me cope with all these new mixed feelings and emotions. Eventually I began to accept that my baby was probably HIV+ and still I am trying to cope with each

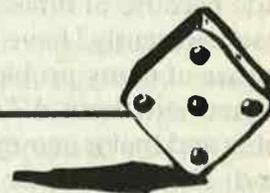


8. Should I breastfeed my baby?

The virus has been found in breastmilk which also contains important nutrients. It appears the infant can become infected through breastfeeding. The World Health Organisation recommends that children in developing countries be breastfed because the lack of hygiene presents greater risks to the child than breastfeeding. In developed countries where high levels of sterility can be achieved, bottle feeding appears preferable. Higher rates of transmission from mother to child in developing countries show increasing evidence of the transmission role of breastfeeding.

incident or illness that occurs which I find hard as each cold my baby gets or each infection I wonder if my child is starting to be symptomatic. I try to quell these fears but rarely with success.

I still frequently ask myself whether I did the right thing having my baby and the only way I seem to be able to justify my actions is to simply look at my child: a beautiful happy baby without whom I couldn't imagine life and at least this way my child is able to enjoy some sort of life time.



9. Should my baby be immunised in the same way as other babies?

Immunisation is strongly recommended, including measles, mumps and rubella. However, when the infant is symptomatic, live poliovirus vaccine should be avoided (a killed polio vaccine called Salk is used instead).

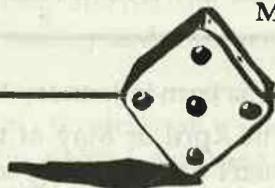
My son Jai was born in January 1982 and I contracted HIV in April or May of that year. Fortunately I wasn't breastfeeding so my son remained HIV negative. I had decided to wait until my son was about four years old to have another baby, mainly because I was a single parent. In February of 1985 I was informed that I was AIDS positive or HIV positive as it is now known. I still wished to have children and asked my specialist about this and was told very harshly to forget it as it would be totally irresponsible. I was given no further information and could find no information about the subject myself. It seemed that once diagnosed with HIV the right to choice in regards to having a child was taken away.

I didn't believe this and over the years kept

an eye out for any relevant information. My own feelings about this subject were that, like most 'hereditary' illnesses, some babies contracted it, some didn't. Over the last few years more and more information has been printed about HIV+ women and their babies. The most recent study gives the statistics of vertical transmission at about 12% - 18%. Because of this I once again began to think of having another child and just recently have decided not to.

This decision not to have children has been made because of illness and not for any other reason. Recently I have had to start taking AZT because of many problems. There is very little information about AZT and the effect on the foetus and that is enough in itself to change my mind. The other factor is simply that I am not well. I could not think of anything worse for myself than bringing a child into this world who in all likelihood would not have a mother in five or so years time. I have enough problems at the moment dealing with the fact that I may not see my son reach his teens. If I do then that will be fantastic but he is the only child I wish to worry about.

Michelle Morrison



10. How will my child be affected if I die from AIDS?

Children of all ages are devastated by the death of their mother. For young children the loss is of their main care-taker and support, whereas older children better understand the implications of their mother's death and remember their mother much more clearly. However children do overcome this loss provided they have a loving, familiar father and satisfactory family supports. The child who will be orphaned by its mother's death, or whose father has died or is likely to die is at serious risk of severe psychological problems.

ACON

AIDS Council of New South Wales Inc.

AGM 30 September

If you're a member of ACON it's important you vote for who you think best represents the HIV communities on the ACON committee.

ACON elections are by postal ballot. A call for nominations for the committee and executive was mailed out to all financial members on 26 August. If you didn't get yours, call ACON on 283 3222.

Nominations and any motions for special resolutions (such as changes to the constitution) close on 9 September.

Ballot papers will be sent to current members on 12 September. To be valid, the completed papers must be back at ACON by 6pm on 26 September.

The poll for ACON committee and executive will be declared at the AGM.

NPLWAC gets funded for needs analysis

If you're wondering about the bizarre acronym, NPLWAC stands for the National People Living With AIDS Coalition. NPLWAC has been around for some time, but hasn't been in the news much or been very active in the past few months - or so it has appeared to the casual observer. In fact, NPLWAC has been extensively lobbying for funding on the grounds that a national organisation for PWHIV/AIDS is essential to make sure that all PWHIV/AIDS, especially those in remote, poorly serviced areas, receive the support they need.

NPLWAC has now received funding for a position to undertake a needs analysis into the roles, duties and function of a national organisation for PWHIV/AIDS. On 5 August *Matt Bradshaw* started in this position as Project Officer with NPLWAC. Here he introduces himself and outlines what he expects the project to accomplish.

I'm an HIV+ gay man, (not necessarily in that order). I come from a social work/welfare background and have been a volunteer for various AIDS Councils and gay groups here, in Europe and in the US since 1979. Having lived in Darwin for almost two years prior to my relocation to Canberra I had a good chance to experience the special circumstances of gays and PWHIV/AIDS in remote areas. An experience I'm sure will prove beneficial in this position.

In the past ten years we have succeeded in setting up PWHIV/AIDS groups in every state and territory of Australia. This network has on more than one occasion proven its value. I think

that whichever way a national PWHIV/AIDS Coalition is set up it should support and enhance the functioning of the state / territory PWHIV/AIDS organisations and not follow the example of federal and state politicians who seem to be getting their kicks out of making each other's life as difficult as possible.

I therefore intend to co-operate closely with local organisations. I have already contacted convenors of PWHIV/AIDS organisations around the country and plan to visit all groups in the near future. If any group has not yet heard from me, please contact me on (06)247 3411.

At this stage I hope to be able to run a workshop with members in each state / territory to get a sound idea of how members feel about a national organisation and what they hope to get out of it. Also there is a questionnaire for PWHIV/AIDS in the pipeline (yes, yet another questionnaire) to be completed by relevant organisations.

I hope that this degree of liaison with client groups will ensure that all members feel able to endorse the final report, without it being too laborious and causing too much confusion and paperwork.

I invite anybody to contact me with comments or ideas at the above number or by writing to NPLWAC, GPO Box 164, Canberra ACT 2601.

As a final note I would like to point out that the recent action around the Baume report has made it blatantly clear that issues of a federal nature certainly exist for PWHIV/AIDS. It is now time that we decide how we want to tackle those issues and what structure will best serve our purpose.

Matt Bradshaw

Anguish in

BOHEMIA

Part 3

By Dara Toad

The story so far... Robbie has found out his sister Nancy's secret - when Brad tells him she is HIV+ he attacks Brad with a dinner knife! Meanwhile, Nigel has overheard a revealing conversation between Brad and Nancy - and he recognises Nancy as a woman he had unsafe sex with a year ago...

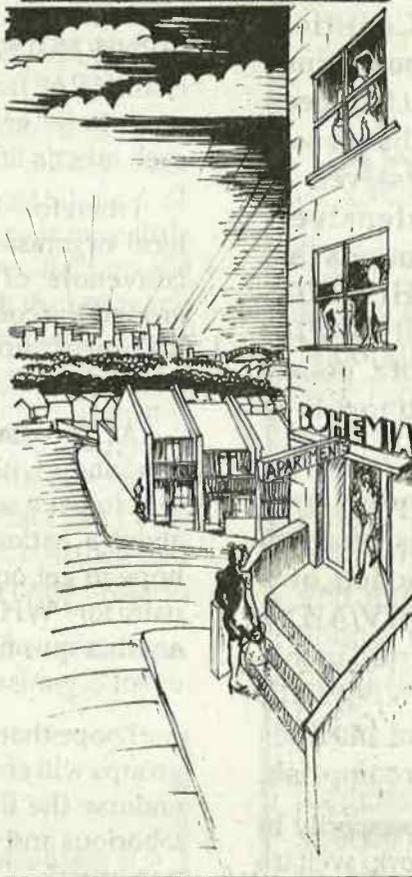
Nigel's place looked tidy and he couldn't work out why. Then he realised that for the first time in about three weeks Kurt wasn't slouched on the sofa. His grimy backpack was missing as well. The only trace of him was one balled-up sock under the coffee table.

Funny that, thought Nigel. Just after I told him I was going to get the results of my HIV test.

The doorbell rang. It was Nancy.

They didn't talk much on the short walk to the clinic. Nancy held his arm and smiled sweetly when their eyes met.

Sitting in the waiting room she began whispering, "It's not much fun, is it? Just remember, even if your test does come back positive, it's not the end. There are heaps of things you can do. It takes a bit of getting used to - oh, shit, that's an understatement if ever there was - but you won't be alone, Nigel."



Nigel sighed. He half-wanted her to shut up, but was relieved she was with him.

He felt hot and out of breath. His neck was tingling. For the past three weeks he had agonised so much, he was exhausted. He was convinced that he was positive. It would be a relief to find out for sure.

"Hey, kid, you forgot your change!" the woman behind the counter called as Robbie turned to walk out.

Robbie walked back to the counter and took the money then left the shop. This was the second time this had happened to him today. He felt really tired and his mind was still so muddled he was acting quite vague.

It was three weeks since Brad's disastrous dinner party and Robbie was still trying to work things out for himself. He had more or less apologised to Brad for attacking him with the dinner knife and was now reservedly friendly towards him. He and Nancy had tried to talk about her HIV infection, but Robbie still had difficulty coming to terms with the idea of his sister having *that* disease.

Robbie's reflections were interrupted by a loud chanting noise coming from the Pitt Street Mall area. As he turned the corner he was confronted with a large crowd of protesters, and

a huge banner with ACT UP written on it.

The demonstrators were standing outside a small clothing shop and yelling out something about bigots. Robbie couldn't quite work out what they were saying, so he moved in closer.

After watching the protest for several minutes, Robbie noticed that he was being watched by one of the demonstrators - a large, solid man in a black leather jacket littered in badges. Robbie looked away embarrassed, feeling as if he should not be staring so much.

Suddenly the demonstration had grown out of control. One of the protesters had accidentally smashed the window of the shop and the police, who had been standing nearby, moved in. It did not take long for the police and the protesters to start tussling with each other.

Before Robbie knew what was happening, he found himself in amongst the melee. He started to panic and did not know which way to turn. Then without warning he felt a someone grab him from behind. Robbie turned to find it was the man in the leather jacket who had hold of him. He was quite speechless and did not protest as the man dragged him away from the fight. It was only when they were at a safe distance that the man let go of him.

"Are you alright? I saw you standing there as if you didn't know what to do so I thought you might need a little help." Robbie felt slightly embarrassed.

"Look," said the man, "I'm going to find a coffee shop to sit down in and have a rest. You look like you could do with the same. Want to join me?"

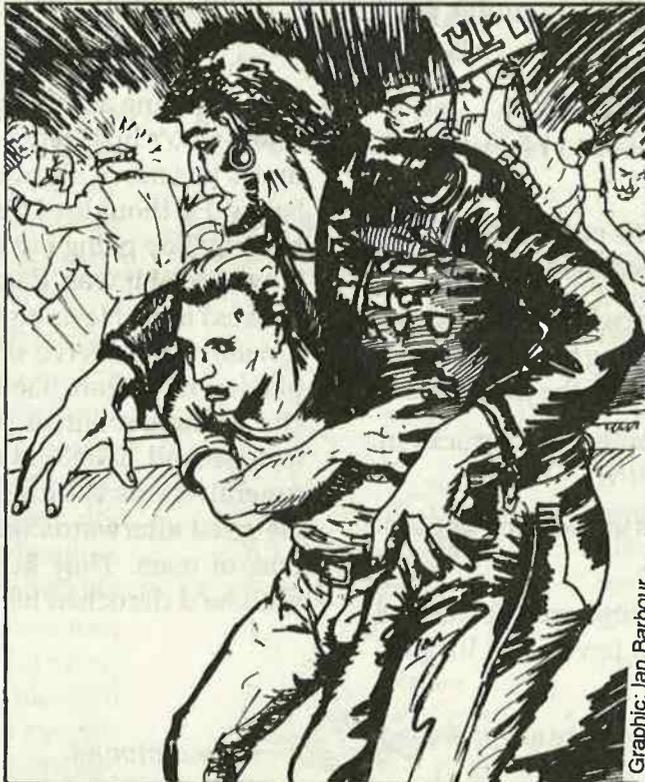
At first Robbie thought he should say no, but remembering what his sister had told him about ACT UP decided that it might be interesting to talk to someone besides Nancy about AIDS.

"Um, okay. I would like that," he said hesitantly.

"Good. By the way, I'm Wayne. There's a good place around the corner. Shall we go there?"

Today was the day Brad had been dreading for a week. He had thought of every excuse possible that he might use to delay his visit to the AIDS Clinic. His top five were :-

5. I'm sorry, I'm "tied up" at the moment.
4. The electrician can only come today and I need my vibrator fixed urgently.
3. I can't walk today because I have had an allergic reaction to condoms and that combined with my haemorrhoids...
2. My "sister" told me to "stop worrying".
1. Today is the only day I can get in for a massage and everyone is talking about the new masseur...



Graphic: Ian Barbour

None of these even came close to one out of ten on the scale of reasonable excuses so Brad relented, sighed and left for the clinic.

The clinic was hours late with their appointments as usual. Brad had been sharing the waiting room for two hours with ten other people, five of whom he had tricked with. Unfortunately girly conversation of cocks and frocks didn't match the dull surrounds of the clinic waiting room.

Finally Brad's clinic number was called. In he walked to an obviously run down and over-worked doctor. No time for doctor-patient relationships here.

"How's that purple spot?"

"Well it's getting bigger. At least it matches my wallpaper now."

"Let's have a look."

Off with clothes and onto the "casting" couch.

"Yes, it is bigger. What's that cut on your bum."

"A turn on for rough trade."

The doctor was not about to be distracted from his mission.

"Well, we got the results of the biopsy and I'm afraid we have some bad news."

Brad's life flashed before him. Panic set in and he thought of the first thing that could come into his head that might delay the inevitable.

"Didn't I trick with you in the Barracks in 1981?"

Not a reaction! Doctors are so good at picking up psychological cues.

"The news is that the biopsy result was not conclusive. We're going to have to do it again I'm afraid."

Relief and then almost at once anger welled up in Brad.

"Do you mean because you stuffed it up I'm going to have to go through another two weeks of hell to find out if I have Kaposi's Sarcoma!"

"Look, we can actually get the results a lot quicker. If I remember correctly it was you who wanted not to find out for a fortnight. Until we do know what it is we're dealing with here, I suggest you stop worrying."

Brad was dumbfounded. "Don't worry" he thought - only someone who didn't understand could calmly tell you not to worry.

Brad relented to the biopsy and was to return for the results in two days...

"You have been exposed to HIV, Nigel. But this does not mean you have AIDS. Now I can't stress that enough. What it does mean is that we will need to monitor your health regularly ..."

The room became surreal. Nigel could see himself sitting across a desk from a man with a beard who's lips were moving. He watched the man's lips move. A car roared past in the street below. He thought of his parents and himself as a young boy going out to lunch with them and how special it was. Everything was so uncomplicated then. He thought of his grandmother's funeral, remembered sitting behind the woman playing the organ. She had a strange bone-like clip through a bun at the back of neck and he focussed all his attention on it. He hated the funeral. It was the funeral that made him sad. He cried afterwards on his cousin's shoulder. Lots of tears. They kept coming and coming until he'd drenched his cousin's blouse.

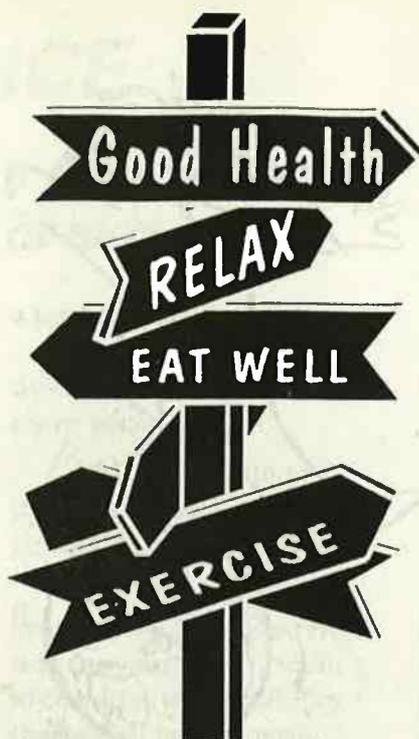
To be continued....

How do we, as care givers, stay well? How do we deal with our personal pain of being helpless to help another? Petrea King, from the Quest For Life Foundation writes from her own experience working with HIV/AIDS clients, to offer advice to other care givers

For the past seven years I have been working with people with life threatening diseases. This work has included facilitating support groups, one-to-one counselling and nursing people through the final stages of their illness.

My work has been spread equally between people with cancer and those infected with HIV. I have seen almost three thousand people with HIV on a one-to-one basis and many more have passed through the weekly support group I have facilitated at the Albion Street centre during these last seven years.

In all aspects of this work I have witnessed and shared the deepest emotions possible to our common human experience. Together we have plummeted to the depths of blackest despair, fear and powerlessness and soared to the dizzy heights of acceptance, forgiveness and peace. It is an honour and privilege to share with people who are contemplating their mortality with such simple honesty,



Living well in a war zone



insight and courage.

Four years ago I attained a high distinction from the University of Burn Out. Preceding that time I was facilitating three support groups each week, teaching meditation to two more and seeing ten clients each day, six days a week. On the seventh day I would often visit people in their homes or at hospital if they were too ill to come to me. All of the people I saw had cancer, AIDS or HIV.

For me, 'burn out' (or emotional exhaustion) took hold on a 'holiday' my family/friends had insisted I take. For two weeks I wept, sobbed and cried. I collapsed and slept in exhaustion only to awaken to more tears. People say you feel so much better for a good cry. I didn't. I felt like I was weeping for the whole history of humankind - why does it have to hurt so much to be human?

For my own sanity I began to look at how to stay well whilst living in the midst of a war zone. And more than just staying well, how might I grow in wisdom, understanding and in my capacity to love whilst working with people in crisis? Questions began to arise in my mind. I find that these are good questions to review at any time in my work/life.

- * Why do I need to be needed?
- * Who am I doing this for?
- * Am I taking responsibility

for other people's perceptions or experience?

* What are the things which nurture me and am I practising them now?

In the past four years I have worked with many care givers who are endeavouring to discover the art of living well in the midst of chronic crisis. These have included professional care givers as well as the unsung heroes of caring - the mothers, relatives, friends and lovers. The following symptoms are typical of emotional exhaustion.

Symptoms of Burn Out

- * Constant fatigue
- * Frequent illnesses
- * depression (emotional flatness)
- * A tendency to isolate from others
- * Carelessness
- * Addictive behaviours - abuse of alcohol, drugs, sex, food, sugar etc.

It is difficult to recognise we are in need of nurturing ourselves when we are overwhelmed by the needs of others.

The only way to deal effectively with the future is to live



Graphics: Allison Wiseman

efficiently in the present moment. For this reason it is wise to take preventative steps so that emotional health and well being can be maintained. Implementing these suggestions makes for an excellent beginning. The suggestions aren't in any preferential order.

What helps?

- * recreation - FUN times in which you laugh and replenish yourself
- * limits and boundaries - learning to say NO
- * Non-Co-Dependency - taking responsibility for your own feelings and allowing

others to do the same

- * regular physical exercise
- * regular spiritual exercise
- * Continuing professional and personal education
- * An attitude of openness and honesty
- * Support groups and/or supervision which deal with **your** emotions/feelings
- * Listening to oneself as keenly as one listens to others
- * Nutrition - an adequate, balanced diet

By taking responsibility for our own emotional health and well being we lay the foundations for greater peace in our lives. Peace is not a wishy washy, saccharine sweet, passive state. peace is a dynamic state of being. With peace of mind as our companion we become more effective care givers who have the staying power to continue our chosen work and to grow in wisdom and our capacity to love.

*"That which oppresses me,
is it my soul trying to come
out in the open,*

*or the soul of the world knocking
at my heart for its entrance?"*

Rabindranath Tagore

CHOICE:

A support group for people dealing with hiv or aids

The common thread which unites this group is a desire to explore and find support for the variety of choices each of us is making to deal with our individual relationships with hiv. However, we do tend to align ourselves with such people as George Melton, Louise Hay, Petrea King and Richard Moss.

We are finding that each member has a particular resource to bring to the group which is a benefit to one another - one may have new age tapes, another meditation techniques, personal anecdotes....

It seems that regardless of what actually unfolds in each meeting, we get a special value simply by getting together on a regular basis (and this builds over time) to address 'where we are at' in relation to living well and the virus. However, the focus often moves beyond a direct association with hiv, to broader gay issues - old age, permissiveness, the 'scene' and others.

We have a loose structure which incorporates

a time for meditation/visualisation - a time to talk/discuss/seek support - and a more 'social' chat.

We have begun to incorporate such events as going to a play about aids.

CHOICE is a small group, keen to gain strength from anyone who is willing to consider the possibility that we all have choices.

Meetings are held on Wednesday evenings from 7pm to 9pm in Rose Bay.

Please feel free to phone Kim for further information on 371 9868.

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

LONGTERM SURVIVAL Working Group

The Longterm Survival Working group is an independent non-profit organisation which is interested in looking at all relevant treatments for HIV/AIDS, including conventional, complementary and alternative therapies.

We hope to contribute to the setting up of an experiential data base which can be easily accessed by the HIV community.

We also seek to offer information and support for suggested lifestyle changes that are useful in becoming a long term survivor - healthy diet, the benefits of regular exercise and stress management techniques like meditation, yoga or massage. We believe affirmation in self-esteem and building of confidence for people with HIV/AIDS is helpful in learning to live with the virus.

The Longterm Survival Working Group is here to create a positive approach to HIV/AIDS and it is with your support and welcome that we can achieve the goals mentioned above.

If you have information you would like to contribute or if you would like to come along and share your story with others and maybe pick up some useful tips or motivation, then come to our weekly meetings at:

Maitraya Day Centre
396 Bourke St, Surry Hills,
Friday nights at 7.30pm

or alternatively, contact:
Cameron Mahoney 331 2610 or
Graeme Petri 555 1830

Pop goes Imuthiol? (and other stories)

Leading the news is Imuthiol (ditiocarb sodium or DTC) which has been withdrawn from sales world-wide by manufacturer Pasteur Merieux. They did a preliminary analysis of a large clinical trial of Imuthiol in asymptomatic people with HIV, and there seem to be conflicting opinions on the results.

The company maintains that the analysis found no differences between the treatment and placebo groups, simply that the people on Imuthiol were obtaining no benefits from the drug. However some independent evaluators of the data found that people on Imuthiol were progressing to ARC or AIDS faster than the control group. This difference was found to be statistically significant. At any rate Pasteur Merieux emphasizes that this is still a preliminary result.

This result is inconsistent with what has been found from earlier trials, which studied symptomatic people with HIV. However the current trial is

much larger than all previous ones, and hence may be more statistically reliable.

Until these data are completely analysed, Pasteur Merieux is recommending that all use of Imuthiol, including use in symptomatic persons, be stopped. The more thorough analysis will take at least 3-6 months, and will be looking at factors like the specific batches of the drug used, subpopulation biases and randomisation, etc.

Just where the ddCkens is it?

The Treatments Access Group (buyers club) at ACON is still experiencing a delay in getting ddC in from New York. The suppliers in NY have depleted their stocks of ddC and are waiting for a new batch to come in. However they can't exactly say when this will happen. In the meantime ACON is investigating Los Angeles as a possible source of ddC although the news is that the entire country (US) is having a ddC shortage.

On the brighter side of things, the US Food and Drug

Administration has granted ddC manufacturers Roche an export permit to ship the drug into Australia. Roche Australia will provide the drug on a compassionate use basis for people who cannot tolerate AZT or ddI (this protocol is identical to the compassionate use program in the US).

The bad news is that people who can tolerate and want to go on a AZT+ddC combination will not be covered by this protocol. Well, not officially anyway... In the first phase of the program only major hospitals around the country will be involved. This is expected to be ready to go by the end of September. Roche then intends to involve general physicians through the soon-to-be *Community HIV/AIDS Trials Network* (CHATN). But it doesn't seem like CHATN will be up and running before year's end.

d-d-I want it and I want it now

In late July the Antiviral Advisory Subcommittee of the US Food and Drug Administration recommended that ddI be approved for marketing in

TREATMENT NEWS

the US. That recommendation went to FDA Commissioner David Kessler, where it has stalled. A decision is expected to come out of that office any moment now, and Kessler will most probably agree with the subcommittee. Australian AIDS activists and organisations are pushing for the Therapeutic Goods Administration to recognize the imminent US approval of ddI and follow suit, and soon.

Just trialing in the rain, what a glorious feeling, just ...

Finally Australia is getting a chance to do an early trial of a major new drug! *Nevirapine*, or *BI RG 587*, is a non-nucleoside analog inhibitor of HIV-1 reverse transcriptase. It appears to bind to HIV-1 RT at the same site as the TIBO derivatives, but is not effective against HIV-2 RT. Only 21 persons have received the drug so far in a US study to assess dosage and safety, and some minor (relatively!) adverse events occurred: headache, nausea, sleepiness, diarrhea and some others.

The present trial is a phase I/II study (to investigate safety,



Photo: Jamie Dunbar

efficacy and dosage) and Australia is one of three participating countries, each of which will enroll 12 patients making a total of 36. There will be three treatment arms of different doses of *nevirapine* and no placebo arm. The study will last only 12 weeks, and those who complete the study will have the option of continuing on long-term *nevirapine* therapy. The drug is administered orally as a tablet.

Entry criteria are: nucleoside analog-naive (you must never have taken AZT or ddI or ddC before), p24 antigen positive, and have fewer than 400 CD4 cells per milliliter. Women must be postmenopausal or practicing sexual abstinence or using barrier contraception. When are they ever going to design trials that allow for the possibility of pregnancy?

The restriction to nucle-

oside naive individuals caused alarm bells to ring in the AIDS activist communities, but the argument from the researchers is that this is a very short trial and the "clean" data

from this trial will expedite the creation of phase II/III trials which will be large, not restricted to nucleoside-naive people, and possibly in combination with other drugs (like the nucleosides).

Interested people should contact Dr. Mark Lowenthal now at (02) 332 4648. The trial will start in mid-September.

The amazing technicolor MAC maze

No news yet on the suggested trial of *azithromycin* as prophylaxis for *Mycobacterium avium* complex (MAC). David Goldstein of the National Centre says that they are working on it with Pfizer (*azithromycin* manufacturers) and the whole thing is only at the stage of the "concept sheet". Moles however are saying that a placebo-controlled trial is being considered (STOP THIS TRIAL! STOP THIS TRIAL!). Pfizer will claim it needs a pla-

cebo trial in order to get marketing approval. This will not be granted on the basis of more humane trials such as *azithromycin + clofazimine vs. placebo + clofazimine*. Can anyone out there come up with a better trial design?

By the way, there are still places in the trial of *rifabutin* (*ansamycin*) as a single agent prophylaxis against MAC. This trial is placebo-controlled, and persons with less than 200 CD4 cells/ml are eligible. Contact Albion St Centre or Prince Henry Hospital in Sydney, or Fairfield Hospital in Melbourne. But hold on...aren't people saying that just about every MAC strain isolated in Australia has been shown to be *rifabutin*-resistant?

Politics - oh yucky.

The Baume report (that long-awaited sequel to the ANCA report, done with different producers and actors but the same villains) was released on July 3. It's called "A Question of Balance" and it's pretty good.

Some highlights of the report: it builds in limits for the amount of time a drug's application for marketing approval can sit on the desk of TGA bureaucrats, after which penalties apply. It does away with the awkward IPU sys-

tem for drugs not yet approved by the TGA and replaces it with something called the Special Access Scheme, where patients don't have to prove they have tried all "conventional" therapy before requesting an "experimental" drug. The power to authorize use of a non-approved drug will be decentralized from the TGA to select hospitals and general physicians.

An encouraging fact is that the Department of Health has announced it will implement the Baume report in its entirety. Of course, some problems remain. The biggest one and the most difficult to solve is: who will pay for the drugs once they are approved? A solution must be found so that hospitals don't live in constant fear of budget blow-outs and don't say things like, "We just don't use clarithromycin here, it's too expensive."

For more thorough discussions of the Baume report, see *HIV Herald* May-June 91, or the AFAO response to the Baume report, or wade through all 232 pages of the report itself (all available from your friendly neighborhood AIDS Council).

Lyle Chan
Acting project Administrator
AFAO Treatments Project

Tips and sundry

☛ **People on ddl take note:** If you take dapsone, ketoconazole, itraconazole, pyrimethamine, trimethoprim or any enterically coated capsules, **wait at least 2 hours** after taking any of these before taking your ddl. The alkaline buffer in ddl may interfere with the absorption of these other medications because they require an acidic environment. (From *ACT UP/NY Treatments + Data Digest #89*).

And while we're at it, when will we in Australia see ddl tablets rather than the diarrhea-causing sachets?

☛ **Drug interaction:** rifampicin (or Rifadin), a drug sometimes used to treat MAC, can cause low blood plasma levels of the antifungal drugs itraconazole, fluconazole and ketoconazole, meaning that higher doses of these antifungals are necessary. (from *Notes from the Underground #2*)

☛ **Foscarnet** can produce low levels of ionized calcium in the blood, which can lead to things like leg cramps, nausea, dizziness and even seizures. This problem has been successfully solved by administering calcium intravenously. Make sure that the catheter gets properly flushed afterwards so that no calcium deposits harden and destroy the catheter. (from *AIDS Treatment News #129*)

PLWA Tasmania

PLWA Tasmania has recently acquired an office in the Tasmanian AIDS Council Building in Hobart at 59 Tasma St North Hobart.

PLWA Tashas, at present, only very few members due to: 1) the current laws pertaining to homosexuality, 2) real and imagined stigma attached to being seen anywhere near an AIDS Council, 3) very few diagnosed HIV/AIDS persons in Tasmania know of our (PLWA's) existence (a fact we are in the process of rectifying).

As readers will realise, Tasmania has an extremely small population, (approx 460,000), 160,000 of which live in Hobart and suburbs, so the old cliché that 'everybody knows everybody's business' takes on real meaning. Confidentiality regarding personal HIV status is practically an art form, but it's one we are good at.

We hope to attract much needed membership so as to facilitate such programs as peer support, group discussions, 'nights on the town' etc. So if anyone reading this article has friends or relatives living in Tasmania who are affected or infected, please let them know of our existence. Similarly, anyone travelling to Tasma-

nia on holidays etc. please feel free to contact me at the above address should you require any assistance - or just drop in for a cup of coffee.

John Geddes
PLWA Tasmania

Hep A - Don't panic!

Several hundred gay men in Sydney's eastern suburbs have recently been sick with Hepatitis A, an infection that infects the liver. Hep A is easier to catch than Hepatitis B or C. It is mainly passed on through particles of infected faeces getting into the mouth.

Simple hygiene is your best protection. Wash your hands after going to the toilet or having sex, wash your hands before preparing or sharing food and avoid sharing food utensils. Over the next few months, while the Hepatitis A danger is high, use condoms or latex to make oral sex safer.

If you think you have been in contact with someone with hepatitis A or have one or more of the following symptoms, see your doctor for a check up. If you have been exposed to Hepatitis A, the earlier you are treated the better.

Symptoms: loss of appetite, abdominal discomfort, nausea, vomiting, change in the colour of your skin and eyes (jaundice) change in the colour of your urine.

Gamma Globulin injections provide some protection for up to six months.

For more information call the Public Health Unit ph:(02)398 9100, TTY:(02)332 4268 or see your local doctor.

ADB HIV/AIDS Inquiry

As *Talkabout* goes to press, The Anti-Discrimination Board was holding three public hearings as part of the public inquiry it is conducting into discrimination against people who have or are presumed to have HIV or AIDS.

Over the past few months the ADB has been gathering evidence of discrimination from PLW-AIDS/HIV. Some of these were to be read out to the Inquiry. The first hearing on August 21 focussed on discrimination in relation to health services; the second focussed on employment issues, and the final hearing concentrated on other areas such as prisons, legal services, insurance and provision of goods and services. A report will be released in December.

NEWS

Future directions for PLWA

On 6 July PLWA held a Structural Planning Day to take stock of our structure and our direction. Most discussion centred on establishing what our priorities should be - there are a lot!

Since the planning day a firm of management consultants called Common Ground have been contacted and have offered their services free of charge. Common Ground are the consultants who have been commissioned by ACON to review their structure and have considerable experience in strategic and management planning.

At the last meeting of Committee it was decided to enlist the help of Common Ground in devising a management and strategic plan for PLWA. Saturday, 9 November has been set as the date for the Committee to get together with interested members and Common Ground for a Planning Day.

The Committee encourages all members to participate in the Planning Day as it will set the long and short term directions of PLWA Inc (NSW).

To make the day successful the Committee has scheduled 17 October to get together be-

fore the planning day to look at a firm agenda and our Mission Statement. All members are also encouraged to come along to this afternoon.

Some of the suggested topics up for discussion are:

- * Review our Mission
- * Write a Mission Statement (if changes are needed)
- * Set long and short term objectives
- * **Define our identity**
- * Set proactive mechanisms for dealing with issues
- * Evaluate our past achievements/failures.

We again encourage all members to get involved with the Planning Day. This is your organisation. We represent your interests to government and the community. For us to be truly representative of your interests we need your input into our directions, coming along once a year to the Annual General meeting is not enough!

So take out your diaries and write the dates in and come along. And we'll supply a yummy lunch.

Meeting times: A significant decision at the Strategic Planning Day in July was to hold Committee meetings twice a month rather than once.

This decision was made because of the increasing number of issues and work being placed on the Committee. Meetings are on the 1st and 3rd Thursdays of the month at 6pm, 2nd floor, 188 Goulburn St Surry Hills.

New Committee members: Peter Hornby and James Skelton.

Discrimination: The Anti-Discrimination Board's Inquiry into HIV Related Discrimination is now in full swing with the employment of Julie Whyllie as Project Officer. (see page 25).

Outreach: As reported in the last *Talkabout*, Nicholaas van Schalkwyck travelled to the north coast and conducted some very successful research into our reach into non-metropolitan centres. The Committee would like to extend its great thanks to Nicholaas for his excellent work. A full report back to members will be included in the next *Talkabout*.

PLANNING DAY
Saturday, 9 November

**Planning Day
preparation**
Saturday, 17 October

AIDS in the third world

A report from VII International Conference on AIDS, Florence, June 1991

Issues concerning the growing problem of AIDS in third world countries were prominent at the International Conference on AIDS in Florence. While there were few presentations from the South East Asia and Pacific regions, there were valuable contributions from other third world regions, particularly Africa.

Clearly, Asia/Pacific countries need a much stronger representation at future conferences to make the world more aware of the situation in our region.

Although the epidemiological picture is still incomplete as to the extent of AIDS in the third world, there was a broad consensus at the Conference that we cannot afford to wait for research results before intervention.

The World Health Organisation (WHO) estimates that 80% of new infections world wide will occur in the third world by the end of the 1990s, and 10-15 million children under 15 will be orphaned by AIDS, six million of whom will be in Africa.

A clear message of the Conference was that AIDS must be placed in the context of the broader health and social problems faced by third world countries - as Ankrah, a Ugandan delegate put it: "AIDS is a problem of underdevelopment". National health budgets in many African countries are less than \$10 per person per year.

Third world countries need to develop appropriate prevention education strategies; to care for ill or infected people; and to deal with the social damage caused by the epidemic.

Strategies effective against AIDS in third world countries are more familiar to development experts than AIDS workers, highlighting the need for co-operation from development and aid agencies with their particular expertise. One of the major problems is making resources available to the third world. For example one speaker, Jonathon Mann, insisted that if an HIV vaccine is developed it must be made available, through international supervision, to target first the populations identified as most in need. This concern holds for any form of care for people with HIV/AIDS.

At the satellite forum "Communities challenging AIDS" an agreement was reached that it is important to conduct research into the "indigenous and alternative" therapies to which a majority of third world infected populations have access.

Unless current antivirals such as AZT can be made available at a much reduced cost, they will be out of reach to the majority of the world's people with HIV/AIDS. Indigenous and low cost therapies will remain at the front line of treatment in such countries and their development should be supported and encouraged by governments and assisting countries.

Meanwhile, attempts could begin to broaden access to clinical treatments in the third world. Third world Governments should be encouraged to try and attract the international drug companies to sponsor drug trials in their countries as a means of providing treatment.

Robert Ariss

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.



Liverpool meetings

The first meeting is calling together interested people to establish a CSN type program in Sydney's South west.

Time: 7.30 - 9.00pm

Date: Wed 4 September

Venue: Meeting Room - ground floor, New Public Health Building, cnr. Elizabeth & Bigge St.s Liverpool

The second night is for HIV+ people only and will be an inaugural meeting to establish an HIV Support Group for PLW HIV.

Time: 7.30 - 9.00pm

Date: Tuesday 17 Spetmber

Venue: As above

For further information contact John Gardner, Area HIV Co-ordinator on (02)827 8022

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.

September/October dates

11 September

25 September

9 October

23 October

DID YOU KNOW there is a transport service for people living with HIV or AIDS?

It operates Monday - Friday 8.30am - 5.00pm for transport to hospital or clinics.

for more information contact Rob or Monica at central Sydeny Community transport, 360 2043.

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



SACBE es un grupo de gente de habla hispana

Nos dedicamos a apoyar, aconsejar y educar acerca del SIDA.

En nuestra propia lengua. El español.

Nelson quiere comenzar un grupo de apoyo para todos nosotros los infectados con el HIV.

Podemos hablar del SIDA, política, tango, la Flores o de lo que tu quieres.

No dudes en llamarme al 315 7589 aunque mas no sea que para que nos conozcamos telefonicamente.

Salud, amor y pesetas.....

AFAO National Treatments Project publications

1. HIV Briefs - a four page pamphlet about AIDS treatment issues designed for PLWAs, their cares and their health service providers.

2. The HIV Herald - a monthly newsletter designed to collate overseas information and put it in an Australian context.

Both these publications are free.

To get these publications contact the **National Treatments Project**

c/- ACON, PO Box 350, Darlinghurst 2010

Ph: (02)283 3222

CENTRAL COAST

Sexual Health Services

is offering HIV clinical services; HIV+ Support Group and Carers Support Group; local Community Support Network contacts.

Please ring Paul Drielsma or Pauline Wallace for information.
(043020 3399 or 20 2241.

SERVICING THE WESTERN SUBURBS

the

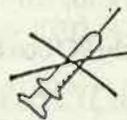
KENDALL CENTRE

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	

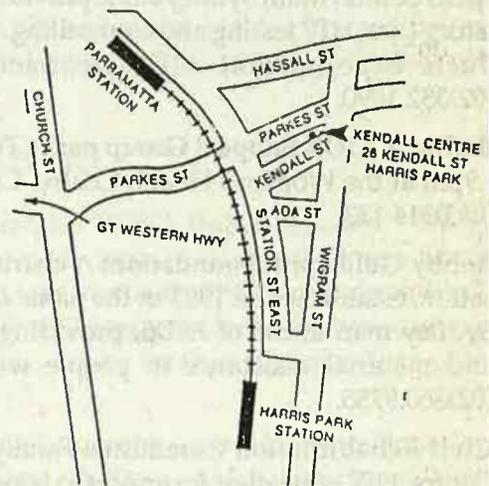
A unit of the Western Sydney Area Health Service

Don't share
needles &
syringes



ANYONE CAN GET AIDS

Always use
condoms



CONTACT LIST: AIDS ORGANISATIONS AND SUPPORT GROUPS

GENERAL

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

AIDS Coalition to Unleash Power (ACT UP): A diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis. Phone the info line (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.

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 75 Darlinghurst NSW 2010.

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

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.

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.

ACCOMODATION

Share Accomodation Register: for people affected by HIV/AIDS and others seeking accomodation. Free, not restricted to HIV+ people. For details ph: 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): Operates every Thursday from 11.00am - 4.00pm at McKillop House, Carrington. Contact John (049)62.1140 or the Hunter

Branch of the AIDS Council on (049)29.3464.

Sydney (Maitraya): Daytime recreation/relaxation centre for people with AIDS. 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 (020350 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: _____