No. 57 August 1995

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆

Every wall has a door

PLWH/A News

THE PAST FEW MONTHS HAVE BEEN A busy time for PLWH/A (NSW).

We've filled vacancies on the PLWH/A Committee, we've elected a new Convenor and Treasurer — and we've created seven key portfolio areas (including Treatments, Housing, Legal Issues, Services and Care), and shared responsibility for these among our committee members.

On the administration side, we're recruiting new staff and we're about to reorganise our office to make it more functional for staff and committee — and more user friendly for volunteers and people dropping by for information and advice.

To focus our attention more on the *real* issues of concern to people with HIV (as opposed to just moving the paperwork), we've changed the structure of our Committee meetings. Under this plan, every second Committee meeting will become a 'big picture' meeting, where we will focus solely on big issues — such as treatments and housing for example. At these meetings we will aim to come up with concrete, realistic strategies for solving problems and improving services for people with HIV.

So what has prompted all this activity?

If you are a regular reader of this page in *Talkabout,* you will know that PLWH/A has been going through difficult times. After a decade of the AIDS crisis — you will also be very familiar with some of the reasons why — resignations, burnout, anger, frustration, people getting sick, and people dying.

These problems are all too familiar to AIDS organisations. However, people with HIV groups — like PLWH/A — are by their very nature much more vulnerable to them. Indeed, the PLWHA movement worldwide — like AIDS activism itself — has been going through some pretty low times over the past two or three years.

But there is another factor which has been affecting us at PLWH/A: We have at times lost sight of what we are really here for. So we have been trying to overcome this by asking ourselves some very basic (but important) questions like: *What are we really achieving for people with HIV? Are we an advocacy organisation or are we a service provider?*

Through our recent Committee discussions we now have a much clearer understanding that we are an *advocacy organisation.* We recognise that Governments provide millions of dollars for AIDS services — and that it is our role to see these funds translated into high quality services for people with HIV. It is our role to identify problems and demand changes. It is *not* our role to actually provide services — if we start doing this, our focus on activism and advocacy will inevitably become distracted.

We are optimistic that the time spent rethinking and reorganising will mean we can improve our advocacy for people with HIV/AIDS. But we also know our limitations — we remain a small, essentially volunteer-based organisation, with personal, health, and organisational constraints.

Ultimately, if we are to become a more effective voice we need to reach out and involve you — the community we serve. We can't do it all ourselves. This is the fundamental basis of activism — informing people and galvanizing them into action. Until we start to do this better, PLWH/A and other people living with HIV groups, will not realise their role and potential. And as a result some people with HIV/AIDS will not get the services and treatments they should be getting.

Meeting these challenges is a goal for PLWH/A over the next six months. The changes we have made recently are a first step.

Finally, we at PLWH/A — and all people with HIV — should be encouraged to try harder by the fact that there are things to be optimistic about —especially in the treatments area. New research has confirmed the benefits of early, aggressive treatment of HIV disease, putting to rest much of the doom and gloom of the Concorde trial. And new drugs like protease inhibitors and 3TC give a lot of hope to those with damaged immune systems that access to these and other new treatments can give a real chance of living longer, and living better.

— Bill Whittaker, Convenor

PLWHA

People Living With HIV/AIDS Inc. (NSW)

Current committee

Bill Whittaker: Convenor
Vivienne Munro: Deputy Convenor
Eric Sleight: Treasurer
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This month's cover

By Bo Vilan. *Finding out that you're HIV positive can make you feel like you've hit a brick wall. But there's a door in that wall, and once you open it, you'll discover a world of new possibilities. Find out about these possibilities in our special issue for people new to HIV, which starts page 11.*

Talkabout

Talkabout welcomes unsolicited contributions. However, we cannot accept responsibility for manuscripts and photographs or for material lost or damaged in the post.
Letters submitted to *Talkabout* or its editorial coordinator are assumed to be for publication in whole or in part unless specified otherwise.
For further information contact Jill Sergeant (Tuesday, Wednesday or Friday). For advertising contact Paul Canning. Send contributions to: PO Box 831 Darlinghurst, NSW 2010.

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Briefs

- The Philippines Health Ministry has reported a 25% increase in HIV cases in the last year, 60% of which they say were due to heterosexual transmission. The Catholic church in that country has vigorously opposed the government's advocacy of condoms and this has, according to health authorities, stigmatised positive people and dissuaded them from reporting to health authorities. (*AIDS & Society*)
- The World Health Organisation (WHO) has warned that Africa's food supply may be threatened by the AIDS epidemic. Problems will be localised to areas of high HIV, as in Central Africa, where food production, as well as other economic activity, will be seriously affected. *(AIDS & Society)*
- In New York State, AIDS is the leading cause of death among Hispanic children and the second leading cause of death among African American children ages one to four. *(Positively Aware)*
- The US Centers for Disease Control (CDC) has suspended their HIV Survey in Childbearing Women. This was the largest study to collect statistics about the number of HIV infected women and children, and was dropped due to pressures to change the study to incorporate forced HIV testing and the identification of HIV positive people. AIDS and women's health activists have accused the CDC of political cowardice, as the survey was an excellent tool for targeting care and services for Positive women. Mandatory testing of pregnant women and newborns remains a threat despite the suspension of the study. *(World)*
- A US trial of AZT in children has been halted after it was found that AZT given to children (ages three months to 18 years) proved ineffective in preventing disease progression and had unexpectedly high rates of side effects. ACTG 076, the clinical trial of AZT during pregnancy, which suggested that AZT reduced the rate of maternal transmission of HIV, has also come under criticism. *(World)*
- A third of people living with HIV/AIDS worldwide are likely to get tuberculosis, according to the World Health Organisation (WHO).
- AIDS funding in the US is under threat as the Republican dominated Congress has begun steps to eliminate all federal funding for AIDS research. Republican Senator Jesse Helms says that AIDS funding should be cut because it is the "deliberate, disgusting, revolting conduct" of those who contract HIV that is responsible for the disease.
- The Report of the International Community of Women's (ICW) pre conference in Cape Town in March has now been released. It's available from ICW, Livingstone House, 11 Clarendon St London SW1H9DL, UK. The ICW is the only international network run for and by HIV positive women

Ritonavir

THE AIDS COUNCIL OF NSW (ACON) has condemned pharmaceutical company Abbott Australasia for failing to provide compassionate access to ABT-538 (ritonavir). "Abbott is effectively denying the drug to people who may well not be alive by the time this trial is finished," said ACON Executive Director Don Baxter.

ACON also criticised Abbott's decision to prohibit trial participants from taking 3TC and called on them to allow participants to take it. "By the time this trial ends 3TC will be part of the standard treatment for people such as the trial participants; it is unjust and short sighted to deny them access to it during the trial", Baxter said.

PLWH/A (NSW) will be seeking to meet with Abbott in the near future to take up the issues of compassionate access to ABT-538 and changing the trial design to allow people who are on the trial to take 3TC. "We will be working closely with ACON and the Australian Federation of AIDS Organisations (AFAO to achieve these changes", PLWH/A Convenor, Bill Whittaker, told *Talkabout*.

Abbott have said that the availability of the drug is limited due to a slow and difficult manufacturing process, and claim they do not have enough information about dosage and side effects to provide wider access to it.

AFAO has issued a briefing note stating that they support PLWH/A's position on the ABT-538 trial.

For more on ABT-538, see pp 8 and 34.

3TC update

GLAXO WELLCOME HAVE APPLIED TO the US Federal Drug Authority for accelerated approval for their new HIV antiviral drug 3TC. The application was lodged on June 30.

Glaxo are seeking approval for 3TC to be used in combination with AZT as first-line treatment for adults with CD4 (T4) counts under 500 and for children who meet the CDC guidelines for treatment with antiretrovirals. If 3TC is approved on this basis, it will probably make combination treatment the standard of care for many (though not all) HIV positive people with CD4 counts under 500. It will also encourage experimentation with three-drug antiviral combinations, as approved drugs like ddI and ddC (and possibly d4T) are added to the regimen. Then there is the potential to add new drugs under development, like protease inhibitors.

In Australia, 3TC is not licensed yet. However 3TC is available under the Special Access Scheme (SAS) for persons with less than 300 CD4 cells who are intolerant to AZT, or for those with less than 25 CD4 cells who can take AZT, but are intolerant of other approved antiviral therapies. Because of "production difficulties" Glaxo have put a quota on the number of new SAS applications they approve each week, so you may have to wait a while to get the drug. Your doctor needs to lodge an SAS form for 3TC with Glaxo.

— Bill Whittaker

Tree talk

THERE ARE MANY SHARED THEMES IN approaches to death, dying and grief. For some it may mean planting a seed in the home garden for a life lost. For others it may mean a more public tribute to the memory of that life. Planting a tree in a specific memorial grove may be the answer.

Mannie, a CSN carer inspired by AIDS tree planting projects in the US and the Blue Mountains, resolved to establish such a project in Sydney. It was over a year before the project got under way and South Sydney Council provided a site in Sydney Park.

The first two plantings took place last year and the third planting took place on June 25 this year.

Throughout the day, an estimated 70 people planted about 300 young trees. Sisters of the Order of Perpetual Indulgence—gay male nuns in habit— blessed the trees in a special 'green' ceremony.

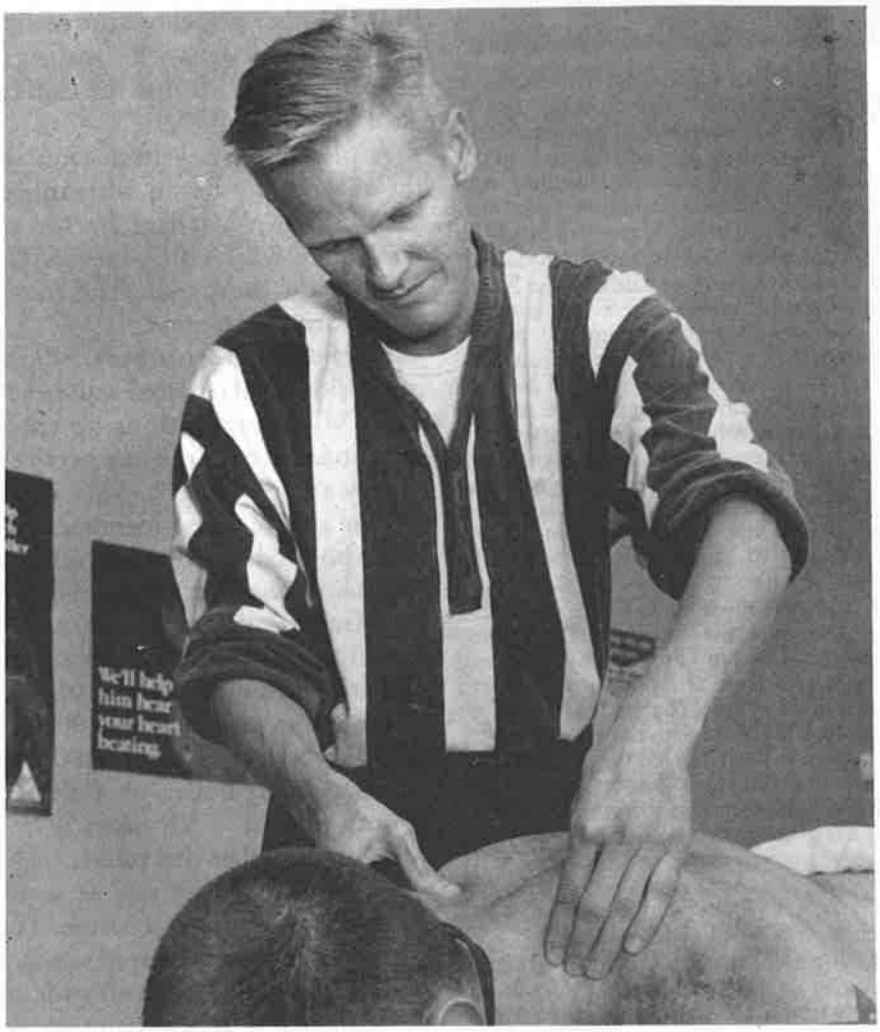
The weekend of June 25 was the 26th anniversary of the Stonewall gay riots in New York in 1969. It was also the 17th anniversary of the savage arrests of lesbians and gays in the first Sydney Gay Mardi Gras in 1978.

Two historic banners were displayed at the plantings. One was the original 1983 banner displaying the words: "AIDS ACTION COMMITTEE: An initiative of the Sydney Gay Communities" (forerunner of ACON); the other banner said "Stonewall 26— Affirming the Human Rights of Lesbians and Gays Internationally".

People were able to read the stories of the banners as well as make suggestions for an HIV/AIDS flower symbol. The most popular appears to have been the spiky banksia serrata.

Tentative dates have been set for plantings in September and November. Negotiations are still under way for appropriate and permanent markings of the groves.

— Kendall Lovett



David Murray, author of HIV health guide* Just Around The Corner ... Just Down The Street, *massages client/practitioner Mike Dowling at The Sanctuary. The guide to services in Central Sydney was launched by Chris Puplick, President of the Anti-Discrimination Board, on June 27. Call 516 7830 for a copy.

Marinol approved

THE COMMONWEALTH GOVERNMENT'S Therapeutic Goods Administration (TGA) has approved a legal alternative to marijuana for people living with HIV/AIDS. Dronabinol— trade name Marinol— has been approved for treating weight loss and nausea.

A spokesperson for the NSW Health Department said that dronabinol has also been reclassified as a 'drug of dependence with some therapeutic benefits'. Doctors registered on a list compiled by the Australian Society in HIV Medicine (ASHM) will be able to prescribe it locally.

The TGA's decision was welcomed by PLWH/A (NSW) Convenor Bill Whittaker, however he said that the group "will want to look at the [ASHM] lists to ensure they're not unnecessarily restrictive".

Whittaker also criticised the Federal Government's decision not to subsidise the drug— which will cost $250 for a month's dose.

— Paul Canning

Talkfest concerns

THE 3RD ANNUAL HIV, AIDS AND Society Conference, hosted by The National Centre for HIV Social Research, took place at Macquarie University in July.

In a stimulating session entitled "Transitions", Bill O'Loughlin and David Stephens from Melbourne reported on their research work, which looked at the experience of AIDS related illness and the meaning of work.

In the more creative "Positive Bodies" session, Mark Counter, Convenor of NAPWA, presented his vision of Positive Living Centres in major cities across Australia by the year 2000. Emma King used a personal narrative approach and included some of her recent paintings as further representation of her experiences as a Positive woman. Once again, it was the more personal perspective provided by

Briefs

- *ACCESS PositHIV Radio*, in its new timeslot on 2SER, Tuesdays at 9.30 pm, needs volunteers. If you'd like to help out — jobs are writing scripts, handling mail outs, publicity and promotion, interviewing, editing and producing — call 516 4772. 2SER provides training and support.
- If you live, work or study on the North Shore, you're invited to become involved in a new newsletter, instigated by the Northern Beaches AIDS Prevention Centre. Call Helen or Sandie on 977 2666, or Gary on 858 0606, if you'd like to contribute to, or help produce the newsletter. The newsletter, which is still in the planning stage, is designed to give you a say on HIV/AIDS, drug issues and any other topics you may be interested in. Confidentiality of all contributors will be protected.
- *Blue Moon to Turn to Gold* is an AIDS Trust of Australia Benefit by the Sydney Gay and Lesbian Choir. The Choir will sing a selection of Rodgers and Hart's most memorable songs, including, of course, Blue Moon. An impressive line up of soloists joins the Choir for this performance on Friday, August 4.
- Cronulla Gay Group, wishing to place an AIDS memorial in Rockdale Park, have been knocked back by Rockdale City Council, despite the group's offer to pay all costs. The intended memorial was a bench with a dedication plaque.
- NorthAIDS respite and day centre is running its next volunteer training on the August 5 6. Anyone interested please phone Diana or Carrie on 998 22310.

Photo: Mazz Images/Nadine

The coveted title of Mlle. Muroroa 1995 was awarded to Ms. MuchRoom (of CSN Western Sydney). The gala evening raised $2,500 for ACON's vitamin and supplement service.

PLWHA that presented the reality behind the research findings, breathing some life into the conference.

A plenary panel discussion on the second day began with an explanation by Michael Bartos of why there wasn't a Sydney AIDS activist on the panel. The panel posed three questions:

"Is the AIDS crisis over?" "Has professionalism replaced activism?" and "What implications do these questions have for the link between theory and practice?".

One of the panel members politely pointed out that he couldn't think how the first question could be posed at all. No matter, we all silently agreed that it wasn't over, and sailed on quite comfortably.

On the second question, 90% of those at the session regarded themselves as being both a professional and an activist. I felt more than a little disturbed at this point.

Following the six speakers was an opportunity for discussion. The issues raised by several speakers (activists perhaps?) in relation to activism were deftly manoeuvred around, leaving me with a distinct feeling of frustration about this session and the conference in general.

The conference concluded with a "PLWHA Research Round Table" session conducted by Claire Parsons and the team from the National Centre in HIV Social Research at La Trobe University. They explained the nature of the social research being undertaken with participants in the 3TC clinical drug trial.

The conference provided new information on current social research across a wide spectrum. It also provided the opportunity to connect with a range of people working in the HIV/AIDS field.

What concerns me is the impression that the HIV positive community has been lulled into a state of inaction, particularly in speaking for ourselves and claiming our role in the ongoing fight against AIDS. In relying on others to represent us we may run the risk of losing our ability to articulate those issues of importance to the HIV positive communities. We may also be in danger of losing our ability to achieve the best outcomes in actually resolving those issues.

— Larry Wellings

Boy's Own

THE 1995 BOY'S OWN BAKE OFF, (see photo top right) hosted once again by the Oxford Hotel, was a great expression of community support for the work of the Bobby Goldsmith Foundation (BGF). $30,463 was raised for BGF in one afternoon, over $10,000 more than last year. The Oxford generously hosted the event at no cost to BGF.

A crowd of over 1,000 people enjoyed a star spangled event, with host Dot Dingle, assisted by Rose Leaf, Trudi Valentine, Wyness Mongrel-Bitch, Lana Turnip, Montez and Caroline Clarke. A highlight of the day was an appearance by Fanny Farquhar.

Cake judges Peter Howard, Maggie Kirkpatrick and Denise Roberts awarded prizes in each section as well as:

Best of show: the Dinosaur cake, sold to Brooke Beaves of the Midnight Shift for $3,000 and Best non-edible cake: The Crown, sold to Ken Holmes of Aussie Boys for $3,500.

Many restaurants donated superb cakes for the day.

Illawarra gap

A LONG-AWAITED REPORT INTO THE needs of the HIV community in the Illawarra and Shoalhaven region — released as *Talkabout* was going to press — has found significant gaps in service and health care provision, regular breaches in confidentiality, and many people living with HIV/AIDS (PLWHA) traveling to Sydney for treatment.

HIV Community Development worker Frank Velozzi, said that the

establishment of a Positive Space Project would be the main activity arising from the report.

Velozzi can be contacted at ACON on (042) 26 1163.

— Paul Canning

Writing HIV

THE SECOND *QUEERLIT* CONFERENCE will feature a panel discussion called *Writing HIV* (see ad page 13).

Speakers so far confirmed include Kathy Triffit (Self Imaging AIDS Project), Colin Griffiths (Queensland educator and activist), Chris Jones (*NUAA News* Editor and poet) and Dominic O'Grady (*Sydney Star Observer* and former ACON Media Liaison Officer).

More info from David Urquhart on 557 7190.

Edgy Gallo

DR ROBERT GALLO, ONE OF THE MOST familiar names in AIDS research, will open his own, private, research facility, the Institute of Human Virology.

Gallo has been regularly pilloried as a 'self-serving egomaniac' by AIDS activists and was only recently cleared of misconduct surrounding the discovery of HIV. However, the attitude of activists towards him has begun to soften.

In a rare interview with PLWHA magazine Positively Aware in July Gallo was positive about the future for PLWHA, saying that "you have a large [AIDS] research community right now. It's going to improve. It's going to be a curable disease. [But] with AIDS you can't tell from where some big advance will occur."

Controversially, he reacted against recent calls for an increased focus on so-called 'basic research' saying that "we are not going to learn enough if the idea is to understand everything from basic science. We need more clinical trials." Further, he argued that "academia" should remove itself from the development of antiretroviral pharmaceuticals (such as protease inhibitors) saying that his Institute will focus on 'cutting-edge' technology including gene and DNA/RNA based therapy alongside cellular factors and therapeutic vaccines.

— Paul Canning

Photo: Mazz Images

Drag Museum of Australia at the Boys Own Bake-Off (see story page 6).

Benetton

FOLLOWING THE EXAMPLE OF A French judge earlier this year, a German court has found that Benetton's controversial advertisements breach competition rules because they exploit human suffering.

The adverts which offended the judge included one featuring a buttock stamped 'HIV Positive'. Benetton pledged to appeal the ruling saying that they are not the only company using emotion for commercial gain. The man behind Benetton, photographer Oliver Toscani said "I think the Germans are particularly sensitive about this matter because they possess a great sense of guilt." The magazine which published the adverts, *Stern*, described the decision as an infringement of freedom of speech. However the German advertising industry has welcomed the ruling saying that it had drawn a clear line under what is acceptable.

German Benetton retailers protested against the company's adverts earlier this year by refusing to pay for stock delivered to their stores.

— Paul Canning

Notice

***Talkabout* distribution** has not been up to its usual standard for the past couple of issues, for a number of reasons including PLWH/A staff turnover and ill health.

Apologies to anyone who received their June or July *Talkabouts* late, or not at all. We are working on this and hope to be back on track real soon!

Brenton Heath-Kerr, renowned HIV Positive artist, died on July 23. A tribute to Brenton will be published next month.

STOP PRESS

Abbott Australasia have committed to making Ritonavir available under compassionate access — in about eleven months time.

Statement by PLWH/A (NSW) Inc., Call for campaign against ABBOTT PHARMACEUTICALS

FOLLOWING CRITICISMS OF THE Abbott Pharmaceuticals clinical trial of ABT 538, and the failure of Abbott to release ABT 538 for compassionate use, People Living With HIV/AIDS (NSW) is issuing the following statement:

ABT 538 is one of an exciting new group of antiviral drugs called protease inhibitors.

In Australia there are a substantial number of people with HIV with very depressed immune systems. Most of these people will have already tried AZT, ddI and ddC. and are failing on these treatments. They need something new. If they don't get new treatments, their health will deteriorate further. Some will inevitably die.

For those in this desperate situation, access to ABT 538 would arrest decline in their health and increase their chances of survival.

A clinical trial of ABT 538, involving 50 people, has recently begun in Sydney, through St Vincent's Hospital and the Albion Street Centre. PLWH/A believes this clinical trial is unethical and should not have been allowed to proceed. Our reasons for this are:

- the trial has a placebo arm, so half the participants will not get ABT 538 or any other new antiviral therapy. Trial participants must have a very low immune function (less than 100 CD4 cells — well below the US definition of AIDS which is 200 CD4 cells). So the health of those who draw a placebo will be placed in considerable jeopardy. The design of this trial actually requires people to get sick to prove the drug is effective. Australian AIDS groups have a long history of opposing placebo based trials, particularly on people with very depressed immune systems;
- the ABT 538 trial does not have a compassionate access arm for those who are failing therapy and who don't want to enter a placebo based trial. Because of this, people desperate for a new treatment are being forced into this clinical trial;
- this trial requires participants to agree to a lower standard of care than PLWHA believes acceptable. Trial participants are not allowed to take the new antiviral drug 3TC. Most people with less than 100 CD4 cells will have already tried and used up their benefit from AZT, ddC and ddI. If they do not get ABT 538 in this trial, then at minimum they should have the right to take 3TC.

PLWH/A notes that the ABT 538 trial is not being run by the National Centre for HIV Clinical Research. As a result, the usual National Centre and governmental mechanisms for consultation with community AIDS groups about proposed HIV clinical trials were bypassed. There was no consultation with AIDS community groups on the design of the Abbott protease inhibitor clinical trial and its conduct in NSW.

PLWH/A is very concerned at this development. Close co-operation between researchers, people with HIV/AIDS groups and AIDS organisations is one of the main reasons why Australia is viewed as an excellent country to do AIDS research. *The lack of consultation on the ABT 538 trial is completely unacceptable.*

At a meeting on July 31, PLWH/A will be seeking an assurance from Professor David Cooper, chief investigator for the ABT 538 trial, other HIV researchers, and the pharmaceutical industry, that before any major HIV related clinical trial goes ahead in this State, there must be full consultation with ACON and PLWHA (NSW).

Compassionate access to ABT 538 must be resolved urgently.

PLWH/A notes that in the USA over 60 major AIDS groups, including ACT UP chapters, the San Francisco AIDS Foundation, AIDS Project Los Angeles, and the National Association of People with AIDS have recently signed a consensus statement demanding that Abbott and other manufacturers of protease inhibitors make their drugs available on a compassionate basis.

PLWH/A has asked ACON and AFAO to lead a community campaign to force Abbott to make ABT 538 available to all those who need compassionate access to it.

Abbott is behaving like a rogue pharmaceutical company. They cannot be allowed to get away with their callous, inhumane attitude towards people with HIV/AIDS.

ABBOTT PHARMACEUTICALS — NO COMPASSION — NO PEACE

See page 34 for Colin Batrouney's article on protease inhibitors.

Professor David Cooper Responds

In a letter of response to the PLWH/A statement (page 8), Professor Cooper addressed a number of points. Extracts from his response are printed below, paragraph numbers refer to the PLWH/A statement.

MANY ANTIRETROVIRAL DRUGS CAUSE drops in virus load and an increase in CD4 count, but not since the first AZT trial in 1986 has a new antiretroviral . . . been shown to improve survival. . . . Not enough is yet know about Ritonavir to make this claim. The two . . . patients from Sydney in the phase II study whose KS lesions responded to drug therapy both relapsed quickly.

I want, and I expect virtually every worker in HIV research wants, new and effective treatments to become available. . . .

ABT 538 will only arrest a decline in the health of PLWHA if it works. We don't yet know much at all about its efficacy and levels of toxicity, and that's why this study is being conducted.

Australia was allocated 40 places [in this trial] and enrolled 44 people. The study is now closed to enrolment. Internationally the total enrolment was 1,100. We therefore were allocated 3.6% of places in the trial.

The trial has been approved by the Ethics Committees of the Eastern Area Health Service, St Vincent's Hospital and The University of New South Wales. These are not bodies known for habitual conspiracy to pass unethical proposals.

Paragraph six

It is an internationally accepted requirement for the licensing of new drugs to randomise the drug against a placebo. In this trial, patients have the option of continuing on their licensed antiretrovirals. At the present time, the only way regulatory agencies will allow drugs to be licensed is if they have been tested against a placebo arm ... apart from the licensing issue, placebo-controlled trials address issues of drug safety and to establish whether the efficacy of a drug outweighs the toxicity of that drug.

Preliminary data from Ritonavir suggests that it is *not* a clean drug. We are seeing abnormal liver tests, high triglycerides, severe nausea and diarrhoea, unpleasant skin sensations and a strongly unpleasant taste of the liquid drug. Because of the latter, Abbott is attempting to develop a solid formulation.

Trial participants have low immune capacities for a practical reason: to accumulate quickly the study endpoints, which in turn is the fastest way to get useful results on the drug. The alternative is to wait perhaps years for meaningful results, which is hardly the desirably outcome if the drug proves to be useful and tolerable. These endpoints of course will occur in the treated group as well as the placebo arm.

. . . If toxicities prove to be the most significant issue with Ritonavir, which seems possible . . . then those people on the placebo arm may do considerably better than those on the active treatment arm. If the drug works, then at least 22 people could benefit.

Paragraph eight

3TC is not licensed in Europe, North America or Australia. The Food and Drug Administration, the TGA and other licensing bodies will not allow people taking one unlicensed antiviral to enrol on a trial of another unlicensed antivital agent. If you have a problem with this, complain to the FDA. . . .

Paragraph nine

44 people were enrolled with the protection of Ethics Committees' approval and exhaustive informed consent. Does the community have to be involved in decision making for such a small number of sub

(Continued on page 37)

Briefs

- Thalidomide, the demon pregnancy drug whose potential anti-HIV use has often been touted, has come to the fore again with researchers now believing that it may be of use in fighting a number of infections including TB related wasting, MAC/MAI and KS. (*Body Positive*)
- A live yeast, Saccharomyches boulardii, has been found in a number of studies to be useful in the treatment of antibiotic-related diarrhoea. A side effect of certain antibiotics can be the killing of helpful gut organisms and the encouragement of disease causing gut organisms. S. boulardii was shown to reduce diarrhoea incidence by 50%. (*Body Positive*)
- The maximum tolerated dose of 3TC monotherapy is still unknown as a study has found doses ranging form 0.5 to 12mg/kg/day tolerable. Although side-effects were reported they were described as relatively mild and not related to dosage. The study also found that CD4-cell counts retuned to baseline after 12 weeks. Viral load was not examined. Further studies on maximum dosage are now under way. (*AIDS Clinical Care*)
- A Baltimore study of IDUs has found that vitamin A deficiency is a marker of increased mortality risk. Although the study did not prove that deficiency contributed to mortality vitamin A supplementation has been shown to reduce child mortality in developing countries. (*AIDS Clinical Care*)
- Early trials of a new drug aimed at delaying CMV have suggested it is twice as effective as either oral or intravenous ganciclovir, but it is only available in a intravenously administered formulation and has some side-effects. The drug cidofovir (HPMPC), made by Gilead Sciences, delayed CMV retinitis for an average of 120 days as opposed to 62 days for intravenous ganciclovir. (*Positively Aware*)
- In the race for the emerging protease inhibitor market Auguron Pharmaceuticals has joined the leading pack with the announcement of preliminary results from a stage II trial. Its AG1343 produced "signifiant acute antiHIV activity." The first patient on the study had achieved a CD4 cell increase of 116 and a virla load reduction of 99%.
- The US Government has stopped researchers from injecting the bone marrow of baboons into patients with AIDS citing ethical problems. The research is part of a broader effort looking at restoring immune systems through transplantation. Previous transplants of human bone marrow into baboons have been successful. (*Reuters*)

(Treatment briefs/Paul Canning)

Talkback

Re-appropriated

In response to the letter titled "Inappropriated" from Peter Rawlinson (*Talkabout* June '95), it is distressing when support groups do not live up to expectations and in some instances groups do not always run their full ten weeks. The HIV Support Project has come to accept from experience that some groups do not necessarily 'work' But in the last seven years the HIV Support Project has conducted over 110 groups with over 1,000 participants, facilitated by volunteer peer facilitators. Given this number of groups it is to be expected that while the majority of groups have been found to be beneficial by most participants, some groups are not.

ACON has a comprehensive list of health care providers. GPs listed on ACON's database are those who have HIV experience, are members of the Australasian Society of HIV Medicine and who can prescribe anti-retrovirals. Bulk-billing arrangements made by most GPs are assessed upon individual need. Their billing arrangements can be easily ascertained by inquiring when telephoning for an appointment. As one needs a referral from a GP to see a specialist in Australia, information about specialists' billing arrangements can be simply obtained by asking your GP. (In most instances if your GP bulk bills s/he will make a bulk bill request in the referral.)

The three ACON staff who attended the GNP+ conference in Capetown were either sponsored or self funded. ACON does not have the resources to send 'delegations' to overseas conferences. I attended the *HIV95* conference in Montreal, Canada, after obtaining corporate funding. As a regular reader of *Talkabout* Peter obviously missed the three page article by Les Szaraz on the Capetown conference in May's issue (perhaps he may wish to obtain a copy from PLWH/A) and will no doubt read my report in this issue on *HIV95 Montreal*.

I trust this will address some of the concerns Peter raised in his letter.

— Stephen Gallagher
HIV Health Maintenance/
Education Officer, ACON

PS. transcripts and conference abstracts from *HIV95 Montreal* are available on request from the HIV Support Project.

Notice

Volunteer assistance urgently needed for herbal trial. Typing on an Apple Mac computer. Phone Jan on 552 2243.

living in the country?

Do you want ...

- to talk about being gay or living with HIV
- referrals to HIV-friendly local health services
- info about support & social groups for gay men

... then call Nigel or Rob

008 802 612
or 02 206 2000

RURAL PROJECT ACON

We welcome your letters. They should ideally be <300 words and may be edited for space. Please include your name and Phone number or address and send them to:

***Talkabout*, Po Box 831**
Darlinghurst 2010

Olga's Personals

Mid North Coast, 47 yr old male HIV +, still healthy, seeks friendship with non-scene type guys. Visitos welcome to enjoy the area and stay over in quiet rural area.
#950705

How to respond to an advertisement

- Write your response letter and seal it in an envelope with a 45c stamp on it
- Write the Box # in pencil on the outside
- Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on

How to place your advertisement

- Write an ad of up to 40 words and be totally honest about what you are after
- Claims of HIV negativity cannot be made as it is not possible to verify such claims, however, claims of HIV positivity are welcomed and encouraged
- It is OK to mention that you are straight, bisexual, gay or transgender
- Any ad that refers to illegal activity or is racist or sexist will not be published.
- Send the ad to Olga, and be sure to include your name and address so that responses can be forwarded on to you. This information is not published and is kept confidentially by Olga.

... with Complements

IN AUGUST
*A new yeast for diarrhoea
*AIDS & the dampening of desire
*Naturopathy

"Maybe you have tested HIV positive very recently;

maybe you've known about it for some time, but this is the first time you've reached out for information or support. You need to know that you are not alone. There are an estimated 19.5 million HIV positive people in the world. About 18,000 of us are in Australia.

Testing positive for HIV does not mean that you have AIDS, but HIV is probably the biggest threat to your life that you have ever faced. It's a good thing you found this out. As upsetting as testing positive may have been for you, you are better off knowing, so you can learn about HIV and decide what you want to do about it. The fact that you cared enough about yourself to get the HIV test and the fact that you are reading this magazine show that you are concerned about your health. So give yourself some credit. You have taken important first steps to take care of yourself, and you should be glad about it.

One of the truths of testing HIV positive is that once you know, you can never not know again. For better or worse, your life will always be different now. You may be experiencing great feelings of loss about this. You may feel that certain areas of your life are now in the hands of doctors, insurance companies, or symptoms. This can make you feel as though you have less control over your life and may cause you incredible anxiety.

Know this - you do not have to give up control of your life. By arming yourself with information, and deciding what is right for you, you will soon realise that you are still the same person you were. It is your life, your body, your health. Allow yourself to take time to decide what you want to do. Then go do it.

Your life does not have to be gloom and doom. It is possible to have a very positive attitude as a person with HIV - millions are doing it right now - but it is much more difficult to get on with your life and live happily if you're trying to do it alone.

There's no need for you to handle this by yourself, and it's probably a mistake even to try to do it. You are not the only person facing this. Learn who the others are and what they have to offer.

Wherever you are, you can find support, or the means to create it. It just doesn't make sense to face the same issues without helping each other out. We are not alone. And neither are you."

adapted extracts from You Are Not Alone, *an essay by Michael Slocum and Jim Lewis originally published in the US publication* The Body Positive.

WELCOME! *to* Talkabout*'s first ever special edition for people who have just been diagnosed with HIV.*

Finding out you are HIV positive opens up a whole new world of tests, treatments, decisions about your health, lifestyle and relationships. It's not familiar territory.

In this issue, Talkabout *opens a few doors into this new world, mapping out some of the new terrain and sign posting the kinds of things you can do. You can also read about how other people reacted to their HIV diagnosis, and the kinds of changes it's made in their lives.*

It's true: you're not alone.

But what does it all mean?

WHEN YOU'VE JUST BEEN DIAGNOSED HIV positive, finding out about HIV, its effects on the body and treatments can seem a daunting task. But you don't have to become an expert in biology. Ross Duffin outlines the basics you need to know.

You will be faced with new decisions about your health so it's a good idea to learn about HIV and treatments. Only with information that you can understand can you make an informed decision about what you need to do to keep as healthy as possible.

Let's start at the beginning. You've been told you are HIV-positive. What does that mean? It means that you have been infected with HIV and that your body has produced antibodies to fight the infection. It does not mean you are sick or that you have AIDS.

Antibodies are chemicals the immune system makes. When a bug or germ gets into the body, the immune system generates antibodies which can grab onto them. Different germs cause the body to make different sets of antibodies. There are antibodies for measles and different antibodies for the flu. The HIV test detects the presence of antibodies made by the body to fight HIV infection. When the antibody grabs onto the bug, it attracts other parts of the immune system which try to destroy it.

What is HIV? The initials HIV stand for Human Immunodeficiency Virus. Human because it infects human beings, Immunodeficiency because it can be associated with a loss or deficiency of the immune system. Viruses are germs that can cause illnesses, such as mumps, measles, chicken pox and the flu. Viruses cannot reproduce on their own — they can only reproduce by using the cells of other animals. In humans, different viruses infect different sorts of cells and cause different sorts of illness. For example, hepatitis viruses infect liver cells. HIV infects all sorts of different cells in the body. In particular, it infects cells of the immune system — the very thing the body uses to fight germs.

And what's an immune system? Human bodies have lots of mechanisms to help them fight germs and prevent infections. The skin provides a barrier to most germs. The nose has a filtering system which traps many germs in the air and prevents them getting into the body. Once bugs get into the body, there are ways the body tries to fight them. There are a number of different types of cells which work together to try and overcome the invader. These cells recognise that something doesn't belong and then try to destroy it. The term 'immune system' describes all the ways used by the body to protect itself.

The immune system is made up of lots of different types of cells. One important group of these cells is called T-cells — some people even name their T-cells. There are subgroups of T-cells and the two you'll hear most about are the T4 cells and the T8 cells. In people with HIV, the number of T4 cells usually goes down and the number of T8 cells usually goes up.

T4 cells and T8 cells have different roles. T4 cells are important in switching the immune system on and in controlling the immune system response. T8 cells are involved in removing cells infected with virus and in switching an immune response off.

The term 'T-cells' is often used to refer to the T4 cells. The 'T-cell count' refers to the number of T4 cells. This number is a rough guide to the state of your immune system. The T-cell count in a healthy person is usually between 600 to 1200. (This number is not the total number of T-cells in the body — it the concentration of cells in a tiny amount of blood). Regular T-cell counts indicate the state of your immune system. If your T-cells are above 500 then it is unlikely that any illness you experience has anything to do with HIV.

Another blood test that you are likely to hear more about in the future is a test for what's called 'viral load'. This measures the concentration of HIV in your blood. It is believed that the amount of virus is a good indication of the level of its activity. If your viral load is high then that may indicate that the virus is very active. It is only a new test but it is likely to become an important test in monitoring your health.

So what happens over time? There are four phases of HIV disease. The first phase occurs just after you've been infected. Some people experience a brief illness characterised by high temperature

and a rash. This illness is called the 'seroconversion illness'. Not everyone who gets HIV has this illness. It is called 'seroconversion illness' because at about the same time the body produces antibodies to HIV and the HIV antibody test (done by taking blood) changes from negative to positive. (Sero = blood, conversion = change).

After that time, people with HIV generally stay well for a number of years. This phase of HIV disease is called the asymptomatic (or no symptoms) phase.

Some people go on to develop symptoms of HIV disease such as tiredness, sweats and loss of weight. This phase of HIV disease is called the symptomatic phase. People can experience these symptoms for long periods of time and the symptoms can come and go.

Some people go on to develop more severe illnesses or symptoms. This phase of HIV disease is referred to as AIDS and the illnesses are called opportunistic illnesses. They can occur once the T-cell count drops below 250. They are called 'opportunistic' because they are illnesses which don't usually occur and only have the 'opportunity' in people whose immune systems are not working very well.

It is important to monitor your health. This involves both an awareness of how you feel and visiting your doctor regularly to have a physical examination and blood tests. These blood tests will include a T-cell count and in the future measure your viral load. If you're well (ie more than 500 T-cells and no symptoms) then you usually will visit your doctor every six months. If you're less well, your doctor will recommended you visit more often.

One of the things that most people with HIV face is decisions about treatments and lifestyle. How soon you have to face these decisions depends on your health. How much you choose to find out depends on how you prefer to manage living with HIV. Different people have different ways of coping with it. The only guideline I use is to be informed as possible about decisions which affect me. It doesn't mean I want to know everything — HIV is not the only defining thing in my life.

There are many different ways of attempting to treat and live with HIV. They include :

- Adopting a healthy lifestyle. The belief is the healthier you are the more likely it is that your body will be able to fight HIV. Unfortunately there's not a simple 'healthy' lifestyle that's been proven to work. Also, it is easy to say but often hard to implement.
- Anti-viral treatments. These treatments attempt to stop HIV reproducing inside the body (hence anti-viral) and doing further damage. Despite lots of effort, these treatments have so far been of limited use, although there are a number of new treatments under investigation.
- Treatments for the symptoms of HIV disease. Experiencing symptoms of HIV disease for long periods of time can dramatically affect your quality of life. There are many treatments (both Western and alternative) which can be used.
- Treatments which work on the immune system. These treatments try to modify or restore the immune system to either reverse the impact of HIV or to improve the ability of the immune system to fight HIV
- Treatments that prevent common illnesses. Many of the illnesses that can occur can be prevented. It's much better to prevent them than to treat them once they occur.
- Treatments for opportunistic illnesses. For some illnesses no prevention treatments are available and they are treated if they occur. If your T-cells do drop to below 250 then a knowledge of common illnesses and their symptoms can make it easier to get early treatment.

Another phrase you'll hear is early intervention. It is believed that when there are proven and effective treatments, the best time to start them is as early as possible. Early intervention means treating HIV disease early, and trying to maintain the immune system in as healthy a state as possible.

There's a lot to take in. This article is meant to be a very simple beginning. It won't answer all your questions and you might have other things to deal with before you're ready to ask those questions. When you need to know ask your doctor, your local AIDS Council or PLWA group, read *Talkabout* and find out about other treatments magazines. HIV information sessions conducted at some AIDS Councils and treatments officers at some AIDS Councils may offer further more detailed information and answer your specific questions. The information changes all the time so it's good to get updates from time to time.

Second QueerLit conference

August 26 & 27 1995

NSW Writers Centre Rozelle - Registration $30, $15 conc

QueerLit PO Box 359 Glebe NSW 2037

-Writing HIV Panel-

10:30am 27-8-95

Info: David Urquhart 557 7190

Talkabout

Adrianne

Tell me about your diagnosis and how you reacted to it.

I was living with a man for about four and a half years, he was married for twenty seven years before he met me, and he had a family. We wanted to get married, but there was something that wasn't quite right, it was like there was another woman involved. When it came to the crunch, it was another man. So I went and had the test, which was to me just a formality.

That was in March. I was absolutely unbelieving. This happens to drug users and prostitutes and members of the gay community, I'm just a fifty year old heterosexual woman in a monogamous relationship. My man was waiting in the car when I went out, after the diagnosis, and I screamed at him, "you've killed me, you bastard". Of course he had it too, but I wasn't very compassionate towards him at that stage.

Then there was trying to get myself back together again. Waking up in the middle of the night crying and trying to think why I was crying, and then thinking "shit, yes, I forgot".

Lots and lots of self-pity and anger and lots of hatred for everybody. Hatred against men's public toilets. I'd drive past them and think, you bastards, which one of you did this to me. I wanted to stand outside them and call out "come on out you lot, come and face me (laughs)".

Nausea, lots of nausea and itching and all that sort of thing for a couple of weeks. Wanting to tell everyone and terrified they're going to find out at the same time. Feeling dirty. I was having three or four showers a day, scrubbing my skin, my nails. It was a beautiful feeling when that passed.

That went on for a little while until the most unbelievable thing happened to me. I'd used the expression "I was shattered", but I'd never known what it really meant. But I actually shattered. All my body broke up into lots of little pieces, a bit smaller than a tennis ball, and they were all over the floor, and they were rolling under the couch, and under plants and things, and I sat there and looked at all these pieces for about a week, thinking "how the hell can I get myself back together"? Where does it belong if I pick up a bit? And there are loose bits and I won't know where they are. I could see all these little bits of me all over the floor.

Nearly all the pieces are back together, they just went back without me noticing. I think there's about three little pieces down there still, I'm not quite sure where they go, but they're not really important ones. I'd be interested if anybody else had ever experienced that, it was unreal.

After that it was just a matter of getting stronger.

I'm starting to go to a few meetings, support groups and things. It's still something I'd rather wasn't there, but I think that maybe it can be good, if I can do something good with it, rather than something negative. Maybe it might make me a better person than I was.

I don't mean to sound holier-than-thou, because I have some shit times, I really do. I have some times when I don't get out of bed. I put some old soapies on and open a bottle of Scotch and wallow in self-pity. When I do that I feel so guilty, but the day after I get out of bed I feel a better person, I'm stronger. So when I have these crashes now I go with them because I know that tomorrow I'll be feeling better because of it.

I'm still bouncing of the walls a bit, and I'm so full of information my head is about to explode. I don't know which is the direction I should take, but I'm feeling positive and I'm feeling strong. If I get my ten years, I'm going to reach sixty, so it's not such a short life is it?

You were very angry about finding out that your partner was bisexual. How do you feel about gay and bisexual people now?

At first I wanted to kill the lot of them, but I have a lot of compassion, more than I thought I had in me. It had been my biggest dread, the worst thing I could imagine my son being. But now, of course, it would make absolutely no difference to me whatsoever. In fact I feel rather drawn to them, I don't know why. I'd like to have a gay male friend.

I feel a lot of compassion for the man who gave it to me. He can't help what he is. I can't understand what he is, but he can't help it. He's got a lot more to carry than I have, he's the one who gave it to me.

Interview by Jill Sergeant

If you're a positive woman and you're interested in receiving occasional information, social news, invites and medical updates — especially for women — then call Vivienne Munro, at ACON's HIV Support Project on 206 2012 to join the mailing list

Tony McNaughten

I WAS DIAGNOSED IN 1984. I WENT quite mad, I actually ended up in Pentridge gaol for a short time. I had the test as a sort of joke — I needed an excuse to see a doctor to get some pills, so I asked for a test. It came back positive.

I went out of the waiting room and told my friends. I hadn't thought about it at all. All my friends left me and I found myself very alone.

I told everybody about it. I used to tell complete strangers. I think I needed to. You need to evaluate what life means to you, it's a process. I'd always been shy and introverted. I guess I went to an extreme, I'd cry in public.

People were telling me it wasn't cool to be so open. I think it actually saved my sanity. If someone tells you they're positive, it's one of the times you have to put 'cool' on hold and be supportive. Otherwise what's the gay and lesbian community all about? That fear is still there.

My doctor said it's not a death sentence, but all the way through that's been a difficult thing, not knowing if I'm going to live or die or get sick. I'm termed a long term survivor now, I've still got over 1,000 T cells. I've kept using, except for 18 months when I straightened out, around 1986. My health actually got worse during that time!

Having something to focus on — HIV — has changed my whole life. Now I'm settled, have a job, a partner. I was very isolated before. I know it's sickening when people say "it changed my life", but it has.

I went to a support group, but it was mainly middle aged gay men who I felt quite different from. I was a young punk. A lot of them thought I was straight because I didn't fit in much. I found I didn't relate to them because I injected and I was a sex worker. It's taken me years to find people I can relate to.

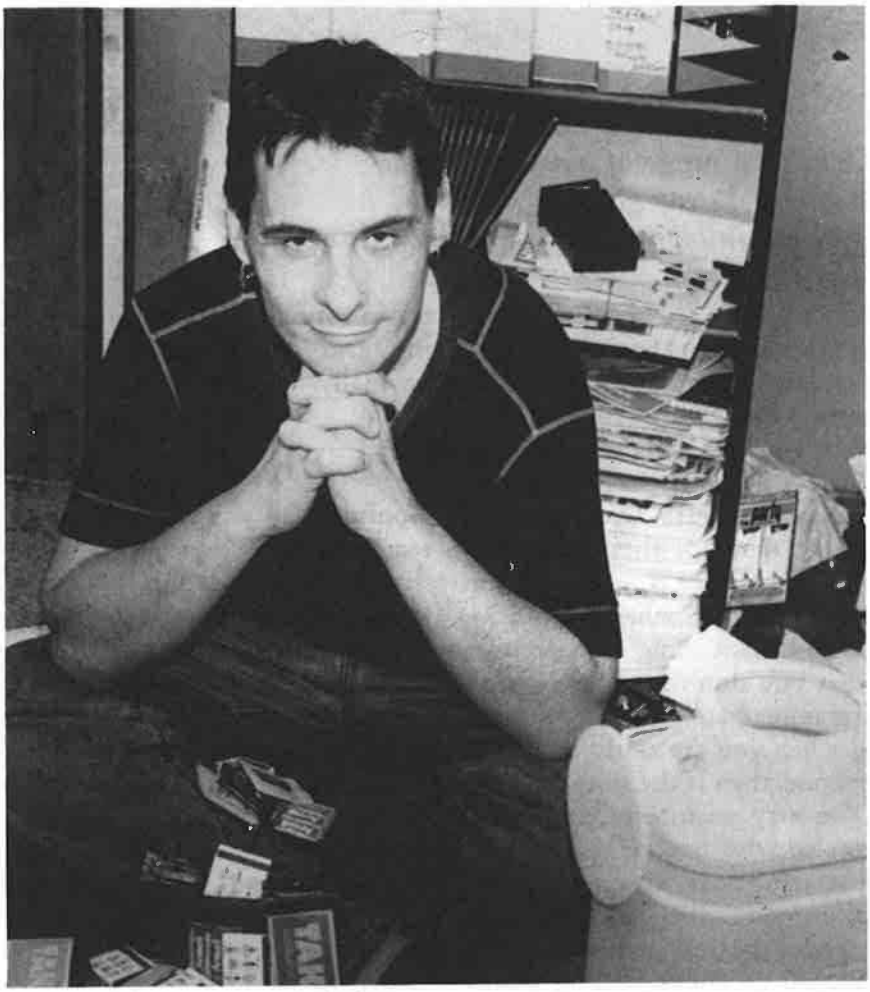


Photo: Mazz Images

One thing people have going for them now is all the support that's available — ACON, PLWH/A, the Luncheon Club, the Positive Injector's Group. These days you can have a group of friends who are also Positive.

Finding a relationship was difficult for me for years. I didn't think I would. I found it difficult to disclose in that context. I'm in a relationship now with someone who's also Positive. That's the only thing that can work for me, to be with someone who understands that side of me.

Fear of transmitting the virus is one of the worst things we face, a lot of us — being branded a 'carrier'. People are scared of me. I had one friend who said if I got sick she'd come and stay with me. I was really touched, because it took guts to say that. It's something she had to think about.

HIV has allowed really intense bonding between people. It's such an extreme time. I understand what it must have felt like during war times.

Interview by Jill Sergeant

The ABC of HIV

So you've got your test result back and it's bad news.
The doctor or counsellor who gave you the positive test results will have discussed a range of issues with you.
So where do you go from here?
***Stephen Gallagher** points out some directions.*

WHAT DO I DO NOW? WHO CAN I talk to? Where do I begin? Do these questions sound familiar? You would be very unusual if they didn't. The first thing to remember is there isn't a right or wrong way in dealing with HIV. Everyone handles the news of their diagnosis differently. There is no instruction book to tell you what to do next. The important thing to remember is that you don't have to do anything immediately. Take your time and when you are ready to talk to someone, then is the time to start.

You may want to talk to someone else who has HIV. You may want to know about support groups, counselling, or where you can go for medical advice, or maybe how you go about finding a doctor experienced in HIV. You may have many other questions you want answered. If you are feeling confused that's natural, there is a seemingly insurmountable amount of information.

The first step, which is often the hardest, may be just talking to someone who understands. This may be a friend who has HIV or someone at an AIDS council or PLWHA organisation. In the quest for information, many people put their support needs and emotional health on the back burner; they rush out and read everything they can get their hands on. Other people prefer to just talk to someone who understands, while others may try to forget HIV for the time being and go about their lives normally.

Confidentiality

Confidentiality is one of those often misunderstood terms. It means that no one will divulge your HIV status to anybody under any circumstances. All health care workers are bound by professional confidentiality, including workers in PLWHA organisations and AIDS councils. Staff in these organisations go to great lengths to ensure people's confidentiality — to the extent that staff do not identify what organisations they are telephoning from when they leave messages.

In Australia nobody has the right to ask you if you are HIV positive. This includes government departments, employers and the police. If they do ask, you are under no obligation to tell them. Nobody in Australia has the right to make you undergo a test for HIV unless under exceptional circumstances (eg being imprisoned). In theory you may not be discriminated against on the grounds of your HIV status (although certain insurance companies won't offer you insurance). The NSW Anti Vilification Act includes HIV (legally, no one may ridicule you because you are HIV positive).

Dental care

An often forgotten aspect of looking after our health is dental care. Many people express concern that they may be discriminated against or charged extra by their dentist if they reveal their HIV status. Dental care and HIV is a specialised area of dentistry. AIDS councils and PLWHA organisations have contact details for HIV experienced dentists who can attend to your special dental requirements.

Emotional support — who to talk to?

Counsellors

Counselling is the general term that encompasses people who are social workers, psychologists or therapists. They are found mainly in hospitals, clinics and community health centres although increasingly there are more in private practice. It pays to look around for a counsellor you are happy with. A long term relationship with a counsellor can be an important part of ongoing support. A good place to start is either the clinic or hospital where you were first diagnosed, or ask your GP. It is important to feel comfortable with your counsellor. Just because somebody recommends a specific counsellor to you does not mean they are necessarily the 'right' one for you.

You can contact the Social Work departments at major hospitals by telephoning their main switchboard number. To be eligible you must be an outpatient or previous patient. Counselling services are available to anyone with HIV/AIDS at ACON or the Albion Street Centre. You do not need a referral just call the number in the *Talkabout* Contact Pages for an appointment.

What is a support group?

There are several different types of support groups for HIV positive people. Knowing what types of support group are available will enable you to decide if it's the right type of group for you. Groups are not therapy sessions and are not set up to make everyone think or act in the same way. Their primary aim is to provide a supportive, confidential environment to discuss whatever you feel comfortable with. Many people choose to do a group because they wish to learn from other people's experiences and don't have anyone they can talk to who understands what it's like living with HIV.

HIV Peer Support Groups

Peer support groups, as the name suggests, are groups where all the participants including the facilitator are HIVpositive. These groups are usually 'closed' groups, which means that they run for a few weeks and once the group has begun, nobody new joins the group. Many people prefer this type of closed group as a sense of trust develops over a few weeks enabling people to speak freely.

Support Groups

These groups are run by health care professionals (social workers or psychologists). They can be ongoing drop-in groups or groups structured to discuss various topics on any given night. The benefit with this type of group is that you aren't committed to attending every week, you can drop in when you please.

There are confidential groups that provide support for HIV positive women, heterosexuals, injecting drug users, gay men, and people of non English speaking backgrounds. ACON has recently started a series of confidential groups for people who have become HIV positive in the last two years.

There are also two telephone support lines, one for positive women and one for positive heterosexuals who are isolated and cannot get to a support group.

There are many different types from which to choose. The *Talkabout* 'Contacts pullout' lists all these groups.

General Information

Questions regarding legal rights and obligations, work issues, international travel, insurance policies — the list is endless — can be answered by contacting your local AIDS Council or PLWHA organisation.

Information sessions run by the AIDS councils, some clinics and PLWHA organisations are also a good source of information, and cover a range of topics from treatments, recreational drug use, nutrition, international travel and complementary therapies.

Lifestyle and HIV

There are many questions on lifestyle issues and the progression of HIV disease. Nutrition, smoking, alcohol and recreational drugs are subjects that many people would like to know more about. Information on these topics is available from ACON and the NSW Users and AIDS Association (NUAA). Specialist HIV dietitians are available at HIV/AIDS clinics or outpatient departments of some hospitals.

Stress is another often mentioned concern (God! Who isn't stressed about being HIV positive). Many people use exercise, meditation, yoga etc. to reduce stress in their lives. Check the contacts section for information about these classes and venues.

Medical matters — finding the right doctor

Finding a doctor you like and trust who is HIV knowledgeable is a tall order — but they do exist. PLWH/A and AIDS councils have lists of doctors with HIV caseloads and experience who are gay friendly, drug user friendly etc. AFAO has published a booklet titled "Your Doctor and You," which is available from PLWH/A, ACON and some clinics. There is an article in the May '94 edition of *Talkabout* called "Shopping for a doctor," (back copies of *Talkabout* are available from the PLWH/A office).

Pregnancy

Unfortunately some women only discover their HIV status when they are pregnant. Some HIV positive women plan to have a baby and would like to find out more about available choices. Information and support around HIV and pregnancy can be obtained from the women's unit at ACON, or the HIV worker at the Prince of Wales Children's Hospital.

Reading Material

Three libraries with HIV/AIDS collections in Sydney are open to the public by appointment: at ACON, the Albion Street Centre and the Family Planning Association in Ashfield.

Other major sources of information (besides *Talkabout* of course) are publications like the *HIV Herald* and *HIV Briefs*, both published

lished by the National Treatments Project at AFAO); *With Complements* published by the Complementary Therapies Collective and *AIDS-X*, a bi-monthly treatments update. With notable exceptions, the quality of treatment information in the mainstream press is appalling and often incorrect. Unfortunately it isn't much better in the gay press, so your best sources of written information are the specific HIV publications.

Referral Services

There are various referral services available from your local AIDS Council or PLWHA organisation. In rural NSW you can call the ACON Rural Project or get in touch with your region's HIV/AIDS support worker. These information services can put you in touch with an HIV experienced GP, complementary therapist, counsellor, support group etc.

Treatments Information

Many people with HIV/AIDS want an active role in their treatment decisions. Learning more about the immune system, HIV and available treatments may seem like a daunting task. You can speak to a treatments officer or health promotion officer at your AIDS Council or PLWHA. The advantage of obtaining information this way is that these organisations have a philosophy of advising you of your options without promoting or endorsing any particular treatments.

Who to tell?

Telling people that you are HIV positive (disclosing) is never easy and there is no formula for the 'right' way. The important thing to remember about revealing your HIV status, is that you do not have to tell anyone you do not want to. To decide who to tell you could ask yourself the following questions. Who do I feel ought to know? What benefit is there for me by telling them? Who will still support me, is my friend?

When you want to tell the important people in your life, there are people you can talk to beforehand. There are support services for families and friends of positive people. There is a booklet called "Access" which answers some of the questions that family and friends may wish to ask. It is available from PLWH/A or ACON and some clinics and doctors' surgeries.

Work issues, retirement, superannuation

Information about retirement eligibility, pensions and housing is obtainable through your social worker. Legal advice about superannuation, wills etc. is available through the HIV/AIDS Legal Centre at ACON. Information about eligibility and assistance in applying for Department of Social Security pensions and NSW Department of Housing applications can be obtained through ACON's HIV Support Project.

This will hopefully cover some issues that you would like addressed. All these services and contacts are listed in the *Talkabout* contact section. Your first step in reaching these services may be the hardest — but remember there is someone to help you. Many of these services are provided by HIV positive people or people who have chosen to work in service provision specifically for positive people. All these services are completely confidential.

ACON: AIDS Council of NSW
AFAO: Australian Federation of AIDS Organisations
PLWHA: People Living With HIV/AIDS. This term can refer to people but is also the name for organisations of HIV positive people — such as PLWH/A Inc (NSW), the publisher of this magazine.

HIV living

NEWLY DIAGNOSED HIV+?

WE CAN OFFER YOU

COUNSELLING

Our team of professional counsellors are available for anyone affected by HIV/AIDS. Free and confidential service including one to one, couples and telephone counselling. Call 206 2000 to make an appointment. A Spanish speaking counsellor is available on 206 2016.

WORKSHOPS AND SUPPORT GROUPS

Including weekend workshops for the newly diagnosed, peer support groups and HIV Information Forums. Call Stephen on 206 2011 for information on upcoming events.

TREATMENTS INFORMATION

The ACON Treatments Officer can be contacted for free and confidential information and discussion on treatment options. Call Jaimie on 206 2015

HIV/AIDS LEGAL CENTRE

Legal advice and advocacy on HIV/AIDS related issues. Call our solicitors on 206 2060.

Pull Out

Contacts

AIDS Council of NSW (ACON)

9 Commonwealth St, Surry Hills
(near Museum Train Station).
Switchboard: 206 2000.

Community Support Network (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.

Counselling Professional counsellors available for anyone living with or affected by HIV/AIDS. Free and confidential service, including: One-to-one counselling; home or hospital visits; telephone counselling. Call 206 2000 for appointment

CSN Western Sydney Pat Kennedy 204 2404.

Fun and Esteem Workshops For gay and bisexual men under the age of 26. Groups in Parramatta, Campbelltown and city. 206 2077.

Gay & Lesbian Injecting Drug Use Project (GLID UP). Outreach, information & referral. We are sensitive to the issues faced by lesbians & gay men who inject drugs. 206 2096.

HIV/AIDS Legal Centre Legal advice/advocacy on HIV/AIDS related problems. 206 2060.

HIV living

Support Groups give you the chance to meet others with HIV, exchange ideas and make friends. If you'd like to join a group, become a facilitator, or just find out more about them, give us a call on 206 2014.

Positive Asian Men's Project Looks at the needs of all HIV+ Asian men. Michael Camit. 206 2036 or 206 2090.

Positive Women Individual or group support for and by HIV/AIDS positive woman. Non-judgemental and completely confidential. Women and AIDS Project Officer or Women's HIV Support Officer, 206 2000, TTY for the Deaf 283 2088.

ACON Western Sydney 9 Charles St, Parramatta. 204 2400.

ACON Illawarra 129 Kembla St, Wollongong. (042) 26 1163.

ACON Mid-North Coast 93 High St, Coffs Harbour. (066) 51 4056.

ACON Northern Rivers 147 Laurel Ave, Lismore. (066) 22 1555.

ACON Hunter 13-15 Watt St, Newcastle. (049) 29 3464.

General

AIDS Trust of Australia 221 2955.

Albion Street Centre Information Line 332 4000.

Asians & Friends Sydney A social, cultural and support group for gay Asians and their friends, meets every Friday from 7.30-10pm. Gus or Jim (02) 558 0061 a/h.

Australian Federation of AIDS Organisations (AFAO) 231 2111.

Australian Nurses in AIDS Special interest group for nurses. John Miller 339 1111 or Maggie Tomkins 332 1090.

Civil Rehabilitation Committee Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Joanne Wing 289 2670.

Kids With AIDS (KWAIDS) and parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772.

Hands On Project Community based HIV/AIDS training program for youth workers. 267 6387.

Innerskill Needle & syringe exchange, information & referral, also a range of free services for unemployed people. 810 1122.

Metropolitan Community Church (MCC) 638 3298. MCC Sydney 32 2457.

Multicultural HIV/AIDS Education and Support Project Workers in 15 languages who provide HIV/AIDS information. Also provides cultural information, training & consultancy. Peter Todaro 516 6395.

National AIDS/HIV Counsellors Association Mark Cashman 206 2000.

National Audio Visual Archive of PLWA Royce 319 1887 (after 1 pm).

National Centre in HIV Epidemiology & Clinical Research 332 4648.

National Centre for HIV Social Research (Macquarie Unit). 805 8046.

National Association of People Living With AIDS (NAPWA). Russell Westacott, 231 2111.

NSW Anti-Discrimination Board Takes complaints of AIDS related discrimination. 318 5400.

NSW Users and AIDS Association (NUAA) Community/peer based organisation providing support, referral and advocacy for injecting drug users and their friends.Needle exchange services. 369 3455.

Quilt Project Memorial project for those who have died of AIDS. 360 9422.

Sex Workers' Outreach Project (SWOP) 212 2600.

Silk Road Social and support group for Asian gay and bisexual men. Meets every Friday. Workshops, discussions, social activities. Arnel 206 2000.

Social Workers in AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Also acts as a lobby group for people affected by HIV/AIDS. Anthony Shembri or Pina Commarano on 661 0111.

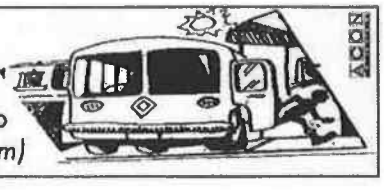
ACON Housing Project We offer help & advice about public housing, in particular: accessing priority housing; transfer; and the special rental subsidy as well as housing discrimination, harassment and homelessness

The Housing Project also has a number of houses and units available to clients who are waiting for public housing. You must be eligible for priority housing and in the process of applying

Call Arnel or Fred on **206 2043** *for an appointment*

Tiffy's Transport 206 2040

Tiffy's provides transport for PLWHA to hospital or clinic appointments. The service operates early morning to early evening, Monday to Friday. For more info, or to make a booking, please call 206 2040. Ask for Monica. *(Office open 8am — 3pm)*



Sydney Sexual Health Centre

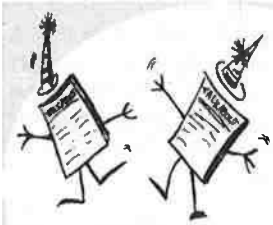
>Needle syringe exchange
Sydney Hospital
Macquarie St (near Martin Place Station)
for an appointment or information
223 7066
*no medicare card required for recorded information

Services provided:
>STD test, treatment and information
>HIV/AIDS tests and care
>Hepatitis B tests and vaccinations
>Counselling
>Safe sex information
>Free condoms, dams and lube
>Multicultural information and interpreter services

All this could be yours!
Promote your services by advertising — only fifty bucks for this space, even less for a year of repeats
Call Paul ☎ 361 6750

TAYLOR SQUARE PRIVATE CLINIC
Dr Robert Finlayson ○ Dr Ross Price ○ Dr Mark Robertson
Dr Anna McNulty ○ Dr Neil Bodsworth ○ Dr Debbie Couldwell
Fellows of the Australian College of Venereologists
and Dr John Byrne
8am to 8pm Monday to Friday • 10am to 12 noon Saturday
302 Bourke St Darlinghurst
331 6151
Call for appointment ○ Health Care Card Holders Bulk Billed

Livingstone Road Clinic
We provide HIV/STD testing, treatment, counselling and education in a friendly cottage enviroment. We provide total confidentiality (medicare cards are not required) and there is easy off street parking.
182 Livingston Rd, Marrickville
560 3057



Please let us know if you want to update your listing or add a new one!

SUPPORTING POSITIVE ASIANS Volunteer group for Asians (men and women) who are positive. Do you need support, info? 206 2036.

SYDNEY PLWHA DAY CENTRE The Day Centre offers a safe space to PLWHA where they can relax amongst their peers in an informal, supportive atmosphere. We offer a range of services including: delicious lunches Tue-Fri; massage; acupuncture; reiki; feldenkrais; international healing; shiatsu; yoga & meditation; child care facilities; library; sewing facilities; pool table. We also have access to a retreat throughout the year. Advice and information also available. All our services are offered free of charge. Donations welcome. 20 William Lane Woolloomooloo. 357 3011.

SYDNEY SOUTH WEST NEEDLE EXCHANGE For access and locations 827 2222, 828 4844 or Mobile 018 25 1920.

TREE PLANTING PROJECT AIDS Memorial Groves. Sydney park, St Peters, in conjunction with South Sydney City Council. Mannie De Saxe 718 1452.

VOLUNTARY EUTHANASIA SOCIETY OF NSW INC. 212 4782.

WORLD AIDS DAY NSW 350 2611

CLINICS & HOSPITALS

ALBION STREET AIDS CENTRE Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. No Medicare card required. 332 1090.

CALVARY HOSPITAL Rocky Point Rd, Kogarah. Inpatient, respite and pain/symptom control (care by Victoria Furner). Full community support team. Stuart Pullen 587 8333.

EVERSLEIGH HOSPITAL A palliative care inpatient facility and community service. 560 3866.

GREENWICH HOSPITAL Palliative care inpatient unit, day hospital and community outreach. 439 7588.

HAEMOPHILIA UNIT Royal Prince Alfred Hospital. 516 7013.

KIRKETON ROAD CENTRE Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am-8pm, Mon-Fri. Social welfare service, needle & syringe exchange 2-6pm, Sat-Sun. Outreach bus 8pm-midnight, 7 days. Darlinghurst Fire Station, Victoria Rd, Kings Cross. 360 2766.

LIVERPOOL SEXUAL HEALTH CLINIC/HIV OUTPATIENT CLINIC Elizabeth/Bigge Sts., Liverpool. Free, confidential HIV/STD services, counselling, HIV support groups, practical support. 827 8022.

LIVINGSTONE ROAD SEXUAL HEALTH CLINIC 182 Livingstone Rd Marrickville. Open Mon, Wed, Thur 1-5pm. For appointment, 560 3057. No medicare card required.

NERINGAH HOSPITAL A palliative care inpatient facility, domiciliary and community service. 4-12 Neringah Ave. South, Wahroongah. 487 1000.

PRINCE HENRY (Special Care Unit) Anzac Parade, Little Bay. 694 5237 or 661 0111.

PRINCE OF WALES Children's Hospital (Paediatric AIDS Unit) High St Randwick. 399 2772/4. Dental Clinic, Acoca St, 399 2369.

ROYAL NORTH SHORE HIV outpatient, day treatment, medical consultations, inpatient services, counselling, support groups, sexual health clinic, testing. 438 7414/7415. Needle & syringe exchange 906 7083. Pacific Highway, St Leonards (by railway station).

ROYAL PRINCE ALFRED (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

SACRED HEART HOSPICE A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

ST GEORGE HOSPITAL HIV/AIDS Services Inpatient, Outpatient and Day Treatment Centre: South St, Kogarah. 350 2960 Sexual Health Clinic: Belgrave St, Kogarah. 350 2742.

ST VINCENTS HOSPITAL HIV MEDICINE UNIT Victoria St, Darlinghurst. Multidisciplinary HIV specialist care including medical, nursing, counselling, physiotherapy, occupational therapy, nutritional advice and community liaison. Switch 339 1111. **Inpatient care**: Ward Cahill 17, 361 2337/2285. **Outpatient care**: Immunology B clinics, Tu, Thur and Fri AM by referral, 361 7111. Ambulatory care/Urgent triage nurse practitioner on call, 339 1111. Clinical Trials, 361 2435. Dental Department, 361 7129.

SYDNEY SEXUAL HEALTH CENTRE Sydney Hospital, Macquarie St. 223 7066.

TRANSFUSION RELATED AIDS (TRAIDS) UNIT. Crisis/long term counselling, welfare support. Pam 843 3143. **Red Cross BTS**: Jenny 262 1764

UNITED DENTAL HOSPITAL Chalmers St, Surry Hills. HIV/AIDS service, Sue Mathieson 282 0246.

WESTMEAD CENTRE (Westmead and Parramatta Hospitals). Westmead 633 6333. Parramatta 843 3111.

EMOTIONAL SUPPORT

ACON COUNSELLING SERVICE (see under ACON, previous page). Call 206 2000 for appointment

ANKALI Emotional support to PLWAs, their partners, family and friends. Trained volunteers provide one-to-one non-judgemental and confidential support. 332 1090.

CARERS SUPPORT GROUP South West Sydney. Runs Wednesday Evening in Liverpool, 6pm. Janelle or Julie on 827 8022

CLASH Confidential group of HIV+ heterosexuals who support each other by taking away some of the hardship of being alone. (Free call)1-800 812 404.
FAMILY SUPPORT City: A support group for family members of people with AIDS. Regular short term groups. Helen Golding on 361 2213. Outer Western suburbs: Meets evenings on a regular basis. Claire Black or Kevin Goode at Wentworth Sexual Health and HIV Services on (047) 24 2598.
FRIDAY DROP-IN for PLWHA at ACON Western Sydney. Scott on 204 2402 for confidential information.
HIV+ SUPPORT GROUP South Western Sydney. Meets in Liverpool Wed 6.30pm. Julie 827 8022. Transport can be arranged.
PARENT'S FLAG Parents and friends of lesbians and gays. Meets 2nd Mon of the month. Heather, 899 1101, or Mollie 630 5681.
POR LA VIDA Un servicio de informacion y apoyo para personas afectades por el VIH y El Sida. 206 2016.
QUEST FOR LIFE FOUNDATION Emotional support and education for people with life threatening illnesses, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.
SUPPORT GROUP FOR PARENTS OF HIV+ ADULTS Every 3rd Fri in the month 7-9pm at Ankali House 335 Crown St. Confidentiality assured. Grahame Colditz/ Bern McPhee 332 1090.
SUPPORT OF POSITIVE YOUTH 360 2945
SYDNEY WEST GROUP A Parramatta based support group. Pip Bowden 635 4595.
YOUTH HIV SUPPORT WORKER Counselling, advice, information to positive youth and their peers in the Central Sydney area. 690 1222.
YOUNG & POSITIVE A confidential service for young HIV+ gay guys. Support, information, groups, workshops, social events. Call Aldo or Jaimie 206 2076.

PRACTICAL HELP

BADLANDS Residential harm reduction service providing safe, non-coercive space for people who are at high risk of HIV transmission or acquiring HIV. Residents are mainly injecting drug users and/or sex workers. 211 0544.
BARNADOS FAMILY SERVICES Support for families affected by HIV/AIDS. Respite care, short/long term foster care and assistance with permanency planning for children whose parents have HIV/AIDS. 387 3311.
BOBBY GOLDSMITH FOUNDATION A community based, registered charity providing some financial assistance to approved clients. 360 9755.
DES KILKEARY LODGE Respite and Step-down support for PLWHA and their carers. Small day centre. Located on the Northern Beaches. Paul, 982 2310.
FUNERAL CELEBRANT General funerals, free in cases of financial hardship. Patrick Foley on (018) 61 1255.
FOOD DISTRIBUTION NETWORK Cooperative distributing cheap boxes of fruit & vegetables. 9am - 4pm M-F, 699 1614.
HANDS ON MASSAGE AND REIKI for PLWHAs. Training of volunteer masseurs. Richard 660 6392.
PETS The Inner West Vetinary Hospital will never refuse urgent treatment for a pet because of lack of money. Please call 516 1466 for more information.
THE SANCTUARY Centre for complementary Thearies focussing on relation therapies. Tu-Fri 1.30-5.30pm. Gebe Neighbourhood Centre. Transport can be arranged. Bookings essential. Phone Lindy on 516 7830.
SHOPPING SERVICE FOR PLWHAS Fortnightly on Fridays, inner-city only. Bookings/& further information 360 2043.
YOGA Posture, breathing, meditation with Miren. Sydney PLWHA Day Centre Tuesdays 2-4pm. 357 3011 for more info.

OUTSIDE SYDNEY

HAWKESBURY & BLUE MOUNTAINS

BLUE MOUNTAINS HIV/AIDS CLINIC Services include testing, treatment, monitoring and counselling/support. (047) 82 0360. 9am-Noon, M/W/F.
BLUE MOUNTAINS PLWA SUPPORT CENTRE Wed 11am-3pm (lunch). Fri 6.30-10.30pm (dinner). (047) 82 2119 or Dennis (047) 88 1110.
CSN BLUE MOUNTAINS Hands on practical help for people with HIV/AIDS. Pat Kennedy, (02)204 2404.
KARUNA BLUE MOUNTAINS Emotional support for PLWHA, their partners, family and friends. Ann (047)82 2120.
SOUTHERN HIGHLANDS HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional and practical support for PLWHAs, their family and friends, living in the Bowral district. Marion Flood (048) 61 2744 or David Willis (018)48 3345.
WENTWORTH SEXUAL HEALTH & HIV CLINICS Nepean Hospital Mon 3-8, Thurs 9-4. Ross St Clinic, Windsor, Tues 4-8pm. (047) 24 2507 for all appointments.

CENTRAL COAST & HUNTER

CENTRAL COAST SEXUAL HEALTH SERVICE Offering HIV clinic for testing, monitoring, treatments, support. Patrick (043) 20 2114.
CSN NEWCASTLE Rosemary Bristow, ACON Hunter, 13-15 Watt St, Newcastle. (049) 29 3464.
COASTAL CONNECTIONS Gay & lesbian social group. (043) 65 3461. PO Box 259, Toukley 2263.
HUNTER AREA HIV SUPPORT/ACTION GROUP 6.30pm, 4th Wed every month at ACON. Inquiries (049)29 3464.
JOHN HUNTER HOSPITAL (Clinical Immunology Ward). Lookout Rd, New Lambton, Newcastle. (049) 21 4766.
KARUMAH DAY CENTRE. First floor, 101 Scott St, opposite Newcastle Railway Station. Open Tues 6-9pm (games night), Wed 6-9pm (games night & masseur when available), Thur 11am -3pm (lunch & activities). (049) 29 6367.

NSW HIV/AIDS Information line
Mon-Fri 9am-8pm, Sat 10am-6pm
Advice and referral information for HIV/AIDS
008 451 600
Rural Project, ACON
Mon-Fri 10am-6pm
General advice and referrals on HIV/AIDS in country areas
008 802 612
Take Control Line
Mon-Fri 10am-6pm
Confidential and frank information on treatments for HIV/AIDS
008 816 518
CLASH
Confidential group of HIV Positive heterosexuals
1 800 812 404

PLWHA New South Wales People Living with HIV/AIDS
People Living With HIV/AIDS (NSW) Inc.
A/Coordinator Claude Fabian 361 6023
A/ Admin Asst Paul Roberts 361 6011
Positive Speakers Bureau Coordinator David Wallace 361 6864
Talkabout Editorial Coordinator Jill Sergeant 361 6750
Advertising/Design Paul Canning 361 6750
Fax 360 3504
Post: PO Box 831, Darlinghurst NSW 2010
Office: Suite 5, Level 1, 94 Oxford St, Darlinghurst

ACCESS
PositHIV Radio
2SER FM 107.3 Tuesday 9.30pm
PO Box 473 Broadway NSW 2007
ph: 516 4772 fx: 330 3099
2SER FM 330 3000

KONNEXIONS DAY CENTRE 11am-3.30pm Mon for lunch & social. Lesley. (043) 23 2095.
NSW ANTI-DISCRIMINATION BOARD Newcastle. (049) 26 4300.
NEWCASTLE GAY FRIENDSHIP NETWORK Peer support, workshops and activities for gay men under 26. ACON (049) 29 3464.
POSITIVE SUPPORT NETWORK Emotional/ hands on support for PLWHAs on the Central Coast. Lesley Digram (043) 23 2905. Suite 3, No6 Burns Cres, Gosford 2250, PO Box 2429 Gosford.
THE LAKES CLINIC (Tuncurry,) A sexual Health Service. Bridgepoint Building 2nd flr. Manning St. Thu 10 -2pm. Free and confidential.(065) 55 6822.
WOMEN'S HIV/AIDS & SEXUAL HEALTH SUPPORT NETWORK For positive women, their partners and friends. Awareness raising. Helen (049) 524362.

NEW ENGLAND & NORTH COAST

ARMIDALE HIV EDUCATOR Melinda Spinks (067) 73 4 712.
BLIGH STREET SEXUAL HEALTH CLINIC. (Tamworth) Free & confidential STD/HIV testing & management. (067) 66 3095.
CHAPS OUT BACK (Coffs Harbour) Assistance & advice for PLWHAs. Drop in centre/coffee shop each Thur 10am-4pm, support group first Sat each month 2pm-4pm at ACON. Steven (066) 51 5703 or ACON.
CLARENCE VALLEY PLWHA Support Group. Peter (066) 46 2395.
CLUB 2430 (Taree) Manning Area Gay and Lesbian Support Group. Social functions, newsletter, monthly meetings. Lloyd (065) 52 7154 or Liz (065) 51 1409.
COASTAL LYNX Mid north coast gay & lesbian support group. (065) 62 7091.
GAY/MSM WORKER Bernie Green. Bligh St Clinic Tamworth. (067) 66 2226.
GRAFTON HIV/NESB WORKER Sharyn Dillossa. (066) 42 3333x229
HASTE (Hastings AIDS Support Team & Network). Craig Gallon (065) 62 6155.
KEMPSEY AIDS NETWORK Madelaine Mainey (065) 62 6155, HIV Program officer Craig Gallon 018 66 4186.
LISMORE SEXUAL HEALTH/AIDS SERVICE A free, confidential service for all STD and HIV testing and treatment. (066) 20 2980.
NEW ENGLAND NEEDLE EXCHANGE PROGRAM (067) 662 626 (message). 018 66 8382.
NORTH COAST POSITIVE TIME GROUP A support and social group for PLWHAs in the North Coast region. (066) 22 1555.
TAGLS (The Armidale Lesbian & Gay Society) Norman (067) 71 1890.
TAREE SEXUAL HEALTH SERVICE 93 High St Taree, Tue 2-6pm, Thurs by appointment. (065) 51 1315.
TBAGS (Tamworth Boys & Girls Society) Bernie (067) 85 2147.
TROPICAL FRUITS Gay & lesbian social group. Regular events. (066) 22 4353.
WOLLUMBIN CARES (North Coast) Community AIDS Resources, Education and Support. Gerry or Keven (066) 79 5191.

ILLAWARRA

CSN WOLLONGONG (042) 26 1163.
NSW ANTI-DISCRIMINATION BOARD Wollongong. (042) 26 8190.
PORT KEMBLA SEXUAL HEALTH CLINIC Confidential and free support for PLWHAs. Fairfax Rd, Warrawong. (042) 76 2399.
POSITIVE SPACE ILLAWARRA A confidential meeting place to chat, listen and share with other positive people. Don't hesitate to call (042) 26 1238 to chat with or meet others. Wednesdays and Fridays 12pm-5pm.

SOUTH WEST/EAST

ALBURY AIDS SERVICES Community Health Centre 665 Dean St (060) 23 0206. Needle & Syringe Exchange, Judy Davis.
ALBURY/WODONGA HIV/AIDS BORDER SUPPORT GROUP (060) 23 0340.
BEGA VALLEY HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional and practical support to PLWHA, their family & friends living in this area. Jenni Somers or Ann Young (064) 92 9120.
BEGAY Bega area gay & lesbian social group 018 60 4180.
COOMA/SNOWY MOUNTAINS HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional support for PLWHA, their family and friends living in this area. Lorraine on (018) 48 4834 or (064) 52 1324.
EUROBODALLA HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional and practical support to PLWHA, their family and friends in the Narooma to Batemans Bay area. Jenni Somers or Liz Follan on (044) 76 2344.
GRIFFITH HIV EDUCATOR/SUPPORT WORKER Laurane Pierce. (069) 62 3900.
NOWRA SEXUAL HEALTH CLINIC Confidential and free support for PLWHAs. Nowra Hospital, (044) 23 9353.
QUEANBEYAN HIV/AIDS/STD WORKER Yantene Heyligers (06) 29 89236.
SOUTHERN HIGHLANDS HIV/AIDS/STD WORKER David Williams 018 48 3345.
SOUTHERN TABLELANDS HIV/AIDS WORKER Paul Davies, Goulburn Community Health Centre (048) 27 3113/018 48 2671.
WAGGA WAGGA HIV & SEXUAL HEALTH SERVICES Paula Denham (069) 38 6411. AIDS Task Force (069) 25 3055 or (069) 38 6411.
YOUNG HIV/AIDS VOLUNTEER SUPPORTER GROUP Valerie, (063) 82 1522.

WEST

BROKEN HILL HIV/STD WORKER Darriea Turley. Community Health Centre. (080) 88 5800.

Regional Health Service HIV/AIDS Coordinators

CENTRAL COAST
Karen Naim
Ph: (043) 20 3399 (018) 43 6044
CENTRAL SYDNEY
Lesley Painter
Ph: 550 5366
CENTRAL WEST
Dr. Dan Russell
Ph: (063) 32 8576/8538/8571
EASTERN SYDNEY
Marlene Velecky
Ph: 399 4832
HUNTER
Tony Butler
Ph: (049) 29 1292
ILLAWARRA
Vivienne Cunningham Smith
Ph: (042) 75 5823/76 2399
NEW ENGLAND
Christine Robertson
Ph: (067) 66 2288
NORTH COAST
Wendi Evans
Ph: (066) 20 2145
NORTHERN SYDNEY
Graham Stone
Ph: 438 8237
SOUTH EAST
Greg Ussher
Ph: (048) 27 3148
SOUTHERN SYDNEY
Colin Clews
Ph: 350 2959
SOUTH WEST REGION
Dalton Dupuy
Ph: (060) 23 0350
SOUTH WEST SYDNEY
Mark McPherson
Ph: 827 8033
WENTWORTH
Elizabeth O'Neil
Ph: (047) 22 2255
WESTERN SYDNEY
Chris O'Reilly
Ph: 843 3118
WESTERN NSW
Dr Michael Douglas
Ph: (068) 81 2222/2242

DUBBO/MUDGEE SEXUAL HEALTH/HIV SERVICE Robert Baldwin. HIV/STD Worker. Community Health Centres Dubbo (068) 85 8937 & Mudgee (063) 72 6555.
OUT WEST A social & support group for gays & lesbians in western NSW. Grant (068) 82 5033 or Paul (063) 72 4477.
ORANGE COMMUNITY AIDS TASK FORCE Shirley-Ann Bailey. Central West HIV Support worker, Luke Austin. Community Health Centre. (063) 62 6422.

Belinda Darlington

Photo: Mazz Images

Tell me about when you were first diagnosed.

About five years ago I was having regular checkups and it was completely out of the blue. When I found out I went running through the office like a mad person. At first it was shock. I cried, I was upset, I was totally not thinking, I didn't know what was going on.

I gave up my job, the stress was too much. I got angry at everybody. I wouldn't speak to my mother, everybody who rang I wouldn't talk to. It was the "Why me?" stage, and I went through that for months. I was angry at myself and I was angry at everybody else who wasn't HIV. I locked myself away totally.

What came after that?

I saw a therapist and it started sinking in, like "this is it, it's happened, you can't reverse it" and I started thinking "well, why not me?"

The main thing that hit me then and really has stayed with me today is that I've got no future. I was single, running around doing the nightclub scene and dance parties, and I always wanted to settle down, get married and have a regular nine-to-five job. So it was like my future's gone. It didn't turn out that way, I found a wonderful guy, got married, and have a promising career.

I got really sick straight away. I had my glands swell up, diarrhoea. I went down to about nine stone (that's really skinny for me). I knew absolutely nothing about HIV and AIDS. I thought I was dying. I tried to commit suicide by taking an overdose of pills, but I woke up in hospital. I didn't know I could go on to live a good fifteen years.

Where did you go for support?

I went to the Albion Street Centre looking for a group. I haven't any transsexual friends, I have three or four gay friends. All of our friends are heterosexual, so I'm really quite isolated. Transsexuals don't seem to talk about it, because a lot of them are show girls and working girls. Of course working girls can't, and for show girls HIV isn't good for the image.

My family know, they're so accepting, they're just brilliant. But the one thing that really bugs me is there's still a shame to being HIV. I think the more people talk about it, the more blase people will become and the shame will be taken away.

When did you start telling people about it?

It took a couple of years for me to feel comfortable enough to talk about it. Over the last couple of years I just tell everybody. I think talking about it takes the stigma away.

Do you think that there are particular issues for transsexuals with HIV?

I think there should be a transsexual support group. If I could I would start it myself. Years ago I had a transsexual girl friend who confided in me that she was HIV, so I told her. It was such a huge weight off our shoulders.

There's a lot of transsexuals out there like me, who have got nobody to talk to. We're isolated because we're not gay, we're not straight. We're in the middle somewhere. It's hard enough being transgender, not quite this, not quite that, but HIV puts you in no category at all.

Interview by Jill Sergeant

Since doing this interview, Belinda has decided to go ahead and start a support group for HIV positive transsexuals, call Camille at the Gender Centre on 569 2366 for more details. The Gender Centre provides a range of services and information to people with gender issues.

Mark Cochrane

Who says you can't cry over spilt milk?

It is only now that some of the dust from the bomb has settled since I heard from my doctor. "I'm afraid the news is not good". In some ways Mark died that day. How was it possible to get HIV, now, after ten years of safe sex. I immediately informed those necessary. It was humiliating and without dignity. I felt removed from my own body like I was speaking at my own funeral.

How can I get relaxed with the idea that I have a virus that the whole world is terrified of? That I am fucking terrified of.

I feel so afraid that I can't get into sex or intimacy. That I am preoccupied with gloom. That my career is shot to pieces. That my dick is a death stick. That I have Grim Reaper on my bank. That I don't know what future means. That every day I have to live with loss. That I've seen people dying along with the hopes of a cure. That I have to suffer. That I can't believe it is possible to continue with these thoughts every day. That nobody has the answers to my questions. That I have to accept rejection from those I love. That I have to accept other peoples fears. That I have to accept my own. That I have to accept, accept, accept. That life seems hopeless and without any reason. That I am lost.

I've been thrown into a minefield and somewhere there is a path for me to walk. I don't know what I should be doing. There are so many different things to think about and analyse. I'm scared.

I wait for a letter from my ex boy friend, some sort of response. He has turned his back. He doesn't want to know me. He is the type living at home, in denial, living in a closet, insecure. Is it possible to forget me, to not care? I feel so abandoned, cheap, nothing. Do I have to accept his fears? And that our relationship can be so easily disclaimed? Does his desertion mean that I could suffer prejudice and discrimination from the very community that I belong to, because I am living with HIV? Do I have to deal with HIV phobia from the gay community? I find this devastating.

Some gays are not proud. I think they fear the word HIV because it could expose them as being gay. I feel no shame about being HIV positive except for the way that other people think or have dealt with me. That it is not the virus that discriminates but that people do. That we are dealing with homophobia and that a lot of people, especially gays have internalised this homophobia.

Fortunately I have some incredible friends. People who will never be ashamed of me. People who are proud of me, proud of Mark. This drama has reassured me that what you put into real quality friendships, you inevitably get back.

I'm getting involved in politics, it is inevitable for me. It is stimulating and a great way to keep ahead of the treatments debate.

Doctors do not know everything. I've looked into alternative treatments, I already know more about new alternatives than some of the so called alternate treatment officers. I've made contact internationally by computer and I am empowering myself with information. I can and have made my own educated choices. There is hope.

One of the hardest things I realise is to deal with the fears, prejudices and ignorance of others. The whole idea that HIV = AIDS = DEATH. It's like we are programmed to see it like this. I have learnt this is not the case. I'm here for living and I will not tolerate weak and shallow people in my life. I do not have the energy to waste. I have too much energy for enjoying life. And there is so much to live for.

In this society we rarely talk about death. It even seemed to me that life was kind of infinite. For me this is probably the hardest thing of all to come to terms with, that death is a reality. But there is so much life to be lived until that point. I feel that I have almost been given an insight into life. To enjoy it even more, not less. To love it more and resent things less.

I must say that I have become wiser. I can now see how trivial some things really are. I can also see how important things are. That people can waste away a life doing nothing, seeing nothing, living nothing. Living nothing but a life built around what other people think. Built around others' ideals, fears, limitations and expectations.

I will most definitely buy a big American car and drive across the United States. Big time fun. That's my next big plan. Driving through Texas, Las Vegas, San Fransisco, Miami, Dolly Parton land, etc. It will be one big adventure. Like a huge roller coaster ride of experiences. Do you remember "Thelma and Louise"? That's what I want to do, maybe without the same ending. Maybe.

Carlos Roberto

What happened the day you found out you had HIV?

I remember it was just near Christmas and it hit me right there in the middle of Grace Brothers. I just sat down on the floor and cried for awhile, and then slowly began to accept that it was part of me. I don't accept it as part of me all the time. It does get me down but I try not to let it. For sure I feel afraid, because it is a journey into the unknown. But if you try to be at peace and live with it, you don't feel it; knowing that tomorrow will come with new hope, and in fact it does arrive and with even more desire to live.

Of course I would love to have the luxury of knowing that it is going to go away, but in reality it doesn't go away. It is there. It is stuck solid. And it doesn't move.

We all know that in the end, in one way or another, we are all going to arrive at the same end. What can I say, this is but another one of life's accidents. It needs to be taken with a bit of humour. I am laughing to myself, because what is the use of crying, I have cried enough. But what I try to do now is live, to enjoy life as much as I can for as long as I can.

How has your life changed since finding out you have HIV?

I found out that I had the virus almost four years ago, although I have probably had it longer than that. Since then I have changed. I used to like going out and visiting places, enjoy having sex and doing all those things, but all of this is now in the past as if it was too much pleasure. Not that it is still not happening, but it is not as before, everything is more cautious.

People with all their knowledge and good intentions say that they understand, but in the end when they do find out they keep their distance. People fear the virus just like I do. I am afraid of it because it is going to kill me, if I don't look after myself. There is a struggle with the virus all the time. I try to live in harmony to keep my spirits up and always with the hope that tomorrow they will find something. I think not just about myself nor just about the gay community but for everyone. How marvellous it would be be for everyone if something was discovered!

Have you learnt anything new about life and friendship?

I no longer have many friends, real friends with whom I can talk about my situation. I can count on the fingers of one hand the friends that know I have the virus. Amongst them, two are sick but we never talk about it, as if forgetting about it means it doesn't exist. But there isn't a single conversation in which it isn't there in our thoughts.

Any advice for people recently diagnosed with HIV?

That they take it with a little bit of humour. That they see it as yet another friend who has come into their lives, and that they are careful how they look after this new friend, and that they don't do anything that is inappropriate or that will cause regret the following day. And when they feel sad or depressed, hopefully there will be a friend to contact and talk to or something to distract them. Maybe they can knit like I do; I really like to knit when I have problems or feel depressed because it is like a therapy for me.

Interview by Grant Farquharson

Health issues for women

Is HIV infection different for women?
***Dr Kate Clezy** looks at some of the health issues HIV positive women need to consider.*

ALMOST ALL WOMEN, AT SOME STAGE in their lives, experience symptoms related to their genitals (vagina, vulva), their urinary tract, breasts, menstrual cycle and their fertility. These are all specifically female issues and it is often difficult for women to initiate discussions with their doctor about related symptoms as they are often perceived to be unimportant, especially in the setting of a recent HIV diagnosis.

Women with HIV infection are known to have a number of complications involving the reproductive system. Of particular importance is the known association of HIV infection and cervical cancer. Cervical cancer is much more common in HIV positive women and is recognised as an AIDS defining condition. Cervical cancer is preventable by having regular pap smears.

Other conditions known to be more common are vaginal thrush, recurrent herpes and menstrual irregularities. These conditions are treatable and if they occur, help should be sought from a doctor.

For all women, a knowledge of their anatomy, and what is normal for them, is essential in order to look after their health.

For any newly diagnosed women, it is important as a part of a general medical examination that the following issues are addressed.

Medical history

- Menstrual history — are there any problems, heavy bleeding, cramps, irregular periods. Many women when they are under a lot of stress stop having periods for a while.
- Any history of sexually transmitted diseases (for example chlamydia, NSU, thrush, herpes, warts, gonorrhoea, vaginitis and syphilis) and what treatment if any you have had.
- A discussion about contraception, safer sexual practices and whether or not you have any children, are considering becoming pregnant or whether you are pregnant.
- When was your last pap smear, have you had any abnormal pap smears in the past, and have you had any treatment for an abnormal pap smear?
- Is there any history of cancer in the family especially breast or ovarian cancer?
- Do you have frequent urinary tract infections?
- Do you have any symptoms you are concerned about at the moment (for example abnormal bleeding, discharge and pain on urination)?
- If you are post-menopausal, then what symptoms, if any, do you have and are you having any treatment?

Examination

- Breast examination for lumps.
- Vaginal examination and pap smear (unless there has been a pap smear in the past six months and the results are available).
- If there is any discharge or ulcers, these should be swabbed to determine what is causing the discharge.

Pregnancy

If you are pregnant, and wish to have a child, or are considering becoming pregnant there are several important areas to cover. The first is your health. All the large studies have shown that if an HIV positive woman is well, pregnancy does not adversely affect her HIV infection. This is not the case if the woman has significant HIV symptoms, when pregnancy usually makes HIV infection much worse.

The second is the health of the baby. A baby has about a one in four (25%) chance of being HIV positive as a result of the mother's infection. If AZT (zidovudine) is given to the mother and the baby, this is reduced to about 8%. Breast feeding also is known to transmit HIV and therefore is not suggested. The risk of a baby becoming HIV infected is also linked to the health of the mother. If the mother is unwell with HIV, the baby is more likely to be infected also.

If you are concerned about any symptoms, and particularly ones that you may find embarrassing, it is important to discuss them with your doctor. It is very important to look after your body and other HIV related health issues are discussed elsewhere in this issue of *Talkabout*.

Dr. Kate Clezy is HIV Physician at Prince Henry Hospital.

What about sex?

For most of us, sex is something we can't give up. It's a basic need. It's fun. For people with HIV/AIDS, sex is often redefined as a health issue and although sexual health is important, other issues about sex can be more difficult. ***Ross Duffin*** *guides a brief tour through some of the common questions about HIV positive sexuality.*

Should I have safe sex if my partner is HIV positive?

Many people with HIV choose to throw away the condoms with each other. Often this is an informed decision that the psychological benefits and enjoyment, for them, outweigh any health risk. Two health questions about unprotected sex with another person with HIV are getting 'reinfected' with another strain of HIV; and the possibility of getting other sexually transmitted infections. For heterosexuals, the risk of pregnancy is also a consideration.

What about reinfection?

After thirteen years of HIV research there is not strong evidence to support reinfection as a significant health risk for HIV positive people. That doesn't mean it can't happen — and it may become important if in the future there are effective treatments which HIV can become resistant to.

What about other STDs?

These infections may have greater consequences because you're Positive. To reduce the risk of other infections have safe sex and use Gladwrap for rimming (bum licking).

What about transmitting HIV?

Although it's often the case that people make it entirely our responsibility not to spread HIV — it's everyone's responsibility.

The buzz word among gay men these days is 'shared responsibility' — it just happens that we often get more of the share. Despite this, it is our collective responsibility not to transmit this virus and there are still some common misconceptions about HIV transmission. Such as: you can't transmit HIV if you get fucked. You can. Or: it's OK if you pull out before cumming, or they pull out before cumming. The virus likes it both ways

Do I have to tell my sex partners?

The law may say so, but the law has little to do with real life in this case. If you practise safe sex then you may decide it's not necessary or compulsory. If you want to find another person with HIV to have sex with, or if you want an on going relationship, you may decide to tell. Telling is not easy and can take courage and practice. If you get hassled — it's their problem. They don't realise that people would be more able to be honest and open if they changed their attitudes. Having support and talking over how to disclose with other people with HIV is a good place to start.

"It's our right"

How do I find another person with HIV?

Of course, it's easier if you're a gay man in Sydney because there's lots of us. Some people join a support group or a positive organisation or social group where they don't have to make assumptions or guesses or deal with 'negative' attitudes. You can't tell a person's HIV status by looking, by assuming things, from gossip or because they offer you unsafe sex.

There are many reasons why we may be confronted with difficult questions about our sexuality. Often we get HIV through sex. People with HIV are often stigmatised, and some people strongly believe that we shouldn't have sex. For these reasons, we can have complex psychological issues about our sex lives. Some of us have found counselling or therapy helpful — just make sure you get a counsellor or therapist who believes in your right to a satisfactory sex life.

I remember running from my diagnosis thinking: there goes my sex life. Sex isn't the same and difficult issues do arise, but many of us have found solutions that work. We have managed to construct a healthy and satisfactory sex life and regard sexuality as a basic need and right.

For more information on sex, see Talkabout, *May 1992 — a special edition on Positive Sex.*

Joy Bremond

Could you tell me about your diagnosis?

I was diagnosed three weeks ago. I normally go for blood tests every three months. In the past they were all right. It never entered my mind it might be positive. I was going more for Hep C. I don't know much about my case at the moment because I haven't been back to the doctor to find out where I'm at. I find it really scary. It's something that I don't want to face up to yet, but I'm doing the best I can.

I'm still shocked and still very confused at the moment. I'm still angry. I'm just going through this self-blame stage I think. I've gone past the self-pity stage. But there's a lot of anger at myself and whoever I caught it from.

What did you do after you saw the doctor?

I told a close friend of my mother, and she was the one who rang around and got me numbers to ring, like ACON Positive Women, and Albion St. When I first got to Positive Women they were very helpful and that made me feel at ease for the first few days, knowing that I wasn't the only one and they were there to support me.

You've acted pretty fast.

At this stage I need to, because I'm an extremist. I either grab on to something that helps me or I do the opposite. One thing I don't want is to fall back into my old drug habit. That's why I've got to grasp every good thing that comes my way, like supportive groups, and hold on to it.

You said before the interview that you know that a lot of your friends are positive. Did you know that before?

No, it was only when I told my close friends. They didn't appear shocked at all, and I've shared needles with a few of them also.

Have you told your family?

I had to tell my mum. I don't think she's coping very well at the moment. She did at first, but now I've actually got two weeks to get out of home. My mother's blaming me for my stupidity for getting this, and doesn't want to have anything to do with me.

Why did you decide to do this interview so soon after finding out?

I think it's not fair me getting it, and the way I look at it, people who are HIV positive are all put in a box. There's not that much awareness about it. Most of my friends are HIV positive and are still hiding away, running away from it. Maybe if I take this step, they'll follow, and make people around them more aware.

How do you see the future?

Well this is one negative person. I don't. Not at all, just yet. Hopefully I will soon, but I'm all cramped up on the inside and I don't see much of the future at all. The way I look at it, it's not fair, just not fair. Just when I'm getting my life together I find out this. So I feel as if I've gone back to square one, in a confused daze again. That's my future.

Interview by Jill Sergeant

HIV POSITIVEWOMEN and the law — Where do we stand?

Has anyone ever disclosed about your status without your consent?

Do you have any legal complaints about service providers?

Do you have queries about your superannuation?

Get your legal questions answered!!!

At a free discussion forum for HIV Positive Women only

Monday August 14

3pm — 5pm at ACON, 9 Commonwealth St, Surry Hills

RSVP by August 10 to Kath on (02) 206 2085

ACON AIDS Council of New South Wales Inc.

TK August

The day of diagnosis (D-Day)

*By coincidence, this issue marks **Paul Maudlin's** second anniversary of living with the virus. Paul, who was diagnosed in August 1993, shares his experience of a Positive diagnosis.*

SEVERAL MONTHS AFTER MY DIAGnosis, I finally set in motion something that I'd been putting off since D-Day, and that was writing an account of my life as a positive person in what I call my HIV Journal. Initially I had to back track back to my first test and recall everything up to and including the present day. It took seven weeks before I was writing in the present tense. What follows is an extract from my journal.

12/8/93

Today my blood results came back and I'd seroconverted to anti-body positive. My doctor, Chris, was his usual cheerful self (lovely man) and after asking how I was he said, "Your syphilis result was negative, but the HIV result was positive." My reaction to that was, "Oh shit". We both laughed.

Once again he asked, "How do you feel?" I said that I was fine and somehow I wasn't surprised. I told him that I had a lot left to do in life and I was determined that now more than ever, I was going to do it. HIV wasn't going to stop me! I then got a complete physical and Chris said that I was very healthy.

Then I had a full set of blood tests. The clinic nurse, (Allan), took seven vials of blood which almost made me faint (It was 7:30 pm and I hadn't eaten since lunch). Allan made me lay down for a few minutes to relax. He asked all the right questions and seemed very concerned and understanding.

My main concern was how to tell my partner, Steve, that I'd seroconverted, or should I tell him at all, as he was dying. I didn't know if it was fair to tell him. I was more concerned for Steve than myself.

I ended up discussing this with Rob, my newly assigned counsellor. He was amazed at my positive (there's that word again) attitude and how well I was handling my new status. He told me that many a time he'd had to pull people off the window of his office.

Rob explained that I didn't have to rush out and tell the world, but could disclose when I was comfortable and ready. This I guess also includes Steve. I later decided to discuss it with Steve's counsellor. Rob talked about some of the good/positive things about being anti-body positive. He told me that there was a lot happening with HIV/AIDS and that a lot of things would change in my life (and a lot wouldn't), but anything that did change would do so for the better. He went on to tell me that I could have possibly ten good years ahead of me, but nobody knew for sure (ironically, I was almost wiped out in a near fatal car accident an hour later). He further explained that it was important to set goals for the future and basically live as normally as possible.

July '95

Of course things did change, but they did so for the better. I can't undo what has happened, there is a lot of living to do before I discharge out of this life and see what lays ahead in the next.

Make your feelings work for you

It's important to get emotional support after your diagnosis. Your whole being is attempting to come to terms with momentous news. ***Philip Oldfield*** *gives the whys and hows of emotional support.*

THE INITIAL RESPONSE CAN RANGE from feeling vague and overwhelmed through to crystal clarity, but it can also seem like watching a movie: "This is not really to do with me". These reactions are quite normal — shock is a protective mechanism at a time of great stress.

You might experience trembling and hot and cold sensations. It is important to allow these responses to occur and make sure you are in an environment where it's okay to have them. Being with someone who will support your emotional responses can help this process. Your body is responding naturally and this is part of your attempt to find some solid ground to stand on. What you are confronted with is the prospect of your future being very different from what you ever imagined — even just ten minutes before. This is too much to adjust to in a short space of time. Your feelings are a vital response mechanism that can work for you.

You may need to get some information about what your options are in terms of treatments etc., but information is not the same as emotional support. Although information is important it may not be what *you* need most urgently. Your counsellor's or therapist's job is to support you fully as you deal with the initial shock. Your doctor may not be appropriately trained or willing to be with you through this stage so you need to go to a counsellor as quickly as possible.

You have rights as an emotional human being. I'll briefly outline the kind of reactions which are *not* emotionally supportive. Remember you have the right to leave any situation where people say or do the following things: it is not appropriate to be told to pull yourself together, to be discouraged from crying or to be told how you have to respond. Any judgement or implied put down from a doctor or counsellor will most likely just help bury your feelings and leave you numb and confused. This is a worst case scenario, but it doesn't take much to get the message that you have to stay well controlled.

It is of course appropriate for your therapist or counsellor, if you have had a strong emotional response, to help you get together enough to leave the room when it is time for you to go back into the outside world at the end of your time together. It is important at this stage that you have some sense of where you can go from here. It is not a good idea to get your results, have a session with a counsellor and then go out into the world with no sense of what to do next.

What is good emotional support?

It is being with someone, a trained counsellor or therapist or good friend, who is available to really listen to you. You need someone to be there to hear you out, not interrupt or try to direct you or cut you short. Through the process of talking through what is going on for you, it's likely you will have sensations, movements of energy, physical responses or emotions that match up with what you are saying. Allowing these responses to come out is emotionally supporting yourself.

There are some decisions you may need to make fairly quickly as part of an ongoing strategy to provide yourself with emotional support. Possibly the most important is what you do with the information about your HIV status. This information belongs to you. You have the right to have *your* status treated as confidential information by medical staff and not spread around as gossip. This is important as you get to choose who you inform and under what circumstances you choose to tell them.

It has been my experience working with HIV positive clients that generally there has been real benefit for them in choosing who to tell and when. Telling a partner or friend is a difficult step for most people and you can discuss this with your counsellor or therapist. It may be that you need some time to come to terms with the information yourself and to arrange ongoing support, before you take this step. You may want to arrange some private space and ideally not be interrupted when you tell someone who is important to you.

Even a close person may have a different series of responses to what you might expect or different to what you yourself are experiencing. One parent I remember continually asked "Who gave this to you?" and "What did you do to get this?".

This blaming or wanting to know is essentially an angry response and should be dealt with by that individual themselves in therapy or counselling. It is not your job to be looking after the needs and responses of those around you. You have enough to deal with already. Encourage them to get the support and caring they need for themselves and not expect it from you.

You are dealing with a loss, a change and are engaged in a grieving process. This involves going through different stages. It can be useful to look at a grieving model and what you might expect if you look after yourself emotionally.

Shock

This occurs initially. It's really buying a bit of time before responding and can 'recur' when later you experience another related loss or hurtful experience. It usually doesn't last too long and you may need time out and rest to let your body 'catch up'.

Denial

This can often be useful. It stops you having to deal with overwhelming feelings or information. It gives you time to adjust by slipping back into the 'before' reality while you work out a response to the 'after' reality. It's also useful if you are aware you are operating in this mode and choose to put everything else aside and have a good time. It's dangerous to get stuck here as you overload yourself with avoidance and don't get what you really need, emotionally and physically.

Bargaining

This is also an important stage as you attempt to sort out what you want from your future. If you get stuck by going back into old events, regrets, depression and helplessness you may need a therapist, counsellor, or support group to help you move on. This is a dangerous time emotionally if you start giving yourself a hard time or if you are being very self critical as this is disguised anger turned back against yourself.

Sadness

This can occur at any stage but in its deeper healing form it's more of a gut response to the experience of loss and hurt. A heaving sad response from our belly with sounds and tears is part of the healing process. This is very different from feeling teary and miserable.

Anger

Anger can emerge here and there in the overall process but it comes out more fully when you have exhausted much of the energy of denial and bargaining. This is a clear strong emotional response where it can often be useful to have a therapist so you don't stop yourself or let any one else stop or interrupt you. Anger needs to be directed outwards and involves your body and often your voice (sounds are often as good or better than words). The danger here is that you can direct anger back in towards yourself and experience this as depression or feeling suicidal. Griping or complaining can be a good lead in to expressing anger and part of emotional self support. This has none of the intensity or healing capacity of clearly expressed and directed anger.

Resolution

Partial resolution or a sense of something having passed on and feeling less blocked is the usual experience after a strong feeling is allowed its full expression. You may go back into the previous stages to express more sadness or anger or both as you get in touch with more areas of loss and hurt.

A grieving process is our natural response to loss and involves our whole being. Rather than fighting feelings down it involves a full acknowledgement of them as they arrive in a safe environment. The overall experience is one of honouring oneself and responding authentically.

The effect is a greater experience of inner peace, of feelings resolved, and of joy and relief. There is also a sense of being more grounded and in control. Your head can catch up with the emotional experiences and make sense of them later and as you go along. What is true is that you cannot think your way through a process that requires the participation of your feelings for you to live more fully and joyfully.

Philip Oldfield is a Gestalt therapist.

Cần giúp đỡ hay hướng dẫn về siêu vi khuẩn HIV/Bệnh AIDS trong vùng Nam Sydney?

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No longer ALONE

*Earlier this year, **Paul de Koning** went to a Positive Retreat at Kyabra in the Southern Highlands. What's a Positive Retreat, you ask? It's a few days away with other people who are HIV positive to relax, get support and share your experiences. And, according to Paul, it's great!*

BEFORE I LEFT SYDNEY, I FELT NERVOUS about going into the countryside with a group of people that I didn't know, especially a group of Positive people, some of whom were bound to "have AIDS". I wasn't sure how, or if, I would handle being around lots of guys who were sick. I hadn't had much to do with people with AIDS, and I was frightened.

Being so uptight about the people I would be with, I hadn't really given much thought to what the retreat could offer me, for myself. I was diagnosed in '92, and have been asymptomatic up until now. I'm an AZT virgin, and hadn't considered complementary therapies. All I did know was that I was stressed, and that I needed to start giving some time to how I felt about this virus inside of me. I hoped the retreat would give me that time.

Kyabra is a very special place. From the moment I arrived I felt welcome. The land is beautiful, the accommodation inviting, and the hosts were incredibly supportive of our space. I had the opportunity to take long and rambling walks, and I went swimming in a natural spring on the property. I also began to relax.

I have only lived in Sydney for a couple of months, having fled a city where HIV and AIDS are not mentioned in polite conversation, and where it seems that when people get sick and when they die, they do it in private, without causing much fuss. I felt isolated and frustrated that so few of my negative friends could handle my status enough to really be able to hear me talk about it. I had felt very alone, and the retreat provided space for me to feel heard. More importantly, I got to know myself a bit better too. For the first time since my diagnosis, I was able to come to grips with my own response to being HIV. I realised that in my panic, I had switched off from a lot of my feelings, because they all seemed so bad. Over the five days, I allowed myself to feel those emotions, and began to see that it wasn't so bad after all. As I relaxed, I found myself experiencing a warmth from within, that I hadn't felt for such a long time. It felt calming and reassuring, and I think it's made me feel stronger too. More together than I was before.

I found a very gentle camaraderie develop between a lot of the men on the retreat. Being around other positive men was so enlightening for me. I realised that a lot of my experiences were shared by other people, and I learned about their experiences as well. We also had some great fun together with lots of laughs, and I got to know a few of the guys really well. I made some friends. I also learned that whether someone is positive or negative, category one or four, the person is still the same. Everything else is just a description of the body. There were guys in all stages of HIV disease on the retreat, and I found that my discomfort eased away and I could see the people for who they were.

When I arrived back in Sydney I didn't feel so alone, and I didn't feel so frightened, any more.

***Positive Retreats** are run several times a year by PLWH/A Inc (NSW) and the ACON HIV Support Project. The next Retreat will be in September or October, the dates have yet to be confirmed. Call 019 98 2525 for more details.*

هل أنت بحاجة إلى معلومات
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Jamie Richards

I WAS DIAGNOSED IN 1991, AFTER being sick for a while. Prior to that I was told I was probably HIV positive and sero-converting, but the tests weren't definite. In a way it was a relief, but in a way it wasn't. Under the circumstances, I was expecting it. I'd had a year and a half to prepare for it.

How did you feel while waiting for a definite result?

I went crazy, that was the most destructive period of my life. I got severely into drugs, I couldn't hold down a job. Waking up every day thinking, is today the day I find out? I couldn't sleep, didn't eat. I attempted suicide. I had all these guilt trips, like I'd never slept with anyone, I'd never slutted around — at the time I put the blame on the person who I think infected me (through needle sharing).

I didn't know anything about HIV or AIDS, except the attitude that they've got out in the suburbs, "oh my god, its a terrible thing, better off dying now".

Did you look for support?

Oh yeah, mainly towards my family but of course that wasn't there at all. Then I got involved in the groups at ACON and that helped. And having a gay friend who was also Positive was a great help.

I'd being doing the Fun & Esteem groups at ACON before I had the definite diagnosis, so I had become more aware about HIV and AIDS. Once I knew I was positive I started going to HIV support groups. After I met my lover, he and a close friend were my main support. Unfortunately we've been separated a year now.

Photo: Mazz Images

How do you feel about being HIV positive now?

I hate it, I really do. I hate what it's done to me, how it made me so weak and so scared. How destructive it was to my relationship. Lately I've been coming up with little infections here and there, and it's scaring me.

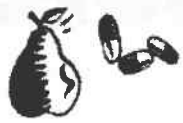
I'm trying to think what can I do, should I continue my studies, should I get a job, should I just pack it in and go walkabout? It's like there's three years of my life that I've got to catch up on, I was so messy and so confused and so hurt during those years. I've got to straighten things out. I've also got to live and I don't know how to.

What advice would you give to someone who's just been diagnosed?

Oh, services, support, go straight away. Don't leave it, thinking you'll cope. Don't take drugs, because you're not dealing with your problems. They're locked away in a cupboard but when you come off your drugs and open the cupboard door, you're going to get squashed to death by all those problems. That's what's happened to me.

I've found the best thing is to talk with other people who are Positive, especially older people who've lived with it a long time. I didn't have that opportunity, to talk to someone else who had HIV, was doing drugs and was young. I'd like to offer that to other people. If there's anyone in a similar situation, I'm happy to talk to them.

Interview by Jill Sergeant



Protease inhibitors

By Colin Batrouney

WITH ALL THE CONCENTRATION IN recent months on the antiviral combination of 3TC and AZT, a new class of drugs which could represent a more spectacular advance in HIV medicine has been relatively ignored.

These new drugs are called protease inhibitors and general research opinion is it that they will become a key element in antivital combination treatment in the future. So what are protease inhibitors and how are they different?

Put simply, the protease enzyme is involved in the assembly of virus particles, and protease inhibitors are drugs which interfere with the process of breaking down the proteins HIV needs to grow. In this way they differ from nucleoside analogues (AZT, ddl, ddC, etc.) which inhibit the process by which the virus integrates with the nucleus of healthy cells and reprogrammes them to produce more virus.

Unlike these older drugs, protease inhibitors have been developed to only block HIV, by binding with its protease enzyme, and so it is hoped that they will be more potent and less toxic. The combination of nucleoside analogues and protease inhibitors would probably form the basis of a very potent two pronged attack against HIV because the target enzymes for both classes of drugs are different, attacking the virus at two separate and important points in its life cycle.

In human trials, protease inhibitors from the drug companies Merck, Roche and Abbott have shown a stronger antiviral activity than any previous anti-HIV drug. Other companies developing protease compounds are Agouron, Vertex/Glaxo-Wellcome).

Merck

In earlier studies in humans the Merck protease inhibitor, MK639 (formerly known as L-735, 524) showed that the drug was safe, well-tolerated, and adequately absorbed. However it is the least promising of the protease compounds curently being trialled, with minimal beneficial effect, and resistance developing after six months. The researchers also found resistance, in the test tube, to other protease inhibitor drugs from Abbott, Searle, Wellcome, and Roche. This is what is known as cross-resistance. The drug may prove useful in combination with nucleoside analogues.

The Merck protease inhibitor will be studied here as a part of a large international trial. Merck have recently announced there will be a limited program of compassionate access for people not on the trial.

AIDS buyer club networks in the United States expected that an underground version of MK-639 would be on sale there in July, but supplies would be limited and prices high — as much as US$10,000 a year.

Abbott

Abbott Laboratories presented results from a placebo controlled study of its protease inhibitor, ritonavir (ABT-538) at the Second International Conference on Drug Therapy in HIV Infection in Glasgow late last year. After using the drug there was an average drop in viral load of 99. 1 percent. CD4 counts rose on average 300% from a baseline average of 182.

People on the highest dose levels had higher CD4 rises (300 to 400) and a larger reduction in viral load (99.8 percent) than those on the lower doses. The most frequently reported side effects were nausea and lightheadedness.

Professor David Cooper of the National Centre in HIV Epidemiology and Clinical Research has reported on a study he has conducted using the drug on 24 people. Along with increases in CD4 counts and a reduction in viral load, two people on ritonavir had their KS lesions clear up and in another two people oral hairy leukoplakia went away.

People on ritonavir at lower doses (600mg per day) show signs of HIV resistance to the drug after six months. Ritonavir appears to be cross resistant to the Merck protease but not to saquinavir making it suitable for combination with this drug.

A controversial new study of ritonavir is now recruiting 50 participants in NSW at St Vincent's Hospital and Albion Street. (See p. 9 and back page)

Roche

The Roche protease inhibitor, saquinavir, is the only protease

compound in development which is planned for accelerated approval in the US before the end of 1995. Currently there are two large ongoing phase III studies of saquinavir, one in the US and one being conducted internationally, in which Australia is taking part.

There are four arms of the trial, which includes AZT and ddC. The daily dose of saquinavir, on this trial is 1800 mg daily and is reportedly well tolerated with relatively few side-effects, the most serious being nausea and diarrhoea. People who enter the trial and have to discontinue due to a bad reaction to other drugs on the trial will be offered free saquinavir until the drug is marketed.

Questions remain about the potency of saquinavir. Early data from a Stanford University study in the US of 'high dose' saquinavir (3600 and 7200 mg daily) suggest that these higher doses reduce viral load more significantly than the 1800 mg dose. The current formulation of saquinavir is poorly bioavailable, meaning that only 2—5% of the active drug reaches the bloodstream. Roche have recently announced the development of an improved formulation of saquinavir which addresses this problem.

Resistance to Saquinavir, even at the lower dose of 1800 mg daily, does not develop as quickly as in other protease compounds. After one year of treatment, about 50% of people using the drug show some signs of low level resistance, and that resistance does not lead to a large reduction in sensitivity to the drug. Virus that has grown resistant to saquinavir is not automatically resistant to other protease inhibitors.

Roche is committed to sponsoring an expanded access program to provide saquinavir to people with AIDS. This expanded access will be using the new formulation of saquinavir and will involve 4,000 people worldwide (2,000 in the US alone) and will increase in size as greater quanitities of the drug are manufactured. It is unclear what percentage of the remaining 2,000 places on this expanded access program will be allocated to Australia. The protocol for compassionate use has yet to be drawn up but it is certain that the drug will be available for at least 50 people with CD4 counts below 50 and will combine saquinavir with d4T.

Clearly one of the major priorities of the international research community is the development and clinical application of this new class of anti-HIV drugs. The implications for the HIV/AIDS infected and affected communities are potentially enormously beneficial. But firstly we need to address some very serious issues.

Community response

Without an effective activist voice in this country we will not have any meaningful contribution to make to the ongoing treatments debate and subsequently no access to promising treatments for HIV/AIDS outside clinical trials or restrictive compassionate access programs. These will be determined by the drug companies and the research community at *their* discretion and based on *their* priorities. it's not up to the researchers or the drug companies to guarantee us access, it is up to *us* as a community.

The primary advocacy group for PLWHAs in each state are the AIDS Councils and their silence with regard to treatment issues, with a very few exceptions, has been deafening. They simply need to do more on every level of the treatments debate. This includes treatments education and a more dynamic role in what was once known as activism, hand in hand with advocacy.

The need for activism is as urgent as it's ever been because we can see what could happen if the voice of the community is diminished.

Our views will not be taken into account and, quite simply, our agenda will be determined for us. In the absence of a clear activist voice in the HIV/AIDS debate in this country, the balance has slipped in favour of the priorities of the academic medical research community and the drug companies and you don't have to look too hard to see who the losers are in all this. There is an urgent need for the HIV/AIDS infected and affected communities to reposition themselves central to the treatments debate in this country.

Trial Access (NSW)

The Merck, Abbott and Roche Protease inhibitor trials are being conducted from various centres, but all are under the auspices of Andrew Carr and Prof. David Cooper at St Vincent's Hospital, ph: 339 1111.

Colin Batrouney is the HIV Treatment Info Counsellor at the Positive Living Centre in Melbourne. This article is condensed from an article which originally appeared in AIDS X, *June 1995.*

Bobby Goldsmith Foundation BGF

provides assistance to people with advanced HIV/AIDS to enable them to maintain a reasonable standard of living by helping to alleviate some of the financial stresses during an extremely difficult time in their lives.

For more information about BGF guidelines for assistance, or to make an application for assistance, please contact the BGF Office.

***BGF**, L4, **376 Victoria St** PO Box 97 **Darlinghurst** NSW 2010*
*Fax 360 9334 Tel **360 9755***

(Continued from page 9)
jects? In any event, in a multinational trial of this size, such community input would have been swamped by the competing objectives of the pharmaceutical companies, the investigators, the licensing bodies and the patient groups of other countries which represent much larger numbers of trial participants.

Paragraph ten

There are a number of significant factors which propelled Australian clinical researchers into international trial participation. Our track record of consultation and co-operation with the affected community figured somewhat behind our ability to produce results of the highest quality, many of which required placebo-controlled trials.

Paragraph eleven

In my view, an obligation for consultation arises when Commonwealth money is used to support the infrastructure of trials. This trial of Ritonavir is funded in its entirety by the pharmaceutical company and the funds are transmitted directly to the hospital and clinic in question.

Paragraph fifteen

Far from behaving like a rogue pharmaceutical company, Abbott has conducted each phase of this trial in a responsible and ethical fashion. It would be callous to hound them into withdrawing altogether from the field of HIV drug development — callous and inhumane toward those PLWHA who could in the future benefit from such drugs. Inappropriate attacks on drug manufacturers can only lead to fewer effective therapies. Surely the objective of all of us is to achieve more effective therapies for our clients and friends.

Poetry

For my Daughter Ebony:

Your smile lights up my morning,
and fills my heart with love
I swear you are an angel
Sent from heaven above.
I live to see your future
to watch you learn and grow
I want to hold you in my arms
and never let you go.
So if ever I'm not there for you
remember just one thing
I'm with you heart and mind and soul
whatever life may bring.

Melissa

Pick one up. Now.

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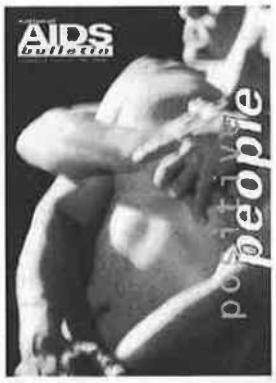

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Screamline is a project auspiced by ACON

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TK August

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For further information contact:

Pat Kennedy (02) 204 2404 or 016 020 page 278 671.

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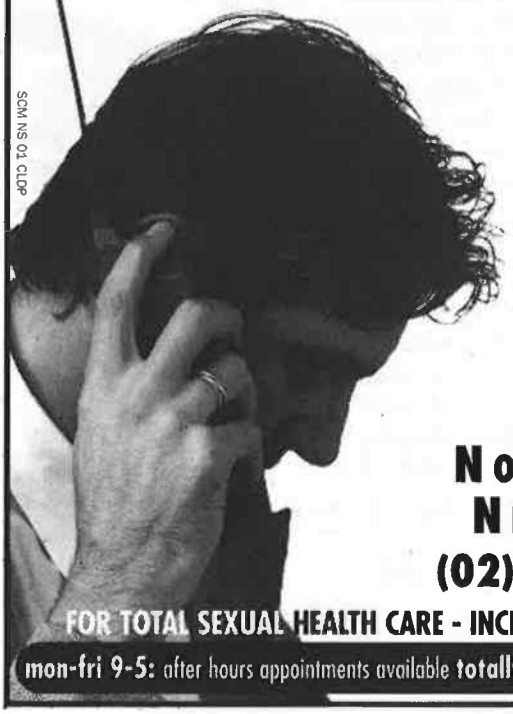

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ACTION REQUIRED ON ABBOTT PROTEASE INHIBITOR ABT-538

PLWH/A (NSW) Inc view

ABT-538 is one of an exciting new group of antiviral drugs called protease inhibitors.

There are a substantial number of people with HIV with very depressed immune systems. Most of these people will have already tried other treatments and failed. They need something new. For those in this desperate situation, access to ABT-538 would arrest decline in their health and increase their chances of survival.

Compassionate access must be resolved urgently.

PLWH/A (NSW) notes that in the USA over sixty major AIDS groups have recently signed a consensus statement demanding that Abbott and other manufacturers of protease inhibitors make their drug available on a compassionate basis.

PLWH/A (NSW) will be asking ACON and AFAO to lead a community campaign to force Abbott to make ABT-538 available to all those who need compassionate access to it.

Abbott is behaving like a rogue pharmaceutical company. They cannot be allowed to get away with their callous, inhumane attitude towards people with HIV/AIDS.

What you can do

Protest to:

Mark Haywood (Managing Director)

Susan Alder (Medical Director)

Phone: (02) 668 9711

Fax: (02) 668 8459

Write: Abbott Australasia Pty Ltd. (Health Care) Captain Cook Drive, Kurnell, NSW 2231

N.B. Send copies to PLWH/A