

No. 60 November 1995

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



Signs of Life

PLWH/A News



AS SOME OF YOU WILL KNOW, THE Evaluation Report on the 2nd National AIDS Strategy has just been released with great fanfare. The good news is that the evaluation found the Strategy worked reasonably well. As a result Prime Minister Keating has committed the Government to funding a third National Strategy.

The bad news is that there are no clear recommendations in the Evaluation Report for solving drug access and drug funding problems. And while there are recommendations about "involving people with HIV in decision making", no practical recommendations are made about how this will happen. If governments want us to be involved, then we have to be supported and encouraged to do this. For people with HIV, "being involved in decision making" often costs us financially, as well as in terms of our often limited energy and compromised health.

The next step is the writing of the 3rd National AIDS Strategy. PLWH/A will be writing to the Government about what needs to be in the 3rd Strategy over the next month.

The issue of poverty among people with HIV/AIDS continues to be a major concern. Meetings of AIDS groups and other interested people have been held in recent months to discuss poverty and what to do about it. However, it is difficult to really tackle poverty unless we have a clear understanding of the extent of the problem. PLWH/A has just written to the State Health Minister asking him to fund a short needs assessment, aimed at identifying the extent of poverty among people with HIV/AIDS and coming up with recommendations to address the problem.

On the treatments front, we have continued to work on accessing promising new antiviral drugs, particularly the new protease in-

hibitor drugs made by Roche, Abbott and Merck.

Roche Pharmaceuticals agreed with our position that their compassionate access program for the new antiviral Saquinavir should give priority to those with low immune function (less than 50 CD4 cells), who are failing on current therapy. We worked with Roche to help develop the system for allocating Saquinavir. The program seems to have worked well — over 200 applications from people with HIV were received for the first 50 places in the program. What is obviously needed now is a lot more access to Saquinavir to meet the demand. We are about to meet with Roche about this.

Negotiations are continuing with Abbott and Merck about the compassionate access programs for their protease inhibitors — we should be able to report more on this in the next *Talkabout*.

In the last issue I reported that the PLWH/A Committee decided to create a new staff position of Treatment Advocacy Support Officer, to help us deal more effectively with the huge treatment lobbying workload. Henry Forester is joining us to fill this new position. Henry has a lot of experience in research and policy areas and we look forward to him joining our staff team.

A reminder to all PLWH/A members that membership renewals are now due. You will need to be financial to vote at the forthcoming annual general meeting, which will be held on November 28 (further details will be posted to members shortly). If you haven't received your membership renewal form, please telephone the PLWH/A office on 361 6011.

Finally, special thanks to Claude Fabian and his team of volunteers who ran the Time Out

rooms at the recent Sleaze Ball. Once again, this space provided a welcome haven for positive partygoers to adjust their makeup and gather their thoughts!

— **Bill Whittaker, Convenor**

Notices

The next edition of *Talkabout* will explore the theme of World AIDS Day: Shared Rights, Shared Responsibilities. What does this mean to you? Share your opinions — send your contributions in!

Readers are welcome to a *Talkabout* Planning Meeting, at which we will plan content for the next year and discuss issues relevant to the production and promotion of *Talkabout*. The meeting will be held from 10.30 - 4.00pm on Wednesday, December 13 at ACON. If you'd like to come, call Jill on 361 6750 to confirm the date and venue.



People Living With HIV/AIDS (NSW) Inc.

Current committee

Bill Whittaker: Convenor

Vivienne Munro: Deputy Convenor

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Current staff

Ryan McGlaughlin: Manager

Paul Roberts: A/Admin Asst

Luke Smith: A/Positive Speakers Bureau Coordinator

Jill Sergeant: *Talkabout* Editorial Coordinator

Sandy Thompson: *Talkabout* DTP/Advertising

Post: Box 831, Darlinghurst NSW 2010

Office: Suite 5, Level 1, 94 Oxford St, Darlinghurst

Phone: 361 6011

Talkabout: 361 6750

Fax: 360 3504

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This month's cover

By Antoinette State of the art information on pregnancy for positive women has changed a lot over the past decade. Women now face quite different pregnancy decisions than even a couple of years ago. So it was definitely time for *Talkabout* to do a special issue on the subject. Our pregnancy feature starts page 12.

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 Sandra. Send contributions to:
PO Box 831, Darlinghurst, NSW 2010.

Deadline for the next issue: November 17

If your venue/organisation is interested in distributing *Talkabout*, contact the editorial coordinator. Call the editorial coordinator on 361 6750 for the date and time of the next Newsletter Working Group meeting.

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Briefs



● The first 24 hour AIDS hotline in the Arab world opened in Egypt's capital, Cairo, in October. According to Ministry of Health figures there are 478 people known to be HIV+ and 110 with AIDS in Egypt. (*AIDS Analysis Africa*)

● The World Health Organisation estimates the current number of HIV cases in India at between 1.5 and 2 million, which may increase to around 10 million by the year 2000. The Indian Health Organisation, by contrast, estimates there are 4 million HIV infections and over 200,000 cases of AIDS. (*AIDS & Society*)

● Medical experts in Zimbabwe estimate that 20 to 25% of the sexually active population is infected with HIV. However, Health Minister Timothy Stamps believes the incidence of new infections may have peaked. (*AIDS & Society*)

● The number of orphans in East Africa is growing rapidly following the atrocities in Rwanda and Burundi. In one part of Tanzania, the number of orphans has increased more than 100-fold. Community based and international groups can assist only 47% of these children. Ukimwi Orphans Assistance is a non profit East African organisation that has been effectively working for orphans since 1990, using a culture based approach that emphasises family support, sustainable development and income generating/food producing projects. (*AIDS & Society*)

● HIV/AIDS could increase labour costs for some Kenyan businesses by 17% by the year 2005, according to preliminary findings from a recent study. Absenteeism, training costs and HIV related health care will cause the greatest losses to Kenyan businesses. Larger businesses are unlikely to be affected but some could find their profits cut by 15 - 25% within the next ten years. (*AIDS Cap*)

● Zambian prison authorities, worried about the spread of HIV in gaols, have started releasing HIV+ prisoners. So far, 10 PLWHA have been released, with more releases planned. It is not clear exactly how many inmates have HIV or AIDS. The decision, which is based on a Zambian law which allows people with terminal illness to be released, has met with a mixed response from the public. (*AIDS Analysis Africa*)

● The Eleventh International Conference on AIDS will take place in Vancouver in July 1996. The Conference organisers have committed themselves to ensuring community representation on every committee related to conference planning, including a minimum of 2 community reps on each of the 4 scientific program tracks. There will be a scholarship program for delegates in need, particularly PLWHA and those from developing countries.

Combination benefit

TWO LONG TERM DRUG TRIALS, ACTG 175 and the Delta trial have now confirmed that taking those tablets in combination can delay disease progression and show a definitive survival benefit.

The Delta trial started in 1992 and was divided into two: Delta 1 and Delta 2. Trial participants were asymptomatic or had AIDS, with CD4 counts between 50 and 350. Delta 1 had 2,131 people who had not taken AZT before. Delta 2 had 1,083 people who had already taken AZT for three months or more. In both groups people were randomised to receive either AZT alone, AZT + ddC or AZT + ddI.

The results from Delta 1 were of particular importance, showing that those on combination treatment had a greatly reduced risk of clinical progression or death compared to those who were only receiving AZT. Taking combination therapy reduced the risk of death in this group by 38% over a two year period. It was also shown to delay disease progression for people who were asymptomatic, mildly symptomatic and people with AIDS.

In Delta 2 there did not appear to be any significant difference between the groups taking combination treatment and those remaining on AZT.

ACTG 175 started to recruit people in 1991 with CD4 counts between 200 - 500 and without an AIDS diagnosis. They were randomised to receive either AZT alone, ddI alone, AZT + ddC or AZT + ddI. The groups were separated into those had previously taken AZT and those who had not.

In the AZT naive group, those on AZT alone experienced less benefit from treatment than those who were on the combination treatment or on ddI alone. In the other arms the benefit was the prevention of events such as ma-

jor CD4 count decline, the development of AIDS, or death.

In the AZT experienced group those who received most benefit were the people who switched to ddI alone or who were taking AZT + ddI.

The information obtained from ACTG 175 is a bit confusing when compared to the clear benefits shown by combination treatment in the Delta trial. Some of the reasons for this are that many people in ACTG 175 were lost to follow-up and few of the people who remained in the trial actually reached the trial end points before they stopped taking treatment.

In all, the main body of evidence falls on the results of the Delta Trial which strongly shows that people beginning antiviral treatment for the first time should start with combination treatment for the most benefit to be achieved.

— Alan Strum

Protease trial

INDINAVIR, ONE OF THE NEW protease inhibitors, is about to be made available in a clinical trial to people whose CD4 count is less than 50, who have taken AZT for six months and who have never taken 3TC.

Results from trials of Indinavir have indicated that when it's taken in combination with AZT there CD4 cells can increase by about 75 and a considerable reduction in the amount of virus in the blood — about 2.5 log (AZT alone usually reduces viral load by only 0.7 log).

This new trial is specifically designed to look at the effect of Indinavir in people whose CD4 count is less than 50. Information on drug treatments for these people is often quite hard to come by. Hopefully this trial will fill part of this void.

The trial will have four arms: Indinavir; AZT + 3TC; AZT + 3TC + Indinavir and Open Label (for people who don't quite fulfil the inclusion criteria).

There will be about 28 places

available. If the trial is filled there will be up to 16 additional places available. For more information, call me on 206 2000 or 1800 063 060.

— Alan Strum

What is UNAIDS?

IN JULY THIS YEAR, A DECISION WAS taken to create a new United Nations Program to deal specifically with the issues of HIV/AIDS. UNAIDS (the Joint United Nations Program on HIV/AIDS), which will officially come into existence on January 1, 1996, brings together six agencies who have been involved in responding to HIV/AIDS — five UN agencies and the World Bank.

The major rationale behind this decision was to make the work of these agencies in developing countries more focused and effective. (The UN is not famous for inter-agency co-operation generally and HIV/AIDS has been no exception).

Australia has played a key role in the development of UNAIDS through Government and non government (NGO) channels. Rob Moodie, formerly from the Macfarlane Burnet Centre in Melbourne, has been appointed to one of the senior positions in UNAIDS.

UNAIDS will place emphasis on building national capacities to respond to HIV/AIDS. It will act as an advocate for appropriate policies, including appropriate social and legal environments and appropriate funding levels. It will also provide technical and strategic guidance.

UNAIDS has expressed a strong commitment to the inclusion, of "all national actors" in the response. An indication of this commitment is that, for the first time in UN history, non-government representatives will have official seats on the Program Coordinating Board (PCB), effectively the Board of Directors



John Hughes and Kell Boston with Alice Bear-Bear Bear-Bear and Octavia Bear. The auction of 69 bears on October 16 raised almost \$46,000, to be divided between the AIDS Councils of NSW and Victoria.

PHOTO: MAZZ IMAGES

of UNAIDS. The PCB is made up of the following: 22 country representatives (currently including Australia — Helen Evans), representation from the six co-sponsoring agencies referred to above, and a five-member NGO Liaison Committee.

This Committee, selected on a regional basis, includes two positive representatives, Martina Clark (United States) and Arnaud Marty-Lavauzelle (France). The Asia-Pacific representative is Bai Bagasao from the Philippines. Five Alternates have also been named and include Bill O'Loughlin from Australia.

For further information please contact me. Ph: (06) 285 1816; E-mail: acfao@peg.apc.org

— Phil Marshall

Don't scream

ATTENTION WOMEN LIVING WITH HIV or AIDS in NSW or the ACT! Your peer support phone line, "Screamline" is up and running. And even though the name is "Screamline", *you don't have to be screaming to use it!*

If you would like to chat with another positive woman, Screamline volunteers are 'on duty',

between 11.00am and 4.00pm, Tuesdays and Fridays.

Screamline has been in operation for just over a month and volunteers have taken a wide variety of calls — from women wanting general info, enquiries about complementary therapies, locations of HIV/women friendly GPs, services in rural areas, plus women who wanted to have a general talk, and 'compare notes' with another positive woman.

For many women, their call to Screamline was their first contact with another positive woman and the first chance they have had to speak openly about their feelings around their serostatus. Making that initial call is often the hardest part of accessing a support service, so it's reassuring to hear the friendly voice of someone who has been in a similar situation.

Some of the resources available through Screamline include: locations of services that are women and HIV friendly, (including GPs and community health centres), information on trials, medications, complementary therapies, crisis accommodation, housing, transport ... and more! The vol-

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• The final HIV/AIDS Memorial Tree Planting for 1995 will take place between 10.30am and 4.00pm on Sunday, November 5 in Sydney Park, St Peters. For info call Mannie on 718 1452.

• The Bobby Goldsmith Foundation will again stage the BGF Reserved Seating at Mardi Gras on Saturday March 2, next year. The seating, with a guaranteed unobstructed view of the Parade, will be situated right in Moore Park Rd. Amenities include ushers, private toilets, full security, pre Parade entertainment, special lighting of the floats and celebrity commentary. Tickets are now on sale from First Call Ticketing on 320 9000 for \$45 each plus booking fee.

• The Pride HIV/AIDS Community Development Project is holding community consultation meetings. The consultation aims to find out the needs of various sub groups in the community, in particular Koori, differently abled, younger, older and non-anglo lesbians and gays. Call Amanda Nickson on 331 1333.

• Partner a celebrity at golf at the Illawarra AIDS Task Force fundraising celebrity golf day on November 30. Tickets \$25, call David Wain on (042) 28 8033 or Robyn Langlands on (042) 75 5823. Proceeds to the Positive Space Project.

• Illawarra readers can tune into Positive Voice, Mondays at 8.55am, ABC Illawarra, 97.3FM.

• A Victorian survey of carers has found that people who care full time for a loved one pay a high cost psychologically, socially, and in terms of physical illness. The survey highlights the need for much higher levels of support for care-givers. (*Capital Q*)

• Newcastle City Council has approved a development application to use a house in Hudson St, Hamilton, as a day centre for PLWHA. The Karumah Day Centre's former home in Scott St is due to be demolished. (*Sydney Star Observer*)

• On October 25 the State Government announced the allocation of more than \$4.3 million increased funding to improve housing choices for PLWHA. This will allow \$3.4 million to be spent on special rental assistance. The funding will also be used to implement individual client service plans, increase joint venture projects with community organisations and allow hospitalised people improved access to housing advice and support.

• The Metropolitan Community Church is extending their food relief to the Newcastle/Hunter and Central Coast area. Donations can be made through the Karumah Day Centre, (049) 40 8393. For assistance in the Hunter, call Steve, (049) 67 1265; in the Central Coast, Chris, (043) 43 4363

unteers have easy access to people with a wide range of expertise.

So, whether you find yourself in a crisis situation, or would like specific or general information, or would just like to talk to another positive woman, Screamline is there. The freecall number from anywhere in NSW or the ACT is 1 800 630 075.

The next move

"VALUING THE PAST . . . INVESTING in the future", a 227-page report on the evaluation of the 2nd National HIV/AIDS Strategy, was launched in a ceremony at Parliament House in Canberra on September 27. The author of the report, Professor Richard Feachem, handed the report to PM Paul Keating, who spoke movingly of the contribution made by people with HIV in fighting the epidemic. "People living with HIV/AIDS could be excused for concentrating solely on personal and family concerns" said Mr Keating "But they haven't. Over the past decade, people with HIV/AIDS have transcended their circumstances, and the daily burden of coping with the virus, to make often outstanding contributions to our HIV/AIDS policies — not to mention the general life of the nation". He concluded by pledging his Government's support for a Third National HIV/AIDS Strategy, "with dedicated, secure and adequate funding for five years".

This announcement and the report were greeted warmly by most community organisations, though the National Association of People with HIV/AIDS (NAPWA) had some reservations about the report. Speaking at the launch, the convenor of NAPWA, Mark Counter, applauded the openness of the process and the way in which information was gathered for the evaluation. "Equally important was the community participation on the steering committee" he

said, but went on to describe the report as a "mixed bag" for people with HIV/AIDS. He said there were "major concerns" in relation to drugs funding, the development of standards of care in casemix and the role of people with HIV/AIDS in treatment and care programs.

Despite the PM's kind words and the report's recommendation that "the Commonwealth, the States and Territories, and non-government organisations support the very important role of people living with HIV/AIDS" in both prevention and treatment and care programs, the report avoids any specific recommendations on these matters.

Herbal trial

THE KM1 HERBAL TRIAL FOR PLWHA is in the final stages of preparation and due to start in February next year.

The trial will use a combination of natural herbs in an effort to improve the immune function and general well being of the participants. Participants are supplied with the formula on a monthly basis over a six month period, and asked to have three monthly testing (CD4, CD8, liver function and P24 antigen levels).

This trial is unique in Australia in that it does not discriminate on basis of sex, sexuality or past medical history. Women, indigenous and ethnic groups, IV drug users etc. are all encouraged to apply for access to the trial. In fact, the trial co-ordinators wish to obtain as broad a cross-section of the HIV community as possible, especially to provide more data for marginalised HIV groups. The simple structure of the trial (one monthly visit and special access for those not close to Sydney) means that country and interstate participants are very welcome. And best of all, access to the trial is *free*. It will be conducted at the Sydney PWA

Day Centre, not the College of Natural Therapies, as previously advertised.

The trial co-ordinators are particularly interested in gathering more HIV positive women participants. We realise that positive women face specific problems and we are organising a more flexible access system for women, including childcare, to attempt to cater to some of these specific needs. If there is a particular way to reach women out there — like using a friend's post box number or telephone — please contact me on the number below.

This trial will be independent research, with the support of the Community HIV/AIDS Research Network and the Australian Federation of AIDS Organisations. It will operate according to Therapeutic Goods Regulations guidelines and is approved by the South Eastern Sydney Area Health Ethics Committee. Confidentiality will be respected at all times with participants identified only by code in any trial reporting. For full details of the trial and its criteria, call me on 552 2243.

— Jan Kneen-McDaid
KM1 trial co-ordinator

IDUs and trials

THE INVOLVEMENT OF INTRAVENOUS drug users (IDUs) and people on methadone programs in trials of experimental HIV/AIDS drugs is set to become an issue following claims that they are being effectively excluded. The NSW Users and AIDS Association (NUAA) is to ask the Australian Federation of AIDS Organisations (AFAO) to campaign on the issue.

Policy Officer at NUAA, Tony Rance, claimed that exclusion criteria contained in many trial protocols stopped IDUs from participating. Some protocols explicitly exclude those taking opiates or other illicit pharmaceuticals because of safety concerns or their effects on the body's abil-



PHOTO: C. MOORE HARDY

**Over 300 volunteers made over 160,00 red ribbons on October 15.
The AIDS Trust hopes to raise \$320,000 from sale of the ribbons.**

ity to clear a drug or their effect on trial statistics.

As well, investigators can reject a person's participation in a trial if they consider that the person will not comply with the protocol or follow-up. But Rance says that the real reason is often prejudice. He said that fears that IDUs won't turn up or take their medication regularly are a "myth".

"We're putting IDUs in the position of not even having the option of trying an experimental drug. It's unacceptable." Rance also criticised what he claimed was a lack of research into interactions between antivirals and street drugs.

A scientist involved in organising clinical trials, who asked to remain anonymous, reacted strongly to the claims of prejudice. He said that there was no policy to exclude IDUs as a group, only those individuals who didn't match the requirements.

"The reality is that clinical trials are complicated, resource-intensive and they have a purpose. If you include people who are going to fuck about then your tri-

al is screwed." He said that there were exceptions to the rule, but due to their known high rates of mobility IDUs generally represent a difficulty in running trials.

Nevertheless, the scientist said that there would be a desire "by everybody" to identify issues relevant to the participation of IDUs, and others, in trials.

— Paul Canning

Crypto-swim?

RECENT MEDIA HYPE MAY HAVE scared a few people away from using their local swimming pool for fear of being exposed to the bug that causes cryptosporidiosis. A newspaper article in the *Telegraph Mirror* would have had us believe that 50% of Sydney's pools were unsafe to swim in. In fact crypto was found in only two pools (out of 18 tested — six had Giardia). But it was not known whether the bugs that were found would have caused someone to become ill with crypto.

There was an outbreak of crypto in the Sutherland area in early 1995 in which 74 people were reported to have been infected, but the pool involved was

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X American and Dutch researchers have worked out the structure of an enzyme called integrase which HIV uses to copy its genetic information into human DNA. In theory, it should be possible to develop antiretroviral treatments which would target this enzyme and leave human cells unharmed. (Body Positive UK)

• Results of a Harvard study among Senegalese sex workers suggest that infection with HIV-2, a less pathogenic form of the virus, may protect against infection with HIV-1. This finding may lead to an experimental vaccine for use both as preventative and treatment in areas where HIV-1 is prevalent. (Beta)

• The US Food and Drugs Administration (FDA) has approved a compassionate use study of thalidomide as a treatment for wasting. Thalidomide is already being studied for its effectiveness in treating aphthous ulcers, weight loss and to gauge its ability to lower the level of TNF, a cytokine that may increase HIV disease progression. (Beta)

• Rifabutin is to be studied in a large international trial for its ability to prevent tuberculosis in HIV+ individuals who are also infected with mycobacterium TB. Rifabutin is already FDA approved for MAC prophylaxis and has been used in combination treatments for active TB. (Beta)

• Past research has indicated that PLWHA have a higher baseline rate of metabolism than HIV negative people, which has been thought to be a factor in wasting syndrome. However, new research from London indicates that decreased intake of food and calories is the cause of wasting. (Beta)

• Although AIDS patients experience pain as frequently and intensely as cancer patients, they rarely receive adequate pain relief medication, according to experts in AIDS care in the US. "Pain in AIDS is dramatically undertreated and is associated with significant functional and psychological morbidity", according to William Breitbart, psychiatrist at the Memorial Sloane Kettering Cancer Center, NY. (AIDS Alert)

• A new Federal Government initiative, brand substitution, allows consumers to ask their pharmacist to substitute a less expensive, (but equally effective) medicine for that prescribed. You may save up to \$4.88 on over 160 brands. Ask your doctor or pharmacist about this scheme.

emptied of the contaminated water. According to the Department of Health this was the only outbreak of Crypto on record in Australia that has been linked to a public pool, and only five other outbreaks from pools have been reported world wide.

— Alan Strum

Couples and families

PROFESSOR DAVID COOPER, ONE OF Australia's leading authorities on HIV/AIDS, launched a new program to assist partners, family members and friends of people with HIV/AIDS on Tuesday, September 12.

The Couple and Family HIV/AIDS Project is a joint project between St Vincents Hospital and Relationships Australia (NSW) to address the emotional and psychological issues — such as communication problems, dis-

tress or anxiety, disclosure, depression, grief reactions, violence — that surface in relationships where HIV/AIDS is a factor. Discussing these issues with a counsellor can be a helpful way of resolving some of the problems and improving communication and understanding.

The pilot project is sponsored by the Mercy Foundation and is not restricted to patients of St Vincent's hospital. The service is available to people with HIV/AIDS, their partners, family and friends.

People will be seen (for free) by qualified clinical social workers and psychologists. Client information is held in strictest confidence. Clients can refer themselves. Sessions will take place at the Social Work Department, level 2, Xavier building, St Vincent's hospital on Tuesday afternoon between 1.00 and 5.00pm. For more info call me on 361 2213.

— Helen Golding

Olgas Personals

Guy 50 HIV+ seeks honest guy to share my home with magnificent river views in TAREE, on the mid north coast. Enjoys gardening, CDs, movies, reading and sport. I'm NOT looking for a lover but a good man with whom to share my life. HIV+ person more than welcome. Discretion essential. #951105

If we handed you some rope, a short piece of wood, a leather glove, and a packet of clothes pegs, what would you do with them? Two sexy positive boys would like to hear from boys with imagination, sex appeal, and individual flair. Oh, and send a photo, too. #951110

Guy 34 HIV+, looking for sane playmate/s. Some of the things that tickle my fancy are toys, FF, imagination, a sling, TT, cuddles, videos, pushing boundaries sanely, fun times, companionship. I am versatile and if the above tickles your fancy, drop me a line and let's meet. #951115

Straight HIV+ guy 23 dark hair, blue eyes would like to meet +ve female for friendship and possible relationship - up to 35yrs. I have a great outlook on life and enjoy every minute. #951120

Sydney: MAG, passive, HIV+ healthy, working; likes music, DTP, dining in/out, movies; social drinker, smoker, young mind trapped in a mature body; non-possessive; easy going; seeks guy over 25 to spend quality time with. #951125

Olgas Personals

Inner west, 37, 6'4", gay, good body and head. Prof and positive. Intelligent well read many interests ranging from competitive swimming, travel, films and fun. Off sense of humour looking for friends maybe more. ALA #951130

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 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.

Tribute



Recipe

A send off to heaven
or
A thanksgiving 'from hell'
for
Anthony Charles Carden

Ingredients

- A 33-year-old life filled with passionate devotion to the arts (especially the Theatrical Arts),
- to his family (especially nieces and nephews),
- to his friends (especially all of them),
- to the inertia-ridden AIDS/HIV cause (especially the creation of Ward 17 South at St Vincent's)
- to Bette Davis . . . (especially her accent).
- An army of tireless volunteer care-givers and the 'ab-fab' staff at St V's.
- Four remarkable performers in their own right — Hugo Weaving, Will Conyers, Simon Hunt and Lesley Adams.
- Not to mention ump-teen artists of all kinds who used Tony as their inspiration.
- The ever-astonishing, personally devoted and cause-driven Clover Moore.
- The un-typically droll but "Oh-so-suited-to-the-cloth", Rev Erica Mathieson.
- A beautiful Bichon-Frieze dog called 'Biche'.
- The 'Ladies in White'
- Brother and Sisters — Phillip, Jane and Carolyn.
- And a mother who, through exhausting and *endless* vigil, not only brought a child into the world, but also, just 33 years later, gave him every opportunity, in God's sense of the word 'humanity', to leave it with peace, pride, dignity and not only a sense of



PHOTO: JAMIE DUNBAR

completion, but a sense that more work was to come Elsewhere. A mother, who by her son's death had only 11 days to learn all of the life's paths on which Anthony Charles Carden had left immovable footprints. More angels on earth like that, please. A *'Lesley Saddington' is really the Vital Ingredient.* (But a belief that all Mums are like that ensures this recipe's success.)

- As many coloured balloons as represent the years of your life.
- Oh! And a video for all to watch that ensures that you have the last word . . . which is what we all really want anyway.

Method

1. About 18 months before the 'send off', start ringing the above at any time of the day or night, reverse-charge if possible (International? Of course.) And *tell* them what they are going to do, be and how they are going to dress.
2. Bear no mind that most of your friends will find it difficult to talk

about your funeral. It's a part of life so you may as well count it in.

3. Fax or post umpteen 'Orders of Service' to everyone you want involved. These should all be slightly different if possible — that way your family and friends get to do all the tricky negotiations and you can get some well deserved rest.

4. Have your dog there at the funeral and at the graveside. Any whimper, wail or howl will have the desired impact.

5. A brother and sister both contributing at the service with resolute courage and indomitable spirit will not only be extremely emotional for the listeners but it will assure others that your family love you for *who* you are, not *what* you are. Don't be unsure. They do!

6. The music that you love should be there throughout. Music is a language that transcends judgement — everyone will know you better as a result.

7. Release all the balloons at the

graveside. In your few days before the event, try to arrange with Him upstairs that as the balloons ascend that they should look like they are all going to party over Oxford Street and then do a U-turn. Once over the grave they should ascend further and the clouds should part in expectation of their arrival. It requires Divine Stage Management, but the act of releasing a balloon and seeing it disappear into the Heavens is very therapeutic for those who have to trudge back to a car, contemplate life without you, face the traffic and then get pissed. It's a release in the truest sense of the word.

Use something like the above and you will give to your family and friends that most beneficial understanding of who you are/were.

Tony 'Max' Carden never failed to drop the most profound bread-crumbs of his life on 'the path to Grandma's house'. I was picking them up that day. No doubt I will continue to do so until my balloons go through the clouds too.

— Will Conyers

Amelia

PLWH/A staff and Committee were deeply saddened to hear of the death of Amelia Menia (nee Tyler) on October 20. Amelia, a pivotal founding figure in the development of services for Positive women, was a PLWH/A Committee member and Co-convenor 1990 - 1991 and the first Women's HIV Support Officer at ACON. She was also involved with the *Talkabout* Newsletter Working Group at this time and over the years has made many contributions to the magazine, including advice, cartoons, personal stories, interviews and a stint as one of the writers of our (in)famous soap opera, *Anguish in Bohemia*. There will be a Tribute to Amelia in the next *Talkabout*.

Camp Goodtime 1995

*The adrenalin's pumping, nerves are jumping
no children are whining, the day is truly shining.
Something amazing is the air (wind).
You can feel it all about to happen.
That very special time of year,
Camp Goodtime '95 is finally here.*

*Planes, trains, buses and cars coming from
everywhere and all heading in one direction,
with just one destination: Camp Goodtime.
No-one really cares where it will be,
in the country or by the sea.*

THANKS TO THE PAEDIATRIC AIDS Unit of Prince of Wales Children's Hospital and many other caring people, families that have been affected by HIV are given the opportunity to get together once a year for an understated goodtime camp.

This year the camp was held at the base of the beautiful Blue Mountains, a magical spot of lush open countryside with cows and horses grazing nearby. There's even a dam with wild ducks, so picturesque.

Then there's all the activities you can enjoy — this country retreat has the lot: bushwalks, canoeing, horse and pony rides, sheep shearing, the baby animal farm, even the flying fox, if you're game. To add to all this there's the usual activities that are at every Camp Goodtime, such as a craft room so fully equipped it can turn anyone arty, pantomimes, the Quilt Project, a remembrance ceremony where hundreds of balloons are released. Then there's

the best ever (totally unsexual) full body massage you'll ever get, from the 'Hands On' massage group and lots more support groups, medical info etc.

Now if this all seems a little too laid back, well that's certainly not the case. Once night time arrives there's sing-a-longs, slide shows and a boot scooting nite to boot, that has everyone raising their hats, stomping those boots, turning and twirling to the best country rock music around — it's fantastic and far from tame.

Take all this, add motel style accommodation, buffet style meals, the most wonderful carers and professionals to take care of every need, with the added bonus of being able to talk freely about yourself and your lifestyle without the everyday worries of society and their reactions to those of us living with the virus.

Camp Goodtime is the *best time* that I have all year. This was my third camp and I look forward to my fourth.

— Melinda (a mum)

Gone bush

THE RUMBLINGS BEGAN PRE-DAWN and by the time Saturday was fully awake, the two legged ones had taken over. Face paint mixed with that first cup of caffeine was just a taste of things to come. Huddled over Camp programs, those who had survived the hot break-

fast were getting serious about the day's events. Tossing up between jumping off a cliff (they call it abseiling) or bounding out of a bloody great tree (something to do with flying animals), the decisions proved almost as challenging as the activities. Despite

a scuffle over height discrimination breaking out, everyone eventually found their niche and got down to some boisterous and incredibly messy fun.

Morning turned to afternoon and the high energy shifted to high gear. Looking desperately for the off switch, getting weary volunteers continued the two legged chase. Competition for massages was hotting up along with the contest for the best kitchen duty avoidance tactic. Some went for the simple no show while others gabbled off fanciful tales of surprise attacks by paintbrush wielding toddlers.

In the midst of a looming nicotine shortage, some of the parents were beginning to get that workshopped look about them, so headed off in the direction of the almost wooden horses for a plod around the paddock, (not even a bribe could get them past first gear). As the afternoon wore on, sheep shearing drew a decent crowd until the treasure hunt got the more interesting vote (you can't beat a bright pink pig with sparkles, especially when it's stuffed full of lollies).

Then it was evening again and as the pumpkin-orange sunset did its bit, what was left of the hay bales were positioned for the after dinner spectacle. Yes, all you down home country folk, it was bootscooting time . . . yeeeah! It was a hot 'n hollerin' hoedown and even if you couldn't slap both feet, do a three sixty and smile all at once, no-one cared because it was how you wore your jeans that mattered — or for those without the denim, the capacity to do it with

a two year old attached was impressive enough.

By now running dangerously low on Dencorub and Aspirin, morning two of the Camp greeted us with a satisfied grumpf and the creative energy flowed on — all over the carpet in fact, and

day morning sky and watched as they made their way heavenwards. As the balloons disappeared and the volume began to rise again, we slowly came back to the present with a cough, a snuffle and a sigh. Then, with another coffee and (if you hadn't already run out) cigarette in hand, we wandered back into the warming day and another hectic round of painting, plodding and pursuing.

Just as we were gearing up for the evening's campfire sing along the skies opened up — there was nothing for it — we would have to karaoke. Making the most of the theatre-sports-till-you-drop technique and with the microphone toddler roadtested, the evening's entertainment began. Having discovered every known reason why the chicken had crossed the road, indulged in what could best be described as 'sing-giggling', and watched an absolutely fabulous fairy story with a twist, the pint size performers took the stage. And oh what a show! Gyrating in a very stylish array of pink dressing gowns and over sized t-shirts, they sure put on a siz-

zler. We were all in fits with smiles a mile wide by the end of it.

Still recovering from the previous night's hysterics, a very weary crowd (except, it seemed for those under four feet), made their way towards a much needed AM caffeine fix. The last of the paint and the first of the good-byes converged — Camp Goodtime 1995 was coming to a close.

— Ursula King (a Volunteer)



Bethany, age 11, writing a name on a balloon for the remembrance ceremony

PHOTO: TEGAN SADDLIER

someone had forgotten to pack the stain remover . . . oops!

With another hot (and thankfully recognisable) breakfast to our credit, we gathered for the balloon bit. Having issued the helium filled messengers, (remembering to weigh down the little two leggeds *before* tying one to their wrist), we sat in a moment of reflection. Then, in a spectacular sea of colour, we released our memories into the waiting Sun-

Signs of life

There's a pink plus sign in the plastic test kit you hold in your hand. It means you're pregnant. Once, you might have greeted this signal with joy — but now? Robyn describes how she felt when this happened to her — and what she decided to do.

I'LL NEVER FORGET THE FEELING. Going into a chemist on a Friday night and buying a home pregnancy kit. A few years before I wouldn't have worried but now, 23, about to be married and with a good job, I was worried. Actually I was scared to death. Not because of the impact a child would have on my life, but because of what my life could do to my child.

As I did the test and waited for the result I was numb. I didn't know what I'd do if the test was positive. I don't believe in abortion, but I don't believe in having a baby with a birth certificate in one hand and a death certificate in the other. Having an HIV positive baby was something I knew I couldn't face.

The test was complete. The result was clear. I was pregnant.

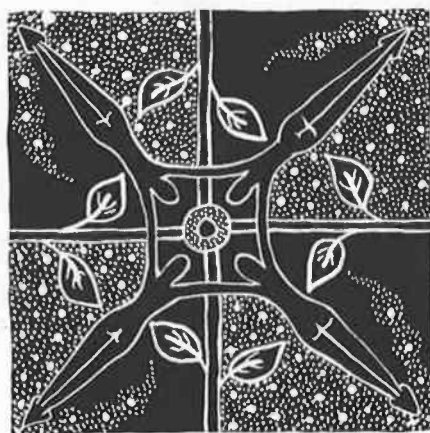
All I could do was cry. I was standing in my kitchen just holding the test device and crying. I thought that if I kept looking at it it would change and I wouldn't be pregnant. It didn't change. I knew it wouldn't. I went straight to the phone and rang my sister.

"Kelly, I have a problem and just need to ask you a question", I said sheepishly, not even giving her time to answer. "I think I'm pregnant and I just wanted to know that if I am and I do have the baby, would you still be its Aunt? Would you still love my baby whatever happens, even if the baby is sick?"

My sister and I talked some more and I explained about the pregnancy and how I felt about the baby having the disease.

Kelly told me to try to pull myself together and call ACON and my doctors ASAP to find out the real facts so I knew the exact risk to both me and my baby. I was scared for us both.

I don't think my fiancée quite knew how to react. It was a huge decision for us to make and we were both scared. He just put his arms around me and with tears in his eyes said, "Whatever you decide to do is fine by me". It was a



Encircled Bond by Tracey Bostock

COURTESY OF FAMILY PLANNING NSW

great relief to hear something reassuring. To know that he wasn't going to pressure me to decide what he wanted, just to put myself and my own health first.

On the Monday we went to the Albion Street Centre in Sydney and had another pregnancy test and spoke to a specialist who had dealt with HIV positive pregnancies before.

Much to my surprise the risk of transmitting the disease to my baby was as low as 15-25% and my health wouldn't be affected

either. We both had a look of relief on our faces. We did have a chance! Our baby had a chance!

We went through the pregnancy and had a beautiful blonde haired, blue-eyed little girl. It had been a challenging pregnancy. Nothing like morning sickness or anything, but nightmares and daydreams. I found myself getting scared as my due date approached. I had to keep reminding myself of the risk. I had to keep remembering that my baby was at possible risk of contracting HIV — it was not a certainty.

After she was born and I'd washed, the medical staff left us in the room by ourselves. The three of us. A family — a mummy, daddy and beautiful baby girl. My fiancée and I just watched her sleeping peacefully, held each other tight and cried. We'd had a daughter. A sign of life from a mother whose life is measured by the progression of a disease that may destroy her.

After we came home from hospital we did all the usual 'new mum' things and although it was hard work, it really did seem worth it.

I suppose out of all the sleepless nights, dirty nappies and everything, something I wasn't prepared for was my reaction to my baby's first blood test. She was so tiny, just one week old and I felt like I had to go with her into the room when they took her blood. It was horrible! Not the needle or anything clinical, but the way I felt. I was so riddled with guilt because she was crying and screaming and I knew that it was my fault she was going through this. It was my disease that they were checking for and I just wasn't coping with the situation at all.

Vinya was about six months old when it all happened again. I fell pregnant a second time and this time, although we were still not 100% sure of my daughter's HIV status, I felt a little more relaxed about being pregnant.

When it was confirmed that I was pregnant I found out that this time the risk of the baby being infected was less than with Vinya. All I had to do was to take AZT for a few months, have AZT during labour and give it to the baby for six weeks.

To be honest the thought of

taking AZT was a little hairy because I'd heard some stories about side affects, but it was all okay and earlier this year I was blessed with an amazing little boy.

As with Vinya, we went through all the tests. Sometimes both the children had them on the same day which was a challenge, but really it has been worth it.

I was lucky enough to have two beautiful children and it looks like neither of them have taken on the virus. They are happy healthy children and I am extremely proud of them. There is just one

more thing I have to do that I'm scared of and that is telling them about the virus.

One day I'll have to break my children's hearts and tell them that I am HIV positive.

How long do I wait? How old should they be? Or do I not tell them until I absolutely have to? When the disease gets to the stage where I can't hide it anymore?

Only time will tell. I'll grow with my children and my husband. As a family we'll get through. We'll always be together — HIV or not. ♦

Things to think about

Weighing your desire for a baby against the fear of the baby being HIV positive, against possible disapproval, perhaps against your own personal ethics, can be tough. Vivienne Munro devised a list of questions you may want to ask yourself and discuss with others, when deciding to become — or remain — pregnant.

- What are the reasons you do or do not want to have a child?
- There is a low chance of your baby being infected. Depending on which tests are available to you, you won't know your baby's status for up to 18 months after the baby's born (see p14). How will you feel during this time? How will you be able to cope? Who will be there to support you, both emotionally and physically? Will you have to look outside your circle of family and friends to find this support?
- What would you feel about yourself if the baby was infected? How would you feel towards the baby?
- You may tell yourself "Every woman has the right to be pregnant". If you decide to get pregnant or continue with a pregnancy, how will you cope with the attitudes and values of people who don't support your views?
- What if your family aren't educated about HIV and AIDS? Have you told them about your status?
- If your decision is not supported by family and friends, where will you get emotional and practical support?
- What hospital will you attend — will they ensure confidentiality?
- Do you have enough information to make an informed decision? Are you making a decision to please someone else, for example your doctor or family? Do you have enough information about which therapies to use or avoid? Can you access this information?
- Do you have access to health care providers who will support your decisions?
- If you are pregnant, the person who tested you (unless a home kit was used) will be the first to know. This person will have ideas of their own; they have the same feelings as you initially, or they may not. Do not be afraid to get a second opinion. Talk to your closest friend. If you are in a support group talk with other women who have been in a similar situation. Your local AIDS Council, they should be able to put you in touch with other people you can consult and get information from.
- Can you be flexible if new information becomes known? If you do choose to take treatments, what if your body can't handle it? Would you continue treatment? If you didn't take AZT, and your baby became HIV positive, would you blame yourself?
- If you become sick, hospitalised, or die, is there some one in your life who can care for and teach your child/ren about their culture, who would help your child remember you and raise him or her according to your values?
- Do you have the support and strength to carry out your decisions?
- Are you feeling good about yourself and really positive about the choice you have made?
- These decisions aren't just made overnight.

Positively Pregnant

Answers to common questions

Will my baby be born with HIV or AIDS?

There is a 75-92% chance that your baby will **not** be HIV positive. A number of studies have shown that there is a 12.9-25% chance (internationally) the baby will have HIV. These studies have indicated that in the US and developing countries the risk is closer to 30%, whereas in European countries it's closer to 13%. A recent trial of AZT (ACTG 076) has shown that use of this drug during pregnancy, labour and delivery can reduce the risk of transmission to as low as 8%. (See article p22)

A number of factors have been found to contribute to the likelihood of transmission from mother to baby. Babies are more likely to have HIV if their mothers had low T-cell counts and high p24 antigen levels; if the mother had other infections during pregnancy; if her viral load is high; and if there were complications during delivery, particularly premature rupture of the membranes.

Viral load seems to be the single most important factor. A recent study of 30 pregnant women found that the eight women whose babies became positive were those with the highest level of viral load. Vitamin A deficiency and premature birth (before 34 weeks) have also been associated with higher rates of HIV in infants. It appears that about 60% of HIV transmission occurs late in pregnancy or during labour. There is an increased risk of transmission if HIV is acquired during pregnancy.

There is no way of predicting, whether or not a baby is more likely to be infected.

How are newborn babies diagnosed?

All babies born to HIV positive women will have their mother's antibodies to HIV (newborns have their mother's antibodies to many infections). This does not mean they are infected with HIV themselves. These maternal antibodies remain in the baby for up to 18 months, and only then can a child be definitely diagnosed HIV positive or negative. However, clinical symptoms such as oral thrush, failure to thrive, bacterial infections etc. may indicate an HIV or AIDS diagnosis.

There are two tests which can indicate whether or not a child has HIV by the time they are six months old. In the viral culture test, pathologists try to grow virus from a sample of the baby's blood. If they can, it means the baby is almost certainly infected. The Polymerase Chain Reaction test (PCR) looks for the DNA of the virus. If it's found in the baby's blood, then the baby is probably infected, although there have been rare cases of false positives. Using these tests, a positive diagnosis can be made within four to six months. There is no test before birth which can indicate whether the unborn baby is infected.

It is very important that the baby be checked regularly (at least every six - twelve weeks) so as to maximise the possibility of early diagnosis and hence the prompt use of appropriate treatment.

Will pregnancy affect my health?

Pregnancy does not hasten the progression of HIV or adversely affect the health of + women. However there may be a slight, but not necessarily permanent deterioration of their immune system just after the baby is born.

Should I take medication for opportunistic illnesses (OIs)?

As OIs can both damage your health and increase the risk of your baby being infected, it's advisable to take prophylaxis and treat infections aggressively. Bactrim is recommended for PCP and toxoplasmosis and has no major effect on the foetus. There is no data on the use of Rifabutin during pregnancy but as MAC could have severe effects on a pregnancy, it may be advisable as MAC prophylaxis after the twelfth week. CMV should be treated with foscarnet or IV ganciclovir.

Handwashing, care around cat litter boxes and avoidance of raw or undercooked meats are effective precautions against CMV and Toxo, which could be devastating both for you and your foetus.

Do not take Zovirax, which is dangerous to the foetus.

What are the effects of recreational drugs?

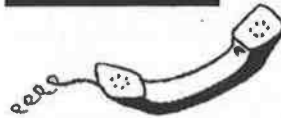
Various drugs (legal and illegal) can affect the development of the foetus. Some recreational drugs are associated with immune depression, lower birth rate, prematurity and increased risk of congenital birth defects. As a positive pregnant woman you may be at much greater risk from the effects of these drugs.

It's best to avoid alcohol completely. It's also advisable to stop using amphetamines or cocaine because of the damage they can do your own health and to the pregnancy. There's a lot of debate about marijuana but not a great deal of evidence about its effects on pregnancy. Moderate use is probably okay.

If you've been using heroin, don't stop using suddenly — it could cause miscarriage or prema-

CONTINUED ON PAGE 19 ➤

Contacts



AIDS Council of NSW (ACON)

Commonwealth St, Surry Hills (near Museum Train Station) 206 2000

COMMUNITY SUPPORT NETWORK (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.

CSN WESTERN SYDNEY Pat Kennedy 204 2404.

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

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. 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 women. Non-judgemental and completely confidential. Women and AIDS Project Officer or Women's HIV Support Officer, 206 2000, TTY 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.

GAY MEN FIGHTING AIDS A gay men's promotion project for men who live in the inner west. This volunteer driven project provides health education, advocacy and social support. A project of Central Sydney Area Health Service. Ring 519 5202 anytime.

GENDER CENTRE (THE) Services for people with gender issues. Counselling and support, outreach, information, accommodation. Provides referral to a range of specialist counselling, medical, HIV/AIDS, education, employment, legal, housing. (02) 569 2366.

KIDS WITH AIDS (KWAIDS) and parents of KWAIDS. 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. 810 1122.

METROPOLITAN COMMUNITY CHURCH (MCC) 638 3298. Sydney 332 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 515 3098.

NATIONAL AIDS/HIV COUNSELLORS ASSOCIATION 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 Uni) 805 8046.

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH AIDS (NAPWA) 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. 369 3455.

QUILT PROJECT Memorial project for those who have died of AIDS. 360 9422.

SEX WORKERS' OUTREACH PROJECT (SWOP) 319 4866.

SILK ROAD Social and support group for Asian gay and bisexual men. 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. Andrew Harvey 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

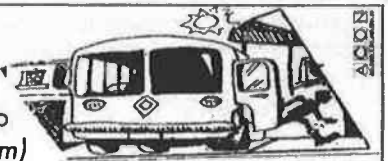
The Housing Project also has a number of houses and units available to clients who are waiting for public housing. You must be eligible for priority housing and in the process of applying

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)



Are you an HIV Positive Woman?



Screamline
1800 630 075 (Toll Free)

**You don't have to be alone
Talk to another Positive Woman**

ACON Mid North Coast

We offer support for PLWHA's alternative therapy subsidies; vitamin co-op; home based care & support; short-term accommodation; links to other PLWHA's; various health information

The branch also runs HIV prevention and safer sex education

93 High St, Coffs Harbour PH:
(066) 514 056



Sydney Sexual Health Centre

Sydney Hospital
Macquarie St
(near Martin Place Station)
for an appointment
or information
223 7066
for recorded information
11646
*no medicare card required

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
-Needle syringe exchange

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 environment.
We provide total confidentiality (medicare
cards are not required) and there is easy off
street parking.

182 Livingstone Rd, Marrickville
560 3057

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

SYDNEY PLWHA DAY CENTRE A safe space to relax among peers. Services include: delicious lunches Tue-Fri; massage; acupuncture; reiki; feldenkraus; international healing; shiatsu; yoga & meditation; child care facilities; library; sewing facilities; pool table. We also have access to a retreat throughout the year. All our services are free of charge. 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.

TROY LOVEGROVE FOUNDATION Provides financial assistance for children living with HIV/AIDS. Sam Corrie 018 290 889.

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.

KIRKTON 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, Wahrenghah. 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. 382 1653. Dental Clinic, Avoca 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.

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 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. 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 afectadas 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 Veterinary 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 Theories 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. 9.30am-1pm, M&F.

BLUE MOUNTAINS PLWA SUPPORT CENTRE Wed 11am-3pm (lunch) & Fri 6.30-10.30pm (dinner) (047) 82 2119 or Sue (047) 591611.

CSN BLUE MOUNTAINS Hands on practical help for people with HIV/AIDS. Pat Kennedy, (02) 204 2404.

HAWKESBURY SEXUAL HEALTH/HIV CLINIC 8 Ross, Windsor Tues 4-7. Appointments (045) 78 1622.

KARUNA BLUE MOUNTAINS Emotional support for PLWHA, their partners, family and friends. Ann (047) 82 2120.

NEPEAN HIV CLINIC Nepean Hospital Mon 3-8, Thurs 9-5. (047) 24 2507 for all appointments. Counselling & Support (047) 24 2598.

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 HIV/AIDS CLINICAL NURSE CONSULTANT (018) 47 9321

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
C. L A S H

Confidential group of HIV Positive heterosexuals

1 800 812 404



People Living With HIV/AIDS (NSW) Inc.

361 6011 Fax 360 3504

Post: PO Box 831, Darlinghurst NSW 2010
Office: Suite 5, Level 1, 94 Oxford St, Darlinghurst

ACCESS

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PO Box 473 Broadway NSW 2007
ph: 516 4772 fx: 330 3099
2SER FM 330 3000

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.

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)
Confidential support, advice & social
activities. Hydrotherapy & gym classes
Tues/Thurs. John (066) 51 2664 or Victor
(066) 51 6869 or Chris (066) 52 1658.

CLARENCE VALLEY PLWHA Support Group.
Peter (066) 46 2395.

CLINICAL NURSE CONSULTANT Karin Fisher
Providing service to barwon, Lower North
Coast, New England & North West (067)
66 9870, page 016 020 x 61 1476.

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
Dilossa. (066) 42 3333x229.

**GUNNDAH & DISTRICTS HIV/AIDS
SUPPORT EDUCATION GROUP** Elaine (067)
44 1212 or Val (067) 69 7522.

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 & treatment. (066) 20 2980.

**NEW ENGLAND NEEDLE EXCHANGE
PROGRAM** (067) 662 626 or 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.

**TAMWORTH & DISTRICTS HIV SUPPORT
NETWORK** A confidential meeting space for
PLWHA to get together for emotional &
practical support & share experiences. Karin
(067) 66 9870, page 016 020 x 61 1476.

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.

THE CLUB Social & Support group. Contact
Frank Velozzi (042) 26 1163.

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 & EUROBODALLA SHIRES-HIV/AIDS
WORKER** Jenni Somers, 018 604 180 for
free, confidential info, counselling & support
from Bateman's Bay to the Vic. border.

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.

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.

W E S T

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

**DUBBO/MUDGEES SEXUAL HEALTH/HIV
SERVICE** Robert Baldwin. HIV/STD Worker.
Community Health Centres Dubbo (068)
85 8937 & Mudgee (063) 72 6555.

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

Vacant

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

OUT WEST A social & support group for
gays & lesbians in western NSW. Grant
(068) 82 5033 or Paul (063) 72 4477.

ORANGE COMMUNITY HEALTH CENTRE
Shirley-Ann Bailey, Sexual health info,
referral and support. Central West HIV/
AIDS Task Force, contact Shirley-Ann (063)
62 6422.

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

... FROM PAGE 14

ture birth. Seek medical advice before you decide what to do. You can go on methadone to stabilise your drug use for the period of the pregnancy. Hanging out can be damaging to the developing foetus. HIV positive women often find that the functioning of their immune system improves on methadone. There is no known increase in the risk of transmission of HIV from mother to baby as a result of methadone use. There are no conclusive studies on the interaction of AZT or other antivirals and methadone.

The baby is likely to withdraw from methadone (or other drugs) after birth — but may not. Babies don't generally die from withdrawal, however, they may fit and that needs to be treated. Newborns will have to be admitted to a special care unit for observation and treatment if necessary. You can learn techniques such as baby massage to help calm your baby if it does withdraw.

If you are also Hepatitis B or C positive, you have a higher chance of transmitting this to your baby than you would if you were not HIV positive. If you've used IV drugs and don't know your Hep B or C status, it's a good idea to find out.

For more information you can call Jennifer Holmes at Drugs in Pregnancy, Camperdown: 515 7583 or the drugs in pregnancy social workers at King George V hospital on 515 7882. *NUAA News* # 19 has a feature on drugs and pregnancy which you may find useful, although it is not HIV specific.

Is there anything unusual about HIV positive pregnancies?

In the early years of the epidemic there were concerns that HIV infection would lead to higher rates of prematurity, low birth weight, premature rupture of the membrane or other poor pregnancy outcomes. It now appears that for asymptomatic women, this is not necessarily so.

HIV positive women appear to have a higher than normal inci-

dence of twins. In twin pregnancies, the first twin is more likely to be infected.

Should I have a vaginal or caesarean delivery?

Some studies (pre-ACTG 076) have shown a greater risk of transmission associated with vaginal delivery, however it is possible for transmission to occur during either form of delivery. Expert opinion has not reached consensus on which is best. Caesarean section has its own risks for the mother, regardless of HIV. Invasive procedures such as foetal scalp monitors should be avoided. Swabbing the vagina with a microbicide, and the use of AZT, may reduce the chances of infection during vaginal delivery.

Should I breastfeed my baby?

HIV has been found in breast-milk and cases of infection through breastfeeding have been documented. Breastfeeding is believed to account for 10 - 20% of maternal — infant infections. The World Health Organisation recommends that children in developing countries be breast-fed because bottle feeding can present greater risks than HIV in situations where water quality is suspect and it's difficult to sterilise feeding equipment. Bottle feeding is advised in developed countries.

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

Immunisation is strongly recommended, including measles, mumps and rubella. Avoid the live polio vaccine. A killed polio vaccine called Salk can be used instead. The vaccines' effects may be reduced in positive children who are therefore at risk of reinfection.

These questions and answers are updated from an article which appeared in Talkabout, Sept/Oct '91.

For more information, contact the Paediatric AIDS Unit at Prince of Wales Children's Hospital, 382 1653.



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Change of Heart

Michelle Morrison wrote a story for Talkabout a few years ago in which she explained why she had decided not to have any more children. Since then, she's had another baby. She told Jill Sergeant why.

Why did you change your mind about having another baby?

I didn't really change my mind — it was an accidental pregnancy. Steven and I had a long talk about the pregnancy, what it would mean. We actually got quite happy about it, after about three days of discussing what could happen, all the ifs and buts of a positive pregnancy. It's not just "congratulations, you're pregnant", you don't get that.

We rang up the doctor and told her we'd decided to go ahead and she demanded we come straight into the office to talk about it. I felt she was trying to convince me to have an abortion, which we didn't want. Then she turned on Steven and asked him how he was going to look after the baby. The whole thing was like I wasn't there. I was going to die in the next year, so I wasn't considered — Charlotte's two and four months now, and I'm still well.

Why did you decide against the abortion?

I'd always wanted another child, and it was like the decision was taken out of my hands in some respect because my tubes were blocked, no doctor would have unblocked them for me. It was a completely unexpected pregnancy, I'd been told by three or four doctors that I could not have any more children. Steven and I have a belief in God and we felt that if she'd managed to get through a blocked tube, then she was meant to be there, and she would be well

and healthy. I think that was how we came to the final decision to go on with the pregnancy.

How did the pregnancy go?

I had morning, afternoon and night sickness for nearly the whole nine months! Other than that I was really healthy, my T-cells flew up to something like 1500. I had Charlotte at the Women's Hospital in Paddington and the doctor there was really supportive.

The other thing was I was on morphine for the neuropathy in my legs — I reduced the morphine down as much as I could, without being in a lot of pain and stayed off my legs. We knew the baby was going to be born addicted, but we hoped it wouldn't be too bad an addiction, and because the doctors knew about it, she was monitored and I had several ultrasounds to make sure she was growing properly. But apart from that, it was a happy time. It was a glowing pregnancy I think, even though I was sick. Steven was great.

What kind of delivery did you have?

Great. I was a week overdue and because of the morphine, I just wanted her out, so I asked if they'd induce her. They gave me three more days, until Sunday — I went into labour on the Saturday night. I was really excited.

We went into hospital when the contractions were about

five minutes apart. The midwives were great. I told them I was HIV positive, and they didn't discriminate in any way.

Steven stayed with me the whole time. The pain was most intense in my legs and back. It was only a four hour labour. It was a totally natural labour, I felt so proud that I'd done it without any drugs. We'd planned a natural labour.

Had anyone suggested to you while you were pregnant that you should have a caesarean because you're positive?

It had been mentioned by the doctor I was seeing at first, and a couple of women suggested it. I asked the doctor and he said, no, there's no evidence about it, don't worry.

After Charlotte was born, she started withdrawing about eight hours after she was born. They thought she'd be okay, because I'd brought my morphine down, but it got to the point where I demanded they did because she was crying and trying to scratch and her arms were waving about, it was cruel to watch — so she went to the nursery. Because morphine is acidic, she had a rash, her bottom was actually raw — so all you could see of her was this little bottom poking out — she didn't have a nappy on.

I needed a lot of rest, it really took a lot out of me and in that respect I don't know if a natural birth was so good for me. It was good for my emotional well being but it might not have been so good for my health because it put a lot of stress on my body.

I remember saying to Steven, just after she was born, what have I done? And he said, look what you've done, she's beautiful, don't worry, she's healthy, she's fine. And after I'd watched her for a week I knew she would not be positive. I don't know why I knew, considering she was withdrawing, but I just felt it would be okay. I think that stemmed back to the fact that she shouldn't have been there in the first place — and apparently my tubes are still blocked.

We're now talking about having another one — I'd love another child, and because my T-cell count is still within the normal range and I'm probably not going to be dead two or three years down the track — in all probability I'll be here in ten years time — then I don't see why not. I guess I've got a belief that HIV doesn't always mean AIDS, and it doesn't always mean death.

In the original article you said that your main reason for deciding not to have another child was your own illness and that you were worried about not being around for your child in the future. That belief has obviously changed, — is illness still a factor?

It's still a factor, sometimes I sit and cry and think I'm not going to be here. But then, as Steven says, there's no guarantees on anybody's life — and there's not. I get sad and I cry, and I get on this self pity trip for a day, think, poor me! But Charlotte will never really lose me because she'll have memories. I'm actually writing a diary for her, I've been writing in it since she was born — there's three diaries now. I don't write in it every day, but what I put into it is the little things she's done and the little things she says, like she used to say her words backwards — shoes were ooshes. I've told her all the little things she does.

I constantly tell her now how much I love her. She's a very secure child. I think those diaries will keep me with her, whatever happens.

How has your health affected your ability to care for Charlotte? You have had her in respite care haven't you?

It's a private arrangement. You get very tired, sometimes the pain

in my legs is really intense and she's a very active child. She hasn't been going into care as much this year, it's more day care, which is good, it gives you a bit of a breather. The first year, yes, when she was waking up five or six times a night!

We found that Steven looking after me and looking after the house and looking after Charlotte

CONTINUED OVER PAGE ►



Michelle Morrison with Charlotte in utero

PHOTO: COLLABORATION OF KATHY TRIFFITT AND MICHELLE MORRISON.
COURTESY OF SELF IMAGING, SELF DOCUMENTATION ARCHIVE

was just impossible. We knew that this would be the case and we started looking around when I was about six months pregnant. Well, the situation is that DOCS offer you nothing except foster care, where the child's taken out of the home, but it wouldn't be with the same family, therefore she'd be shoved around. Centa-care could only offer a weekend a month — and you can't tell when you're going to get sick, so that was useless. Barnados were not in our area. So we arranged privately for this woman to look after Charlotte.

That puts you in a really dangerous situation, because that person can keep the children. Anybody can take your child, if they are minding them and they have them overnight, they can say they're not giving them back. The police are powerless to act, welfare can't act, so it's got to go through the court. You end up feeling useless, and it hurts the child a lot.

It's my tiredness that's the problem. I'm going to try acupuncture and natural therapies to control my pain, and hopefully I won't be as tired any more [from the medication], and Charlotte won't need to go into care any more. I've just found out that CSN can help, they can mind Charlotte for a few hours.

There's a lot positive things about having a child. I think she keeps me alive. She keeps me happy, healthy. My lifestyle used to be totally different to what it is now, and it is Charlotte who has changed that. Because she's so beautiful I don't want any harm to come to her. She's going to have to see the bad side of life but I don't want her seeing it in her home. She's made a great deal of difference to our life in that respect. There's that advantage to having children. You've got to be happy when you have children — because they're happy people. ♦

AZT — or not?

Now that AZT has been shown to reduce mother to child transmission of HIV, should it become the standard of care for pregnant women? Definitely not, says Vivienne Munro.

ACTG 076, A SMALL TRIAL WHICH was conducted by the US National Institute of Allergies and Infectious Diseases (NIAID), in collaboration with two French research organisations and the US National Institute of Child Health and Human Development, proposes that the HIV transmission rate from mother to child can be reduced by the use of AZT to as low as 8%.

Trial participants were HIV positive women who had received no antiretroviral treatment in the current pregnancy and had baseline CD4 counts between 200 - 500. They were up to 14-34 weeks pregnant. (The entry criteria were amended later to include women with CD4 (T-cell) counts above 500 as women were not being recruited fast enough. One woman was said to have 1,800 CD4 cells. US standard of care at the time of the trial was to use AZT only in people with CD4s under 500).

Women were given 100 mgs of AZT five times daily during the course of their pregnancy, a loading dose (intravenously) during labour, and newborns were given an oral dose starting from up to eight hours after birth, until six weeks old. 477 women were enrolled in this trial, of which 409 were eligible for analysis. They were randomised into a control arm containing a placebo (183) and an active drug arm containing AZT(180). Newborn infants born to women on the placebo also received the placebo; those born to women on AZT also received AZT.

421 infants were born and 364 had at least one HIV culture result available. Of these, 53 infants had HIV infection. Of these 53,

13 received AZT and 40 received a placebo. At 18 months of age, 8.3% of AZT treated infants were infected, compared with 25.5% of placebo recipients, representing a 68%, or two thirds, reduction in transmission. This result brought about premature termination of the trial.

Why was the vertical rate of transmission in the placebo group higher than normal, at 25.5%? The vertical transmission rate is internationally accepted as 12 - 20% and it is universally agreed that if a woman is young and has a relatively healthy immune function, then the chance of vertical transmission is more likely to be around 12%. The women on this trial fit the bill with an average age of 25 and an average CD4 count of 586, (59% had a CD4 count greater than 500).

It is still unclear when vertical transmission occurs and the relevance of other factors such as p24 antigen levels, placental membrane inflammation, exposure to maternal blood, premature delivery and breastfeeding. These factors need to be taken into account when looking at the likelihood of vertical transmission, whether a woman is on AZT or not. They should also be taken into account when the trial results are used as an argument for pregnant women to be taking AZT. Because AZT was given during pregnancy, birth and to newborns, the trial does not show at what point it is most likely to interrupt transmission.

As well, as Linda Meredith and Maxine Wolfe have pointed out in *World*, "since 80% of children born to infected mothers will never be positive themselves these

children get a toxic drug they don't need and which could be harmful".

NIAID has reported that no congenital anomalies (which also occurred in the control arm) were believed to be related to AZT and that the drug seemed to be tolerated well. Side effects consisted of transient anaemia in both mothers and infants. Forty six infants stopped treatment 'before six weeks (22 because of toxic effects). It seems that although an equal number of infected infants (seven) died on both arms of the trial, these deaths were attributed to serious congenital anomalies present at birth, rapid progression of HIV disease and liver failure.

Michelle Murrain, Ph.D, a neurobiologist and AIDS researcher, believes it's inappropriate to give a pregnant woman — and therefore her foetus — AZT. She told *Poz* magazine "AZT has the effect of slowing down cell replication, particularly in cells that are rapidly reproducing, such as in a developing foetus. If the rate of cell replication is interrupted, it's possible that complex processes, such as cognitive abilities, could be adversely affected." Some HIV positive women on ACTG 076 were taking AZT during the second trimester, which is, as Murrain told *Poz*, a critical growth period for the foetus.

Also in *Poz*, trial participant Gina "worries about the long term affects . . . on her three year old HIV negative son Juan, who is in a follow up study. . . . although he is perfectly healthy his main arteries are double the normal size. . . . while driving with some women on the way to an AIDS meeting, one of them . . . started talking about how she knew of babies born during 076 that had died from enlarged arteries. Gina burst into tears immediately 'I told them that I have such a child! What do the doctors know that I don't?'"

It is not known if the infants on the trial have become resistant

to AZT. Nor does the study provide any information on any later effects of AZT on the infants, whether or not they were infected with HIV. Nor can it indicate the usefulness of AZT as a future treatment for the infants on the trial. NIAID has said that "general recommendations regarding treatment await consensus on the balance between known benefit and known risk". But what exactly does that mean?

Dr Joseph Saba from World Health Organisation Global Program on AIDS has said in *The Lancet* that "ACTG 076 has shown that the concept of reduc-

"No matter whom you speak to, the results of this trial have been accepted as gospel, despite the fact that it was halted before completion and its findings are questionable."

ing mother to child transmission of HIV by use of antiretrovirals is valid where appropriate resources for diagnosis, intervention and follow up are available. However cost and logistical issues are prohibitive of using an ACT 076 regime in many developing countries. Moreover, a particular issue not addressed in 076, is the role of breastfeeding in mother to child transmission. Therefore, no universal recommendations regarding the use of AZT to prevent mother to child transmission of HIV can be made on the basis of ACTG 076 study results."

Saba goes on to say that it is essential to explore simpler and less costly drug regimens which could be suitable for all HIV infected pregnant women and to put the future use of antiretrovirals into perspective by acknowledging that the main mechanism by which AZT may

reduce the mother to child transmission rate is by decreasing the mother's viral load. Therefore most antiretrovirals which decrease the viral load may potentially prevent mother to child transmission.

There has been heavy criticism of the ACTG 076 trial's design, implementation and completion and major controversy is raging over the use of AZT in the United States. Just one example: the trial hypothesis was that AZT given to women during pregnancy would lower the amount of HIV present in maternal blood and therefore, decrease transmission. Yet, neither the original NIAID press release nor the eventual paper that was published in the *New England Journal*, mention any analysis of this.

The trial results are affecting the recommendations for treatment, testing and monitoring of the virus here in Australia. But there are many lingering questions that need to be answered before recommendations for treatment can be made. AZT has never been trialed specifically on women and when women have recently been accepted onto trials, no women specific data has been collected. Anecdotally, we already know it affects the menstrual cycle. We know from trials conducted on men that resistance develops quickly, and that no benefit can be used by taking it earlier rather than later. AZT is currently available to all HIV positive women, including pregnant women, under the same guidelines as men.

Recommendations from this trial are that all pregnant women with CD4s above 200 should use AZT. Since over half of the 076 trial participants had counts above 500 and AZT is recommended for use generally for PLWHA with CD4s no greater than 500, it is scientifically unsound to make this recommendation, and goes outside the standard of care guidelines.

As well, pregnant women who are in earlier stages of HIV disease may develop resistance and not be able to use it later for their own health.

We should not be coerced into treatment regimes, particularly with AZT, when it has been shown (in trial ACTG 152) to be ineffective and unsafe when taken by HIV positive children.

Perinatal guidelines on AZT use are being implemented by the CDC in the US. AZT is not registered for use in pregnant women in Australia, however it is given to them, using the 076 model. Anecdotally, I've heard that women who choose not to take AZT are being given the impression that they are irresponsible mothers.

Michelle Good, Clinical Nurse Consultant at the Paediatric AIDS Unit (PAU), says that although pregnant women are primarily being seen by their private doctor or obstetrician, the PAU do recommend and offer AZT. Since the 076 trial, all women in their care have used AZT. The PAU is aware of the limitations of the trial, and while mindful that all criticisms of the trial are anecdotal, are keeping their minds open. So far they've had good results, with reversible anaemia the only side effect.

Current information casts doubt on the usefulness of encouraging all pregnant women to take this potentially toxic drug. A recently published study presented at the Women and HIV Infection Conference in Washing-

ton, D.C., showed a direct correlation between Vitamin A deficiency and rates of vertical transmission. "Positive women deficient in Vitamin A transmitted HIV at a rate of 32.5%. With higher levels of Vitamin A, transmission rates were only 7.2%", reported *World*.

It's also becoming apparent that viral load may be the most important factor in vertical transmission rates, regardless of the use of AZT. *Treatment Issues* reports on a recent study which found that "researchers could predict which pregnant women infected with HIV were most likely to give birth to infected babies. Women with high viral load in their blood were 75% likely to pass on the infection to the child, whereas women with low viral blood levels had only 3% chance of infecting their babies." Since maternal viral load has been shown to be stable during pregnancy, women could have this test and decide whether to take AZT based on viral load. Significantly, in this study, three mothers with high viral load transmitted HIV to their children, despite the fact that they were taking AZT, and one of these women had participated in 076.

In America the call for mandatory testing followed immediately after the results of 076 were published, on the presumption that eligible positive pregnant women should then go on AZT. In Australia, there have been repeated calls, both before and since ACTG 076, by Dr John Kaldor

(NCHER) and Dr Zeigler (PAU), for 'sentinal testing' of pregnant women (ie. anonymous testing of large groups with test results not linked to individuals tested.) These calls have been strongly resisted by ACON and AFAO. No matter whom you speak to, the results of this trial have been accepted as gospel, despite the fact that it was halted before completion and its findings are questionable.

Difficult access to viral load testing, lack of understanding of vitamin A deficiency and the need for a more comprehensive AZT trial are all factors that complicate already difficult decisions. It is important that positive women aren't caught up in the argument to stop transmission at all costs, and that these results are not translated into a standard of care both in testing and treatment guidelines.

Until we have much more sound information and follow up results from the trial, service providers should inform women, provide options and help them make decisions. They should not pressure women to take AZT. HIV positive women should talk to other women who have had to make similar decisions. Get as much written information as possible. Have a second opinion from another specialist or doctor. We all have the right to make an informed decision on our health and our pregnancy.

Vivienne Munro is Women's HIV Support Officer at ACON.



St Vincents Hospital

Relationships Australia

(NSW)

Relationships... Who needs them?

We all do. And whether its our lover, partner, friends, parents, sisters or children, HIV can affect how our significant relationships work

The HIV/AIDS Couple & Family Project is a free and confidential relationship counselling service for anybody with HIV and partners/carers, friends and family.

For information or an appointment phone 361-2213.



EXPRESSIONS OF INTEREST Health Promotion Conference

8 - 10 November 1995

Sydney NSW

If you are a plwha on a low income and would like to attend the upcoming Health Promotion Conference, the NSW Health Department has sponsored 20 places to the conference. Preference will be given to plwha who can prove they would use this experience to benefit their community. Expressions of interest must be made by 12pm Monday 6 November 1995. Ring Ryan on 361 6011.

HIV Support? *Just do it!*

Hi there, says Scott Berry, the new HIV Support Worker at ACON's Support Project. Scott, who is in his fifth year of living with HIV, reckons you can only benefit from going to an HIV support group.

WHEN I LEARNT ABOUT MY diagnosis I felt terribly alone. I really didn't know what to do (they don't teach you how to live with a life threatening illness in school). Pretty soon I found my way into an HIV Support Group here at ACON. It was a valuable experience. I met others who had been recently diagnosed and I met positive people who had been living with HIV/AIDS for many years. I learnt that I *could really live with HIV!* I was able to laugh, cry and express my anger about being HIV positive. I went from feeling completely powerless over HIV and out of control to a sense of having some control over my life.

The positive people in my group didn't seem depressed by my struggles. They seemed to be heartened and offered their own stories and experiences. Hearing their stories lightened the feeling of heaviness I'd been carrying since the day of my diagnosis. I didn't feel so alone anymore. I stopped feeling like the only one. There were some times in the group when the energy was great! We were all expressing strong feelings and opinions about issues, disagreeing and agreeing on all sorts of things.

I was able to gather a load of information about HIV-friendly GPs, dentists, treatments and lots of other stuff. I learnt where to get help with emotional, legal and financial matters related to HIV. I made friends with several of the group participants and continue to meet with some of them for coffee even now.

Pretty soon after finishing the group I decided to spend some time in London, where I worked

as a peer supporter with Body Positive on several of their programs.

I have learnt through this work that I can live with HIV. That doesn't mean that I don't get sick or feel terrible sometimes, but if I can be open to all my feelings about it I not only feel better about myself but feel I have something valuable to offer other HIV positive people. And that's what peer support is all about!

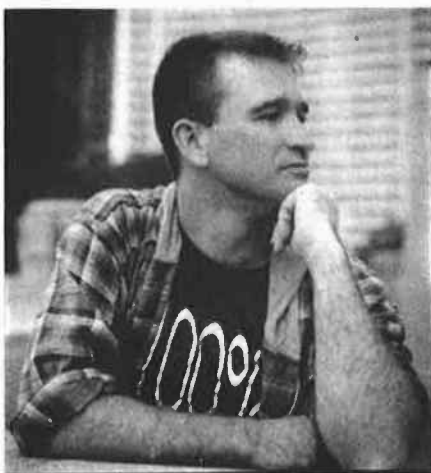


PHOTO: JAMIE DUNBAR

As HIV positive people our stories are extremely important to each other. We all know the pain we've experienced living with HIV/AIDS and, whilst we are all individuals, there are common themes and similarities in our experiences. We've had to learn how to live with life threatening illness, but the important element is that we can come together and find real community with each other.

Some of us are forced to find our way in isolation. This only adds to an already alienating and lonely experience. Those of us who have been lucky enough to meet up with other positive people generally find that we feel less

alone when we share our experiences, feelings and thoughts. This can be confronting and difficult at first. Fears of being criticised or humiliated can be strong. It can feel difficult to be in a room full of HIV Positive people. If we find ourselves in a group where we feel safe there can be great benefit in facing our fear. We learn from the lives of others and feel how valuable it is to hear their stories. We find that some people learn from us - that our stories and our struggles can be significant in supporting others with HIV.

The HIV Support Project is concerned with helping us find valuable meaning out of living with HIV. You can come along and do a support group and there you'll make friends, feel heard and understood and have the opportunity to hear and support other positive people. If you want, you can also undertake a Facilitator Training Course where you'll learn lots about basic counselling skills, group work and important issues in HIV/AIDS. You will then be a part of our facilitator community and your voice will help direct the future of the project. As a facilitator you'll work in groups of HIV positive people where you can offer your experience and support, you'll work with other HIV positive facilitators and make new friends.

My experience with peer support has helped me change my attitude to HIV/AIDS. I have something to offer and so do you! Our lives don't have to be meaningless and empty because of HIV. We can share ourselves and we can support each other.

I don't feel like a victim anymore!

If you want to join the HIV Support Project please call me on 206 2014. Let's get together for coffee and a chat. ♦

African Stories

AIDS has not yet abated in Africa and infection rates have soared to one third of the sexually active population in some areas. Susan Paxton, who visited the continent recently, reports on how African women are dealing with this challenge.

SADLY, AIDS IS BUT ONE MORE incredible challenge that African people face, along with drought and economic readjustments, which result in inflation and poverty and leave people deprived of basic human rights such as medical care, primary education, adequate diet, gainful employment, decent housing and sometimes their dignity.

Much of the hardship Africans face is because of their country's indebtedness to first world countries. \$75 billion dollars is removed from developing countries each year by richer 'developed' countries as interest on debt repayment. If ever there is a cure for AIDS, Africa will not be able to afford it.

Frances

There are thousands upon thousands of AIDS orphans in the rural areas around Masaka, one hundred kilometres from Kampala, Uganda. It is a part of the world most heavily affected by AIDS. The school Frances attends has a population of 150 children. However there are over 400 orphaned children in the area who have applied to go to the school free. The school obviously cannot afford to 'carry' so many non paying students, so the large majority do not attend and are denied the most basic education.

Frances has been twice orphaned. Her mother died of an AIDS related illness in 1992. At the time her mother's younger sister adopted Frances as her own daughter. Last year her aunt also

died of an AIDS related illness. Her two other aunts are unable to look after her. One is currently very ill, probably HIV positive, and the other is still at school herself.

Her father, like many other African fathers, has not taken on the responsibility of care and has not been heard of for some time. Her grandmother, a Tutsi refugee from Rwanda thirty years ago, recently drove her fifty head of cattle back there because her son began selling her cows off behind her back. Fortunately Frances has a sympathetic great uncle who has taken her in, along with his own five children. The uncle's wife died of an AIDS related illness four years ago.

Many people in Uganda have given up on HIV prevention, and do not see AIDS as something that can be avoided. Surprisingly, many others still do not believe AIDS is on their doorstep, even though almost everybody has now lost a family member or friend because of AIDS.

So what are nine year old Frances's chances of remaining HIV free in the future?

Uganda is heavily Catholic. The church's attitude is disapproving of condom use and as the schools reflect the church's attitude they do not teach condom use in schools. Many young people in rural areas are not introduced to them before they become sexually active (if then). For most people condoms are too expensive at half a day's pay for a farm hand. Because of the inferior quality of

condoms (in some areas they are washed and recycled), many people doubt their safety. The message taught in schools is to remain celibate until marriage and then have only one partner.

Communication is poor in Uganda. Roads are some of the worst in Africa and news takes a long time to travel. Telephones are non existent or rarely work. People still listen to the radio but public AIDS education campaigns are now focused on care for positive people and the only prevention initiatives are carried out by overseas aid donors.

One in three new daily HIV infections occur in women under the age of twenty. Most of these young women have no choice in their sexuality. Many are lured into sexual relationships with older men in return for the payment of school fees and the hope of a better life. For Ugandan women the only possibility of attaining any status in society is to marry and produce children. They traditionally do not inherit land and if their husband dies, as in the case of Frances's grandmother, the son(s) can sell off the land his mother uses to grow her subsistence crops without her consent.

For Ugandan women the only feasible HIV prevention is economic autonomy: by obtaining an education and gaining employment or becoming self-sufficient. Frances is lucky that she is still at school. Education is relatively expensive, and when choices are made as to which children in a family will go to school, young women often lose out.

It seems like Frances's hope for survival currently rests with her uncle. If he manages to live long enough for her to finish her education she may have a chance.

Jean

Jean lives in a minuscule two bedroom house in a squalid suburb of Kampala. It is clean and tidy but very cramped with seven people living there. Her husband died almost ten years ago. She has three children of her own and also cares for her three orphaned brothers and sisters who would otherwise remain in the rural areas uneducated.

Jean is a big, jolly woman who envelopes one. She is a rarity in Africa. Not only does she know her HIV status, she has managed to retain a positive approach to her life. She looks so healthy that people don't believe she is HIV positive. But she does get tired, and she worries what will happen to all her dependants if she does get sick or die. Often people with curable conditions are denied treatment in Uganda because medical staff believe there is nothing that can be done. Fortunately for Jean she lives in the 'big city' where attitudes are more enlightened over ten years into the epidemic.

Jean is luckier than many other women because she has a job. She works as a nursing aide for TASO, The AIDS Support Organisation. TASO was one of the first community based AIDS organisations to be established in Africa. Set up by people infected or affected by AIDS, it now has branches in most major centres, and is one of the very few organisations which has a commitment to providing counselling services to people with HIV/AIDS. It also provides medical services at the drop in centres, and has a positive people's speakers bureau which sends members out to schools, workplaces and community groups.

Although Uganda's economy has improved enormously over the past eight years, this has not translated into improved living conditions for most people who are suffering increasing hardship.

"WE HAVE LEARNED THAT 'JUST SAY NO' AND 'USE CONDOMS' campaigns do not work because sexual behaviour does not occur in a vacuum but in a social environment . . . we must improve the social environment . . . prevention has no credibility unless positive people have access to counselling and care . . . discrimination and stigma are still the daily lot of positive people."

— Peter Piot, UN Programme on AIDS, GNP+ Conference, Capetown, March 1995



TASO Drama and Theatre Group rehearsal.

PHOTO: MICHAEL JENSEN

Because of economic structural readjustments imposed by the World Bank, inflation is rife. High taxes have been introduced, even for *matoke* — the staple food, green bananas. The middle classes have been squeezed out and there are either the very poor or the very rich.

Jean brings home 70,000 shillings (about \$100) per month. School fees are 30,000 shillings (approx. \$40) per child per term. Jean is determined to give her own children and her siblings the opportunity of an education, but sending them to school costs over

two and a half months salary each term. She lives in a never ending cycle of debt, borrowing from her employer to pay school fees in advance and then working to pay back her debts. Sometimes she and the children go hungry so that she can afford the school fees, but Jean chooses to make such sacrifices as she sees no other way out of the poverty trap.

With Uganda's unemployment rate soaring, it's a gamble that any of Jean's children or siblings will actually find a job, despite the enormous sacrifices Jean has made to educate them. ♦

Information is power!



Give some of your time and become a volunteer on the ACON Information Team.

The team provides information both over the phone and in person regarding HIV/AIDS services to people contacting ACON.

If you want to help the community, meet new people and learn lots of new skills, we would love to have you on our dynamic new team.

Call Janet on 206 2024 or Paul on 206 2023.



AIDS Council of New South Wales Inc.

PLWH/A Annual General Meeting

Members are advised that the PLWH/A Inc. (NSW) Annual General Meeting will take place

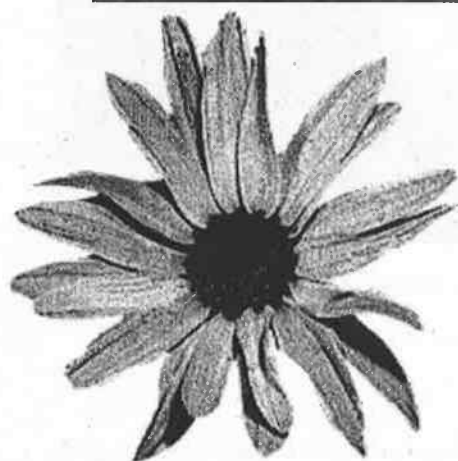
on: **Tuesday November 28 at 7.00pm**

at: **Pride Centre
26 Hutchinson Street
Surry Hills**

Only full financial members are eligible to vote at the AGM. If you wish to renew your membership or join PLWH/A, please telephone the PLWH/A office on 361 6011 or do so at the AGM.

Under the PLWH/A Inc. (NSW) constitution, we have two classes of membership - *full membership* for people with HIV/AIDS and *associate membership* for partners, friends, family members and others directly involved in care and support for people with HIV/AIDS.

Only full members of PLWH/A Inc. (NSW) are eligible to vote for the majority of places on the PLWH/A Committee (9 of the 11 places are reserved for people with HIV; up to 2 places may be filled by associate members).



POSITIVE RETREAT No. 7

Come along to a stress free country location where you can try complementary therapies, enjoy nature, meet other positive people in a relaxed environment, learn about some of the complementary therapies on offer, do yoga, meditation, acupuncture, homoeopathy, reiki and others.

The retreat will be alcohol and recreational drug free.

This retreat will be held from Saturday 2 to Wednesday 6 December 1995.

An investment of \$40 unwaged and \$100 waged is the cost of the retreat.

For more details, and to obtain an application form, call 019 98 25 25,

Monday to Friday, 10am to 6pm.

HIV
living

A joint initiative of HIV Living and PLWH/A (NSW) Inc.



Beyond Prognosis



We are the key

Living with HIV is a hard road to travel. But, says Phillip, we can take courage from the strength within us.

THE VIEW FROM MY WINDOW WAS bleak and unattractive. I kept asking myself how did this happen? How did I let them do this to me? I should be home but instead I felt like a prisoner. Outside I imagined everyone else catching up with friends and going to parties. It was New Year's Eve 1983. From my room in St Vincent's Hospital all I could do was contemplate a quick escape.

I had returned home to Sydney from working overseas. No sooner had I settled back in when I became ill, very ill. It came on hard and sudden. Similar to a bad flu, it clogged my head and choked my lungs, I couldn't move. I ended up at St Vincent's casualty and that's where things went out of control. My sexuality was more important than my sickness. I was expected to tell them about my sex life when all I wanted to do was tell them where it hurt. I was confused, sick, embarrassed and humiliated.

I had no idea what was really happening or what was being set in place for my future. As it happens I did escape the next day, but that episode, I later learnt, was my seroconversion to HIV. For some years to come I remained confused, was frequently sick, embarrassed and humiliated myself more times than I deserved. The 'good' news was that it would all be over for me in about

four years, give or take a bit. How or why it would be over was a mystery to me. I was in my twenties, fiercely independent, successful in my career and had a great lifestyle. I wasn't about to give this up so easily.

I learnt my first lesson quickly. Be sceptical of those offering profoundly morbid news. In this case at this time it was my doctors.

I look back at that time and shiver at the thought of how people were treated in such a frantic manner, born out of ignorance of what they were dealing with. I didn't view myself as different, although I have had to make a big difference to myself now. Over the years I have lost my career, live very simply, almost boringly but I have found something greater. I found myself.

When the virus started making its presence felt I had nothing of substance to throw back at it. I had to forget early medical intervention as I am intolerant of AZT. I had been so preoccupied with my career I never developed any sense of my own self. My identity was all tied up in what I did at work and the material things I had. Here was a thing that knew me and lived with me more intimately than I knew myself. The bottom line was coming, I had to make a choice — fight this thing or give up.

It is a hard road littered with tears and despair but I now know who I am and that the virus is only one part of me. I believe that to do combat with this thing we have to grow. In my case I had to make contact with people who were prepared to share my thoughts and concerns. Don't be afraid to take comfort from people when it is genuinely offered and keep clear of insincerity and ignorance. Our fight is not to change others but to keep living. Seek out acceptance, as for every set of closed arms there are many more open loving ones ready to embrace us. Above all be content in yourself. After all, we have done nothing wrong, why should we beat ourselves up? Give yourself time. Time to work yourself out. All the gifts that others share with you are still secondary to your own inner strength.

Today you hear of many people continuing to live. This is a powerful statement in the fight against AIDS. I believe that we are the key. The strength and will is inside us, we have to nurture this to meet the challenges asked of us. I am happy that I asked for help and chose to fight.

There is no denying that the virus is a powerful enemy but without possession of your heart, your mind or your spirit I believe it is kept at a serious disadvantage.

Beyond Prognosis is an occasional column where readers who identify as long term survivors of HIV/AIDS can share their experiences and insights.

Off your face & on your back

- how to get the best from your drugs.
- avoiding the side-effects of recreational drugs.
- do party drugs speed-up progression to AIDS?
- there's more to sex than HIV when you're positive, like having hot sex and avoiding other sexually transmitted infections.
- negotiating sex and negotiated safety, who to disclose to, when to disclose, do I need to disclose at all?

All this and more will be addressed in this workshop. The next one will be held in mid December. This workshop is only for people with HIV/AIDS accompanied by a partner, carer or friend. The number of participants is limited. So to book a place or find out more call Stephen 206-2011

Immune power workshops

- find out more about how remarkable the immune system really is.
- get more information about the pros and cons of treatment options.
- what about complementary therapies, nutrition and vitamins?
- how do meditation and stress reduction techniques help boost well-being?

All this and more will be addressed in this workshop. The next one will be held in mid December. This workshop is only for people with HIV/AIDS accompanied by a partner, carer or friend. The number of participants is limited. So to book a place or find out more call Stephen 206-2011

HIV and Living go hand in hand.
These workshops are brought to you
by HIV positive people
for HIV positive people.



AIDS Council of NSW
9 Commonwealth Street
Surry Hills



Thank You!

PLWHA Inc (NSW) once again staffed the PLWHA Time-Out Rooms for Sleaze 95.

The room ran very smoothly and it's now time to say a few thank you's as this activity could not happen without the cooperation of a number of organisations and the volunteer labour of lots of people.

Once again ACON continued it's support for this activity by making some of their couches available. Mardi Gras has always provided innumerable and invaluable assistance. This year Mardi Gras provided both the drinks and the food that was available. As there was no budget for the food the members of the Mardi Gras Board paid for this expense.

The following are the people who assisted in one form or other to make the rooms work on the night.

Diana, Shane Parkinson, Juliet Dewar, Rik Gebalski, Andrew Darling, Robert Orr, Michael Lawrence, Bill Rigney, Julie Bates, Chris Hordern, Paul Roberts, John Trigg, Jill Sergeant, Garry Dawson, Mark Peterson, Rodney Cambridge, RAS, Kathy Pavlich, Ian MacMillan, SGLMG staff, board and volunteers, Nicola Addison, Gina's in the Raw, Paul Canning, Bill Evans, Andrew Thomas Clark, Andy Pearce, Michael McDougall, David Edler, Blair Silverlock, Eric Sleight, Lou Glover, Gerald Lawrence, Malcolm Thorne, Paul Maudlin, Nick, Andy Lloyd, Peter Binning, Victoria Uriarte, Bo Vilan, Ryan McGlaughlin, Claude Fabian, Bev Lange, Sirius Transport, and anyone else we have left off this list!

On behalf of the Committee, Staff and members of PLWHA Inc (NSW) THANK YOU. We hope you had a good time, see you at Mardi Gras!

Talkabout

WHERE WE SPEAK FOR OURSELVES

Join PLWH/A in the fight against AIDS! Subscribe now!

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

PLWH/A membership

Yes! I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year as a:

- ☐ Full member (NSW resident with HIV/AIDS)
- ☐ Associate member (NSW residents affected by HIV/AIDS)

Disclosure of HIV status entitles you to full membership of PLWH/A, with the right to vote for all management committee positions. Membership status is strictly confidential.

Talkabout annual subscription rates

Please note that *Talkabout* subscribers also receive *With Complements* Newsletter eight times a year for no extra charge!

Individuals

- ☐ I am a member of PLWH/A Inc. (NSW) \$13 per year
- ☐ I am not a member of PLWH/A Inc. (NSW) and/or I live outside NSW \$30 per year
- ☐ I am receiving benefits and living in New South Wales FREE
- ☐ I am an individual living overseas A\$70 per year

Organisations

- ☐ Full (business, government, universities, hospitals, schools etc.) \$80 per year
 - ☐ (Extra copies \$30 each per year)
- ☐ Concession (PLWHA organisations, non-funded community based groups etc.) \$40 per year
 - ☐ (Extra copies \$15 each per year)
- ☐ Overseas A\$120 per year
 - ☐ (Extra Copies A\$40 each per year)

(Please specify number of extra copies _____)

Donations

Yes! I want to make a donation to *Talkabout*:

- ☐ \$100 ☐ \$50 ☐ \$20 ☐ \$10 ☐ Other amount \$ _____

Total amount forwarded: \$ _____ (include membership fee, if applicable, and fees for extra copies)

Method of payment:

- ☐ Cash ☐ Cheque ☐ Credit card
- ☐ Mastercard ☐ Visa ☐ Bankcard Card # _____

Expiry date _____ Signature _____ Date _____

Make all cheques payable to PLWHA Inc. (NSW), we'll send you a receipt (donations \$2 and over are tax deductible).

Please note that the *Talkabout* database is totally confidential ☺ Rates are negotiable — talk to us

➔ Special note for overseas subscribers: talk to us about exchanges with your publications.

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Please forward this completed form to:

Subscriptions, *Talkabout*, PO Box 831, Darlinghurst NSW 2010.

Thank you!



the time has come to say thank you

On December 1, the NSW World AIDS Day Project will acknowledge the efforts of those in the community who work tirelessly and often anonymously in the battle against HIV/AIDS.

**This inaugural event will take place at
The Paddington Town Hall,
by invitation only.**

Brochures explaining categories, nomination and invitation criteria are available from Aussie Boys, The Bookshop - Newtown and Darlinghurst, Oggi Haircutters and Greed Sisters Emporium.

For more information contact:

**Michael Reid
NSW World AIDS Day Coordinator
Ph: (02) 588 6777 Fx: (02) 588 7666**

**Sue Clark
Quilt Education Officer
World AIDS Day project
Ph: (02) 331 4758 Fx: (02) 331 7628**

**The World AIDS Day Project NSW is funded by the AIDS and Infectious Diseases
Branch of the New South Wales Department of Health**