

The Magazine of People Living With HIV/AIDS NSW Inc.

No.111 November 2000

Talkabout

◆ Where We Speak for Ourselves ◆

you've come a long way

baby

WOMEN LIVING WITH HIV

Positive Heterosexuals

says thank you to its **Women's Team 2000**

who in countless ways with their skills and goodwill

made the Pozhet Calendar of Events such a success



Working with women living heterosexually with HIV/AIDS

Front row L to R: *Lisa Ryan* (Women, HIV and Sexual Health Project FPA Health), *Marie Lavis* (Pozhetwest Coordinator), *Margaret Mines* (Tree of Hope Coordinator), *Irene Coonan* (NSW Midwives Association), *Martina Zangger and baby Lucie* (Youth Outreach SVH Campus), *Maria Petrohilos* (Multicultural HIV/AIDS Service CSAHS)

Back row L to R: *Denise Cummins* (Community CNC HIV/AIDS CSAHS), *Betty Ramsey* (Darlinghurst Community Health Centre), *Kate Griew* (midwife and masseuse), *Diane McCombe* (voice and sound healer), *Patricia Austin* (senior clinical psychologist)

Also on the Women's Team 2000: *Evelyn Argall* (physiotherapist), *Mandy Blacklock* (beauty therapist), *Kirsty Ferrari* (beauty therapist), *Jan Grant* (reflexologist), *Deidre Griffiths* (Volunteer Manager Sacred Heart Hospice), *Jane Kirton* (training consultant), *Toni Ludgate* (reiki), *Miranda Shaw* (Women, HIV and Sexual Health Project FPA Health), *Jan Smallwood* (Vocational Counsellor TAFE NSW), *Gina Svolos* (Executive Officer SIDS), *Renata Mueller* (psychic reader)

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thanks!

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FROM THE PUBLICATIONS WORKING GROUP

It is generally accepted that positive women are less likely to be connected to positive communities and more likely to live in social or geographic isolation. Social isolation will influence how and which services we use, how we make decisions about our health, who we tell and talk to about living with HIV. These themes run through the stories published in this issue of *Talkabout*.

Our knowledge comes from experience, anecdote, and research such as the *HIV Futures* surveys. The 89 women who responded to the second *HIV Futures* survey represent ten percent of Australian women living with HIV/AIDS. One quarter of the women who responded are tertiary educated and three quarters are born in Australia. Yet these women report high levels of discrimination, particularly from health care workers. This is borne out by Rosie's recent experience in a metropolitan hospital – see our story on page 23.

Anecdotal evidence tells us that the women most likely to respond to surveys, like *Futures*, are well connected to services, support and information. If the research paints a picture of poverty, low treatment uptake, social isolation and discrimination, what is the situation for those positive women who live in hiding or alone?

There is hope and certainty for the future. Women are not the sum of their children, but for many having a child is a significant part of their lives. Clinical and public attitudes to the role of positive women in childbirth has changed for the better and with advances in treatments and research it is now possible, with good planning and monitoring, to have a healthy, i.e. negative child – see our stories on page 6 and 30.

Of the women living with HIV in Australia, over half have children and others are confident about having a child in the future. Services are more sensitive and appropriate to women's needs. There are better opportunities for women to meet and support each other. These improvements must continue if service providers and governments are serious about addressing the isolation that positive women experience. The benefits and freedom created when we know that our voices are heard and that we are not alone are too great to lose – as we can see in the wealth and diversity of these stories.

Vivienne Munro





with **amelia mcloughlin**

To celebrate our (mostly) women's issue, **Amelia McLoughlin** – President of PLWH/A (NSW) Inc. – presents PosAction this month.

In September Ryan McGlaughlin completed the hand over of Manager's duties to Antony Nicholas our new Executive Officer. Ryan is now enjoying a well-earned holiday in Europe. We thank him for his commitment over the last 5 years and wish him all the best for the future.

New staff member

Glenn Flanagan has joined the Community Development Unit. Glenn's previous experience in education will bring valuable skills to the organisation. Glenn will focus on advocacy and the Positive Decisions Project that aims to assist PLWHA to return to work through training and work experience. He will also meet regularly with the many service providers working with positive people.

Rural Forum

PLWH/A (NSW) staff and committee members will attend the NSW HIV Rural

It is important to hear the diversity of positive people's lives. It is also a way for this organisation to continue to be informed about issues affecting women.

Forum in Ballina, November 16 – 18. This will be a great opportunity for positive people and health professionals to get together and attend relevant workshops. PLWH/A (NSW) will facilitate a writing workshop on documenting personal stories. We will also run the Positive Advocacy

Project, which aims to empower positive people with skills in self-advocacy.

Celebrity Auction

As this issue hits the streets we are days away from the Notebook of Hope, Celebrity Auction. If you are familiar with the names, Kofi Annan, Whoopi Goldberg, Jason Alexander, Dawn French and many more, this could be for you. If you are interested in attending please call the PLWH/A(NSW) office.

This issue ...

On a personal note, I would just like to say I think it's fantastic so many women contributed to this issue of *Talkabout*. It is important to hear about the diversity of positive people's lives. It is also a way for this organisation to continue to be informed about issues affecting women.



support for women

There was a time when HIV positive women were advised to terminate their pregnancy. These days the risk of transmission can be minimised and many HIV positive women are giving birth to healthy, HIV-negative babies. See our story on page 6. Pictured are Angela Stewart (left), the HIV Family Support Liaison Officer at ACON and Cassandra Romberg (right) of the Paediatric HIV Unit at the Sydney Children's Hospital.

treatment briefs

Placenta protection

Swedish researchers have found that the full-term placenta appears to act as a carrier to the virus, suggesting that if in utero transmission of HIV occurs, it likely takes place at the end of gestation via other means. The findings could lead to new intervention strategies for preventing HIV transmission between mother and child.

Reuters Health Information Services
(25/10/99)

Women and cancer

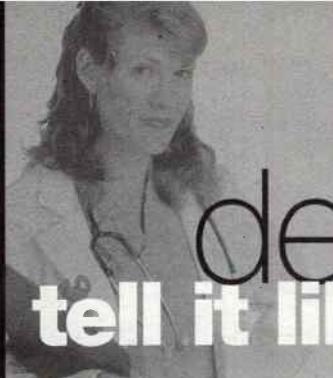
Most people get warts at different times in their lives but these usually disappear because the immune system can fight them off. However people with damaged immune systems who have warts are at increased risk of some kinds of cancers. At a recent international conference in Toronto Canada, information was presented about the effects of HIV medication on HIV positive women infected with HPV, the human papilloma virus that causes warts. Of the 178 women studied, 77 of them were on HIV drugs. Fifty-three women were found to be at increased risk of cancer caused by HPV. Abnormal pap smears were found in 58 women and these women were more likely to have HIV viral loads over 10,000 copies. Women on HIV drugs had a lower incidence of abnormalities on their Pap smears than did women not receiving HIV drugs.

Sex-based difference in viral load

Reports from an International AIDS Conference in Durban suggest that HIV viral load levels in women stabilise at a lower level than in men following seroconversion. Previously, key studies into viral load and disease progression looked mainly at gay men and male haemophiliacs. It was largely assumed that there was no difference between men and women in terms of viral load and disease progression. However, a growing body of evidence has found that there is a sex-based difference in viral load. The new information indicates that in men, low viral load measurement after seroconversion was associated with less risk of disease progression but this was not the case for women. Dr Sterling said that these sex-based differences in viral load have implications for treatment strategies in women and women's access to treatments and clinical trials.

National AIDS Manual
(<http://www.aidsmap.com/sitemap.htm>)

Treatment briefs are supplied by ACON Treatments Officers. For more information please contact John Humming or Barrie Harrison on 02 206 2013/2036, freecall 1800 816 118, email treatments@acon.org.au



de tell it like it is

Tell it like it is is your opportunity to get a straight answer to questions about health, treatments and side effects. Send your questions to Tell it like it is, *Talkabout*, PO Box 831 Darlinghurst 1300.

Dear Doctor,
My GP wants me to go onto a trial that involves an injection. I think he called it IL-2. He told me that my T-cells would increase but that I could suffer from the 'flu. What is this all about?

Potential Guinea Pig.

Dear Potential Guinea Pig,
Your doctor was talking about the SILCAAT and ESPRIT trials. These trials are testing the benefits of IL-2 for patients with HIV. IL-2 is a protein called interleukin-2. This is a natural protein which your immune cells use to send messages from one cell to another (inter means between, leukin means white or immune cell). Patients with HIV infection do not produce enough IL2. We know from previous studies that IL2 treatment causes large increases in CD4 T cell counts. What we don't know is whether these increases in CD4 T cell counts improve your health and stop you from getting sick. Hopefully the SILCAAT and ESPRIT will answer these questions. IL2 is given by injection under the skin twice a day for five days every eight weeks. Each eight week period is called a cycle. One of the expected side effects from IL2 is flu-like symptoms of fever, aches and pains and tiredness. These symptoms usually last only a few days towards the end of each cycle and are gone two or three days after the cycle. Thank you for considering these very important trials which may help to improve treatment options for PLWHA.

Dear Doctor,
My friend in the United States says I should be vaccinated against pneumonia. When I discussed this with my GP she said that it was not necessary. I am worried that I might be doing the wrong thing by not being vaccinated. What should I do?

Worried

Dear Worried,
Your GP is probably right. You are talking about vaccination against a bacterium called pneumococcus that may cause pneumonia. Although the American and Australian guidelines suggest that patients with HIV infection should be vaccinated against pneumococcus, recent studies have suggested that PLWHA do not benefit from this vaccine. It even suggested that the vaccine may be

harmful although the jury is still out. I would advise you not to have the vaccination but to report to your doctor if you develop fever, cough, shortness of breath, coloured sputum or chest pain.

Dear Doctor,
I have HIV and have been on treatment for a long time. I also have hepatitis C but have never worried too much about this. Should I be doing something about it now?

Connie

Dear Connie,
There is probably a twenty percent risk that patients with hepatitis C infection will progress to having cirrhosis of the liver. However, a number of studies show that at least in a select group of patients, HIV is a risk factor for more rapid development of cirrhosis, particularly as a person's CD4 count falls. It is hoped that effective treatment of HIV will also result in improved outcome for hepatitis C.

Whether hepatitis C adversely affects HIV infection remains controversial. We do know that liver disease is becoming more of a problem in patients with HIV infection, particularly with the increasing risk of liver drug reactions. Also of concern is the possibility of flares of hepatitis that may occur in patients with both hepatitis C and B, shortly after commencing effective anti-retroviral therapy for HIV.

So, for many reasons you and your doctor should carefully monitor your co-infection. You should try to protect your liver from further problems. You should be vaccinated against hepatitis A and B if needed and be careful not to drink too much alcohol. It is important for you to discuss the issues with your regular doctor, including getting up-to-date information on what treatment is available for hepatitis C for patients with co-infection. In addition, patients with hepatitis C also experience symptoms due to this virus, so your doctor will be able to discuss ways to treat such symptoms.

Answers provided by Virginia Furner and Mark Kelly - both doctors at the Albion Street Clinic and members of PLWHA (NSW) Treatments Working Group. Decisions about treatments should be made in conjunction with your GP. Virginia and Mark can be contacted on furnerv@sesahs.nsw.gov.au and kellymark@sesahs.nsw.gov.au



PLWH/A (NSW) staff and committee members are active in many projects, consultations and meetings that affect the interests of PLWHA. **Glenn Flanagan** – in his first column as Community Development Project Worker – profiles what's happening in NSW.

Sleaze Time Out Room

If you're going to Sleaze this year, don't forget about the Time Out Room for positive people and their friends. Food, water and a relaxed atmosphere will be available. Look for the PLWH/A Time Out Room signs when you get there.

Peer Support

ACON Peer Support urgently requires more people willing to train as facilitators for support groups. Training starts in November. You will learn how to create a safe and supportive atmosphere where people can comfortably share their feelings. No previous experience is required. If you are interested, ring Graham Norton at ACON on 9206 2011.

Rural Forum

The 2000 HIV Rural Forum will be held in Ballina from November 16 – 18. The new Positive Speakers' Bureau video will be launched at one of the last sessions of the forum. The video was initially made for rural schools, but has been so successful that it will be promoted nationally. PLWH/A will have an information stand at the forum and the staff will be there to answer questions about projects.

The Positive Living Centre

New programs get under way at the PLC in the coming months. One of these is the Brunch Club, which meets on Wednesdays at 11am. After a picnic lunch, people go by bus to the art gallery. This is a program for those who feel well enough to do something regularly, and who want to make new friends in a relaxed environment. Numbers are limited, so please book. The PLC also runs cooking

courses, including a nine-week TAFE course on Mondays from 11am to 3pm. The first course has started but you can still join. A second course will start soon. If you would like some tips budgeting for meals or would just like to broaden your cooking skills, there is also the Budget Cooking Course on Wednesdays from 11am. Cooking instructors include Simon Sadler, Beryl, David Jobling, and Claire de Lune. All ingredients are provided. You can also register for Food Share Australia (FSA) at the PLC on Mondays and earn big discounts on groceries. For two hours community work you can purchase \$40 worth of groceries for \$15. In December the Qantas cabin crew is back on board and will be preparing and serving a Christmas meal at the PLC. Bookings are essential. For all bookings and inquiries about any of these programs ring David Jobling, the PLC's client services coordinator, on 96998756.

The Sanctuary

The Sanctuary, at 6 Mary Street Newtown, offers massage, acupuncture and advice about complimentary therapies for positive people, their partners and carers. They are looking for volunteer masseurs who have had some basic training. If you would like to offer the Sanctuary some time, call Robert on 9519 6142.

Planet Positive

Planet Positive is the popular social night for positive people at Annie's Bar in Surry Hills, organised by ACON, PLWH/A and the PLC. The next Planet Positive will be on Thursday, December 7. Entertainment, food and some drinks are provided. 

Talkabout

welcomes stories and letters from PLWHA.

In our combined December/January issue **Talkabout** reports back from the 2000 HIV Rural Forum, the ASHM conference and the Women's Retreat.



howdy cowdy! meet sam (r) and glenn (l)

Positive people and their pets

Have you got a favourite photo of you and your best animal friend? Send it in to the PLWH/A **Talkabout** PP&P (Positive people and their pets) competition. The winner will be featured on the cover of the December/January **Talkabout**.

For more information please call the Editor, feona studdert on (02) 9361 6750, or email your story to feonas@plwha.org.au.

Deadline for the December/January issue is November October, 2000.

Contributors fees available for PLWHA receiving disability pension or similar low income.



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mother load

If you are an HIV positive woman, the question of whether or not to have a child is complicated by ethical issues such as whose health should be considered the priority – the mother's or the child's – and practical concerns about the best way to prevent transmission. **Kirsty Machon** reports that the answers may well depend on which part of the world you live in.



One of the most difficult emotional questions for HIV positive women is whether or not to have a child. In the early days of the HIV epidemic – in the so-called developed world – women were frequently advised that pregnancy was out of the question because there was almost a 25 percent likelihood that the child would be born HIV positive. The question is a loaded one for women because, although no woman wants her baby to be born with HIV, to be told she cannot have a child can cause considerable grief.

In Australia gay men make up the majority of diagnoses and positive women are a tiny minority. This reinforces the difficulties around the question of pregnancy. More general concerns tend to direct research.

Woman-as-vector

The flipside of this has been a long and depressing history of commentary that has centred on the likelihood of transmission between mother and child. Historically, some controversial practices have resulted. Especially early in the epidemic, positive women were advised to terminate their pregnancies. Women also frequently underwent Caesarean section rather than a natural birth (admittedly, a riskier method). Women were denied potentially life-saving drugs on the basis that there was no evidence that the drugs would not

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cause harm to the unborn child. More recently, echoes of this extreme approach have been seen in an Australian survey of women with hepatitis C. The survey suggested that about 16 percent of the women surveyed who fell pregnant following hep C diagnosis were advised to consider termination.

This 'woman-as-vector' commentary is prominent in contemporary discussions

about mother-to-child transmission in resource-poor countries. Commenting two years ago on routine HIV screening for pregnant women in Malaysia, the head of that country's AIDS advisory council was moved to remind us that the most useful way to prevent positive babies was to prevent women from becoming seropositive in the first place. In the absence of this ideal, research and commentary in resource-poor countries is focused on minimising the risk of transmission from mother to child during pregnancy and childbirth itself (breast-feeding remains a vexed question).

The bang or the buck?

The favoured strategy is to use short-term interventions with drug therapy to reduce the mother's viral load during the crucial final trimester and birth itself. AZT is primarily used, but recently, nevirapine has offered a cheaper and more manageable form of intervention. Nevirapine is taken in a single pill to the mother during birth and a single dose to the child shortly after. This is a simple and attractive option if the intent is to maximise the antiviral bang as cheaply as possible. The use of nevirapine does raise difficult ethical questions, namely, the potential for the mother to develop resistance to nevirapine through short-term use and reduce her future AVT options.

In South Africa, unfortunately, the proposal to make nevirapine widely available to pregnant women is hampered by the government's insistence that nevirapine is a toxic and dangerous drug. The situation is further troubled by that government's flirtation with rogue scientists who suggest that HIV does not cause AIDS. The major trial that led to the widespread use of AZT in mother-to-child transmission recommended that AZT be used as short-term monotherapy. This

approach is scorned in the developed world as a dangerous approach to treatment for the mother. The trial also took mothers off the drug once the child was born. This is a controversial recommendation that clinical trials in resource-rich countries would not tolerate.

The treatment maze

The transmission of HIV from a mother to her child can occur during pregnancy, during the birth and in breast-feeding. Contemporary advice around mother-to-child transmission in Australia, Europe and North America is focused on the question of maternal viral load. As is the case with HIV transmission in general, we do know that viral load is a major factor, and that generally, a low or undetectable viral load can dramatically reduce the likelihood of transmission. This is borne out by research showing that transmission is unusual when the mother has undetectable viral load. AZT is the most extensively researched of the current antiviral drugs. The Australian guidelines suggest that to prevent mother-to-child transmission of HIV, the minimum recommendation should be AZT from 14 to 34 weeks into the pregnancy and a larger dose during labour and delivery. The baby is then given AZT after birth. (Dosage based on protocols from the PACTG 076 trial). For this reason the guidelines suggest that women may wish to conserve AZT for the purpose of pregnancy.

However, triple drug therapy is considered the standard of care for the mother. Certainly, if a woman is already on successful treatment at the time of her pregnancy, guidelines suggest she should keep treating. The limited research into the effects of anti-HIV drugs, especially the newer drugs, on the baby complicates the decision. The issue is how to maintain the

mother's health and wellbeing, especially if she is doing well on her combination, while at the same time not administering drugs which may harm her child. In particular, ddC seems best avoided, since it appears more clearly linked than other drugs to the possibility of harming an unborn child. Another drug, 3TC, has been tentatively linked to possible mitochondrial (cellular) problems in a small number of babies studied overseas, though the implications are unclear and 3TC is often a staple drug in a successful regimen for the mother.

The head of that country's AIDS advisory council was moved to remind us that the most useful way to prevent positive babies was to prevent women from becoming seropositive in the first place.

The main point is to take a cautious approach because research is limited. Women should have a good relationship with an experienced and sympathetic doctor and weigh carefully the pros and cons for their health and the child's.

Putting women into the equation

The issue of pregnancy for women who choose not to take AVT is more vexed. Some paediatricians take a hardline approach, suggesting that the health of the child should take priority over the

mother's decision not to take antiviral drugs. It is worth stressing the importance of the mother's viral load and CD4 count as indicators of both her own health and the likelihood of transmission. While there is not a lot of research into the risk of antiviral drugs for a baby's wellbeing, we do know that many women on combination therapy have successful pregnancies and give birth to HIV negative babies. On the other hand, increased viral load and low CD4 count, which may occur more frequently in the absence of treatment, can place the baby at risk of infection and increase the risk of illness for the mother. Pregnancy may be an added immunological stress if a woman's CD4 count is very low. Low CD4 count and advanced HIV disease in the mother may also increase the likelihood of complications like miscarriage, low birth weight for the baby and premature birth.

The most important issue now is to assist women to get appropriate information, guidance and counselling. Many HIV clinicians are now comfortable with treating HIV-positive pregnant women. This suggests we have come a long way indeed from the emotive old days, and that women are being respected in this equation as something more than potential vectors for disease – at least in the relative affluence of countries like our own. ●

Kirsty Machon is the Publications Officer at the Australian Federation of AIDS Organisations (AFAO) and the editor of HIV Herald and Positive Living.



events

Candlelight Memorial Rally The Candlelight Memorial Rally this year will take place at Hyde Park on Tuesday November 21 – celebrating and remembering lives lost. For more information contact the AIDS Council of New South Wales (ACON) on 02 9206 2000.

Quilt Displays The Australian AIDS Memorial Quilt will be displayed throughout New South Wales during AIDS Awareness Week. For details of where it can be seen in your area contact your local Area Health Service.

Awards Night The World AIDS Day Awards – honouring outstanding work in advocacy, care, education and support – will be presented at an invitation only function at Customs House on Sunday November 26. For more information please contact World AIDS Day Project on 02 9382 8356.

Sydney Food and Wine Fair The annual Food and Wine Fair – one of the AIDS Trust of Australia's main fundraisers – has moved back to AIDS Awareness Week and will take place at Hyde Park on Saturday November 25.

For full details of the hundreds of events taking place throughout New South Wales, please contact your local Area Health Service, the NSW World AIDS Day Project Office on 02 9382 8356 or the World AIDS Day website www.world-aids-day.info.au

community

The experiences of gay men largely determine research and discussion of HIV in Australia. The Living with HIV program at The Australian Research Centre in Sex, Health and Society [ARCSHS] has released a second report into the experiences of women living with HIV. The report reflects significant differences in the use of HIV treatments and the incidence of poverty between women and men. Researcher **Karalyn McDonald** reports on *A Complex Uncertainty*.



The way that women experience living with HIV/AIDS is often significantly different to both heterosexual and gay men. The pattern of these differences was documented in Australia by research in 1998 with the first national report of women living with HIV in Australia, *Standing on Shifting Sand: Women Living with HIV/AIDS in Australia*. In September this year, a second report was released. The title of the latest report – *A Complex Uncertainty: Women on Health, Hope and Living with HIV in 2000* – alludes to developments in the sense of hope, optimism and complexity experienced by positive women in the intervening two years. The findings of the *HIV Futures* surveys conducted by researchers at La Trobe University forms the basis of both reports (see our side bar on page 10).

The reports take their titles from interviews done with positive women who participated in the survey. Neither report would have been possible without the assistance of positive women's organisations around Australia. Staff and volunteers are

instrumental in recruiting women to the *HIV Futures* surveys.

The second *HIV Futures* report surveyed 924 positive people in Australia. Eighty-nine of the people surveyed were women. This represents around ten percent of the total estimated number of women living with HIV/AIDS in Australia. Three-quarters of the women who participated in this survey are Australian born and a further five percent identified

I think that as each year goes by my hope for the future doesn't change. But I think that the issues and means that arise are becoming more complex, not just for me but for all positive people.

themselves as Aboriginal/Torres Strait Islander. The women who participated came from all states and territories with the majority from New South Wales and Victoria. Most women identified as heterosexual (83%), eleven percent as lesbian and six percent as bisexual. Ages ranged from 18 to 62, with an average of 38 years. High levels of education were evident, with twenty-five percent of women holding a university degree, twenty-three percent a tertiary diploma, and a further twenty percent completing secondary education. More than half of the women (52%) had been positive for between five and ten years, eighteen percent for more than ten years and twenty percent for less than five years.

Treatments

Following the pattern established by the first survey, the second *HIV Futures* survey found significant differences in the use of antiviral treatments (ARV) between men and women. Less than two-thirds of women (60%) use ARV. This compares to 75% of men using ARV. Women are also less likely to have ever used ARV (76% compared to men (88%).

Our analysis revealed differences in the attitudes of women and men toward ARV treatments as well. Fewer women than men believed that antiviral drug meant better prospects for most people (60% versus 71%). These important differences between women and men tell us that there is a greater uncertainty or distrust among women towards ARV. Whilst women are no more likely than men to experience side effects, 42.1% of women believe combination ARV drugs are harmful and nearly one half of women (46%) are unsure whether HIV treatment will stop them dying from AIDS. One woman who participated in both our survey and a qualitative interview said, "I think that as each year goes by my hope for the future doesn't change. But I think that the issues and means that arise are becoming more complex, not just for me but for all positive people".

Children

Another issue highlighted by research is the importance of children to women. Most of the women participating in the survey are mothers and one half (51%) currently have dependent children. The ages of these dependent children range from less than one year to eighteen years. Just over half of these children are aged five years and under and thirty percent are two years old or younger.

continued on page 10:

further reading

Many of *Talkabout's* readers will be familiar with the *HIV Futures* surveys. The first national survey of PLWHA in Australia project began in 1997 at the Australian Research Centre in Sex, Health and Society. The survey looked at the health and treatments of PLWHA, and many aspects of social life including community involvement, sex and relationships, finances, accommodation and employment. Researchers were also interested in the effect of treatments on the lives of HIV positive people. Researchers added sections on mental health and recreational drug use to the second survey in 1999.

A number of community reports, conference presentations and academic papers have been published from the findings of the two surveys. Copies of the two national reports: *The HIV Futures Community Report: Health, Relationships, Community and Employment* and *HIV Futures II: The Health and Wellbeing of People with HIV/AIDS in Australia* as well as the state and gender-based reports of the surveys' findings are available from ARCSHS on 03 92955382 or www.latrobe.edu.au/www/hiv_futures 

> from page 9

Nearly twenty percent of the women in our survey are considering having children in the future or actively trying to get pregnant. Twenty-two women have had children born since their diagnosis and one woman was pregnant at the time of the study. Another woman with a young child said in an interview, "... my baby (has) made so much of a difference because I have always wanted to have children ... my baby's really planned and really wanted ... you just wake up every morning [and] you just have to pinch yourself".

Poverty

Our research also found that significantly more women than men are living below the poverty line (46% versus 29%). More than half of the women (53%) rely on government benefits/pension as their primary source of income. Women were significantly more likely than men to report finding it difficult to pay for medical services, co-payments for HIV medication, other prescribed medication, complementary therapies and support services.

This brief sample of the findings of *HIV Futures* demonstrates important differences between women and men and establishes the need for separate analysis and reports. The use of ARV is different for women and they are more likely to delay the commencement of treatment. The importance of children in women's lives is clearly evident. The decisions around having children, disclosure and parenting can be complex. Women must also consider the burden of treatment and the possibility of illness in the context of children. Poverty can be a barrier to health and wellbeing and this reflects the structural inequalities facing women both in Australian society and globally.

Recognising women's needs

Our research program recognises the struggle of positive women's organisations for visibility and a voice in an epidemic that is experienced predominantly within a gay male culture. The staff and volunteers of positive women's organisations work hard to ensure that treatments, education and support services are appropriate for

women and that there is adequate research into women's health issues. We hope that the findings of the *HIV Futures* surveys provide evidence of the different experience of women living with HIV in Australia and assist organisations to achieve their objectives. Many of the women who contributed to the *HIV Futures* survey are already using services and plugged into networks of positive women. It is vital that the results of this research reach all women – and especially those who are not connected with organisations. Recognising the commonality of experience between

Positive women's organisations will always struggle for visibility and a voice within an epidemic that is experienced predominantly within a gay male culture.

women may help break down isolation and encourage women to use available services. Ultimately we hope that our research contributes to the health and wellbeing of all PLWHA in Australia. As a final note I'd like to acknowledge the selfless contribution of positive people in Australia who participate in our research and the positive organisations that help us with distribution and dissemination. 

Karalyn McDonald is a researcher at the Living with HIV program of The Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University, Melbourne. ARCSHS is funded by the Commonwealth Department of Health and Aged Care under a CARG Collaborating Centre Grant to conduct a national program of social research with regard to the particular needs and experiences of HIV positive people and their carers.

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pregnant and positive

Toni is 24. Five months ago she was diagnosed positive and pregnant. She told *Talkabout* that she just wants to get on with life.



When I found out I was HIV positive, I cried for half a day and after that I decided to get on with it. You've got to live with it. It's not going to go away. So just get on with it.

I've told my partner, my mum, my sister and one friend. Mum thought I was dying tomorrow at first but she's all right now. My partner is not positive but he took the news hard at first. He was worried about himself. Then he was worried about what he'd do without me and what might happen to the baby. He took two weeks off work and moped around the house until I convinced him to get off of his butt, get a blood test and see the counsellor. He felt much better after he did that.

Three weeks after I told my friend she got paranoid about it. She said "I hope you don't scratch me while we're playing netball." One time I went to touch her and she pulled away from me. She didn't mean it and she apologised a lot but in the end I took her to Albion St and I made her see the counsellor. She's all right now.

When I was diagnosed, my partner wanted to know where I got it. He was angry and said he would kill whoever it

was. Before my partner I had a four-and-a-half year relationship, and another for six months. Both were abusive and I can't approach them about blood tests. So I don't know where I got it. My partner thinks I'm keeping things from him, like I've got a secret past but it's not like that. I've had a few casual relationships when I was young but it wasn't that. It was a relationship that I got it from. It was from something real.

I did a big assignment about HIV/AIDS in Year 12. I remembered a lot of that when the doctor told me I was HIV positive. So I was okay and was able to educate everyone.

I nearly died when I found out I was pregnant. I've only been with my partner eight months now, so we'd only been together two months at that stage. But I always said I wanted to have a child at this age so it's a bonus.

He took two weeks off work and moped around the house until I convinced him to get off of his butt, get a blood test and see the counsellor. He felt much better after he did that.

I try not to worry but a lot of the time I think the worst. I'm going to do everything I can so the baby doesn't get it. I mean, half the time I forget I'm HIV positive anyway. I've got my tablets every day now, so that reminds me, but I just don't think about it otherwise.

The process of the diagnosis was long and stressful. I went to see my doctor

because I thought I might be pregnant. I got half the results back in the first week and I think it was another three weeks after that he called me in and said we need to do the tests again. Three or four weeks later he came back and said "you're positive". That's when I went home and cried. I asked him what happens about the baby, does the baby get it? He referred me to a specialist, but I couldn't get an appointment for another week or two so I found the Albion Street Clinic in the phone book that afternoon and went to see the doctor the next day. There was no way I was going to wait. I wanted to know there and then.

The people at Albion Street arranged for me to see a psychologist every two or three weeks. It's good to have her there and I get to talk about lots of things when I see her.

I hate the pills. I take them twice a day and I'm bad enough with tablets anyway. It means I have to eat two good meals a day and that's probably good for the baby anyway. I just don't feel like eating much because of heart burn. But it's okay for the whole.

I work in a factory with my mum. I'm working 50 hour weeks now so I can save for the baby. I'd prefer to have a baby, relax and not work. I've always wanted to be a housewife. But I know that will never happen and I can't do that forever because I get bored. I read and watch movies and play netball. I stopped when I found out I was pregnant. But I'll go back and coach and umpire. If my partner has anything to do with it, I'll be pregnant within six months of this one popping out. He'd like to have another child. I want to have another child eventually but not straight away.

Toni is not her real name.

Kay discovered a new path and a stronger sense of identity after her diagnosis.



My HIV diagnosis four and a half years ago changed every aspect of my life. This has not altogether been a bad thing. My diagnosis, amongst many things, has put my identity in focus, allowed me to express myself, share my thoughts and my story and reach out to those who are also affected by this sometimes horrible virus. I think it is important to know that being open about HIV has meant that I am more in touch with those around me and with who I am and where I believe I am supposed to be.

Living as an HIV positive woman can be a frightening experience. Getting medical care, emotional support and understanding is sometimes difficult, often frustrating. I find I am supporting those who should be supporting me. Poverty, fear of social stigma and fear of ignorance regarding the risks of transmission can often result in isolation or, in more extreme circumstances, sometimes depression or even mental illness. But it is not all bad, if you look hard enough there is always a flip side.

At first I was stunned, frightened, angry, anxious, confused and despondent. I discovered my status when I was

diagnosed with Pneumocystis Carinii Pneumonia, complete liver failure (a result of the prophylaxis Bactrim), kidney stones (twice) and shingles. At the time of my diagnosis my viral load was in the range of 3.8 billion (true and hard to believe) and I had a T-cell ratio of 165.

... being open about HIV has meant that I am more in touch with those around me and with who I am and where I believe I am supposed to be.

After a six month recovery I began a simple TAFE art course that became the first step in a total redirection of my career goals and what I wanted to achieve in my life. Before I was diagnosed, I had always worked hard at my studies and had ambitions to take law at the University of NSW. I had been interested in art since my early childhood but considered it a hobby,

rather than something I could make my career. The art course put me in touch with myself and helped me to find the right medium for self expression. This led to a university degree of a totally different nature.

Now two years into my Fine Arts degree, I have no regrets. I am happy working with photography. I am open about my circumstances with my fellow students and lecturers. Using photography I've explored and dispelled many of my fears and issues about life, death and mortality. I have tried to confront each new fear or dilemma in the context of my study. My diagnosis has motivated me to find myself. In this way it has been an important gift. It has also inspired my family, friends and my partner to find strength in my courage and face their own fears head on.

When you tell people that you're HIV positive, it's hard to know what their reaction will be; the shock is often as great for them as it was for me. I have learnt to pause and consider how people will react, whether they will judge me, whether they will be supportive and whether they will respect my privacy. Sometimes I act as an educator and supporter. For me, the best thing has been to talk to someone I trust. I have found these experiences to be an invaluable resource as a representative for positive women on the ACON board.

I don't just identify as an HIV positive person. For me, issues such as gender, sexuality, self-image, lifestyle choice, career and freedom of expression are just as important. I have turned my diagnosis into a kind of motivation or driving force for myself and hope that my story will encourage other women to speak out about their personal experience of living with HIV. ①

Kay is 25 and the HIV Women's representative on the board of the AIDS Council of New South Wales (ACON).

a passionate journey

By Juliet

I have so many stories to tell but the one I have chosen is about the strategies I use to help me through this most difficult of journeys. I believe we have the choice to dig the hole deeper or discover ways to grow as never before. Initially at the point of diagnosis I was astonished at how dreadful I felt, the wind completely taken out of my sails. I was overwhelmed by fear and a sense of death. But how powerful we are! I made a conscious decision to live passionately. I had a young daughter to care for, and a handsome son. I wanted to be part of their journey, whatever that would be. I enjoy my two fine children immensely – sometimes I watch them when they are unaware and I just soak them up – my heart explodes with the moment.

I surround myself with loving friends. I let them know how special they are and how much I value their friendships. I create events such as Wonderful Women's Gatherings where we avoid the "poor me"s as much as possible and focus on our personal development. Few know about my HIV status as this is a personal part of my life. My choice.

I still work, which is difficult as my job is stressful and academic. I enjoy working and it fuels my beleaguered and floundering self esteem. I need the money to buy the natural health therapies that cost me thousands of dollars. But they give me a comfortable sense of being actively responsible for my health care.

I do yoga four times a week and use weights. "Pumping iron" doesn't quite seem the appropriate terminology. It provides a sense of balance and I look better for it. It is part of my physical maintenance program and makes me feel powerful despite my petite and somewhat lipodystrophic frame.

I love to walk, in fact I have a passion for it. I live near the ocean and even when it rains I walk along the beach with an umbrella. I watch spellbound as a Currawong pecks at the berries of a Bangalow Palm and hurries them off to the nest. The down side of living in the country is the isolation from HIV treatments and support groups. The burden of confidentiality is also a more dramatic issue.

I made a conscious decision to live passionately. I had a young daughter to care for, and a handsome son. I wanted to be part of their journey, whatever that would be.

I keep a gratitude journal and write in it five things each day that please me. I don't keep this religiously but it helps get me out of the black holes and focus on the positive rather than the negative. I include drawings, poems, inspirational sayings and ideas, positive words etcetera.

I find symbols in life and attach meanings according to the message I feel these symbols identify, for example, the eagles that I often see represent to me my strength and clarity. Sometimes I lose this sense of strength – I just need to remind myself that I am strong.

I've set myself many goals and chip away at them. I've gone outside my normal comfort zone, white water rafting, abailing, and writing poetry; it's amazing what you can achieve. I'm learning Latin American dancing now. Dancing makes me feel alive, taps in a rhythm of life that

is energising, and just grooving around feels sooo good.

I read many books about healing though I believe it is useful to discerning. For instance, much new literature suggests we have "asked for illness". Well, I absolutely do not accept that one. But overall I find many of books inspire a sense of peace, understanding and wellbeing.

When I meditate I travel much better, worry less, stay balanced and less fearful. I practice visualisation to transport me to my perfect space. It's a lot of fun – I'm surrounded with fairy wings and swim underwater with the dolphins.

For the first two months of diagnosis I avoided sex – after all that's how I got into this mess. My libido went completely into hiding. The beautiful man with whom I shared so much of this journey has since died, ironically not AIDS, but that is another story. This I have been almost unbearable. I believe that love, and passion and tenderness and loving are synonymous with the life force energy coursing through our bodies. I'm a person who enjoys being in love. Love is the fire chakra and the colour is red.

I use SHAIDS and ACON counselling and this was particularly important to me during the first couple of years. I am fortunate to have excellent doctors who take time to ensure that I am able to make informed decisions. I wouldn't have it any other way.

I see my life as a faceted jewel, like amethyst. There is an intensity and passion in my life that wasn't there before. Of course there is also tremendous sadness and sorrow. I will never say as some people that "I love my illness" but it has been an extraordinary journey with much new work and ways of seeing things. It keeps me quite busy.

Juliet is not her real name.

By **Jacqueline**

Once upon a time there was a little girl who asked her mummy "what shall I be?" "Oh, you'll live with HIV/AIDS when you grow up" replied her Mummy. So that little girl prepared herself emotionally and physically for her set path in life and lived happily ever after!

Actually, that's not how it went. There was a little girl and she did ask her mother about life and growing up and what it was all about. "Am I supposed to get married, have children, live in a three bedroom house in the suburbs and that's it?" she implored.

"Well, that's what it's all about, you've just got to accept it", said her mother.

However, the little girl was not content with that menu for life, she didn't want to just accept a fate that seemed so boring and monotonous so she promised herself that she would find the real meaning of life - there must be something more!

Her spirit was rebellious, her hopes were high, her faith in the "real thing" would sustain her and spur her on in her journey. She set out to find a meaning to life. She wanted something more than the accepted, conditioned, doctrine she saw in the flock of sheep leading a life of imitation bliss. No way. She would rather die than adhere to their way just "because". Apart from that, she had ambitions of being an actress and wanted to experience the full spectrum of emotions from ecstasy to pain, to be able to passionately portray any role and the best way to experience it all was to travel.

She left her hometown, family and friends, and that familiar safe support network that dampened her spirit, and traveled the world. I suppose it was inevitable that along the way she found herself. She landed in a country where she could only communicate with hand

language, and was totally removed from what she considered "normal". She realised she didn't have the option of asking the neighbour or calling her Mum. She learnt to rely on her own nature and instinct for guidance and accepted responsibility for her actions. In this way she began to understand just who she was.

What adventures, what sunsets, what smiles along the way. No schooling or university could ever promise to teach her this experience.

She put faith in life itself and imagined it as a fast flowing river. She could hang onto the banks and slowly, without risk, make her way downstream or she could leap into the middle and let the water's full momentum land her on unknown shores. She chose the latter and found herself in untried waters, sometimes scared but unchained, experiencing the utmost.

There were laughter and tears, blues and reds and purples, at times a joy that bubbled and peaked, at others, a pain that etched itself in her heart. Above all, she found love, a love that filled her to the brim and gave her hope. She gave as much as she took, holding fragments, discarding those she thought undesirable.

One day she returned home, whole in spirit but weak in body, to discover another challenge now lay in her path, a challenge with the name of AIDS, and surprisingly, even to herself, she faced the news with dignity and little fear. After all, hadn't she been through hell? Hadn't she touched the roof of heaven and flown? Hadn't she climbed mountains and walked every corner of the earth to find herself? Hadn't she found love in a child's smile? In the petals of a flower? In the colours of a rainbow? In the song of a bird? In the eyes of the old? Maybe this is why it was so easy to accept her fate and get on with living. Don't get me wrong - she doesn't want to die, she loves being alive. She

*To laugh often and much,
To appreciate beauty,
To find the best in others,
To leave the world a bit better ...
To know that even one life
has breathed easier
because you have lived;
That is to have succeeded.*

Ralph Waldo Emerson

doesn't ponder that aspect. She knows that one day she will die - young or old, with AIDS or without but she's not afraid of it. She doesn't see this virus as doom and gloom - quite the contrary, it's probably a godsend to make her realise that each day is special and worth living to the maximum. So what - I am living with HIV/AIDS!

Jacqueline is not her real name

the sweetest thing

By Jules



I met Michael just over four years ago. I was six months clean of heroin – in fact, clean of all drugs, – and two days out of rehab. I was alone and frightened in a new city. Although not really conscious of it, I was looking for romance, adventure and a way of life that didn't involve the endless – but strangely fulfilling – drudgery of heroin addiction.

I felt as if I knew nothing. I was incredibly shy with no confidence and couldn't speak to people without blushing and averting my eyes; I felt like I was from another planet.

Then across the room – in a 12 steps meeting – I saw Michael. He was an artist and a musician, compellingly handsome and sexy beyond words. We spoke, briefly, and he asked me out for coffee. We talked about caring for people who were HIV positive and of the people we had loved who had died of AIDS.

I found him beautiful, with his wild, mesmerising, blue-green eyes, and beguiling mouth – I wanted him in an overwhelming way. I hadn't had sex in a long time – and couldn't remember the last time I had sex without being out of it. I felt explosive with desire.

Over the next couple of days we went out a few times, with me feverishly pursuing him, and then he told me he was HIV positive. I already had a feeling that he was – so in a way I wasn't shocked, I still wanted him just as much. Things were murky, Michael was concerned because I wasn't positive, and what that would mean. There was mad passion, lust, sadness, tears, fear, guilt (I felt guilty because I wasn't HIV positive), pain and dreams.

I was so, so raw – with only one level of feeling – intense. Two days later, I put it on him. He wanted to talk about the details but I just wanted to hold, kiss, fuck, and merge. I wanted us to absorb each other. To me we were tragic lovers and I

wanted to shut out the world. Have I mentioned that I can be a drama queen?

Then trouble. I was living in a halfway house, and I wasn't allowed to see Michael. He was much more humble and responsible about the separation – he knew that I needed to look after myself.

I was grief stricken; I just wanted to be with him. I was afraid of losing Michael; to HIV and to other partners.

I questioned if I really loved Michael – or whether I was parched for love and closeness, and used to living in chaos and drama, and being with Michael was the essence of all that? Reality and dealing with consequences are not my forte, I operated on wanting things and going after them.

I felt beautiful with Michael. I came to understand the beauty of being still and holding someone you love, of butterfly kisses and secret messages of love purred to each other over the phone.

I felt safe and joyous sexually with Michael, it became not only a wild and adventurous expression of how we felt, but also one of the few times that I have felt connected and not afraid. Michael was incredibly thoughtful and careful, I was still the one that was geared to taking risks – he wouldn't hear of it.

We found each other bewitching and delicious, we admired, nurtured and celebrated each other. Even though there were times of great doubt, mostly we believed in our love and each other.

Then Michael decided to live in the country where he had family and friends, and where he found life more peaceful.

Since then he has come and gone between the city and the country. There has been an enormous amount of love and pain between us. We wanted children; we talked of taking the risk, decided against it, living together – back and forth, back and forth. We were lovers always, even if that wasn't always physically or emotionally demonstrated.

This brings me to where Michael and I are now. Over the last six months, we have been compellingly close – and there have been periods when he has banished me from his life. I don't know what it is like to be faced with death. I fight to comprehend his feelings. As I write, he is in the country, dying of complications from HIV. There is pain as we come to terms with that reality, and he pushes me away. I have had an enormous amount of support and love, and I am finally challenging my pain when he pushes. Rather than stay in my pain, I am trying to come from a place of compassion and respect; I said trying.

Sometimes my grief threatens to topple me because I love him and get scared that he will not be in my world. I

I found him beautiful, with his wild, mesmerising, blue-green eyes, and beguiling mouth – I wanted him in an overwhelmingly way. I hadn't had sex in a long time – and couldn't remember the last time I had sex without being out of it. I felt explosive with desire.

have huge regrets that we have not spent our lives entirely together in the last four years, but most of all – I feel incredibly grateful, joyous and honored that we have shared our time.

Michael wants me to come and stay with him in a few weeks; until then it is phone calls and cards. My nights are full of photos, tears, dreams and wishes as I re-read old letters, light candles and say prayers for my boy.

The sweetest thing now would be to hold him again. ●

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mums do matter

Grief is still a part of living with HIV/AIDS. Two mothers – **Helen and Mary** – whose sons have died after an AIDS-related



I am sixty years old and I have lived in Western Sydney for most of my life. My husband died a few years ago. I have two daughters living interstate, and two sons here in Sydney.

Twelve years ago my son Andrew, whom I knew was gay, told me that he had been diagnosed with HIV. He was in shock and couldn't digest the news. He had friends who had died and knew the path ahead. The news bowled me over. He asked me not to say anything about his illness from that day on. The silence and secrecy nearly killed me but I understood that he needed this buffer zone so I went along with it. He was scared of the treatments and decided to take care of himself in his own way.

That worried, anxious feeling never left. I knew something was eating away at my son and I was helpless to help. I became anxious, watching for signs of ill health. I felt ripped to pieces and drained inside.

Some of the family didn't know for a long time. My daughters knew but they lived in another state so I just had to get on with life. When I told my husband he didn't seem able to show his feelings. I felt on my own. When Andrew was admitted to Liverpool Hospital, a social worker and counsellor from Bigge Park Sexual Health Centre visited us. Her help was wonderful. She arranged an Ankali for both of us and got the Community Support Network to help us in the home and with transport. Volunteers from the Haven visited Andrew whenever I couldn't. The social worker arranged respite care at Bethany, where we were also offered pastoral care. It was such a relief because I couldn't care for Andrew on my own, especially when he couldn't walk. When he died Ankali and the pastoral workers continued to support me. I went to a bereavement group for ten weeks and it was helpful to share with other women who had lost sons and husbands.

I need to meet new people, have new challenges, and breathe in fresh air and new life.

I still find it bloody hard to grapple with the reality that he has gone. There are so many memories. I ask myself, "What if I ...". So I've decided to sell up and move closer to my daughters and grandchildren. It is scary because it's the first move since I married but I am also looking forward to something new. I need to meet new people, have new challenges, and breathe in fresh air and new life. ●

Helen and Andrew are not their real names.



mary's story

I came here from Scotland twenty-three years ago and have lived in our family home in Western Sydney for twenty-two years. I had three sons. James, my eldest, died last year in early November from an AIDS-related illness. I have five granddaughters.

I discovered that James was HIV positive by chance. A clinical psychologist kept ringing for James. When I asked James what this was about he said, "No one could help me". Eventually I guessed. He had his back to me and nodded his head. I was rooted to the spot, a big lump came into my throat and I couldn't speak. Then I sat down with him and we talked.

My first thoughts were that James is going to die before me, how could that be? How would I explain it to the family but more especially how was James going to cope. Slowly, over the period of his illness, I saw his personality change. I wasn't to mention the virus unless he did.

... share their stories.

He was in hospital a lot and I was worried about his mental capacity. I always had a close relationship with him and since he had no partner and no children I drew closer to him. I felt I was being put to the test. I had a choice and I did my best by him.

When his health worsened I gave away my job and spent more time with him. I was lucky to be in a position to do this. No matter how low or down I got, I knew it was nothing to what my son was going through. I lived at the hospital when he was coming to the end of his life.

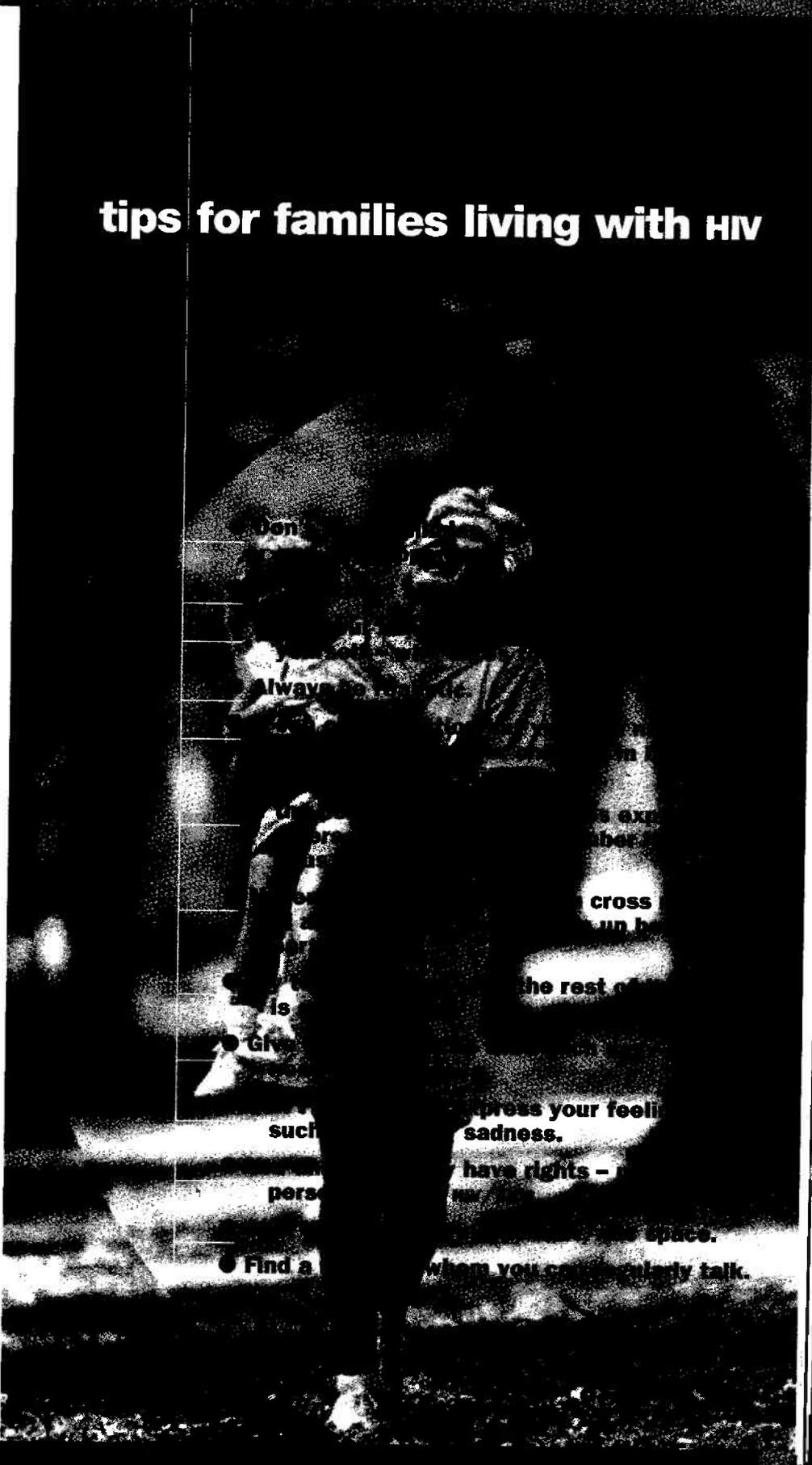
My husband and my other two sons didn't always understand or agree with my way of thinking but there was only one road for me and that was to follow my heart.

There is a big gap in my life. If I had to do it all again, I would. He was the joy of my life; I miss his wit and ways. To see him fade away to someone I hardly recognised broke my heart.

... but there was only one road for me and that was to follow my heart.

I wrote a poem in the Sacred Heart Hospice while I sat with James:
*Who will mend my broken heart?
So many pieces, where would they start.
An answer I tried to find
But a thousand questions run through
my mind
I whisper in my beloved son's ear
Hoping the words he can still hear
If the God I was brought up to believe in
really exists
I send him to you with a hug
and a kiss. ①*

tips for families living with HIV



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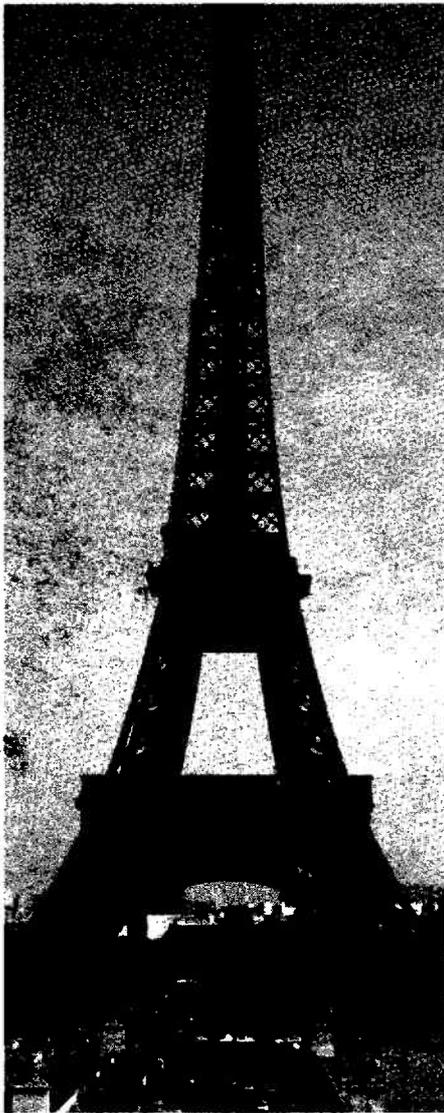
space.

Find a

when you can regularly talk.

candle in the window

by Kerran



It's 4am.

I can't get no sleep!!

Sleeping beside me though is my beautiful husband. I lie awake sometimes at night watching him, wondering what is in his dreams. We always share our dreams. We've just celebrated our third

wedding anniversary. Our relationship is the one I had wished for ever since I was a girl. We are constructive, not destructive. We laugh and we cry. We nurture and we celebrate the inner child. We are boofheads! We learn and we grow. I'm HIV positive. He's not. His crisis last year shook the foundations of all I believe in.

To watch the person with whom you share everything melt before your eyes is incredible. He became afraid. My soul mate, my love, my all. What if you die? What if I wake one morning and you are cold? A complete and utter breakdown. They say a crisis brings out the best and worst in those around you. I think I saw it all. I was told, "This is a difficult situation." "We don't know what to say or do." The ostrich factor: bury our heads and wait. My beautiful husband was on an island all alone, the sharks circling. Some relationship counselling three weeks hence was suggested.

You're not listening!! This intelligent, patient, kind, generous and wicked humoured man who knew me, all of me, was facing his biggest demons. The devil and his gang had knocked down the door. My husband went to war. I put a candle in the window to show him the way home.

Our friends often say, "Just to have a slice of what you two share." We work at it. It's not taken for granted. We are true to ourselves and each other. When you have lived with the devil as I have, you appreciate what you have. We are not perfect. Is there such a thing? Services for people like my husband are thin on the ground. Living in a rural community is not an excuse. We can talk to anyone in the world anytime, but to try to find a professional to help my husband was laughable. It made the experience of being diagnosed a walk in the park.

Years ago, after much debate and having faced the positive and negative

responses to disclosure, we decided not to tell a lot of his family. I'm not a wounded bird. Our fear was that they would turn their backs. We could - and have - accepted this from friends, but family is another matter. Damned if you do, damned if you don't. I told his mother that her eldest son was having a complete breakdown because I was living with HIV. She asked me months later: "How do you think I felt getting a phone call like that?" How does she think I felt making it?

When you have lived with the devil as I have, you appreciate what you have.

My husband went away. The judgements came thick and fast. I was asking for help and understanding, but HIV positive, heterosexual women in Australia are a minority. People sometimes don't realise what you go through as the HIV negative spouse of a HIV positive person. He is the one who shares my pain; my severe intolerance to therapy; the question of whether to have children or not; my tears; my heartache. For six weeks he went to war with himself; questioned the world and its workings. He had two guardian angel friends who helped and made no judgement. They listened and let him be. They let him fight it out with himself. Slowly his strength came back and so did his belief that I wasn't going anywhere. How could I? Shopping in Paris awaits!

It's 4am.

He can't get no sleep.

He saw the candle in the window and came home. ❶

Kerran is a positive woman living in Northern New South Wales.



i can do anything

by Margaret

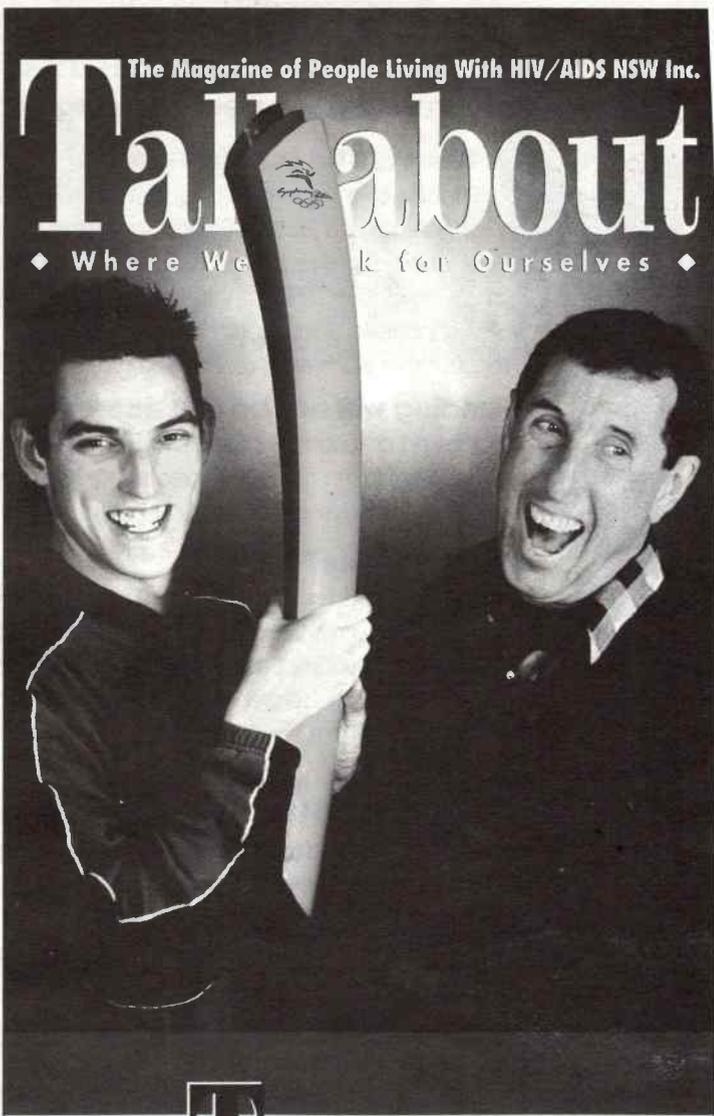
I am living in interesting times. My beloved partner is HIV positive, this fact has shaped my life for many years. However, in the Alice-in-wonderland of HIV/AIDS, because I am negative I am "the partner" and he is "the positive person". I wouldn't mind so much, except that in HIV speak, "partner" is the polite form of invisible person.

I live in two worlds. In one world, HIV is on the outside – people talk about it, doctors advise on it, clinics practice in it. HIV is all around. In this world my role as "the partner" defines me (why am I never the wife, the missus, the main squeeze?). I only occasionally get services in my own right in this world, but at least I can say what I need to.

In the other world HIV is on the inside; that is, inside me. Ironically enough not in those parts of my body that would make me positive and no longer a "partner" (oh dear, who is the partner then?), but in those nerve endings where I negotiate a world where HIV happens on another planet to other people. Here I am just a woman going about her business. Not an HIV care in the world.

Interesting times go on. While ACON has walked off with our cash and infrastructure, deciding that the smart money is no longer on HIV, those of us who are HIV (and straight) must just get on with it. There was a time long ago when I was the grieving widow, mourning a man who was not yet dead. Now I am reinvented as the wife of "Combination Man" (he-who-will-live-forever). If I can do that then I can do anything.

Margaret is not her real name.



The Magazine of People Living With HIV/AIDS NSW Inc.

Talkabout

◆ Where We Talk for Ourselves ◆

Talkabout

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com.

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... and pay us a visit @

www.plwha.org.au



The Bobby Goldsmith Foundation (BGF) announces a new and exciting program for people living with HIV/AIDS and poverty – The Ratten Fund

What is The Ratten Fund?

Thanks to a generous bequest from the late Victor Ratten, the Bobby Goldsmith Foundation (BGF) is launching The Ratten Fund. The Fund makes small one-off grants of \$50–\$5,000 to individuals living with and disadvantaged by HIV/AIDS for projects that develop skills and improve wellbeing. These may include ♦ Equipment purchases such as computers ♦ Back to work-related expenses such as clothes ♦ Recognised education and training courses and programs that develop new skills ♦ Any other reasonable request that will have a real benefit to someone's life

Funding will not be considered for the following:

♦ Ongoing or recurrent projects ♦ Equipment needing regular maintenance or replacements ♦ Projects that have already taken place ♦ Projects that normally are eligible for support from government authorities or other sources ♦ Employment or wage subsidy

Who is eligible?

To be considered for a grant from The Ratten Fund, you must meet ALL of the following criteria ♦ provide a doctors letter or medical certificate stating that you have advanced HIV/AIDS or that you are disadvantaged as a direct result of HIV ♦ be on a low income – for example Disability Support Pension or other form of social security benefit ♦ have little or no resources and assets or savings of less than \$5,000 ♦ not be working full time ♦ be a resident of NSW and have lived at your current address for at least three months

A Committee will meet quarterly to assess applications.

Closing date for first round of applications 15 November 2000

**For further information and an application pack please contact Ben Alfred at:
Bobby Goldsmith Foundation, Level 2, 9 Commonwealth Street, Sydney NSW 2000**

PO Box 97, Darlinghurst NSW 1300 **Telephone** (02) 9283 8666 **Facsimile** (02) 9283 8288

Email ben.alfred@bfg.org.au **Web** www.bfg.org.au (for information only)

The Bobby Goldsmith Foundation – responding to your needs. Providing direct financial assistance, supported housing, financial counselling and employment support to men, women and children directly disadvantaged by HIV/AIDS in NSW.

need a little boost?



WOMEN'S HIV SUPPORT PROJECT

Enquires regarding any of these events, please call Amelia or Vivienne at ACON on 02 9206 2012

www.acon.org.au

to disclose or not to disclose

The decision to disclose is sometimes taken out of your hands as **Rachael** discovered.



When do you disclose and to whom? Usually the question doesn't arise when you deal with health professionals. You assume training in prevention and care as a matter of course and a professional respect for patient confidentiality.

The majority of health professionals adhere meticulously to procedures around confidentiality but it was my rotten luck to get a worker who is either ignorant of the issues surrounding HIV or just plain ignorant.

I recently landed in the emergency room with severe bleeding from a miscarriage. Apart from the obvious danger, there were the unseen ones. Pregnancy meant possible exposure to the virus because my husband is HIV positive. I was only just suspicious that I might be pregnant. I try but I'm not perfect about safe sex, and as I lay in that emergency room, I couldn't help wondering if this was the time when my luck would end. Should I tell these people working hard at saving my life that it was possible that I might be a risk to theirs?

I decided that in fairness to everyone I would disclose. Disclosure would protect the medical staff and give further insights into my life and state of mind.

I had surgery, so I stayed for about a week in a women's gynaecological ward. I had pleasant chats with most nurses and one or two others who weren't so pleasant, but I didn't put too much store in that.

A week after I'd gone home, I found myself back in the emergency room with a wound infection. This time I didn't feel

The majority of health professionals adhere meticulously to procedures around confidentiality but it was my rotten luck to get a worker who is either ignorant of the issues surrounding HIV or just plain ignorant.

obliged to disclose. I was admitted to the same ward for intravenous antibiotic treatment. I saw several of the same nurses and some new. I was admitted there by one of the nurses I had found to be unpleasant the first time round. I hoped I wouldn't see her often during this stay.

Bored on my third day, I picked up my notes at the end of my bed to browse for interest's sake. I had done the same the last time. I was gobsmacked to find on the front page of the notes under "previous illnesses" the words "HIV positive partner".

There were several waves of realisation. Obviously every nurse and attending doctor (I think I had seen at least three doctors and nurses each day) knew of my husband's status. I had disclosed to medical staff in the emergency room that this was a possibility to consider, but it wasn't a proven fact. I looked at the name

of the person who wrote up the notes – and thought I'd found the reason this particular nurse was so snotty with me.

I lacked my usual steely nerve after a miscarriage and a general anesthetic, but I took a deep breath and marched to the desk. I asked to speak to a senior person in private and when the office door shut I somehow got across my point. The words "breach of my confidentiality" and "damage already done" were blurted out to her apologies. She agreed that I was correct and apologised. She promised to remove the information, create a new file and raise it with the particular staff member. "Did I want to see a patient representative?" "Yes" I said, "I did".

Along came Mr Patient Representative. He was apologetic and enthusiastic to launch a damage limitation course.

"I'm sure the nurse wasn't aware", he tells me.

Later I think, "Too right she wasn't aware." What was she trying to achieve by picking out this particular detail from deep in my notes? (I checked the information myself and found this to be the case.) Did she feel she had to warn all who came across me of a risk to them. I'll never know her motives.

I mentioned to Mr Patient Representative that rather than take the issue further what I really wanted to see was education. I hoped that the implications of this breach in procedure would be clarified to the nurse and she would have the opportunity to refresh her knowledge of the procedures surrounding patient confidentiality. He assured me that he would let me know the course of action taken.

I'm still waiting.

I'm not sure now if I will ever have the courage to disclose again in that sort of situation.

By the way, I tested negative last week. ●

Rachael is not her real name.

her royal shortness



Volunteers play a remarkable role in the care and support of positive people. **Pat Kennedy** has been a voluntary carer and organiser since the epidemic first emerged in 1984. She told *Talkabout* why she stays.

I have always wanted to write, but never thought of myself as the subject. It was hard knowing where to start. Should I write only about my involvement with people living with HIV/AIDS, or should I include some of the things that have moulded me? I decided I could not give an account of myself without going back to the past.

I was the third youngest of nine kids. Dad went to war when I was three and we were evacuated to my Mum's home town of Lanark, Scotland. Dad was sent home an invalid and died shortly after his return. There was a lot of discrimination against a pack of kids, poorly dressed and running wild while Mum worked three jobs. I grew up fighting for equality and fair play.

In 1984, when news of AIDS hit the headlines, I was enjoying being a grandmother to my two lovely grandsons and working in a business my husband and I had started. I had been ill for some time, including a severe haemorrhage in 1982 that required five units of blood.

The more I heard about HIV, the more concerned I became about the possibility that I'd received infected blood. After the reaction I received when I went to be tested, I wondered how I would have been treated if the results had been positive rather than negative.

Her Royal Shortness, Pat Kennedy has spent fifteen years as a volunteer in HIV/AIDS in Western Sydney. Her ambitions are to lose weight, see a Mardi Gras in the main streets of Parramatta and live to see a gay or lesbian couple legally married in a church of their choice.

An article in a magazine told of people dying unattended through fear. I rang St Vincent's Hospital to see what I could do. I heard about the Community Support Network (CSN) and made contact. I did much soul searching and made inquiries before participating in their training course. I little realised how my life would change that Friday night as I headed to Sydney. I was dubious about how I would fit in because I didn't know any gay men or lesbians.

What a group! One guy had a huge array of rings covering every part of his ears. Another had streaked his hair in what I later learned were the gay colours. A stunning lot and I learned to respect them all. I also learned that the discrimination against the gay community was worse than I'd imagined.

In my first year, all my rostered shifts were in the city with gay men. When I heard that there were people with the virus in Western Sydney I refused to take any shifts in the city. Within a week I had three people in the West, including my first positive woman.

I was shocked that positive people could be so alone in the city, but I was appalled by how soul destroying the isolation was for those in the west. I was also unprepared for the many issues facing women.

In most cases, women had few people they could talk to or trust. The majority were mothers and their greatest fears were for their children. They worried about confidentiality and the treatment of their kids, and what would happen to the kids if mum became sick. I became a carer for two little girls and saw that although HIV/AIDS can be devastating for a family, it is indescribable for children.

I'm a born organiser and it wasn't long before I coordinated most of the shifts for CSN in Western Sydney. It saddened me to see the terrible loneliness of people I met at the Westmead clinic. It seemed everyone had so much time on their hands and nowhere to go. Peer support relied on one support group held on Thursday evening but many PLWHA were too sick to go out at night.

If I was shocked that positive people could be so alone in the city, I was appalled by how soul destroying the isolation was for those in the west

The clinic became a defacto peer support and working with Pip Bowden we made it very social. I organised outings and events and was thrilled when a couple of guys started a news letter. I believe this was the start of what became the Friday Drop-in and is now The Haven.

I saw a big difference when AZT became available. Many suffered because of the heavy doses they received at the beginning, but others benefited from improved health and I found myself building lasting friendships. In the early days it was wonderful how people came together and gave so much to provide care and support to positive people. I loved being a part of that. It was good to watch

the gay community fight for their rights and take huge steps forward. It was sad to see greed and the lust for power rear its ugly head when funding became available to organisations involved with HIV/AIDS.

In the early days it was wonderful how people came together and gave so much to provide care and support to positive people.

I have always loved people and believe everyone has goodness in them. People credit me with work that rightly belongs to many people in the background. People call me Nanna Smurf, Her Royal Shortness, The Witch of the West and The Boss, to name a few. After fifteen years I still enjoy doing what I do and doing it as a volunteer. ●

The Haven Drop-in Centre offers free lunches, support and referrals, for PLWHA in Western Sydney. Ph 02 9672 3600

CSN Western Sydney is based at the AIDS Council of Western Sydney Ph 02 9204 2404

granny power

After the shock of being diagnosed hiv positive in her sixties, **Patricia** joined the Positive Speaker's Bureau determined to educate others.

I think I was accepted to the Positive Speaker's Bureau (PSB) because I'm a 65-year old grandmother and can give a different point of view about living with HIV. To me, this demonstrates that every walk of life is vulnerable to a blood borne virus.

I live 300 kms from Melbourne and five hours drive from Sydney. There are no support groups in my area so I rely on Sydney-based support groups like Pozhets, PLWH/A (NSW), ACON, Tree of Hope and their Melbourne counterparts for emotional support and information.

Our HIV doctor comes from Sydney fortnightly and we travel to Melbourne for specialist appointments. We need emotional support so we don't always visit the doctor for medical reasons. It's important to me that my husband and I can talk to our GP comfortably. It's been difficult to find a GP who has any knowledge of HIV/AIDS in this area. Our last GP has the receptionist from hell. Our community health nurse is great but travels a lot so is not always easily contactable.

When I received the invitation to attend the PSB training course I was feeling isolated, lonely, frightened and ignorant about the virus. I was desperate to talk to other positive people so I decided to apply.

The course was an awesome experience. I shared my story with ten tremendous people. We laughed and cried together. Despite our differences we were able to listen and talk to each other. We bonded with a common wish to fight our illness and educate others. At the end we were empowered with courage and expertise to fight back against this terrible virus that effects our lives so fundamentally.

A few days after completing the course I gave my first talk to three groups of Year 11 students at a Sydney High School. There were 140 students in each

group. I was nervous and expected trouble but my co-presenter, who had visited the school every year for the last six, spoke first. I told my story then begged the students to respect and protect themselves and to keep their partners safe. I sent them home to educate their friends, parents and grandparents.

You could have heard a pin drop. I was amazed at the maturity of the students. Afterwards we had tremendous feedback. Lots of students came up asking questions and thanked us for coming. One lad in particular wanted to hug me and we were both in tears.

I told my story then begged the students to respect and protect themselves and to keep their partners safe.

I sent them home to educate their friends, parents and grandparents.

The next night I was a co-presenter at a Training Course for Women's Refuge Volunteers. My fellow presenter supplied all the technical details and I told a grandmother's story of family discrimination and isolation.

My most recent talk has been to a group of palliative care workers in a regional centre. When I introduced myself and declared my status, I felt an incredible shock wave run around the room. There wasn't a sound throughout my presentation. My theme was what PLWH/A experienced before they got to palliative care, such as disclosure in a country area when you know everyone - who to tell,

support groups patricia has u

Positive Heterosexuals (Pozhets)

Peer-based support and referrals for positive heterosexual men and women. **Freecall** 812 404

PLWH/A (NSW)

Community organisation of positive people and friends. Advocacy, support and education for all positive people in NSW. **Freecall** 245 677 or

Ph 02 9360 6011

E-mail admin@plwha.org.au

Web www.plwha.org.au

The AIDS Council Of New South Wal

State-wide care, support and prevention services for gay men, lesbians and positive people in New South Wales.

Ph 02 9206 2000

Support services for women and families

Ph 02 9206 2000 **Freecall** 1.800 063

Email acon@acon.org.au

The Tree of Hope

Pastoral care and drop-in centre for positive people, family and friends.

Ph Sister Margaret Mines 02 9698 316

when to tell? The isolation, the stress, tablet taking regime, the side effects of medication and the inevitable breakdown of body functions. The hassle to keep up with friendships, the effort to make new ones etcetera.

One gentleman was very overcome as he realised he had been discriminating in his volunteer work. We re-assured him, he wouldn't have been there at all if he was not willing to learn and change his views on PLWH/A and gay men.

My next booking is at the Pozhets Annual Conference on November 25th. I am looking forward to this very much and hope to meet other *Talkabout* readers there. ☺

Patricia is a member of the Positive Speaker's Bureau.

HALC

HIV/AIDS Legal Centre

The HIV/AIDS Legal Centre is a community legal centre. We provide free legal advice and referral to people living with and affected by HIV/AIDS in NSW. A staff solicitor is available Monday to Friday from 10.00am to 6.00pm. Alternatively HALC holds an information night on alternate Monday evenings where volunteer solicitors give free advice sessions. We deal with topics such as superannuation, discrimination, social security, wills, power of attorney and more.

To make an appointment please call us on

02 9206 2060.

All information is kept strictly confidential.

HALC

HIV/AIDS Legal Centre Incorporated
9 Commonwealth Street, Surry Hills NSW 2010
PO Box 350 Darlinghurst NSW 1300
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AFTERNOONS

street

trials & tribulations



Things are shaking in the jungle this month, particularly with the arrival of our new project officer Barrie Harrison. Barrie has been involved with the Newtown garden from its beginnings and is an extremely keen gardener, so we are all excited that he has come to join us.

November is Community Gardens Month in southern Sydney. If you are looking for something fun to do over the weekend, why not come and join us at the Community Garden Picnic Day on Saturday 4 November. For the grand total of \$3, you can enjoy some live music, face painting for the kids, attend a garden pharmacy workshop (learn how to use fruit, vegetables and herbs as medicine), ecoviving demonstrations, a vegetarian BBQ and you may even meet a special guest celebrity gardener. Now, don't forget to pop in to the Street Jungle Stall and say hi.

Where? I hear you ask: UNSW Permaculture Community Garden, Rear of the Ecoviving Centre, 14 Arthur St Randwick.

See you there!

In the garden with Gladys

The CREST (Can Resistance testing Enhance Selection of Therapy) has now started. The trial is recruiting three hundred people from forty-five sites throughout Australia and New Zealand who have a viral load above 2,000 and who are considering changing their current antiretroviral therapy. It is hoped that the trial will be filled within a year and that interim analysis will commence after six months. If you think that you meet the criteria for the trial, ask your doctor about enrolment.

The purpose of the trial is to gather data about the possible benefits of choosing a new combination (when one is failing) based on resistance testing over choosing a new combination based on treatment history and current treatment guidelines. Trial participants will give blood for genotypic testing. The genotypic test looks at the sequence of the HIV protease and HIV reverse transcriptase genes in the blood samples and maps the genes for each person. The gene sequences are then compared with a library of 50,000 'virtual phenotypes' held in Dublin. Matching of genotype with virtual phenotype provides currently the most reliable information about which drugs a person is resistant to and which drugs are still likely to control the virus.

It may help to think of an HIV protease or reverse transcriptase gene sequence as a page from a book in a library. Each book (phenotype of the virus) in the library is associated with resistance to a particular drug. By finding which book in the library the page comes from it is then possible to say that that page is associated with resistance to a particular drug.

People on the trial can choose their next combination based on the results of the gene testing or based on their doctor's clinical judgement. It is also possible for someone on this trial to start a new combination based on the doctor's clinical recommendation and then to modify the combination when the results of the gene testing are known.

For further information about Trials and Tribulations contact the ACON Treatment Officers on Freecall 1800 816 518

women and complementary therapies going for gold

Women have special needs, particularly when it comes to health.

Mac McMahon offers a few tips on complementary therapies that work for women.

We've all seen Cathy Freeman win gold and how proud that made us feel. More importantly, she won hearts by her sense of who she was. Women are champions at nurturing others, and often put the needs of others before their own wellbeing.

Women who are HIV positive have more difficult choices to make and may have to consider what place sex, pregnancy, menstruation, parenting, children, childcare and often work with less pay (or no work) will play in their overall health care strategies. When it comes to health generally there is less money around and more stress if children and childcare (or lack of) are involved.

Most HIV positive women will need that little bit extra. The need to pamper themselves, and take breaks from stressful situations.

Complementary therapies are often put on the backburner due to time constraints and cost.

Traditionally the Chinese have long known that women need their own medications and have devised specific formulas for women's health, for example:

"Women only" spaces and support groups can provide an important support role.

Ba Chen Tang (Women's Precious Pills). These are generally used after childbirth when the mother needs more nutrients to replace all those lost. They contain nourishing herbs and treat anorexia, anaemia, lack of vitality and poor blood circulation. The nutritive and tonic qualities of this formula are also helpful in HIV illness for promoting sound digestive function, supporting the liver and spleen.

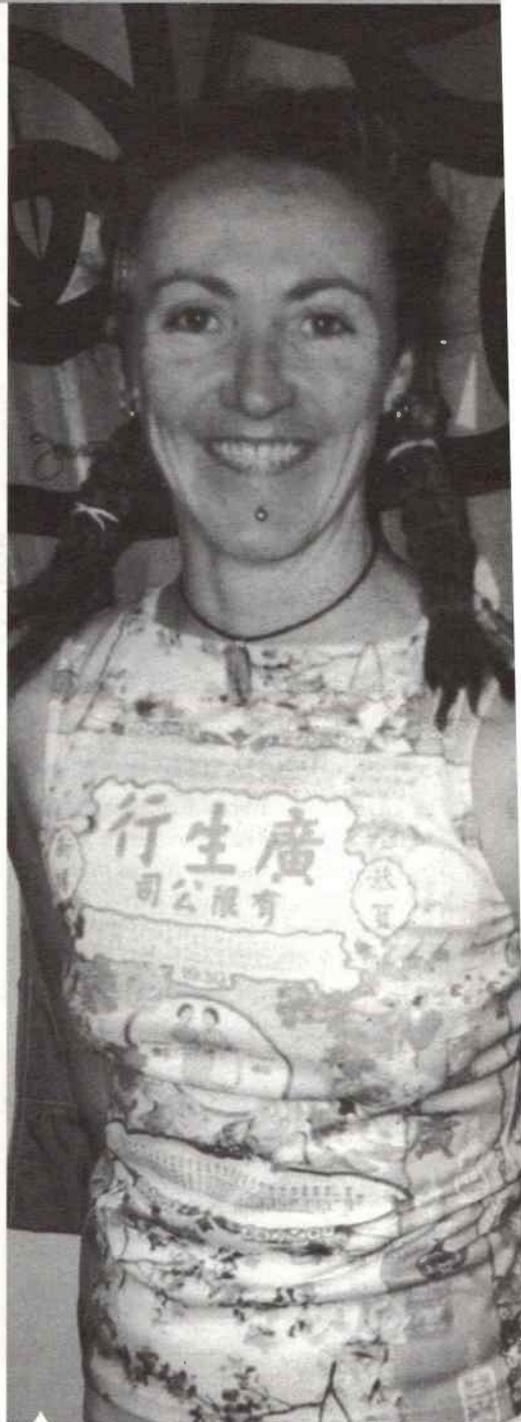
Acupuncture is particularly effective in dealing with discomfort and pain around menstruation as well as many other problems.

Stress, I believe is the greatest contribution to becoming unwell and yet it is probably the easiest to deal with. If you are stressed try any of these therapies:

- ◆ Massage, Swedish or Shiatsu is most beneficial for relaxation and muscle tone, there are other forms too that can also relieve tension and stress.
- ◆ Meditation in its myriad forms can mostly be learnt free, or purchasing a meditation tape can be good value.
- ◆ Tai Chi and Yoga are both gentle forms of exercise that relieve stress, promote flexibility, muscle tone and general well being.
- ◆ Nutrition and diet can play a vital part in your overall health strategy and can be a fun way to discover that "naked chef" buried deep inside.
- ◆ "Women only" spaces and support groups can provide an important support role.

So go for gold, take time out to discover who you are, to find out what your needs are, you deserve nothing less. 

Mac McMahon is a Complementary Therapies Treatments Officer based at The Sanctuary. Mac offers professional assessment and referrals to complementary therapists. For a booking call 9519 6830 between 2pm-6pm Mondays and Fridays, Email: complementarytherapies@hotmail.com or just drop in to The Sanctuary. The Sanctuary also offers massage, shiatsu and acupuncture. Bookings are essential – ask for Robert on 9690 1222. The Sanctuary is at 6 Mary Street Newtown.



Acupuncture and Chinese Medicine in general can help with the side-effects of medication, regulate gynaecological problems and promote relaxation and general wellbeing. Annie Black (above) is one of several professionals who offer their skills free-of charge to PLWHA. Annie offers acupuncture and remedial massage at the Sanctuary on Thursdays from 3-6pm. PLWHA who might want to make a private appointment at other times can contact Annie on 0407 407 058. 

about pregnancy

questions and answers

Advances in treatment of HIV have provided hope for HIV positive women who would like to have children.

Michele Goode reviews the most common questions asked by HIV positive women about pregnancy.



Q. What are the chances of passing on the virus to my baby?

The chances of HIV crossing the placenta and infecting your baby are around 20%. You can decrease this risk to less than two percent. Strategies to reduce risk include taking antiviral treatment (AVT) during pregnancy to reduce your viral load and giving your baby AVT for six weeks after birth (also called post exposure prophylaxis). You can also reduce risk by having a caesarean delivery and bottle feeding your baby with infant formula.

What AVT is available?

If you require treatment for HIV infection it should be optimal treatment for you, regardless of the pregnancy and involves taking triple combination therapy. The effect of triple combination therapy on your baby is unknown. However a number of women living in Australia (and elsewhere) have been through pregnancies on triple combination therapy and produced healthy babies. Certainly the efficacy of therapy for HIV prevention is well documented.

If you are not on AVT and you are pregnant, you should discuss the options with your doctor. A growing foetus makes all the major organs during the first twelve

weeks of pregnancy and putting off AVT until after twelve weeks may be something to consider. Remember that it is important to start antiviral treatment immediately if you have a high viral load. It is important for you and your baby that you reduce your viral load. The choice of treatment for you rests with you, but preventive treatment for the baby is strongly recommended.

Is a vaginal delivery safe for my baby?

Yes. If you are taking triple combination AVT and your viral load is undetectable, it is not clear that a caesarean section will provide your baby with any additional protection against HIV. The choice is yours.

If I decide to have a caesarean section, what should I expect?

You will either be under general anaesthetic or epidural anaesthetic for the caesarean section. A general anaesthetic will put you to sleep and your partner cannot be in the operating theatre. An epidural anaesthetic numbs your body from your waist to your feet, but you are awake for the caesarean section and your partner can stay with you. Most women

describe a sensation of pushing and pulling from a caesarean but do not feel any pain. Speak with your obstetrician about your options.

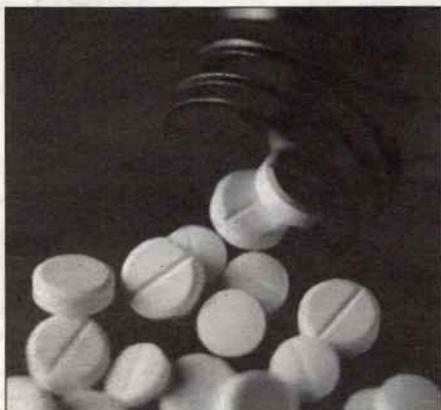
What happens when my baby is born?

The baby is towel dried and given to you for a cuddle. Any blood on your baby is washed off as soon as possible. Then the baby stays with you in your room. He/she should start on AVT immediately and continue for the next six weeks. Medication is twice a day in a syrup. Generally, babies get AZT syrup (and sometimes 3TC syrup) but this depends on your viral load.

How do I know if my baby is HIV positive or negative?

All mothers pass on antibodies to their baby. If you had measles or other infections, or were immunised in the past, your antibodies protect your baby. If you are HIV positive you will pass on HIV antibodies to your baby. This does not mean that your baby is HIV positive, it just means that your baby has the antibodies to the virus. It will take up to eighteen

getting all the facts



months for your baby to clear your antibodies. We use a detailed test called a PCR to test babies less than eighteen months.

We test the baby regularly in the first three-six months. Babies are considered uninfected if you bottle-feed your baby and, at three months of age, all the PCR tests are negative. However, it is important to continue testing until your baby is 18 months old or until HIV antibodies have cleared.

Bottle-feeding is expensive. Can I get financial assistance?

Yes. The Bobby Goldsmith Foundation (BGF) can help. Keep your receipts and give them to your social worker who will refer you for assistance.

Is there any other treatment that my baby requires?

Babies who are HIV positive are prone to pneumonia called PCP. PCP can be life threatening in babies. Initially, it's difficult to tell if a baby is HIV positive, so we recommend an antibiotic called co-trimoxazole (Bactrim, Septrim). This starts at four-six weeks of age, once a day. Treatment with Bactrim stops at three months if the PCR test is negative.

If you are pregnant or considering having a baby, it is still vital to get specialist care and up to date information, including an HIV specialist team, an obstetric team and a paediatric team. These teams work closely with you and your baby to provide the best care available. The HIV specialist can talk to you about your treatment choices; the obstetric team can talk to you about your pregnancy and the paediatric team will talk to you about your baby. So make sure you get all three sides of the story.

What supports are available to me?

You can contact the Paediatric HIV Service at Sydney Children's Hospital, Randwick. The service has a social worker, doctors and a clinical nurse consultant that can help you. ACON's family and peer support projects can also provide invaluable support. 

Michele Goode is a Clinical Nurse Consultant with the Paediatric HIV Service at Sydney Children's Hospital, Randwick. Ph 02 9382 1654



POSITIVE SPEAKERS BUREAU
A COMMITMENT TO POSITIVE SPEAKERS

'The Human Face of HIV/AIDS'

A training video presented by the PSB

will be screened on
community television Channel 31
on Sunday November 12
at 9.30pm



For further details about the PSB Project or to book a positive speaker, contact Paul Maudlin - PSB Project Officer at PLWH/A (NSW) Inc. on (02) 9361 6011

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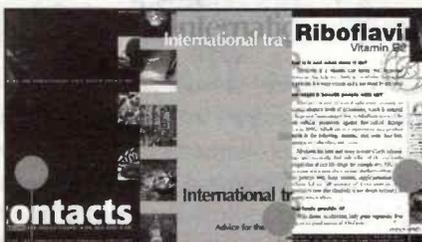
For HIV and STD treatment, testing and counselling as well as a full range of other sexual health services.



Livingstone Road Clinic
182 Livingstone Rd Marrickville
Phone for appointment 9560 3057



Canterbury Sexual Health Centre
Community Health Building
Canterbury Hospital
Phone 9718 7655



Other publications available

Contacts - our directory of HIV services

International Travel for PLWH/A

Riboflavin Factsheet

Produced by
the Publications Unit
of PLWH/A (NSW)

Ph 02 9360 6011
Email admin@plwha.org.au

\$ 2 Full member (NSW resident with HIV/AIDS receiving benefits) \$15 Full member (NSW resident with HIV/AIDS in employment)

\$15 Associate member (NSW residents affected by HIV/AIDS)

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- Individuals**
- I am not a member of PLWH/A (NSW) and/or I live outside NSW **\$30 per year**
 - I am receiving benefits and living in New South Wales (enclose proof of concession) **FREE**
 - I am an individual living overseas **AUS\$70 per year**

- Organisations**
- Full (business, government, universities, hospitals, schools etc.) **\$80 per year** Please specify number of extra copies @ \$30 each per year
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Donations Yes! I want to make a donation to PLWH/A *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 Money Order Mastercard Bankcard Diners Club AMEX Visa

Card number Expiry date

Signature Date

Please make cheques payable to PLWH/A (NSW) Inc. A receipt will be sent upon request. **Donations \$2 and over are tax deductible.**

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First name Last name

Postal address Postcode

Phone (h) (w) Mobile

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Thank you for your support



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diary



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Good looking 37 HIV+ Het Male living in Sydney, I'm a sharing and caring person, want to meet a HIV+ female for friendship/relationship. My first advert. **Reply 010800**

Hot 30 Gay boy HIV+, smooth, slim, well-defined gym fit body. Seeks attractive HIV+ guy to 35 years to share my life and bed with. You must be honest, fit, healthy, looking for 1-1 relationship. I live in Potts Point. **Reply 020800**

HIV+ positive women 42 looks much younger. Intelligent, easy going, warm hearted, attractive, and petite. I have a nice style about me. Love walking, movies, swimming, music and writing. Have a healthy lifestyle, passionate about life, also realistically optimistic, confidentiality important. North Coast, NSW. Would love to connect with a man who could appreciate these qualities. **Reply 030800**

Male 30s HIV+ maintaining good physical and emotional health (never been sick). 6ft - 83kg's. Is caring, affectionate and reliable. Lives in Melbourne. Is seeking a genuine, loving female. Also would like penfriends interstate. **Reply 040800**

Good looking, great body 34 y.o. male in Surry Hills. Recently diagnosed looking for male similar age, looks and interests. Hang out, share experience of becoming recently positive and have some fun. Enjoy keeping well, meditation, movies, drives and coffee. **Reply 010700**

Blue Mountains. Two friendly HIV+ guys (40's) living in the Blue Mountains invite other positive guy/s for day or stay overnight. Own room with double bed (Couple OK). Take this opportunity to visit the beautiful Blue Mountains. **Reply 020700**

Gay guy, 40s HIV+, genuine, DTE GSOH, good health, enjoys what life has to offer and makes the most of it. Seeking friendship with other gay and heterosexual HIV+ people. Could also do with penfriends. **Reply 010600**

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30yo Heterosexual guy HIV+, good in health 6ft, 66kg, Asian background lives in Sydney. Fit, honest, non-smoker, down to earth and caring, easy going and likes quiet times. Would like to meet heterosexual female with positive attitude 20-30, kind, honest, caring, with good sense of humour, for friendship/relationship. Nationality no bars. **Reply 030500**

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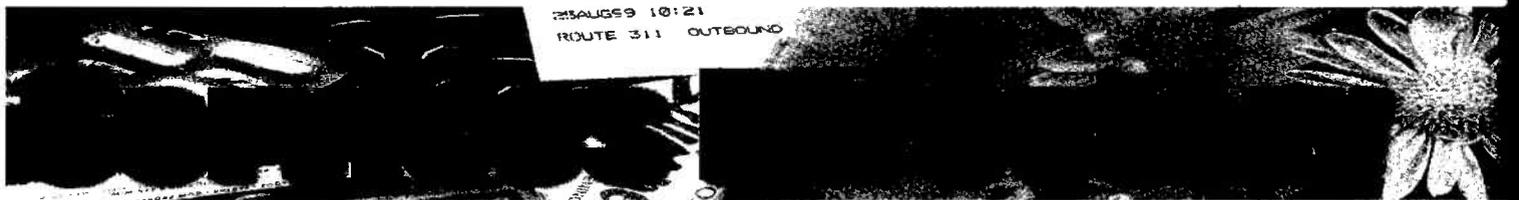
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Rating This site can link you to almost any HIV site!

This is the website of the International Community of Women Living with HIV/AIDS. The web page provides information about the structure and growth of ICW, their membership, and how to apply. You can connect with any of the sixteen representatives of ICW, who are elected by members to support other women and disseminate information across the globe. Read articles from the 13th International Conference on AIDS in Durban, find out about ICW's achievements and current activities, or order from the range of resources on offer. ICW has produced a *Survival Kit* that gives instruction about setting up support groups and shares experiences of women living with HIV about parenting, disclosure, sexuality, grief and loss, getting back to work, and having babies. This kit has been compiled by women from around the world (I was one of them) and helps women to share information that is culture and geographic specific.

www.home.aone.net.au/pos.women

Rating Fab site of Positive Women Victoria.

The site is based in Victoria and gives current information about the organisation, includes women's stories from Durban and also connects to *WeBoard*, a message board that allows you to talk or leave messages for other women living with HIV/AIDS. This site has a link to the HIV/AIDS Webcentral site, a sort of central interchange for HIV/AIDS. Webcentral has stories, images, an Australian directory of services, articles from *Talkabout* and links to Australian

AIDS organisations, international sites, treatment information, women's chat lines and a link to *Dentata*, a women's online magazine from the United States with the catchy slogan of "where positive doesn't have to be negative".

Both of the above sites will link you to www.thebody.com/ and www.hivinsite.ucsf.edu/resources/ or you can go there direct to explore articles, and find advice on testing or treatments, connect to discussion groups and hotlines and find information on public policy, legal or treatment advocacy. Click on *Community Resources* and read up on databases, find news agencies or social contact addresses. Neither of these sites is specifically for women but they certainly lead to women specific information, resources, magazines and chat rooms.

Foundation for Traditional Chinese Medicine

<http://www.ftcm.org.uk>

Rating Informative.

The home page links to *About FTCM*, info about this small yet dynamic organisation committed to promoting high quality research into the benefits, cost effectiveness and safety of acupuncture. To this end, they have a number of interesting research projects. My personal experiences with acupuncture, especially in regard to Peripheral Neuropathy, have been positive. The site tells you of the *Lower Back Pain Project* and a *Women's Health Project* that covers acupuncture for menstrual disorders. *Integrated Medicine* links to national debates, and *Acupuncture in General Practice* lists an actual case study of an acupuncturist working in this area. *Publications* is a comprehensive reading list, and *Links* sends you to various sites worldwide.

Acupuncture.com
<http://www.acupuncture.com>

Rating Very interesting and informative site, full of all the stuff you need to know on this practice, now widely accepted. Several pages including research and the site map are still under construction. You can join the site, and receive free email.

The *Acupuncture* link leads to a long and involved Subject Index, There were links from Back Pain through Irritable bowel Syndrome to Drug, Alcohol and Nicotine Addictions, a section on how westerners can understand acupuncture, student level information (I followed the 'Root, Branch and Smell of AIDS' link. It led to sensible, down-to-earth advice, I'm pleased to say). Also information on Specific Points in Meridian Therapy, Clinical Points Selections and Practitioner Level Information.

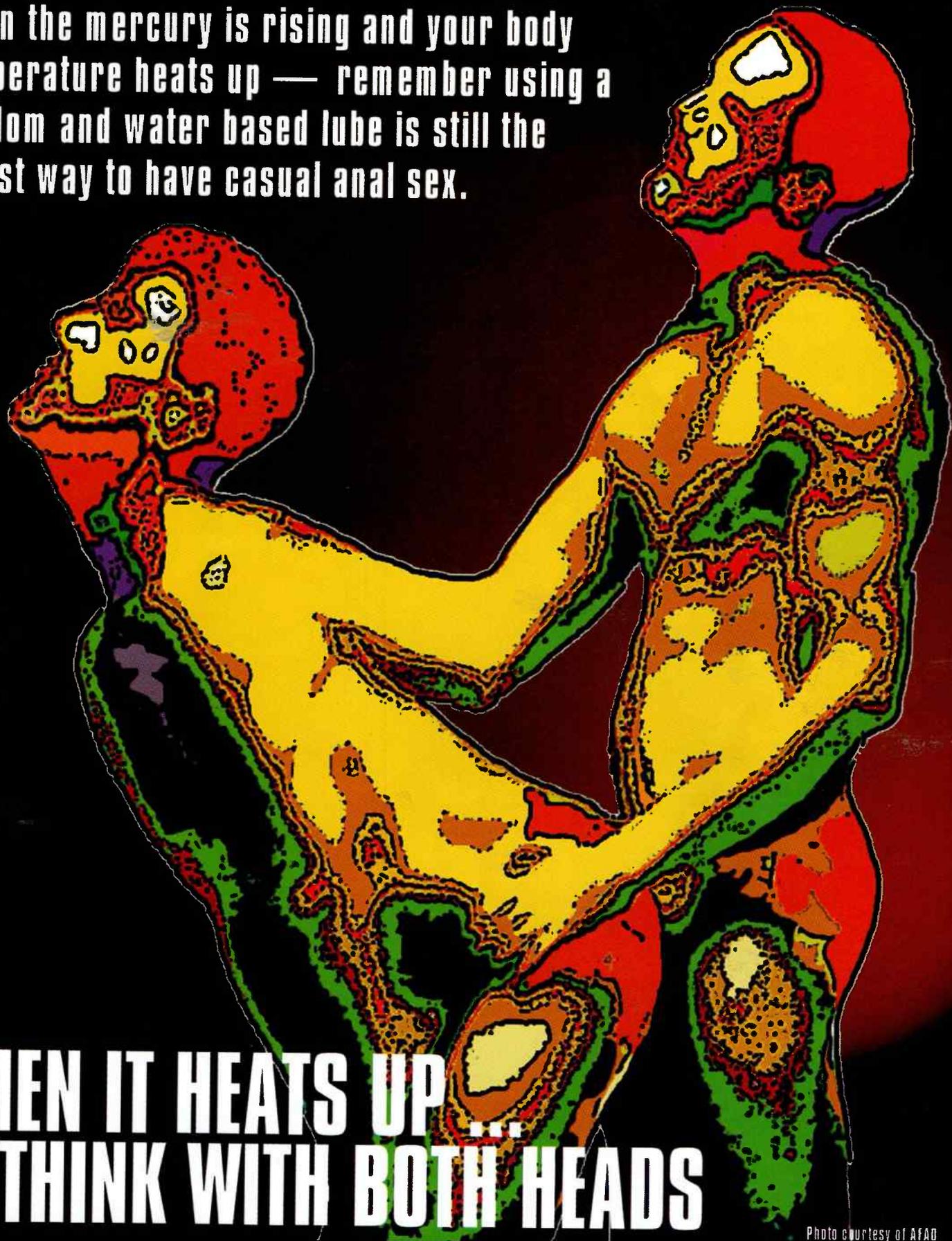
You'll find referrals to North America, Europe, Oceania (including, state-by-state listings in Australia), New Zealand, Carribean, Latin America, Asia, and the Middle East. *FAQ* is the now familiar Frequently Asked Questions, like "Can acupuncture cure my condition?" to "Where can I find Newsgroups, mailing lists and computer programs specific to Traditional Oriental Medicine?".

Albion Street Centre
<http://www.sesahs.nsw.gov.au/albionstreetcentre>

Rating Comprehensive

I remember having my first anonymous HIV test here just after testing was introduced in 1985. My, how things have changed but ASC is still around. I'm glad to say that their counselling techniques have improved greatly since those dim, dark days. A very large, informative site.

When the mercury is rising and your body temperature heats up — remember using a condom and water based lube is still the safest way to have casual anal sex.



WHEN IT HEATS UP... ... THINK WITH BOTH HEADS

Photo courtesy of AFAO

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lifestyles

10am – 3pm **sunday november 26, 2000**

the gardens café **cumberland hospital**

enter from hainsworth street, westmead

your hostess **miss vanessa wagner**



limited transport available **phone 9204 2400** by november 17 to book

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