

No. 77 July 1997

Talkabout

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

◆ Where We Speak for Ourselves ◆



Positive WOMEN



Convenor's Report



PLWH/A's COMMUNITY DISCUSSIONS over the last month have focused on several exciting projects. We are providing input to the PWA Living Centre's Transitional Steering Committee which is overseeing the Centre's devolution to an autonomous organisation. There will be a community forum in July to seek input about the Centre's future operations.

The Bobby Goldsmith Foundation's housing project has hit a last minute snag in the form of rising damp, preventing tenants from moving in, and PLWH/A in conjunction with other organisations are negotiating with the Department of Housing to ensure this problem is remedied. The

quality of accommodation in Bobby Goldsmith House must be nothing less than first class and tenants should not have to endure the noise, inconvenience and dust of renovations. On the treatments front, we are co-operating with other community organisations in advocating for wider compassionate access to 1592 (Abacavir), an important new drug.

Our constituents on the Mid North Coast remain without appropriate services while a solution is sought to last year's closing down of ACON's branch. This delay, while inexcusable, is a result of the complex negotiations between the many community and government organisations involved. As one of those community organisations, PLWH/A will keep pushing for a speedy return to service delivery for those currently without. The Mid North Coast Area Health Service has employed an AIDS Co-ordinator who may provide a service model for the Mid North Coast through ACON's Rural Project.

Larry Wellings has moved on from the Positive Speakers Bureau Co-ordinator's position. We thank him for his commitment to us and to the position and wish him well in his new endeavours. Paul

Maudlin is acting in his position for the next couple of months. Paul has been involved with the Speaker's Bureau since 1994 and the community will benefit from his experience and skills. We hope to make the PSB Co-ordinator's position full-time and expand it to include positive education, depending on funds being made available.

PLWH/A has applied for enhancement funding from the NSW Department of Health's AIDS and Infectious Diseases Branch. If approved, this funding will enable us to provide more community forums and will allow us to convert some of our part-time positions to full-time, relieving the pressure for the people currently filling those positions. Our staff and volunteers have been very busy and under a lot of pressure in the last month and I congratulate them on a job well done.

— Philip Medcalf



Jacqueline, Terri, Janine, Maryanne, Erycka, Robin and Vivienne brave the winds of Clovelly, where our cover photo shoot took place. Kath, Michelle and Heather were unable to be there but C. Moore tracked them down later. PHOTO: C. MOORE HARDY



People Living With HIV/AIDS (NSW) Inc.

Current committee:
 Philip Medcalf: **Convenor**
 Claude Fabian: **Deputy Convenor**
 Vincent Dobbin: **Secretary**
 Erycka Fars: **Treasurer**
 Chris Holland, Andrew Kirk, Bill Whittaker, Ed Moreno, Les Szaraz, John Trigg, Shane Wells

Current staff:
 Ryan McGlaughlin: **Co-ordinator**
 Luke Smith: **Finance/Admin Officer**
 Greg Allen: **Community Dev Officer**
 Jo Watson: **Research Officer**
 Robert Rogers: **A/Research Assistant**
 Paul Maudlin: **A/Positive Speakers Bureau Co-ordinator**
 John Cumming: **A/Talkabout Editorial Co-ordinator**
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This month's cover

By C. Moore Hardy. Erycka, Heather, Jacqueline, Janine, Maryanne, Michelle, Robin, Terri and Vivienne are proud to be positive women. Their cover photos send out messages that cannot be ignored: Positive women are everywhere. They have been invisible for too long. They are uniting, becoming stronger and empowered. In this issue positive women talk about spirituality, treatment choices, relationships and families. Special thanks to C. Moore Hardy: her cooperation and enthusiasm made our cover possible.

Talkabout

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Letters submitted to *Talkabout* or its editorial co-ordinator are assumed to be for publication in whole or in part unless specified otherwise. If you would like to be involved with *Talkabout* call John on 9361 6750 for the date and time of the next Newsletter Working Group meeting.

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B r i e f s

● The International Association of Physicians in AIDS Care (IAPAC) is launching a new quarterly publication for immunocompromised women called *Demimondaine* on July 1. While accessible clinical information is a primary focus of the magazine, its mission is to support women and help change the healthcare system to be more responsive to their needs. Details about accessing this first issue will be available in the next issue of *Talkabout*.

● Results of a study published in *The New England Journal of Medicine* show that treating infants with a combination of AZT, ddI and nevirapine has marked and sustained benefits in reducing HIV-1 RNA levels. The study examined 8 infants aged between 2 & 16 months, with maternally acquired HIV-1 over a period of 6 months. The authors report reductions in HIV plasma levels of at least 96% in 7 out of 8 patients, after four weeks treatment, with no clinically significant adverse events.

● Studies examining the safety and effectiveness of nevirapine monotherapy in reducing perinatal transmission are currently underway. Preliminary findings of a recent study of nevirapine in pregnant women and new born infants showed that a dose of 200mg given to the mother during labour resulted in a ratio of 82% between cord blood levels of nevirapine and those in the maternal circulation at delivery. Subsequent studies are also planned to examine the potential for reducing rates of perinatal transmission by administering 200mg to the mother during labour and 2mg/kg to the infants during the first 48-72 hours of life.

● Roche has applied to the US FDA for approval of its new formulation of Saquinavir (Invirase). The new formulation in a soft gelatin capsule form, provides eight to nine times the drug exposure of the current formulation. This will benefit those who commence saquinavir therapy in the future, but results of one clinical trial suggest that the new formulation will be of little benefit to those already treated with the previous formula of saquinavir.

● A recent study of mother to infant transmission of HIV-1 among non-breast-feeding mothers suggests that maternal viral load has minimal influence on the process. The study indicated that while the risk of transmission increased along with high viral loads, transmission and non transmission took place across the spectrum of values. The researchers concluded that maternal viral load alone does not determine vertical transmission of HIV-1.

- Jo Watson, PLWH/A Research Officer

HIV Futures - have your say

THE NATIONAL CENTRE IN HIV Social Research is planning the "HIV Futures" survey, beginning in June. The survey will investigate in more detail the issues of employment, relationships, and health. It aims to include large numbers of people from all over Australia, and will gather in-depth information about the conventional treatments and complementary therapies used by people living with HIV/AIDS.

It is called the "HIV Futures" survey because of the widespread feeling of a sense of change in the future of people living with HIV/AIDS, particularly in the light of new treatments. In addition to the "HIV Futures" survey, people will be invited to tell their stories in a series of face-to-face interviews about these aspects of living with HIV. These stories will complement the survey and provide more detail than is possible in a statistical survey.

Snapshots

OVER HALF OF ALL PEOPLE LIVING with HIV/AIDS use complementary or alternative therapies, according to a recently released community report titled "PLWHA Snapshots: Treatments, Accommodation and Employment". The report provides a "snapshot" of the longer-term issues of illness, housing and employment within the present, and changeable, context of advances in treatment. Participants in the Snapshots survey used a wide range of complementary/alternative therapies - from aromatherapy to mineral supplements to yoga. The most commonly used therapies were herbal therapies (including Traditional Chinese Medicine) and Vitamin supplements. Many of the PLWHA who completed the survey were also using massage, meditation, reiki, and acupuncture. When asked about sources of information about treatments, 15% of the people who completed the survey said that a naturopath

was an important source of information about treatments for HIV/AIDS.

One interesting finding from the Snapshots report was that some people tend to delay using anti-viral drugs until after they become ill, while people who use complementary or alternative therapies are as likely as not to begin using these therapies before they become ill. What the Snapshots report does not tell us, however, is why people take up complementary therapies, and what their reasons are for using complementary therapies. Given the fact that many PLWHA are using complementary/alternative therapies, it is important to understand what therapies people are using, why they are being used, and how effective they are.

If you are interested in participating in either of the "HIV Futures" studies, please call the National Centre in HIV Social Research now on our toll-free number: 1800 064 398. If enough people take part in the "HIV Futures" survey we will have a greater understanding of the treatments choices of people living with HIV/AIDS, and the National Centre will be able to use this information to provide better services to people living with HIV/AIDS.

- Richard De Visser

Fact Sheets for AIDS Dementia Complex

THE AIDS DEMENTIA AND HIV Psychiatry Team has been taking referrals since March. Based at Darlinghurst Community Health Centre, the team provides a statewide service for people with AIDS Dementia Complex (ADC) and people with HIV related psychiatric conditions. The team also provides assistance to enhance existing services and to help carers make the most positive response to frequently complex situations. Due to staffing and technical difficulties a proposed volunteer and carer education forum has been

postponed to a later time this year. In the meantime the team has prepared eleven fact sheets covering vital issues associated with ADC. They cover: ADC; HIV and mania; caring for people with ADC who have challenging behaviours or are experiencing emotional changes; suggestions for safety in the home; wandering; communicating with people with ADC; and a checklist for physiotherapists and occupational therapists who are working with people with ADC. For more information phone 93392078 or fax 93603678.

- Geoff Cole

International Women's Links



THE INTERNATIONAL COMMUNITY of Women Living with HIV/AIDS (ICW) has started publishing its own newsletter. If you are an HIV+ woman and would like to be on the ICW mailing list or would like further information contact: Vivienne Munro, AIDS Council of NSW, PO Box 350, Darlinghurst, NSW, 2010 or phone (02) 9206 2000.

Chiang Mai Conference

THE 8TH INTERNATIONAL CONFERENCE for People Living with HIV/AIDS 'Basic Needs - Basic Rights' will be held in Chiang Mai, Thailand from 5 to 12 November 1997. Sponsorship application and registration forms can be obtained from the HIV Women's Support Project or HIV Living at the AIDS Council of NSW, phone 9206 2000.



The Luncheon Club's Leather Pride Week Fashion Parade at the Lizard Lounge on May 15 was a creative and financial success, raising \$2 000. The event was a credit to the Luncheon Club diners and volunteers who participated. The cast (above) provided something for almost everyone - (although Linda Evangelista left in a huff!)

PHOTO: JEFF HUDSON

Positive Women funded

THE DEPARTMENT FOR WOMEN has given the AIDS Council of NSW (ACON) a grant of \$18,000 to support its work with HIV positive women and women affected by HIV. "The money will be used to provide skills based training for positive women so that we are able to facilitate our own support groups and become more skilled in offering a women-centred model of peer support," said Erycka Fars, Positive Women Peer Support Co-ordinator at ACON. "Peer support is very important for HIV positive women because it helps overcome the overwhelming sense of isolation which many positive women experience. We work towards raising women's awareness to prevent further HIV transmission and to support positive women with information care, support and resources. As well as services offered by the Women's Unit at ACON, the organisation is able to offer positive women a wide variety of services which they may not be aware of. We have a vitamin service, treatments officers who can give information about the latest drug treatments, a

free homeopathic service for positive women once a month by appointment, and other support and information for women and children."

Gay drug use survey

THE NATIONAL CENTRE IN HIV Social Research wants to hear from gay men about their drug taking experiences. The Gay Men and Drug Use Project has been commissioned by the NSW Health Department to explore meanings of drug use among Sydney gay men and generate harm minimisation recommendations based on experiences of drug users. The study is examining a broad range of drug use. One hour open ended tape recorded interviews will cover personal biography, the most recent occasion of drug use, drug use and sexual practices and their interrelationships. Participation in the study is anonymous and any information or personal details gathered in the course of the study are confidential. Findings will be published in report and article form, available from the National Centre in HIV Social Research, Macquarie University. Continued over page >

Briefs

● Check out the AIDS/HIV related links at this internet web site (<http://www.geko.com.au/~scotty/hiv.html>). They have been chosen for their relevance to people in Australia and for their innovative or outstanding content.

● The AIDS Council of New South Wales is updating their mailing list for participants in their Positive Retreats. The five-day rural escapes provide an informal setting for sharing information with peers, making new friends and relaxing. If you have attended a positive retreat and your contact details have changed, phone David (ph 92062117) to ensure you are kept up-to-date about upcoming barbecues and social events.

● Outreach is a community organisation in Sydney's west that holds fund-raising functions every six months. They donate the proceeds to CSN West, Westmead Hospital, Bethany Respite and the PLWHA drop-in centre. Their next fundraiser will be a play in November and they need cast members. No experience is required, just an eagerness to have fun. For more information phone Brooke on 92042404.

● *Passion - Celebrating Diversity on World AIDS Day* is the title for a Wollongong based art exhibition running for two weeks in November/December. The exhibition attempts to acknowledge and honour PLWHA and their continuing celebration of life, and will bring together artists living with or affected by HIV/AIDS. For many of them this event will be the first time they have expressed what the pandemic means to them within their community/communities. Our Pathways Inc, the positive living centre for PLWHA in the Illawarra/Shoalhaven area, is seeking expressions of interest from artists. Contact Penny or Cameron on 042 292944 for further information.

● The Review of HIV-Related Poverty Report, originally proposed by PLWH/A (Inc) in 1996, was endorsed by a Ministerial Advisory Committee (including PLWHA's Bill Whittaker) on 23 May. The Committee recommended that the Report, which was commissioned by the NSW Department of Health, be forwarded to the NSW Minister for Health Andrew Refshauge to seek his approval for its release. Although his approval was expected two weeks later, as this issue of *Talkabout* went to press the Minister had still not approved its release.

● Sydney's PWA Day centre has a vacancy for a part-time catering officer. The Centre provides lunch Tuesday to Saturday and breakfast Monday to Friday. For further information about this position phone Drew Mollineau on 93573011.

Phone Kate for a 1 hour confidential interview, (02) 9850 8043 or mail to: kireland@bunyip.bhs.mq.edu.au.

NUAA Complaints Pack

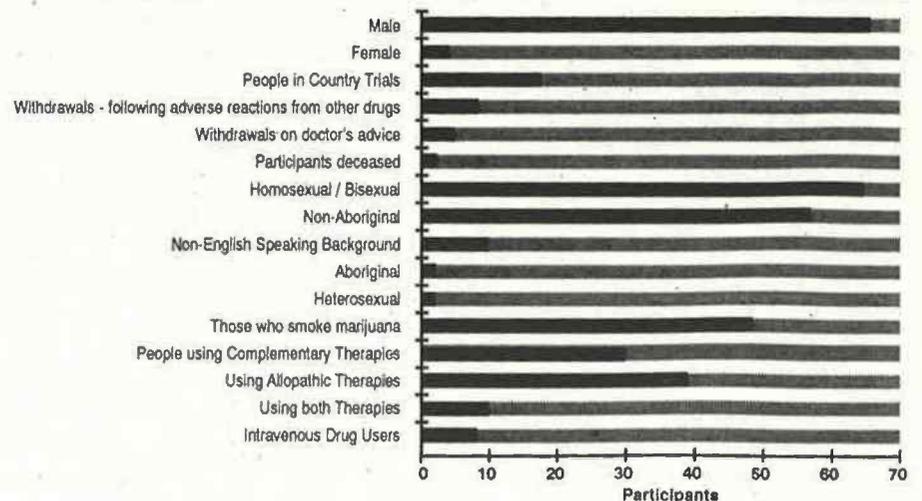
CHRIS PUPLOCK, PRESIDENT OF the NSW Anti Discrimination Board attended the launch of the NSW Users and AIDS Association (NUAA) Complaints Pack Manual on May 28. The resource will provide health professionals with information to assist their clients to lodge complaints when experiencing unsatisfactory or discriminatory service provision. The pack includes a guide to making a complaint in NSW and fact sheets detailing how to make such complaints to key discrimination and complaints bodies throughout NSW. NUAA plans to run a series of training workshops to assist health professionals use the Complaints Pack Manual. For further information contact NUAA on 93693455.

KM1 Trial conference presentation

THE FIRST SCIENTIFICALLY approved trial of complementary therapies for HIV/AIDS, the KM1 herbal formula trial, has been artistically interpreted for

participants at the International AIDS Impact Conference in Melbourne. They were privileged to view a poster, consisting of part of a triptych by artist Walangari Karntawarra. His work *The Milky Way Dreaming* depicts "My sister Nagamarra squirting her breast milk (the stars) across the galaxy. The breast milk settles on every planet and star in the galaxy, healing and nourishing every living thing." His permission for the use of this painting (which will mean that the poster is limited to one) shows the synchronicity of the herbal formula with aboriginal use of "bush tucker" as medicine. The poster includes photos of the last women to enter the trial, illustrating the trial's philosophy of inclusivity. Another photo on the poster is of an aged man (eighty years). At his own request and the discretion of the Trial Director he has become our long term study, just to see how he goes. The poster's family photo represents the global impact of the pandemic. AIDS does not discriminate but wipes out whole families. This family was one of the first registrations for the trial but they never entered the trial. The mother has since died of AIDS-related illness, leaving two negative children, one positive baby, and a positive husband. Further illustrations depict the support for the trial interstate and from people of non-English speaking backgrounds. Of course, gay men, who are most of the trial

KM 1. Herbal Formula Trial Statistic Graph Wave 1 & 2 Over a six month period



participants, are represented as well. Many of them have played a vital role through their contribution to the running of the trial in various ways and this contribution is recognised on the poster.

— Jan Kneen-McDaid,
KM1 Herbal Trial Director

New era for Sydney PWA Day Centre

"THE LIVES OF PLWHA HAVE changed dramatically over the last twelve months. We at the Centre must change with them. The process of moving to a community based non government organisation will ensure that the needs of PLWHA are met," said Drew Mollineau, President of the PWA Day Centre, in a June media release. With the appointment of Mr Joe Kelleher as the Transition Co-ordinator, the transition of the PWA Day Centre is under way. The transition is expected to take eight months and is being overseen by ACON, working with a Steering Committee comprising representatives from South Eastern Sydney Area Health Service, People Living with HIV/AIDS NSW Inc (PLWH/A), PRIDE and the committee of the PWA Day Centre. If you have any enquiries regarding this transition please write to the Day Centre Transition Co-ordinator, PO Box 350 Darlinghurst 2010, fax 92062092. The Day Centre is located at 14-20 William Lane, Woolloomooloo. Visit their web site on the internet at <http://rain-bow.net.au/~living/>

BGF Housing Project to open soon

IN THEIR ANNUAL REPORT FOR 1996 the Bobby Goldsmith Foundation (BGF) announced an operating surplus of \$828,492, compared with \$14,683 in 1995. The community based charity which provides direct financial assistance to PLWHA, released its report in



ACON's Erycka Fars accepts an \$18,000 cheque from MP Clover Moore on June 12. The money will provide training for positive women to facilitate their own support groups.

PHOTO: C. MOORE HARDY

June. Fundraising manager Richard Green said "BGF is now in a position where it can plan for growth, without being hampered by an immediate lack of funds. Next year our services will be growing because of the positive response many PLWHA are having to the new HIV/AIDS drugs and combination therapies. As PLWHA are living longer, they are BGF clients for a greater period of time. This is placing more demand on our services and is a major financial challenge for us. Our focus now, more than ever, is on fundraising." The Foundation has launched a Public Appeal to raise \$80,000 to furnish and equip its soon to be opened Supported Housing Project. The project will provide ten apartments to permanently house people with advanced HIV/AIDS. The Bobby Goldsmith House aims to minimise the impact of HIV illness and allow people with advanced HIV/AIDS to have a better quality of life and greater independence. The project's 10 apartments have already been allocated to tenants and, when furnished will provide safe, clean, secure and affordable housing with practical 24 hour support. To make a tax deductible donation or for more information phone 1800 651011.

1ST National Carers Conference

THE AUSTRALIAN FEDERATION OF AIDS Organisations (AFAO), the peak national organisation representing Australia's community based HIV/AIDS response, will be hosting the First National Conference for Carers on September 20 and 21 in Sydney. The conference will be open to all workers and volunteers in community based HIV/AIDS care and support services.

Topics proposed for the conference include:

- Community Based Care in a Changing Health Environment;
- Volunteer Management, Motivation and Retention;
- Self-care: Caring for the Carer;
- Returning to Work: Issues for PLWHA;
- Changing Needs/New Treatments;
- Multiple Grief and Loss;
- Dementia and Mental Health Issues;
- Supported Accommodation;
- Limits of Care; Legal Issues and Accountability.

Further details on the conference will be available by the end of July. To submit an expression of

Briefs

X ● NAPWA and PLWHA groups around Australia have written to Glaxo-Wellcome regarding the inadequacies of their proposed 1592U89 compassionate access program. The outcome of an international Glaxo company meeting, held in London recently, will be reported next issue. Australian treatment activists are in regular contact with US, Canadian, and European colleagues about joint lobbying actions and demands.

● The Pharmaceutical Benefits Advisory Committee (PBAC) approved Nevirapine for PBS listing on 6 June. Section 100 funding is likely to commence from 1 August 1997. Nevirapine (Viramune) is a Non Nucleoside Reverse Transcriptase Inhibitor (NNRTI), and is also approved for use in a paediatric formulation.

● The new soft gel formulation of Saquinavir (See World Briefs) is being filed with the Australian Therapeutic Goods Association (TGA) by the end of June. It should be approved by ADEC by the end of 1997, with consideration by PBAC in early 1998.

● The Nelfinavir compassionate access program has been operating in Australia for 3 months, but is in short supply outside the US. The manufacturer Agouron is being accused of not supplying sufficient quantities of Nelfinavir to the Australian agent Roche and this could cause an Australian supply problem. The situation to date is that because of the need to give priority to those PLWHA already on Nelfinavir, and not interrupt their supply, doctors are being advised that there may be some short-term problems in the processing of new applications of Nelfinavir. NAPWA and other organisations are monitoring this situation closely.

● La Trobe University is recruiting for participants in either of their two HIV Futures studies. One will be in the form of a written questionnaire survey, (but it's not as long as it looks - a lot of multiple choice!!). The other will be a series of face-to-face interviews in which people are invited to tell their stories about living with HIV. These stories will complement the survey and provide more detail than is possible in a statistical survey. Call toll-free: 1800 064 398 for more details.

● The next issue of *Talkabout* will have reports from the two major conferences being held in Melbourne: the Gay Educators Conference on June 18-20, organised by AFAO, and the Biopsychosocial AIDS Impact Conference on June 22-25, organised by the National Centre for Social Research. Both conferences promise to have some interesting presentations and some even more lively discussions to follow!!!

- Jo Watson, PLWH/A Research Officer

interest, contact Alan Brotherton, Policy Analyst, C/o AFAO, PO Box 876, Darlinghurst NSW 2010, ph 92811999.

ACON/CSN Illawarra News

OUR NEW ACTIVITIES INCLUDE A gay social drop-in on Saturday afternoon; a new Counselling and Health Advisory Team (CHAT) and an up and coming launch of a revamped carers support group and a positive peer support group. We have also just established an Illawarra Mardi Gras Committee to fundraise for next year's float. We have also had some staff changes. Sadly our manager, Jackie Braw has left us. Jackie was a fantastic manager with vision and a style which has seen the Branch grown and develop, both professionally and at a community level. We will miss her terribly. In the meantime I will be Acting Manager and Frank Vellozzi will be acting in my position as HIV Community Development Officer. We also welcome Emma as our new dynamic Administrative Officer. For enquiries call the Branch on (042) 261163. More details next issue!

- Cathy King
Acting Manager

Castaways fundraising success

SINCE OCTOBER 1995, CASTAWAYS, a major social club for the gay community in Sydney's west has been fundraising for Community Support Network West in Parramatta by holding regular dances at the Parramatta Golf Club. Recently, due to crowd numbers, the club has decided to make the dances a fortnightly event. Parramatta Golf Club, Park Parade, Parramatta is the venue for the dances on the second and fourth Saturdays of each month. Castaways ensures that the excess funds from these dances go directly to support people living with HIV/AIDS. The amount raised so

far totals \$11,173.85, a wonderful achievement! Castaways organiser Reg Caines says the dances are a good way to make friends, with new faces at every dance. Guests have full use of the club facilities, with drinks at club prices, bistro meals and an entry fee of only \$5 (on charity nights this increases to \$10). A resident DJ caters to the musical needs of guests. Phone Reg for more information: ph 96745903 or ph 014609757.

✻ Notices ✻

IN OUR PREVIOUS ISSUE, (MAY/June) the photo on page 23 of Emma King's art *Wretched Away* (1995) was taken by Amanda James. Thanks to Malcolm Jones for his help with the layout of that issue.



THE AUGUST ISSUE OF *TALKABOUT* will look at treatments and lifestyle. We don't just mean taking your drugs on time. We want to hear how people cope with the rigid schedule required for some drug regimes. We want to know about quality of life choices: is it worth having a low viral load if it means feeling horrible a lot of the time because of drug side effects?

We would love to hear from you before our deadline! (July 11)

NorthAIDS

Myrtle Place Crows Nest
Monthly Information Night
Monthly Sunday brunch
Lunch every Friday
and Wednesday

*All positive people
welcome*

Phone 9929 4288

Des Kilkeary Lodge
Respite care with respect
and dignity

Phone 9982 2310

ACON NEEDS YOUR FEEDBACK

This survey will help ACON (AIDS Council of NSW) set objectives and priorities for its services for the next 3 years. To meet the real needs of the community and people with HIV/AIDS we need your views on how we've done and what you think we should be doing. The survey will only take 10-15 minutes to complete and it's completely confidential.

You can mail it to us reply paid, or drop it at any ACON office. If you have access to the Internet you'll also find it on <http://www.rainbow.net.au/~acon/> Although we have achieved a lot in a short time, AIDS is not over yet and we need your feedback to continue to do the best for our community.

Please tick your responses and write in the space provided or on additional paper

A Knowledge of ACON

1. Have you heard of ACON or the AIDS Council of New South Wales?
 - yes
 - no
2. Where do you usually hear about ACON?
 - friends
 - gay & lesbian press stories
 - ACON advertising
 - ACON pamphlets & posters
 - doctor
 - other _____
3. What do you think is the main purpose of ACON?

4. How well do you think ACON fulfils that purpose?
 - Very Well
 - Well
 - OK
 - Poorly
 - Very Poorly
5. In 3-5 words what comes to mind when you think of ACON?

6. Please name any ACON activities, services or projects that you know of:

7. Please name any other HIV/AIDS organisations or services which come to mind:

8. Have you ever used an ACON service or been involved in an ACON activity or project?
 - YES (If yes which ones?)
 - NO.

9. Do you use any other HIV/AIDS services other than ACON?
 - YES (If yes which ones?)
 - NO.

B ACON's performance

10. How visible do you think ACON is in the gay and lesbian community?
 - very visible
 - visible
 - not very visible
 - invisible
11. Please list 3 of ACON's strengths:

12. Please list 3 of ACON's weaknesses:

13. Please tell us if you agree or disagree with the following statements:

	agree	disagree	don't know
i) ACON's services are of good quality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) It is difficult to find out about what services ACON provides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) It's easy to use ACON services when they are needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) ACON does not provide the services the community needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) People who use ACON services are made to feel that their issues are important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vi) ACON has been very successful in dealing with governments and political issues.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vii) People in the community do not generally trust ACON's advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
viii) ACON provides reliable accurate information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C The HIV/AIDS epidemic and you.

14. How important is HIV/AIDS in your life? And why?
 - very important
 - important
 - not very important
 - not important at all.

15. Is HIV/AIDS less or more important to you personally now than it used to be? And why?
 - less important
 - more important
 - the same.

16. What HIV/AIDS issues are likely to be important to you over the next 12 months?

17. Do you think HIV/AIDS is more or less important to the gay and lesbian community? And why?

less important more important the same.

18. Has ACON had an impact on your own life in any way? And why is that?

yes no.

19. How personally important is ACON to you? And why?

Very important Important Not very important Not important at all.

20. Is ACON less or more important to you personally now than it used to be? And why?

less important more important the same.

21. How could ACON become more important to you?

D What should ACON be doing

22. What 3 things should ACON be concentrating on over the next year?

23. How important are the following ACON activities:

	very important	important	not very important	not important at all
i) lobbying governments on behalf of gay men and lesbians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) providing support and care services to people with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) working to support the gay and lesbian community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) education with gay men to prevent the spread of HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) lobbying governments on behalf of people with HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vi) education with gay and lesbian injecting drug users	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vii) education and information for people with HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. Do you think our community needs any additional services on the following issues and should ACON be providing them?:

	does community need		should ACON provide	
	yes	no	yes	no
i) gay and lesbian health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) suicide prevention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) alcohol and drug use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) hepatitis C	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vi) general peer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vii) healthy lifestyles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
viii) Sexually Transmitted Diseases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ix) coming out groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) general counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
xi) other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E A few questions about you

25. Please give your age in years

26. Are you:

male female transgender

27. Do you think of yourself as:

gay lesbian heterosexual other _____

28. In order to make the best use of this information for planning and services we would like to know your HIV status.

HIV positive HIV negative untested

29. Have you ever been a staff member or volunteer of ACON?

yes no

30. What is the postcode of the town or suburb where you live?

Thanks for completing the survey.

Your feedback is important as it helps us deliver better services to you and our community.

Please cut out this page, place in an envelope (no stamp is needed) and mail to:

Reply Paid No 451, ACON, PO Box 350, Darlinghurst NSW 2010

Talkback



Sounds of Solace

ALL OF US WHO HAVE LOST LOVED ones might gain solace from a new song on Anne Murray's recently released double CD, "Australian Tour 97". It's called "Good Again." The lyrics say it all – and Anne Murray's sensitive interpretation will bring comfort to many who are mourning a relative or friend. It's on the EMI label – and well worth a listen!

Peter of Taree

Anvil Praise

LAST YEAR IN AN EDITION OF *Talkabout*, Anvil Computers offered 10 computer systems for HIV positive people at a very good price so they could surf the net in their own homes. Keith and I took them up on their offer, and we both have had many happy hours and some very 'fustigated' ones in cyberspace!

I also spend a great deal of time with my new hobby of exchanging emails with other gay men all over the world, thanks to this computer. Special thanks go to Torsten and Jacqueline at Anvil and to *Talkabout* for making this possible. If you would like to email me please do at kebo@bigfoot.com.

Adam & Keith

OS Feedback

WE REGULARLY RECEIVE "*Talkabout*" and find it the most informative and exciting journal! The February "Sex" issue contained some of the best articles to date written on this subject. Unfortunately, probably due to a printing gremlin, a number of pages in our issue were blank. I

would really appreciate it if you could send us another copy. Many thanks.

*Nicci Stein, Triangle Project,
South Africa*

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



*Talkabout, PO Box 831
Darlinghurst 2010*

Work Wanted 32yo graduate. Jack of many trades; hospitality, retail, warehouse, office. Recently updated PC skills. Need work Mon-Fri f/time, p/time, casual. All areas, all considered. Prefer busy, varied, relaxed environment. Interest in the arts. Healthy, active, sense of humour. Ph Steven 9516 1040.

Cross Word Solution

Here it is! The solution to the cross word on page 32 of our May/June issue.

Across: 1.SSO, 3.ban, 5.Dapsone, 10.sago, 11.OI, 12.dementia, 13.one, 15.queer, 18.amyl, 20.US, 21.ask, 22.fa, 23.tar, 24.gay, 26.Mac, 28.no, 30.fairy, 31.subtle, 34.alot, 35.of, 36.virus, 40.drag, 41.HIV, 42.poverty, 44.bone, 45.red, 46.ed, 49.pa, 50.Talkabout, 55.shame, 57.mo, 58.rib, 59.be, 61.best, 66.see, 67.prophylaxis.

Down: 2.Steam, 4.AZT, 5.dose, 6.poo, 7.sin, 8.ecstasy, 9.dealt, 10.Saquinavir, 14.ET, 16.Us, 17.ray, 19.grief, 22.far, 25.ACTUP, 26.mid, 27.is, 29.olive, 30.fa, 32.blab, 33.lo, 37.so, 38.death, 39.it, 40.diet, 43.yoke, 47.dam, 48.sob, 49.pi, 51.lobe, 52.arse, 53.bit, 54.TV, 55.se, 56.ma, 59.Bay, 60.is, 62.er, 64.ta, 65.as.

Olga Personals

Olga apologizes for not placing these ads earlier, but she has not been well. Now that her health is better she is eager to match you with your ideal partner!

Sydney Hello, Secret Lover! Bored! Lonesome! Sexy! Want partner (ASAP) supportive, caring or just need talk, intimately, verbal intercourse. Phone chat, late nite & beyond, privacy, safe, relax favourite accoutrements, fantasies. Exclusive liaison, most exciting, satisfying experience ever! Dominant, naughty, demanding welcome. Mail reply. 970705

Sensible, independent, 35yo gay male HIV+, has always wanted to be a father. Seeks likeminded HIV+ lesbian or woman to talk about issues. Non-smoker, quiet, down to earth lifestyle, no drugs 970710

Two +ve Sydney guys in a relationship. 30/40 interested in camping, travelling, computers, photography and the great out doors, looking for similar non-scene guys/couples. We are interested in visiting country guys too. We can communicate by Australia Post, e-mail, fax or phone. 970715

Olga Personals

How to respond to an advertisement:

- Write your response letter and seal it in an envelope with a 45c stamp on it.
- Write the box no in pencil on the outside.
- Place this envelope in a separate envelope and send it to: Olga's personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on. To protect your confidentiality, make sure the envelope is clearly marked *Olga's Personals*.

How to place your advertisement:

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

'Flickering Candles'



Attendances for the Candlelight Memorial are dwindling. This year's Memorial on May 4 attracted a crowd of only 3,500 people, compared with 10,000 the previous year. John Cumming canvassed some community responses about these changes.

TO BE HONEST, I HAVE NOT BEEN to a Candlelight Memorial. The difficulty I feel is that working in the area of PLWHA can be all consuming and going to an event such as Candlelight for me is too much. The grief that I feel is channelled elsewhere – debriefing at work, remembering at Camp Goodtime and talking to friends. These are very personal views and it is for many people an event which is both cathartic and educational. The attendance at these events reflect the importance it holds for so many people so keep up the good work.

Michele Goode
Paediatric HIV Services

THE WORLD OUT THERE SEEMS TO think we've been cured . . . I'm not sure whether this is better than their previous opinion (that we're all going to die)? The fact is that AIDS is not about death – as much as we miss our friends who've gone. AIDS for us is really about life, not death: it's about living with the virus, living in poverty, living in fear . . . thinking of AIDS in terms of "we're all going to die/live" ignores the reality that for PWAs every day we're alive is the struggle; death, if it comes, is often a relief. For 364 days each year I manage to pretend that I've been relatively untouched by HIV/AIDS. But when they read out all those names I can't pretend



anymore – there are too many familiar names, and even the unfamiliar ones, represent the people I never got to know, which is another tragedy.

Paul

THERE SEEMED TO ME TO BE JUST as many people as last year. Being at the front of the parade and watching all the people stream into the Domain was a moving sight for me as I sat alone under a tree and silently remembered close friends who have died over the years and the trauma that I still seem to go through each day.

Then I went out and partied.

Phill

SOME OF MY REASONS FOR NOT attending for the last couple of years:

1. It's always too damn close to Inquisition and Leather Pride (however that wasn't as much of an excuse this year).
2. I have seen merit in the past with the vigil because I have felt battle fatigued around HIV . . . somehow public displays of grieving assist you in doing it in private because you are still fighting to survive and have trouble with the whole grieving process . . .

Post combination therapy (pct) – I believe that we are all starting to come to terms with the fact that the war may have ceased at present (it may not be over but at least there is a respite) and with that comes the sense of grieving (and a whole bunch of other stuff like – what if our friends had lived another couple of months longer). I am finally finding myself grieving (a very unnerving process sometimes). I am finally able to do it in private, by myself, and start to cope with my loss. I don't need to



have my peers around me anymore to have a sense of loss (as I think Candlelight gave us a perfect forum to see just who wasn't there!!!)

I am sure there is still a need for Candlelight as people still need to be assisted along the grieving process. However I am finally feeling like it's working for me now that I am not fighting the war as fiercely anymore.

Buck

PART OF LIVING WITH OR BEING affected by this virus is dealing personally with our losses. Remembering the laughter, the heartache, the gossiping, the strength. Remembering our people . . . my people, who have died. You could say, even if the drugs get better still and the crisis does go away, HIV/AIDS will always be there as part of our collective memory, part of our learning, our lives.

Gerald Lawrence

I MAY BE SOMEWHAT POLITICALLY incorrect, but I have to admit that the reasons I did not go this year, but did go every other year, are as follows:

1. My bum got sore enough last year (from sitting on the grass) and if that bloody list of names got any longer I was going to need to bring along a deck chair.
2. It was bloody cold last year and the wind kept putting my candle out.
3. It has become a social event. I saw people last year who had brought the Esky, and the crystal goblets. The meaning is draining out of it.

It's not so much that it isn't entertaining and doesn't have a dance party to go to afterwards,

it's depressing enough having a potential future thrust in your face without being damned uncomfortable as well.

Campbell

IN PREVIOUS YEARS I HAVE BEEN more involved with people who were actually in the process of dying, and also I was full of concern/wonder about whether I would become another name. This year was different, tears came more quickly – and passed – and came again. The walk was more casual than previous years. The community spirit as people connect over the need to relight candles is glorious for me. Overall I was very impressed that the practical details were all handled so competently. But more importantly I was enriched to find myself part of a community ritual; for which there is this level of support and participation. It was awesome to notice that I no longer saw this event as preparation for my own progression towards death – but rather a time of reflection and honouring the past. It therefore gave me space to grieve more fully – both as an individual and in the context of community.

Kim Gottlieb

I HAVE ATTENDED OVER THE LAST four years, with the exception of last year. This year's low turn out could be about people feeling over HIV. I don't think it is all about new treatments, though it is possible that some PLWHA who are responding well and feeling better may now be starting to deal with loss and grief issues that they may have put on hold for several years and if so they may not want to attend Candlelight. Perhaps the event needs to change. I think a visible community event is good, but I personally favour a date and time for individual events to happen in venues across Sydney. This needs to be in connection with some community event that non-scene people can attend. Perhaps we don't need a march. My other thought is that the gay communi-

ty still does not want to discuss or deal with it's community response to grief and loss and because of this it will be difficult to get people en mass to know what they really want.

What about a public meeting to discuss these issues, or several small ones in different locations ie. Darlo, Newtown, North Shore, Parramatta – which could be partly organised by your friendly area health services in all those areas so that the maximum amount of discussion occurs? Gay Men Fighting Aids ran a Community Grief and Loss night two years ago and no one came. I suspect the same would be true today, but if you ask people to attend an open community forum to talk about Candlelight I think they will come – because it is an event and they can have something to say and this also gives them an opportunity to talk about community grief in a safe place.

Greg Millan, Senior Community Men's Health Officer (HIV/AIDS)

CANDLELIGHT IS AN EMOTIONAL and moving evening and possibly the most moving part is when we lay our candles down, with all the others, and the enormity of it all hits us . . . Has the memorial changed over the years? I think in the last two years it has, with not reading out all the names of those who have died. I can no longer read out names of people that are so special and it hurts. It's like they've passed their use-by date. Surely that one night of the year, we can take the time to read everybody's name out . . . I am extremely disappointed that the format has changed. I don't accept the argument that there are so many names now, all the more reason to read them out. If those of us alive and in mourning can't spend a few hours once a year in memory of those loved ones lost, then what's the point! At the Quilt we manage to read out over 2000 names in about 40 minutes. I would just like to see the format go back to the way it was. This year, a perfect night, no rain, not

that cold, but compared to recent years a very poor showing of people attending.

Heather Hornvedt, Parents and Friends of Lesbians and Gays

CANDLELIGHT TO ME MEANS ONE night a year to publicly acknowledge and raise awareness of all who have died from AIDS. It's a night to reflect and remember our loved ones and recognise their battle – the war they did not win. The meaning of the memorial has not changed for me over the years – it just gets harder each year. It's not a matter of being bitter but I would like to offer a few suggestions:

1. Assemble at Whitlam Square and walk to Green Park.
2. Read ALL names.
3. Do not have entertainment or speeches during the name reading.
4. Have music in Green Park during commencement of rally.
5. Have the Choir or soloist entertain when everyone is assembled with a short speech before name reading.

I feel like I am whinging but judging from the numbers this year, every avenue must be explored or otherwise Candlelight will be no more.

Carole Ann King, Luncheon Club AIDS Support Group Inc

THE MEANING OF CANDLELIGHT has not changed but there are ways it could be better. Many people find it too cold in the evening: why not hold it in a warmer month? Also the march is too long and tiring for many people. This year, by the time we reached Hyde Park, my partner and I were exhausted.

Malcolm Gleeson

Editor's Note: Michael Nelson, Convenor of the 1997 Candlelight Memorial, told Talkabout that ACON will pursue community consultation to follow up the response to to this year's Candlelight event.

Lack of policy for positive women?

This report, written by Bev Greet, Women's Spokesperson on the National Association of People with AIDS (NAPWA) was submitted to be endorsed and included in the annual report to the Australian Federation of AIDS Organisation. This did not happen and NAPWA has not, for the past two years, endorsed the recommendation for the National Network of Positive Women to be a full member of AFAO. For Positive Women, these recommendations hold no surprises, as they have been a long time in the making with very few being recognised or fulfilled. They have been developed over the years by Positive Women and at the 2nd National Positive Women's Conference, provided an opportunity to examine our needs and devise a comprehensive list of previous recommendations where outcomes still had to be achieved. At the 6th National NAPWA Conference, nearly twenty women met to update and revise the recommendations. Some of these have been taken up: women have welcomed the inclusion of gender in relation to national publications, especially Positive Living and the HIV Herald. With the disbanding of the AFAO Women and AIDS Working Group, and the reluctance from NAPWA to endorse the recommendations for an AFAO Women's Policy Officer, it means there is now no funded National Network or group to fulfil the Women and AIDS Working Group's strategic Plan. AFAO is considering funding some networks, and it is hoped that a National Women's Network will be one of those. Although NAPWA has a Women's Spokesperson, NAPWA cannot be a representative voice for women, because of the exclusive rule of membership to it. In 1997 women living with HIV are still unsupported and unresourced, therefore unable to further develop a National Network and a truly representative voice on the National AIDS agenda.

— Vivienne Munro

FROM BEV GREET,
NAPWA WOMEN'S SPOKESPERSON,
APRIL 19, 1997

IN THE LAST TWO YEARS WOMEN have represented nearly 10% of newly diagnosed cases of HIV. In particular there is concern about the steady increase in the number of heterosexually acquired cases of HIV among women, as acknowledged in the National HIV/AIDS Strategy 1996-99.

For women living with HIV there remain some major obstacles to them accessing the levels of support, treatment, and information services currently enjoyed by most gay men. This is partly due to the specific social consequences of HIV infection for women – the intense need for confidentiality, the subsequent isolation and stigmatisation.

However women's common experience of discrimination from gay specific organisations and their sense of alienation from state and national organisations representing people living with HIV/AIDS have contributed to women's needs not being met.

AFAO has made some progress in addressing women's needs in the last 12 months. The *Positive Living* newspaper and the *HIV Herald* have made commendable efforts to incorporate and maintain a focus on information relevant to women. We look to AFAO to build on these efforts and to build its profile among women by incorporating the issue of gender in its future planning and budget allocation processes. In particular we seek the following:

- funding of specific AFAO publications that target women's needs;
- a policy of gender inclusion in relation to AFAO's general publications;
- the appointment of an AFAO Women's Policy Officer;
- formal recognition of and organisational support for, the National Network of Positive Women as a full member of AFAO;
- formal advocacy by AFAO on behalf of its women con-

stituents in issues of access to treatments for women and children, prevention and education, and service delivery (such as gynaecological services);

- support for the representation of HIV positive women on state and national bodies such as the Australian Council on AIDS and Associated Diseases (AN-CARD);
- publication of a clear policy in relation to women's legal concerns in particular the continuation of attempts within Australia to introduce mandatory ante-natal HIV testing of pregnant women and restrict access to fertility treatments;
- the development of more effective national distribution strategies to ensure that women are able to access information (ie. beyond AIDS specific organisations); and
- lobbying for improved data collection and more research in relation to women and HIV.



NAPWA – representing women

VIVIENNE MUNRO'S COMMENTS, regarding Bev Greet's report, (see p14) and in particular the implications that NAPWA does not support or endorse positive women's issues, need some comment and clarification.

The AFAO April committee meeting was not an Annual General Meeting. The NAPWA report was not an annual report. The deadline for this report was the Monday before the meeting, which began on a Friday. Unfortunately, Bev's report was faxed to the NAPWA office at 5pm on the night before the meeting, by which time a NAPWA report had already been written and submitted. Bev was well aware of these deadlines as they had been discussed at previous NAPWA Executive meetings.

Rather than let the issues fall off the agenda because the fax had been submitted too late, I referred Bev's report to the full NAPWA Committee for consideration. This was especially important as the report makes a claim that women experience dis-

crimination and a sense of alienation from some NAPWA member organisations. State PLWH/A organisations also represent and involve positive women and therefore have a legitimate role in commenting on the recommendations proposed in Bev's document.

Also, some of the recommendations have not been raised with NAPWA before. All NAPWA Executive members are required to submit new policies for approval to the entire executive. While this could be seen as bureaucratic, it does ensure that policies are more than one person's opinion.

It is also not true to say that women have no structured entry point to ensure their presence on the National Agenda – this is the purpose of the NAPWA Women's Spokesperson position on the Executive. There are also a number of women representing state groups on the NAPWA committee.

NAPWA is committed to supporting the needs of all positive people – women, gay men, hetero-

sexuals, indigenous people, injecting drug users, sex workers, people from non English-speaking backgrounds. We have lobbied extensively on issues relevant to women and have played a major role in bringing about the changes to the *HIV-Herald* and *Positive Living* which are endorsed by both Viv and Bev. We recognise that the specific social consequences of HIV infection for women often impose additional burdens and we support positive women-specific support and information services. Advocating for a wide range of often marginalised populations with ever changing needs is a challenge, and open and honest discussion of our achievements and failures is a necessary part of this. Leaping to conclusions and making misleading accusations in public before even talking to us, however, are of little help to anyone.

Alan Brotherton
President NAPWA



Dr Marilyn McMurchie
Dr Andrew Pethebridge

Level 1, 229 Oxford St
Darlinghurst NSW 2010
Ph: 9331 7953 for appointment

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A Positive Dyke's Journey to Spirituality and Empowerment



I'M THE KIND OF PERSON WHO HAS always had a huge fear of death. I can clearly remember the despair I felt growing up in a strictly atheist household where organised religion seemed taboo and instead it was the strong will and achievements of humans that were revered. I was lost. I would sometimes ponder on death and "not existing ever, ever again" and would silently freak out at such "eternal nothingness". At school my bravado led me to become a rebel and a joking attention seeker and when I was fourteen I was relieved to discover the calming effects of recreational drugs and alcohol. And boy, did I go for it! Sometimes, without first checking out the situation, I would get into any drug, drink or person to try and escape the pain in my head and heart. At seventeen I had my first and major clinical depression, where I isolated myself in a darkened room at my parent's home and got into deep levels of self-hatred. My mates broke into the house one day to check on me. Nobody, least of all me, understood what was happening to me. I was treated psychiatrically for this episode and there began four years of manic-depressive behaviour – six months up, six months down. During this time with the

help of loving family and friends and my own iron will, I managed to attain an arts degree, to work in the field of film by day and to rage late into the nights. In one of my major depressions, I picked up heroin, which was at the time, a "saviour" for me. I really didn't care about anything at this point except getting a shot of "peace". Inevitably, such a wild existence and lack of self-protection took its toll and in June 1985 I was diagnosed HIV positive. The lifelong, fragile feelings of fear of death returned with a vengeance but I got on with my life, travelling overseas, working and generally playing around. Although drugs and alcohol were not working for me as well as they had in the past, I began to consume more and more. Then I hit a new sort of rock bottom. The notion that drugs and alcohol were blocking my spiritual growth flashed before my eyes, so I just decided to stop using, one day at a time. That was in 1990. By some miracle I am still clean and sober today. I have still experienced the old familiar depressions during recovery and I

don't know why I haven't picked up at times to try and relieve the pressure.

Six weeks ago I was admitted to Ward 17 at St Vincent's Hospital with really bad oral thrush. I couldn't talk, I couldn't eat and smoking cigarettes (my one true love!) was so painful. Three years previously I had progressed to AIDS. The triple combination HIV drug therapy I had subsequently started had not reduced my viral load or increased my Tcells. But the thrush improved with regular intravenous amphotericin treatment. However my specialist doctor informed me that it was his "hunch" that my viral load would never reach undetectable levels. I said to him "Well, you can't take my spirit from me, though." For some unknown reason, I felt no fear on hearing his comments about my state of health. Deep within me I realised that I had for too long put western medicine and doctor's opinions on a pedestal. And this was the end of the line . . . I needed to be able to fall back on something stronger than human brains and medical re-



search here. Luckily I was not in a clinical depression when I saw my specialist. I don't know how or why but instead of choosing to be consumed with the old fear and self-hatred I just let go . . . I was tired of fighting. I had to rely on the universe to hold me up emotionally, spiritually and physically. Since this time, the last month has been a blessing. It seemed that I was beginning to view HIV treatments in a new light. I am presently taking the last combination drug therapy that I am not already resistant to. I am monitoring the results with viral load tests.

I have done all that I've been prescribed to do to treat the AIDS but I really have changed at my core. I have started to look outwards, to step out of the control-seat sometimes, to be in the moment and appreciate it. My God, am I really grateful now for my existence? I sense that I do exist on this planet for a reason and as part of a whole, much bigger than me. I am special, but more importantly, just one of the crowd. I belong finally . . . this feeling gets stronger and stronger each day as long as I don't try and control any outcomes in my life.

Drugs and alcohol have never given me such completeness in myself. What is this? I don't know, but today I do want to live, to explore the world and to take care of myself. I hope I won't muck* up this newly discovered sense of peace. I really will try to take it gently and slowly as I "keep on walking forward" I want to temper the old instant-gratification dyke that was my old self and just "be" . . .

- Kath Valentine

* Although I am nearly 40 I changed this word to muck to please my father.

Love will find a way

IT SEEMS THAT WHEN A WOMAN becomes positive she often thinks: "That's it! No more Love Story! Who would want me?" I had a boyfriend when I found out HIV was living in me. First I thought he would run away. When I told him the news he answered "Marry me". Yahooo! I felt so happy, so lucky. We went out partying telling everyone we were getting married. Without saying a word about the inside story. (me: "I'm getting married to this man because from today I know I have nothing to lose." Him: "I'm marrying this girl to give her everything before she dies.") We had a good night out, then bed time arrived. My first HIV positive night - nightmare - my flesh could not bare any human touch. How could I have sex ever again? He said: "Don't worry about the sex, you are still my little princess." That's how he took care of me. Eventually I left him. I didn't want to offer him a "blank wedding". With time the thoughts of "sex never again" faded. Bed time swapped place with disclosure in the nightmare field. Relationships were my new wall. Fear, fear of rejection....

The idea of staying single was a hard one to get used to. My friends surrounded me with affection which helped. Anyway this is an old story, my life has proven to me that my fears were displaced.

The only reason I'm here today is to tell every single positive woman: There is someone out there waiting to love you for who you are.

- Erycka



GRAPHIC: DAVINA

Maybe Baby, I'll Have You?

Kate Griew, a qualified midwife practising at the birth centre of a large public hospital in Sydney, is completing a Master's degree in HIV studies. She describes midwifery as "so much more exciting than most other aspects of nursing because it's very positive and generally it's about people with life changes, at a very crucial point in their life, very similar to palliative care and HIV in lots of ways. People go through incredible life changes and are voraciously seeking information and taking control of their lives." She spoke to John Cumming.



GRAPHIC: EMMA KING

KATE FIRST EXPERIENCED THE impact of HIV when she was working in an STD centre in London. "It was in 85/86 so it was very early on in the epidemic. We had a lot of the intravenous drug using people from Scotland coming down and getting care where we were working. I had quite a lot to do with the young women who were coming through. It was very eye opening for me – it was very early in the epidemic, we didn't know anything really. And what we were telling women was what we actually now know to be incorrect. Now it depends on what stage of the infection, what the viral load is, all sorts of different impacts can happen."

Midwives

The role of a midwife, she believes, is to help women find what they need to resource themselves throughout their pregnancy. This might be something as simple as coping with "the minor discomforts of pregnancy", which aren't minor for the women who are suffering them, or it may be linking them up with resources or with people who can do their ante-natal classes. Midwives tend to view pregnancy as a healthy life event and a social thing, because the woman needs knowledge and sup-

port while she goes through the life change whereas an obstetrician might view pregnancy as healthy in retrospect.

"Where I work we get to know the family, and that's a very broad definition of family." She says. "We do have a number of gay women coming through and various different configurations of families. It's also about empowerment. It's about women choosing what they want and us helping as we can."

She believes informed consent is a patient's right, but that it doesn't happen in a lot of hospitals. "When people say 'Oh, I'm just going to take some blood, is that alright?' They assume a consent and they don't necessarily talk about what it is they're actually testing for. Whereas people in my field would say 'This is what we suggest that you have done, which of these do you want? What do you need more information about? Do you need to know anything?'"

Kate has looked after a number of positive women during their pregnancies, delivering their babies in labour wards. "I've had a number of women come to me for information about pregnancy and HIV but it's always been a bit word-of-mouth. I've helped give a

couple of information sessions at Family Planning and through that I've had a number of positive women contact me through the CLASH project."

She believes there are different reasons why women come to midwives. A lot of people are very fearful of hospitals and don't want to be over-medicalised, and other people want a natural birth. She has become aware of moralistic attitudes amongst health care workers in NSW, describing them as similar to attitudes about people who use drugs.

"Some midwives are quite happy to judge women on all sorts of things, not just whether they're HIV or whether they use drugs, but what they look like, or what their partner's like. I'd say doctors do that even more. And people read the media and we all know what the media's done with HIV over the last fifteen years. We're subject to that sort of exposure unless we're critical about it."

Treatments

Today a HIV positive mother is faced with the question of who to treat, herself or the foetus. Although combination therapy is widely accepted as the standard of care for PLWHA's, the risk of birth defects prevents pregnant

women from obtaining that therapy. Positive mothers can take oral AZT during their pregnancy and if they are having their babies in public hospitals, they can have intravenous AZT administered during labour to reduce the risk of transmission (although the birth centre where Kate works does not have these facilities.) "For most women there is a very strong desire to do the very best for her foetus", Kate says, "and I think often that will override what might be best for her." She agrees that putting others first is a feminine trait: "HIV puts a magnifying glass on the whole thing, adds more layers. There's a possibility that the risk of viral transmission can be as low as 13% or as high as 30%, without taking any drugs. For some people that might be an acceptable risk. I guess if it were me, I'd be concentrating on my viral load and state of health. Whilst the woman's in labour you want to do everything you can to minimise exposure of the baby to blood and body secretions of the woman, particularly blood. And if a woman's got a low viral load, not in the seroconversion stage where her viral load tends to be high, that's going to be a less risky period." She agrees that women must be quite overwhelmed with all these options. "For a lot of women whether or not they're going to get pregnant is never something you can be absolutely sure of. I think it's a very courageous decision, given the atmosphere."

Self-Insemination

Most people, she believes, equate pregnancy with unsafe sex, but there are ways around this particularly if the woman is positive and her partner is not. "Women's partners who are negative can ejaculate into a condom that doesn't have spermicide and use that themselves to inseminate. . . certainly doing it yourself is quite a simple thing to do. I've helped a number of my lesbian friends to get pregnant and it's very easy to achieve. I guess the issue is for a woman who wants to

get pregnant whose partner is positive and she's not. A bit of a minefield really."

Breast feeding

Another minefield is breast-feeding. The standard message for positive mothers in developed countries is not to breast feed, but in countries where people have no money or access to clean water they are told to breast feed. Kate agrees that it is probably best not to breast feed, "but that message also assumes that women do have access to money and water. For some women, depending on their living arrangements and economic status, that's just one more drain. Getting it together to boil the bottle - it's much cheaper and more efficient to breast feed. But in this country that's the advice that women are given."

She feels public education campaigns about HIV and women have missed their target: "The thing about telling them 'If it's not on, it's not on' assumes that women have power in their heterosexual relationships. My experience talking to many women in heterosexual relationships is that is not how they experience their life at all. Power is a very complex thing and for a woman to negotiate that raises all sorts of issues about trust. For young women at a specific time it's the last thing on their minds - well it may not be the last thing on their minds, but it may be one of the last things out of their mouths. Some women are incredibly tough about it and fantastic. But probably more than half the women I've ever talked to, it's not as simple as just saying to somebody 'You've got to use a condom' That's very, very simplistic. Particularly for women who are wanting to get pregnant, having safe sex and pregnancy don't go together. For every woman who gets pregnant probably 90% will have had unsafe sex. Only a very small amount will have used artificial insemination or in vitro fertilisation. The rest of them have had to have unsafe sex to get pregnant. The

education campaigns have assumed that pregnancy is not an issue. For a lot of women, particularly women from other cultures, Aboriginal women or Maori women, for a lot of cultures, including white cultures, child-bearing is a really important part of women's cultural existence, particularly races where there has been genocide, like aborigines. To tell an aboriginal culture 'safe sex', is equivalent to saying 'we're happy if your race dies out'. It's just not appropriate to look at it in that incredibly simplistic way."

Education

Kate feels the situation could be improved by lobbying decision-makers in large public hospitals to get education in place for midwives so that they can make it part of their everyday practice in the way they talk with women. "Hospitals need to be resourced so we can sit down and talk with women about these things, because that's not how it's set up at the moment. She regards being tested for HIV without the patient's knowledge or consent as tantamount to assault. "Testing needs to be a confidential process and within most hospital systems it's very hard to promise someone the confidentiality that they may require. Whenever someone does a test in a hospital they should be saying, 'This is the nature of the confidentiality that I can offer you. This is what will happen with the information should it come back positive.' The other thing is, if a woman got pregnant 12 weeks ago and she might have had sex two weeks into that pregnancy, she may have a negative HIV test result but in fact be seroconverting, and that can happen throughout the pregnancy. Having a check doesn't necessarily ensure that you're negative. Some healthcare workers tend to think that one test early in pregnancy ensures that that person is not infected. They haven't quite come to grips with what it means and what it doesn't mean. The only thing certain is the positive result." ♀

It's all about sex



WOMEN AND SEX. IT CAN BE straight, or queer, to plunge into pregnancy, woman to woman, to earn money, for fun, for love, for lust, just because it's time, and you're ready. You may want to engage and have the experience of flesh to flesh, reclaim, and feel you. Get down, get into it, and be empowered by knowing where it's all at.

Risks are relative. Obviously it is up to you and your potential sexual partner to decide what you consider safe, and acceptable, at the time. Known risks for HIV transmission and other STDS include male to female sex (vaginal, anal), especially when the male is HIV + or unknown status. Oral sex is debatable, according to who you listen to, and what you want to take on, so to speak!!!!

We do know that HIV is transmitted by infected body fluids passing into a person's bloodstream, so be aware of how together you and your partner's body, and mouth is, in terms of lesions, broken skin, etc. Menstrual blood is obviously a fluid which can have virus present.

Risk of female to male transmission is lower than the other way around, so many couples weigh up the odds, and make a negotiated choice, according to where they're at.

Low risks are just that, but there are no total guarantees, so if it's woman to woman apply some of the basic principles mentioned above. Don't get obsessed about latex if it's not your thing, but remember it's there if you need the protection. Latex can also be a good idea if toys and hard fucking are about to be shared, whatever the gender!!!

If a woman has HIV and wants to fall pregnant there are several options. Explore the possibilities and risks with some expert advice, but here are some general tips.

You and your HIV negative male partner may wish to have unprotected sex during your most fertile part of a cycle. Keep in mind that this poses some risk to your partner, and should be considered with all the information available.

You could consider self-insemination, using your partner's sperm, to avoid any risk of infecting him.

If your male partner is positive, or you are planning parenthood as a single mother, or with your female partner, sperm can be accessed through anonymous donor insemination, where it has been tested for any STD's or HIV.

Women self-inseminating with sperm from friends need to follow careful procedures to be sure it is

safe. The man should have two HIV tests at least three months apart, and avoid putting himself at risk in the interim, before the sperm is donated. An HIV test may not show a HIV positive result until three months after they were infected.

Above all, the woman is the one who decides how to manage her pregnancy and how she would like to plan her childbirth experience. Find supportive and experienced practitioners and carers who you have confidence in, and let us know when the champagne can be delivered!!!

- Jo Watson

Copies of *Sexual Healing - A Guide for Women with HIV*, produced by the UK's *Positively Women* are available from ACON. Phone 92062012 to request your copy.



GRAPHIC: DAVINA

Being A Positive Mum

Terrilee is a single HIV positive mother with 4 children, the eldest of whom is aged 7. Sarah, her 21 month old daughter, was born HIV positive. Erycka Fars asked her to talk about her situation.

What decisions did you have to make when you knew you were pregnant?

We found out about Sarah's status when she was 18 months old and I didn't know my own positive status until we found out she was positive. I didn't really have to make many decisions when I was pregnant because that was already over and done with.

How's the baby's health now?

She's been on treatment now for about three months and since then she's gone ahead in leaps and bounds. Her Tcells are up from 530 to 1000, and her viral load, which was in the millions, is down to 66,000. But she still develops pneumonia every few weeks and has to go into hospital. She's got encephalopathy (inflammation of or damage to the brain) so that's caused a lot of developmental delay. Her general health is much better than what it was a few months ago.

Do you mind if I ask whether you were offered a HIV test when you were pregnant?

No I was never offered a HIV test and wish I had because we might not be where we are now. But maybe I just didn't look as if I was a candidate for HIV. I think everybody should be offered the option of a HIV test because the choices that other women have to make through their pregnancies about whether to take AZT and things like that are things that I

should have been given. I should have had those choices for my daughter, if for no other reason than she could have been a child that was saved from having HIV. It should have been offered.

Could you explain which drugs the baby takes?

Sarah takes Bactrim, AZT and 3TC, in the form of syrup. It's pretty easy to administer for her because she's had a naso-gastric tube (a tube passed through the back of the nose into the stomach to allow direct feeding) for the last two months so that hasn't been too difficult.



GRAPHIC: EMMA KING

What's the major problem you've experienced getting effective treatment for your baby?

It's been pretty hard with her having the brain infection. We've wanted to get everything we can that crosses the blood-brain barrier. And we've given her what's available now through her having AZT, but there was another protease inhibitor that we wanted to get that's available in the US and not available here and we've had lots of problems trying to get that.

The drugs that are available elsewhere aren't as readily available here. That's been one of the main problems. We want to do as much as we can as quick as we can and the system is holding us up.

What would you say to a HIV positive woman who's thinking about having a baby?

Think about it a lot. They'd have to consider a lot more than they think. There's things that I'd want them to ask themselves. They wouldn't want to think about the worst side of it. Everyone wants their child to be born healthy but if you're positive the chance is there that that's not the way it's going to turn out. I'd probably advise them to talk to a positive mum. The trials and tribulations and everything that has come with having a positive child and having three other children to look after have been at my own expense. It is very, very hard. To think that I have to care for my children and for my daughter, who's positive, and to have to look after my own health as well is something that I think about a lot. I think I'm a very realistic person so I look at the good side and the bad side and weigh up the pros and cons. There's lots of things to take into consideration. In a lot of situations your kids come first and you always come second. It would be a hard decision and I don't think I'd like to find myself in that position. To me it's either giving life or taking life away and I don't believe in taking life away. So I think personally I'd decide to take the risk. I think that the precautions that are available now while you're pregnant are very promising. They cut (the possibility of transmission) down to 8% and that to me is good statistically. But it would be a very hard decision.

♀

Women call CLASH

by David Barton
Coordinator of Project CLASH
- a support group for positive heterosexuals

SINCE 1993, HETEROSEXUAL HIV+ women have been talking about life with HIV to the Heterosexual HIV/AIDS freecall phone line (Project CLASH, Freecall 1 800 812 404). Their stories give us insights into how their experiences can differ from those of other PLWHA in the HIV/AIDS communities.

Relationships

They have been single, married or widowed. Some have had children, some lived alone and others were in a live-in relationship. Their ages have spanned the teens to well into middle age. Most of them have a relatively long HIV history - 7 have been HIV+ since 1989. Several women lived in a household in which both they, their husband or children were HIV+. Some women had lost a husband to AIDS. One caller's partner had suicided. Women who were HIV negative also contacted the freecall service because they were just starting or already in a relationship with a HIV+ male. They asked for information for themselves or their HIV+ partner on suitable support services.

Location

Most lived in Sydney and the western suburbs but others called from the Central Coast, Wollongong, country NSW and the ACT.

Community Support

Women's contact with other HIV+ heterosexuals through the phone line didn't come through their community. These women first found out about the Heterosexual HIV/AIDS phone service while visiting a hospital or were referred to it by ACON. Several women had previous drug-

related problems and kept away from support groups because they found on visiting them that other PLWHA in the groups were still using drugs. In a few cases heterosexual women commented that other PLWHA services for women were strongly linked with lesbian or "hard-core" feminists. They felt uncomfortable confronting these issues in the services as well as dealing with their own HIV+ condition.

Many callers spoke of difficulties in approaching support services as they felt their sexual preference precluded them from being eligible. Most HIV/AIDS pamphlets, brochures and posters did not mention heterosexuals being infected.

Isolation

Isolation and stigmatisation affected many callers and made confidentiality their greatest concern. They preferred to remain anonymous and would only talk about themselves if they were sure it was another HIV+ person who was listening. In general all women said they felt isolated and were glad to talk with another HIV+ heterosexual. Most had not met many other PLWHA and it was not unusual to be told that this was the first time they had spoken with another HIV+ person.

Nearly all attached great importance to their emotional health and to ways of coping better in their daily lives. Their greatest loss since their diagnosis was their social life; they wanted to meet other PLWHA so that they could have fun with the freedom of being open about their status and be supported by people like themselves. One caller said that to meet and "get info from people in the same boat" helped her to accept her HIV+ status.

They said that disclosing their HIV status in the heterosexual

community was extremely difficult and very confronting. They all feared rejection. Their greatest fear was being "found out" by their family and friends.

Most HIV- women called CLASH because they were worried about being alone or having to approach services for help, or they needed help in interpreting test results, finding safe sex practices or getting their HIV+ male partner to a suitable support group.

Treatments

When talking HIV medicine many asked about drug trials for women and how positive women could find better information about their HIV symptoms. They also showed a high degree of interest in alternative therapies, meditation and relaxation. Sometimes they rang up for a talk about their partner's treatments or if their partner had been admitted to hospital.

In Conclusion . . .

It seems clear from the women's stories that HIV/AIDS groups do meet a large proportion of their needs. However it also seems from these stories that a number of heterosexuals living with HIV/AIDS feel many of these services are remote, do not connect with them as heterosexuals and as a result leave them feeling unsupported.

Recent data from the National Centre in HIV Social Research:

- The total number of cases of heterosexually acquired HIV is over 1000 (625 men and 438 women).
- 8% of HIV infections are attributed to heterosexuality.
- Last year one in six (16%) of new infections were attributed to heterosexual transmission. Of these infections 41% were women.

(Data supplied by Richard de Visser and Doug Ezzy from the National Centre in HIV Social Research)



sheet

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TREATMENTS, RESISTANCE and a whole lot more

Sonia Lawless presented a paper on Barriers to Treatments for Women Living with HIV/AIDS at the National Conference on Women and HIV: Innovation for Care, Policy and Prevention, May 4 -7, 1997, Pasadena, Los Angeles, California, USA. She writes about her impressions of the conference.

THIS CONFERENCE WAS TIMELY because we are at an important juncture in HIV/AIDS epidemic. In Australia, told as we are that "based on epidemiology" the epidemic is within the gay male community, it is easy to be lulled into a false sense of security. However in neighbouring countries like Papua New Guinea, Thailand and India, women compose the fastest growing at-risk group for HIV infection. Today women account for almost half of all cases reported world wide and 17 percent of the cases reported in the US. While HIV related death rates are down in the USA and in Australia, deaths amongst women have risen. It is apparent that HIV/AIDS disproportionately affects women of colour, women from developing nations and women who are socially and economically disadvantaged.

Informed by the new opportunities that now exist to reduce the morbidity and mortality of HIV disease in women and children through early detection and treatment, the conference organisers and participants felt a sense of urgency. The importance of disseminating this new information to infected and affected women, to health care providers, researchers and to society as a whole was a driving force for this conference

and for many of the women attending.

The conference program included sessions, symposiums and posters on subjects such as;

- 1 Clinical Manifestations of HIV Infection in Women,
- 2 Opportunistic Diseases in Women,
- 3 Treatments (which included use of Antiretrovirals, Chinese Medicine, Complementary and Alternative Therapies),
- 4 Clinical Trails,
- 5 HIV/AIDS and Older Women /Younger Women,
- 6 Mental Health and Treatment for Women Living with HIV,
- 7 Children and Families,
- 8 Reproductive choice,
- 9 HIV Testing including Mandatory Testing,
- 10 Prevention of HIV and AIDS
- 11 Policy,
- 12 Peer Education,
- 13 Women who have sex with Women, HIV in the female genital tract (including Pap Smear Abnormalities,
- 14 Female Condoms and Topical Microbicides.

TREATMENTS: Clinical Trails, Research and Access to Care:

These topics produced a level of protest from the conference participants and dialogue between researchers, presenters of "state of the art" papers and women living with HIV/AIDS and their supporters that I have not experienced at a "scientific gathering" conference before. Women raising the issues were treated with respect from both the other participants and the speakers that were being challenged. The eye ball rolling, sighing and walkouts of "profes-

sionals" that usually occurs at conferences when a protest or challenge comes from the floor did not seem to occur. This did not mean that presenters were not put on the spot or felt awkward but they were prepared to deal with women's questions, challenges and anger and to show some accountability. For example, when research data was presented about the role of AZT, particularly in perinatal transmission, women challenged the speakers about the findings, the development of resistance and how that would effect both their own and their children's access to other treatment options and about the access to care and follow-up that the trail participants had been "promised" prior to entering the trial. Concerns about side effects in their children were also raised and the suggestion that there were no side effects in mother and child where passionately challenged by women who had participated in the trails. Researchers who also presented data on a plenary panel on Antiviral Therapy: Basic Science, Clinical Care and Policy and presenters on Perinatal Transmission were challenged about the results they presented on how many, if any, women were in the trails, whether the trail was concerned with the women's health and well being or more interested in whether her child or partner will become HIV positive. One message that come across loud and clear is that there is little support for women with HIV+ children who have "failed" research and trails.

The after taste:

The conference and the networking that goes with such gatherings validated for me the strength, compassion and beauty women possess, individually and

collectively. It was a reminder that we should not be complacent about our rights and that there is plenty of space and a need for creative expressions of anger, activism, resistance and direct action. It also brought home to me the continuing lack of policy related to women and HIV/AIDS in our region and more specifically in Australia. Although the USA still does not allow needle exchanges and is only now starting to consider "harm reduction" it is in the very early stages of developing a National Women and AIDS Strategy. It is hard to comprehend why we still have no Women and AIDS Strategy in Australia, no women-specific HIV/AIDS research and women living with HIV/AIDS are still struggling to get information and non-judgmental care.

Networks, Peer Groups and Communities

The role and power of networking and peer based organisations can not be underestimated. It became clear that information is still not getting through to women in many regions and states. As the 13th International AIDS Conference approaches it is time to start organising and agitating to get women's concerns onto the agenda. Also, a conference on Global Strategies for Prevention of HIV transmission between mother and child has been organised for September in Washington USA. Much lobbying and work needs to be done around this conference agenda as mandatory testing of pregnant women is a high priority.



If you would like to join:

- The International AIDS Society Women's Caucus or International AIDS Society Lesbian and Gay Caucus, contact Sonia Lawless at ACON ph 92062049.
- International Community of Women living with HIV/AIDS contact Vivienne Munro at ACON ph 92062083.
- To contact Positive Women Support ph 92062012 or 92062058.

My thanks go to Women Alive and all the other groups and woman that sponsored and organised events and gatherings within and around the conference. My thanks also go to Kia-Ora, Glaxo-Wellcome, Roche and Los Angeles County Dept of Health Services, for sponsorship which enabled me to attend this conference.

Support + Education = Empowerment

THE ATMOSPHERE AT THE US National Conference on Women and HIV in May was very different from that of medical meetings I have previously attended. While incorporating relevant medical and scientific data, it also provided a great deal of information in regard to what is, and very often isn't, happening for women who are positive. The tone at the opening session and throughout the conference was about women's empowerment, support for each other and educating each other. I was pleased to find a "Mentor Board" which had been constantly added to over the time by women willing and eager to share their knowledge with others in their many and varied fields of expertise. Many sessions were loud and full of energy and simultaneously open and supportive. It was an environment which encouraged constructive discussion. It covered just about everything to do with women and HIV including epidemiological data across many races and backgrounds, basic and clinical sciences, current therapies,

alternative therapies and Chinese medicine, prevention, policies and policy development, incarceration and linkage to the community, access to trials and therapy, women's inclusion, or not, in research, women who have sex with women, women and families, and dependency versus empowerment. Numerous satellite meeting supported a great deal of networking outside of the socialising type. The day before the conference officially began, one of the satellite options was a day for women living with HIV - "HIV Basics and Beyond", which not only provided a useful socialising opportunity but a general information day as well. The conference also catered for women at varying degrees of knowledge around HIV as well, providing opportunities for question and answer times around current fundamental and relevant issues such as antiretroviral resistance. Attending the conference were a wide range of people, seemingly all with something to say. People from various HIV/AIDS organisations around

the US and the world, scientists, medics, community people, the odd politician (one such speaker gave a very well-received and optimistic speech during the opening session) and many positive women, both working in the field and not. Unfortunately there were relatively few positive women under 25, but there are many factors which account for that. It was exciting to find that the demand for many of our Australian products was very high. Sonia and I set up a booth and quickly realised that we didn't have a hope of what we brought to stock the stall lasting the whole conference. Many of our posters were very popular, the recently released fact sheets disappeared almost immediately (and off to Kinko we went!), and KIA-ORA's dental dams, "Lollyes" were a hit! Many of the people we met in the process of all this were keen to exchange information too. For all of these reasons; the conference was an enjoyable and educational experience.

- Shellee Korn

Women and HIV Therapies – Missing Links

Following on from the broader discussions about the community setting new agendas for clinical research – a look at some women-specific issues.

AS WOMEN, WE KNOW THAT HIV+ women need an agenda for future research, asking the questions that most directly affect the lives of HIV+ women. This is not only because women's bodies are different from men's, but also because their lives are different. Inevitably, HIV+ women will have complications in organs that men don't have, and theoretically, gender specific areas such as the endocrine system and the hormonal system may interact differently with the virus, as well as the drugs.

Little attention seems to be paid to the critical question of whether all the exciting new treatments work differently in women, either for gender or exposure-related reasons.

It is easy for HIV positive women to feel that their treatment needs have been written off by clinical science. A central plank of the women's agenda has been to uncover the link between gynaecological conditions and HIV, but where are the studies on how to treat these conditions? What is the point of a cure for HIV, if the infected women just go on to die from the cancers and pre-cancers they acquire more frequently?

The presence of HIV in genital secretions has been studied to a certain degree¹, and an important association has been found between hormonal contraception and HIV shedding in cervical secretions. The risk of HIV shedding was increased 4.5 fold in women taking the oral contracep-

tive pill, and 3.2 fold in women using injectable progesterone.

While these findings still require further research, these results suggest a need to focus on clinical trial protocols and the requirement in many of these trials that women take oral contraceptives while participating in the trial studies.

Of course the concern of those living with, or involved in, the issues of women's treatments is that too often trials that are specifically for women are seen as providing advances for women living with HIV, but this is not the case.



GRAPHIC: "PUSSY DOES MATTER" BY EMMA KING

Rather than being women's treatment issues these are infant's prevention issues. Women are being treated as potential or specific reproductive agents. As Robin Gorna² points out, using AZT to prevent babies from becoming infected has been hailed as a breakthrough, but still no one knows whether AZT interferes with women's menstrual cycle, surely a basic quality of life issue. The ethical concerns, and limitations of such studies need to be vigorously highlighted by activists, and an agenda for future research must contribute to these fights. After years of this epidemic we still don't know how HIV is transmitted sexually in women, nor do we know the appropriate

dose of antiretrovirals for women or their long-term effects.

These are not easy issues, but there are several challenges already identified in this area:

- Can the design of clinical trials include the option for a woman to access a trial, while still preserving her right to choose her own pregnancy options?
- Should a woman only have the choices of oral contraception, abstinence, or being post-menopausal before she can access a trial?
- Are trials that are not specifically for obstetric or paediatric analysis really attempting to target women, or are the historical biases, where women of childbearing age were excluded from clinical research, still applied by pharmaceutical and medical investigators?

Finally, there is also evidence to suggest that women are reluctant to participate in HIV/AIDS clinical trials. Reasons include barriers of access, transportation, distrust of the "research system", preference for complementary therapies over pharmaceutical drug treatments, not wanting to be experimented on, child care, and time restraints. These psychosocial and structural barriers can also be experienced by some men, but if future clinical trials are going to successfully include women, and contribute to our knowledge of women specific responses to treatments, then the design of clinical trials need to be addressed so that women are genuinely recruited, and supported.

– Jo Watson

1 Mostad,S: Vancouver XI International Conference on AIDS 1996.

2 Gorna,R: Vamps, *Virgins and Victims*. Cassell. London. 1996.

Fair Treatments



Combination Therapies: One Woman's Story

MY NAME IS KERRY. I HAVE BEEN positive for six years and I am healthy. I remember when I was first diagnosed, there was not a lot of information about women with HIV/AIDS. Most of the information was about men, which didn't relate to me. I became quite sick with thrush and I remember the doctor I went to see put me on Zovirax because he thought I had herpes of the mouth, when in fact I had thrush. After taking the pills for a week and nothing happening, I spoke to friends who said I should get another opinion, and I was then diagnosed with thrush. The thrush would come and go quite regularly and I never had it under control. Further down the track I got pneumonia and ended up in hospital. I was worried about my health, I had not found a doctor I felt comfortable with and I wasn't getting proper treatment.

I had been doctor shopping for the right doctor for 2 years by the time I found my current doctor, who I've been with for 4 years. She had my health back on track and for the first time it was maintained, but I still had trouble with thrush. She had put me on an asthma control program which worked well. We developed a friendship and trust in each other. For the first time I had some maintenance in my health. I had found the right doctor for me. In 1996 I started to read about combination therapies and in the States the news was very good and positive. People's T cells were rising and the virus was at undetectable levels in their blood. I spoke to the

HIV Treatments Officer and he explained in detail how they worked. I also spoke to people I knew who were taking them and asked them about the different side effects they had experienced. Most of the news was positive, but as a healthy person I was deciding whether to try them or not. After



GRAPHIC: EMMA KING

long and extensive talks with my doctor I decided to give them a go. The first combination was Saquinavir, AZT, and 3TC. The AZT made me very sick; vomiting, diarrhoea, head-aches. I went back to my doctor and we had to elimi-

nate the pill which was giving me the problem. She dropped the AZT first; luckily her first guess was correct, so she replaced AZT with D4T. This combination was good and seemed to agree with me. I had to take Maxolon and Loperimide to counteract the side effects. The first thing I noticed was that the thrush had gone. I also had more energy and my eyes became really white again. I have been healthy ever since. Deciding to go onto combination therapy is a huge choice to make especially if you are healthy, but I myself have made a wise choice. If you decide to go onto combination therapy, read the literature about the therapies and ask any questions you have about them. My visits to the doctor are every six months now, with a few colds here and there which is the worst I get. My doctor is really happy with my progress and I believe the drugs are doing me good, as I have had no major problems. My T cells are now 1020 and the virus is undetectable, which is proof in the pudding for me. These drugs may not be for everyone due to their own individual complications. If you decide to take them you need to be strict about taking them and not miss any doses, because if you do, you become resistant to them very quickly. Since the '80s we have come a long way with treatments. The combination therapies are the latest and I believe they will keep us alive for a great deal of time. I feel privileged to be alive while this is all happening.

- Kerry

An Actor's Perspective An Actor's Perspective An Actor's Perspective

David Jobling is one of the driving forces behind the Pride Centre's wildly successful 'Performance Positive' events. He provides a theatre worker's perspective on the importance of community theatre in the AIDS epidemic.

BETWEEN PROFESSIONAL GIGS AS an actor & director, I have also worked as a community artist since the late 1980's. I began working with young people, developing methods of creating plays from scratch and was eventually drawn into the area of working with HIV+ people (probably because I'm HIV+ myself). The first project I worked on with PLWHA was in South Australia for UpFront Community Theatre.

A dozen or so members of the 'Queer' community got together once a week over a period of three months and created a 'Rap, Pulse, Groove about Discrimination' called "Open Line" which included a short play "Hairy Dyke and Useless Poofster - Out on a night" written by myself and directed by Roxxy Bent (Vitalstatistix & House Gang). "Open Line" toured around community venues and played to a wide range of people in Adelaide and its suburbs.

I found it very fulfilling to do this work because I could see how it assisted in the development of peoples' communication skills and their ability to express things that were important to them. I later followed this up with a series of 'Writing as Therapy' workshops with people affected by HIV/AIDS in the City of Prospect (also in South Australia).



Tim Bishop & Pam Drysdale, two of the performers in "Fear", the fifth Performance Positive event which took place at Sydney's Pride Centre on June 13.

PHOTO: C. MOORE HARDY

I then spent three months in Darwin (Northern Territory) as a 'writer-in-community' for the Darwin Gay & Lesbian Society, again with a special emphasis on working with PLWHA.

In those days the major themes we were exploring were mostly Discrimination, Confidentiality, Safe Sex and Prevention (of spreading/getting HIV/AIDS).

Most recently I have been running an HIV+ Mens Theatre Workshop for the PRIDE Gay and Lesbian Community Centre here in Sydney and I have noticed (as you do) how the themes have changed quite a lot since the earlier part of this decade.

Now the focus is Acceptance, Treatments, Self-Determination Identity, and just about anything else you care to mention. So far the workshop has produced a

short film "With Love . . ." and material that has been used in 'Performance Positive', 'Talkabout' and the 'Keeping It Up Treatments Forum'.

Surprisingly there are fewer people in Sydney willing to get up on the stage and perform the work than there were in Adelaide or Darwin - is this because being seen as a PLWHA is still a problem in the community? Or is it because, as one PLWHA put it "I have no intention of getting up and being some kind of side-show tragedy for everyone to gawk at". The thing is, just like AIDS does not equal Death, Community Theatre does not equal Tragedy (or a side-show for that matter).

Community theatre is often perceived as being 'old fashioned' and 'amateur' and yet it is not necessarily either of these things. I've

read articles in the Sydney Star Observer (SSO) of late that bemoan the 'loss of culture' within the gay and lesbian community, but so far the SSO hasn't reviewed 'Performance Positive' or done anything more than pre-publicity for it. If they bothered to attend they would see that there are plenty of community artists around creating work that address issues for the whole community and is much more than just preaching to the seroconverted.

'The Self-Saucing Mouthful' from The PRIDE HIV+ Gay Mens' Theatre Workshop have created a piece for 'Performance Positive 5' with the theme of 'Fear'. The piece is based on universal fears that come up for PLWHA as well as the general fear

of being misunderstood, alien, unknown, invisible.

The words and meaning of the piece are open to interpretation and the style of the piece is anti-theatrical. It is meant to be food for thought rather than a processed product. It may or may not 'work' as they say, but by the time it is seen it will have given a group of PLWHA the opportunity to feed their thoughts and ideas into a presentation that is expressive and empowering for them. It will have provided these PLWHA with an opportunity to see their thoughts translated into a form of performance art, and conveyed to more people than they could hope to communicate to at one time as individuals.

The PRIDE HIV+ Gay Mens Theatre Workshop has created

other material (as yet un-produced) that tackles very pertinent issues such as knowingly transmitting HIV, sharing responsibility for containing the spread of HIV/AIDS, identifying needs that have been neglected by the community, dealing with the change in lifestyle that comes with treatments, exploring alternatives to chemical drugs, and exploring issues that are not necessarily connected to HIV/AIDS at all. Issues such as masculinity, self-expression, communication, celebration, mainstream media, family, religion, culture and poverty.

Although community theatre works as a development tool it would be a very poor show if I didn't end this article stressing one extremely important aspect of it - it's a wad of FUN!

- David Jobling

Vitamin A Cream for Kaposi's Sarcoma

- ◆ Taylor Square Private Clinic is studying an investigational vitamin A derivative (cisretinoic acid) as treatment for Kaposi's sarcoma (KS) skin lesions.
- ◆ Early published work has shown a response in 30% of people with KS, reducing the size and number of skin lesions without causing the side effects of chemotherapy or radiotherapy commonly used.
- ◆ Treatment is with active cream or a placebo for 12 weeks. Everyone then receives the active treatment (or earlier if the lesions enlarge).
- ◆ Clinic visits are every four weeks and payment is made to cover your incidental costs.
- ◆ For further information contact Margaret Slade RN or Neil Bodsworth at Taylor Square Private Clinic at Darlinghurst on 9331 6151.

Women Speak

Ten HIV+ women answer questions about health and longevity

WHAT HINDERS OUR HEALTH?

- I can advocate for others but not for me
- Denial
- Isolation
- Hassle of medications and side effects
- Not being able to get into clinical trials because T-cells are too low
- Trying to do too much
- Caring for others first
- Difficulty setting priorities
- Balancing time and work for me
- Dealing with the emotional roller coaster when I "fail" medication
- Having people you love die or get sick
- Fear of deportation
- Having an abusive partner
- Grief from loss of a family member
- Not knowing how to ask for help
- Scheduling food and medications
- Fear of drugs and their side effects •
- Fear of getting sick
- Taking meds reminds me I have AIDS
- Procrastination
- History of bad medical care
- Volunteerism as denial
- Lack of childcare

WHAT HELPS ME LIVE LONGER?

- Finding a great doctor (& firing bad ones)
- Wanting to be here for my kids
- Being assertive about what I need
- Not worrying about whether people like me
- Having a strong support system
- Alimony (so I'm not so worried about money)
- Having insurance
- Unconditional love
- Having a safe place to talk about real issues
- Being "out" (not having to hide my HIV status)
- Spirituality
- Going to HIV university
- Learning I have choices
- Learning about the emotional side of HIV
- Support Groups
- Faith in God
- Getting a boyfriend with a healthy lifestyle
- Being on the same medications as my child (I'm more likely to take them when we make a ritual

- of taking them together)
- Having a partner who cooks
- Learning to trust people
- Knowing I want to live
- Wanting to live to see my grandchild graduate
- Being in nature
- Walking my dog
- Being OK with dying so I'm not controlled by fear and I can live more fully (I have to relearn this over and over)
- Having a good social worker who calls me
- Not wanting deathbed regrets
- Travelling or having goals to travel
- Having supportive parents, siblings or partner
- Accepting the fact that I have this virus
- Gratitude for the things I do have
- Taking one day at a time
- Learning from my dead husband's mistakes
- My friends
- Learning to accept help (I still can't ask for it)
- Hearing other women's stories

From WORLD Magazine May 1997 - Women Organized to Respond to Life Threatening Diseases, PO Box 11535 Oakland CA 94611, USA

Who do I call?

We compiled this list of contact points specifically for women. They will provide advice and referrals to medical practitioners, counselling and community services.

AIDS Council of New South Wales (ACON)

- SCREAMLINE 1800 630075 (leave a message)
- Positive Women Support 9206 2012 or 9206 2058
- Treatments 9206 2013

Albion St Centre

Specialist clinics, counselling & welfare support
Ph 9332 1090

CLASH

Support group for positive heterosexuals
Ph 1800 812404

HIV/AIDS Legal Centre (HALC)

Ph 9206 2060

Inner City Legal Centre

Ph 9332 1966

Multicultural HIV/AIDS Education and Support Service

Ph 9515 3098

NSW Users & AIDS Association (NUAA)

Support, referral & advocacy for injecting drug users and their friends
Ph 9369 3455

PLWH/A (NSW) Inc

Jo Watson
Treatments/Research Officer
Ph 9361 6011
Ph 1800 245677

Sydney Children's Hospital HIV Services

Ph 9382 1654

Sydney Sexual Health Centre

Ph 9382 7440

Or look for your local Sexual Health Clinic in the phone book

Talkabout Contacts

A directory of services for PLWHA in NSW

Ph 9361 6011 to request a copy



Talkabout

WHERE WE SPEAK FOR OURSELVES
Join PLWH/A in the fight against AIDS!
Subscribe now!

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

PLWH/A Membership

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

- Full member (NSW resident with HIV/AIDS)
- Associate member (NSW residents affected by HIV/AIDS)
Disclosure of HIV status entitles you to full membership of PLWH/A, with the right to vote for all management committee positions.
Membership status is strictly confidential.

Talkabout Annual Subscription Rates

Please note that *Talkabout* subscribers also receive *With Complements* Newsletter eight times a year for no extra charge!
All NSW *Talkabout* subscribers also receive *Contacts* – the directory of services for people living with HIV/AIDS in NSW – quarterly.

Individuals

- I am a member of PLWH/A (NSW) Inc. **\$13** per year
- 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 **FREE** (enclose proof of concession)
- I am an individual living overseas **A\$70** per year

Organisations

- Full – \$80** per year (business, government, universities, hospitals, schools etc.)
 - (Extra copies **\$30** each per year)
- Concession – \$40** per year (PLWHA organisations, non-funded community based groups etc.)
 - (Extra copies **\$13** each per year)
- Overseas – A\$120** per year
 - (Extra copies **A\$40** each per year)(Please specify number of extra copies _____)

Donations

Yes! I want to make a donation to 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 Visa Bankcard Card number _____

Expiry date _____ Signature _____ Date _____

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

Please note that the Membership & Subscriber database is totally confidential.

→ Special note for publishers: talk to us about exchanges with your publication.

First name _____ Last name _____

Postal address _____ Postcode _____

Phone (h) _____ (w) _____

Mobile _____ Fax _____

Please forward this completed form to:

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

Thank you!

WOMEN AND HIV/AIDS

ACON is committed to supporting and empowering all people and communities affected by HIV/AIDS. Whilst much of our work is with gay men, ACON does much more... it is also for women.

THE WOMEN'S TEAM

**For all Women affected by HIV/AIDS
...ACON has specialist services for you**

HIV Positive Women's Peer Support Project

Information, referral and support for women living with HIV by women living with HIV, call **Erycka and Shellee, (02) 9206 2012.**

Women Partners of Bisexual Men

Support groups for women whose male partner has sex with other men, plus information about safe sex and relationship issues call **Sarah, (02) 9206 2026.**

Family Support Project

Support for families living with HIV/AIDS including respite care and alternative care for children, call **Angela and Vivienne, (02) 9206 2079.**

GLIDUP

Information for lesbian and gay drug users on being positive and using, safe injecting information, needle exchange service etc, call **Robyn and Sarah, (02) 9206 2074.**

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Women and AIDS Project

Information, resources and referrals for women who are living with HIV or affected by HIV through friends, lovers, children, partners being HIV positive, call **Sonia and Brigid, (02) 9206 2049.**

Treatment Officers

For information about the latest treatments available.

Vitamin and Nutrition Service

Provides quality vitamins and nutritional supplements at reasonable prices.

Counselling

Trained counsellors for face to face counselling and telephone support.

Community Support Network

Practical home based support

ACON

AIDS Council of New South Wales Inc.