

No. 82 December/January 1997/98

Talkabout

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

◆ Where We Speak for Ourselves ◆



You can't kill the spirit

TALK OPENLY ABOUT HIV WITHOUT ANYONE KNOWING

TOPICS FOR DISCUSSION INCLUDE:

Thursday 25 December 1997 "Incorporating HIV treatments into your lifestyle"

Friday 26 December 1997 "Dealing with the side effects of HIV drug therapy"

Saturday 27 December 1997 "Communicating with your healthcare professional"

Sunday 28 December 1997 "HIV support services"

Thursday 1 January 1998 "Newly diagnosed as HIV positive"

Friday 2 January 1998 "HIV/AIDS in rural Australia"

Saturday 3 January 1998 "Taking HIV/AIDS medications in public"

Sunday 4 January 1998 "HIV drug resistance"

Session times are scheduled for 8pm-9pm and 9.30pm-10.30pm or ring any time between 8pm - 12am for a one on one conversation. For further information on discussion topics, contact the Versa line at anytime.

"Versa" is unlike any other chat line. It allows you to talk freely and anonymously in a live facilitated peer support phone forum. Alternatively you can talk one on one with a peer about the latest on HIV/AIDS and related issues.

A project of PLWHA (NSW) Inc
sponsored by an unconditional educational grant
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VERSA

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This month's cover

By C. Moore Hardy. You can't kill the spirit that helps us all handle this epidemic. In many different ways, we support each other and motivate ourselves to overcome the obstacles that HIV throws in our way. Read about it in our special feature, which starts on page 17.

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If you would like to be involved with *Talkabout* call Jill on 9361 6750 for the date and time of the next Newsletter Working Group meeting.

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Briefs



● The United Nations AIDS program and the World Health Organization announced in November that an estimated 30.6 million people worldwide are infected with HIV, up 30% from last year's estimate of 22.6m. In part, the increase may be attributed to new data collection methods, but researchers also suggest that earlier hopes that the epidemic is stabilising in Africa were overstated. In fact, the latest report found that the prevalence of HIV infection in sub-Saharan Africa is 7.4 percent among people between the ages of 15 and 49, compared to 1 percent in India; 2.3 percent in Thailand; 1.9 percent in the Caribbean; and 0.6 percent in North America. Almost 530,000 African infants acquired HIV from their mothers this year, a figure equivalent to 90% of all perinatal HIV transmission cases worldwide.

● The Centers for Disease Control and Prevention has reported that the number of US children contracting HIV from their mothers at birth fell 43% between 1992 and 1996, thanks to women getting tested earlier and starting treatment with AZT. The rate of infants diagnosed with AIDS before age one, meanwhile, dropped 39%, from 8.4 per 100,000 births in 1992 to 5.1 in 1995.

● In response to a Sept. 27 *Lancet* editorial that argued against the use of placebo groups in intervention trials to reduce perinatal HIV transmission in developing nations, researchers Peter Aaby and colleagues contend that such a stance is unfounded considering the financial and structural limitations in developing countries. In fact, the researchers write in a letter to the editor, many inexpensive interventions that reduce mortality and morbidity in such countries - oral rehydration therapy, vitamin A supplementation, and syndromic treatment of STDs - would never have been evaluated, much less implemented. This would have resulted in the subsequent loss of many lives. The authors add that if such a view is adopted, the research that is conducted may be irrelevant to the needs of developing countries. Also responding to the editorial are Kevin DeCock, et al., from the CDC. They assert that the use of a placebo group in this case is the most ethical and appropriate design, noting that the AZT regimen used in the ACTG 076 trial as a control yielded results that are irrelevant for nations which lack the money and infrastructure to support such complex and expensive treatments.

(*CDC Daily Summaries*)

PLWH/A News

AT THE WORLD AIDS DAY Awards on Sunday December 30, Deputy Premier, Minister for Health and Minister for Aboriginal Affairs, Dr Andrew Refshauge, announced almost one million dollars worth of enhancement grants to non-government organisations working in the area of HIV and AIDS.

PLWH/A (NSW) Inc. received money to provide a more diverse range of information, to expand the Positive Speakers Bureau, for administration of the organisation and to establish meeting rooms. The decision is met with relief as well as delight, as there was uncertainty around the grants. It enables PLWH/A to broaden our organisational capacity and further develop our projects.

Congratulations to Jo Watson, Kim Gotlieb, Vincent Dobbin and John Trigg for their World AIDS Day Service Awards. They were all nominated by PLWH/A. Congratulations also to Paul Roberts and Larry Wellings, who were nominated by others for Service Awards. Paul and Larry are closely associated with PLWH/A and have given much of their time to this organisation.

Whilst it is good to reward these individuals for their efforts, it must be said there are many people who give of their time to PLWH/A who did not receive awards. To all those people; your efforts are as valuable and noticed. We thank you.

It is with deepest regret we see Paul Roberts resigning from the position as *Talkabout* Support Officer. Paul has a long association with PLWH/A. He started work as the acting Administration Assistant in May '95. Some of Paul's achievements during this time are the highly successful GoGo fund-raiser, his strong advocacy on staff issues and his significant contribution to the continued success of *Talkabout* and the *Contacts* directory. Personally, I would like to thank Paul for the support and often constructive criticism he has given

me. On many occasions he would give this when I least expected it. We have come a long way. The PLWH/A staff and committee all give him our heartfelt best wishes in the period ahead.

As *Talkabout* goes to press, preparations for the PLWH/A Annual General Meeting on December 15 are underway. By now members will have received a copy of the PLWH/A 1996 - 1997 Annual Report. This report reflects our successes and continuing growth. If you have not received or seen a copy just call 9361 6011 or come into our office.

In this issue we ask you to fill out the "Issues for HIV+ people in NSW" PLWH/A survey (pp. 11 & 12). We are interested in finding out what HIV positive people in NSW think about this organisation, as well as what you feel are the important needs and issues for positive people over the next year. This information will assist us in determining the strategic direction of PLWH/A, so your support would be much appreciated.

The Positive Speakers Bureau has had a busy time recently with 28 joint talks with the Quilt Project as part of the activities for World AIDS Day.

Finally, we at PLWH/A wish all *Talkabout* readers a warm and enjoyable festive season.

- Ryan McGlaughlin,
PLWH/A Co-ordinator

AFAO Media Awards

C. MOORE HARDY, PHOTOGRAPHER, and Sandra Thompson, *Talkabout* DTP Officer, scooped an AFAO Media Award in November for their joint work on the Cover of the July *Talkabout*, which featured photos of ten HIV positive women. (See photo, facing page).

Sandra Thompson, accepting the Award on behalf of C. Moore and herself, said "It is an immensely powerful cover, a first for Australia, and is a tribute to the strength and dignity of these

women". Sandra thanked Vivienne Munro, who originally suggested the idea, the Women's Unit at ACON, who helped organise the photo shoot of the diverse group of women who appeared on the cover, and C. Moore Hardy, who was instrumental in making it happen.

Other award winners included Mazz Images, whose pictures frequently appear in *Talkabout*, for a photo of Jon and Tim Vincent which appeared in the *Sydney Star Observer*; SSO journalists Ruth Pollard and Brad Johnston; and the ABC TV Compass program, "HIV Kids" which told the story of twin boys, one of whom is HIV positive.

Overall winner of the Awards was Melissa Sweet, for "Maverick MD", her profile of Dr Cassy Workman in the *Sydney Morning Herald*.

Changes at BGF

WELCOME TO MAREE CROSBIE, the new Financial Counsellor at Bobby Goldsmith Foundation (BGF). Financial counselling is a new, free and confidential service of BGF to help people who have financial problems or need information about budgeting or other financial matters. Maree is highly qualified with a good knowledge of financial and para legal matters, small business and practical experience in budgeting.

This service is available to anyone with HIV/AIDS, not only those meeting the usual BGF criteria for assistance. You can make an appointment to see Maree by calling 1 800 651 011 between 9.30 & 5.30 Monday - Friday.

The other big news at BGF is their move on December 15 to new offices on the 2nd floor of the ACON building at 9 Commonwealth St, Surry Hills (right next door to CSN). ACON has offered the space at very low rental, at a time when BGF was facing a rent increase as well as increasing demand on its financial services. The relocation was also made possible



Sandra Thompson with the AFAO Media Awards she accepted on November 24 for herself and C. Moore Hardy. See story page 4. PHOTO: MAZZ IMAGES

by a one-off grant from South Eastern Sydney Area Health Service, for the cost of the fit-out of the new space.

"We are happy to make the move as there is great benefit in consolidating services for all our clients in the same building", said Crispin Rice, BGF's Administration Manager. BGF would like to clarify that this is a move of convenience and common sense. BGF remains an independent organisation.

Ankali review

ANKALI, A PROJECT OF THE Albion Street Centre, released "Responding to Changes in HIV/AIDS", a review of Ankali services, in October. Ankali has been providing one-to-one emotional support to people with AIDS, their partners, family and friends, since 1985.

The Ankali review was initiated in 1996 in response to the evident changes in the community due to hopeful treatment developments. These changes of course have implications for all support and care services which had been geared towards supporting people who were chronically ill and dying. The report outlines the ways in which Ankali will be developing

its service over the next two years in response to the changes. It states that "many positive outcomes have already been realised as a result of this review process".

The review involved consultation with overseas volunteer projects, Project staff meetings, consultation and brainstorming with Project volunteers, consultation with key organisations including ACON's HIV Living and PLWH/A, and interviews with some current clients.

Significant objectives identified by the review include: an expanded role for the Ankali volunteers, changes within the service to help current volunteers adjust to this changing role and a revision of the volunteer recruitment and training processes.

The report discusses the dual responsibility of Ankali Project Co-ordinators to both Ankali clients and to the volunteers and defines the relationships between all parties more clearly.

The report also sets out a number of objectives regarding the support of clients with special needs (for example those with drug and alcohol issues or mental illness, as well as HIV) and their Ankalis. It notes difficulties in the area of supporting children and

Briefs



● Versa, the new chatline for people with HIV, went live on December 11. If you call 1 800 555 047, you will be able to either participate in a live phone forum with other possies, facilitated by a trained HIV+ person, or get one on one support and information. The line operates from 8.00pm to midnight, Thursday to Sunday. Forums will cover a wide range of topics, including HIV drug resistance, HIV & stress, sexuality, travel, and HIV/AIDS in rural Australia. Watch the gay press for details of the topics for each week. The Chatline will run as a pilot project for three months. It is unconditionally funded by Roche Pharmaceuticals.

● Armistead Maupin has donated the autographed manuscript of the first chapter of his new novel, *Almost Anyone*, to the AIDS Trust of Australia. The Trust auctioned the manuscript of the chapter, titled "The Jewelled Elephant Syndrome", at the Annual Red Ribbon Ball in Hobart on November 28, raising \$1,000. The Ball was a great success, with the Police Commissioner & his wife attending for the 3rd year in a row. The Commissioner is 'on side' to such an extent that all police officers in Tassie wore Red Ribbons on World AIDS Day.

● On Monday November 24, 20 AIDS activists carried a black coffin from Circular Quay to Parliament House in Macquarie St, where they paused for a minute's silence as a mark of respect for the 5,370 Australians who have died from AIDS and the many thousands who are living with HIV. The funeral procession then proceeded to Green Park. Organisers wished to draw attention to HIV-related poverty and the need for continued work on developing anti-HIV drugs and the event did attract some radio coverage.

● The long awaited six-bed residential unit for people with AIDS-related dementia will open in Glebe in mid-January. Restoration of the building is nearing completion and staff are being recruited. For more info, call the AIDS Dementia and Psychiatry Team on 9339 2078. There will be an update on dementia services in the February *Talkabout*.

● The city of Sydney Food & Wine Fair held November 30 in Hyde Park made a profit of over \$100,000. This is the best result yet for the seven year old event. Money raised will go to supporting the Trust's work for funding HIV/AIDS education, care and support across Australia. The Trust thanks all those who made the event such a great success.

adolescents directly affected by HIV/AIDS, and prisoners after their release.

There are further objectives regarding updating resources and promotion of the service. A small group of volunteers has been meeting in Parramatta for over eight years, but work in this area has been limited by lack of resources as well as distance. Ankali is looking at strategies to develop the service in this area.

For copies of the report, call Ankali on 9332 1090.

PosHets

IN A FIRST FOR AIDS AWARENESS week, Positive Heterosexuals held the first HIV/AIDS information stall run solely by HIV positive heterosexuals in King St, Newtown, on November 23. The stall was a great success and helped promote awareness about the significance of HIV/AIDS for heterosexual people. This effort follows an exciting couple of months where we recorded 120 attendances at Positive Heterosexual support functions in Sydney. Some members came from country NSW to meet others and get support. Thanks to all our many friends who have helped us over this time.

- David Barton

Positively working

THE POSITIVELY WORKING GROUP aims to explore and advocate for equity and access to employment services for PLWHA. The working group, made up of representation from PRIDE, ACON, PLWH/A, BGF, Area Health Service representatives and vocational educators, continues to meet regularly.

We are currently working on a submission to the Department of Employment, Education, Training and Youth Affairs (DEETYA) for a six month research project which will assess the employment needs of PLWHA and services available to them. This project will involve community consultations and information sessions. The major

outcome will be the production of a directory of employment services and resources. If the submission is successful, this project will begin early in the new year.

Most of you will know about the restructuring of employment services due to be implemented in May 1998. (The replacement of the DSS and CES with Centrelink offices is the first of these changes). Positively Working has been involved in advocating for PLWHA in this process. With an organisation called Job Futures, Positively Working is putting in a tender for funding to provide a range of employment services, including a case manager with a specific focus on HIV, who will be accessible through Centrelink. We will hear about the success of this tender in February 1998.

We have also been working on other options such as a training package (planned for April 1998) dealing with job-seeking skills, confidence building and resume preparation. The training will be in a variety of locations around Sydney.

Positively Working continues to have close links with other employment resources for PLWHA such as the Positive Employment Service, TAFE Outreach computer courses, Skillshare programs and other training resources.

We look forward to some exciting things happening in 1998! For further information or to register your interest in any of these projects please contact me on 9926 6767.

- Sarah Yallop

Attention all NESBians

AFAO AND NAPWA WOULD like to make it easier for people with HIV from culturally and linguistically diverse backgrounds to get the information they need.

If you are HIV positive and from a non-Anglo/Celtic background, then I would be very glad to speak with you about: what information you need about treatments and lifestyle; where you go for infor-

mation; your experiences of trying to get information; how to improve access to information for people from culturally diverse communities; and ways of making information more culturally appropriate for diverse communities.

If you can meet me for an interview, I will pay you \$50 for your help. Call me to arrange a time on 9985 9748. Please leave a message on the answering machine if I am not there. Your identity will remain strictly confidential. If you prefer to send me something in writing you can fax it to 9985 9798 or post it to PO Box 141, Brooklyn, 2083.

Contributions from service providers are also very welcome, but will not be paid for.

- Dr Rigmor Berg, Consultant,
BB Professional Services

Manila conference

COMMUNITY BASED AIDS ORGANISATIONS in the Asia-Pacific region were urged in November to start documenting human rights abuses committed against people living with HIV/AIDS.

Speaking at the fourth International Congress on AIDS in Asia and the Pacific, held in Manila, UNAIDS adviser Teresita Marie Bagasao said that HIV/AIDS prevention and human rights feed off each other. "The sad fact is that people living with HIV and other marginalised groups are often denied many of these basic human rights, therefore rendering prevention efforts less or even ineffective."

The Asian Harm Reduction Network (AHRN), a collection of organisations working to stem the spread of the virus through injecting drug use, took up the call. It convened a press briefing during the conference where it revealed that HIV positive drug users are regularly refused treatment in hospitals across the region.

Mr Jimmy Dorabjee from New Delhi, who is a member of the network, told of a sick 22-year-old male injecting drug user who died



World AIDS Day marked the formal handover of the Sydney PWA Living Centre from Area Health Service to community management. Pictured are committee members who oversaw the transition.

PHOTO: MAZZ IMAGES

after being repeatedly refused treatment by hospitals who suspected that he was HIV positive. "When he finally entered hospital and a blood test found that he was HIV positive, he was treated as a health hazard and nobody even entered his room," said Mr Dorabjee. When the man died, labels declaring that he was HIV positive were put on his body.

The Network's president, Mr Palani Narayanan of Kuala Lumpur, said: "We strongly condemn the refusal by hospitals in many countries in this region to provide medical treatment or help to HIV positive drug users, even when they are dying.

"To refuse assistance in this way is a denial of basic human rights and should be considered a criminal act. In some countries, hospitals have no policies about admitting HIV positive people. These countries need to put appropriate policies in place."

Commenting on the state of the epidemic in Australia, the executive director of UNAIDS, Dr Peter Piot, urged caution against complacency and the dilution of government support for AIDS programs. Dr Piot said a widespread public belief that the new combination treatments for HIV represented a "cure", coupled with falling rates of HIV transmis-

sion, could lead Australia to drop its guard against the epidemic.

"One of the biggest dangers in the epidemic today is the perception in many western countries that the epidemic is over because there is combination therapy which is quite effective and there is a decline in mortality from AIDS. The challenge is to maintain AIDS efforts in these times of low-level infection, and particularly political commitment."

On a regional basis, he told the conference that Asia-Pacific needed to "wake up" and take immediate action to avert a disaster on the scale experienced by sub-Saharan Africa, the region that is worst affected by AIDS in the world. UNAIDS estimates that there are between five and seven million people with HIV in the Asia-Pacific region. "What is most worrying is the epidemic trend. Infections in the Asia-Pacific region have doubled in the last three years. Just as ominously, UNAIDS projects that the total could easily double again by the end of this century," said Dr Piot.

"The AIDS clock in Asia's most populous countries is clearly ticking fast. These countries can afford the cost of preventative measures today. But they would not be able to afford a rampant epidemic, whose human and eco-

Briefs



● "AIDS Dementia Complex, A guide to Management & Care at Home", is a smart and comprehensive new booklet published by AFAO using a grant from the AIDS Trust. The booklet explains ADC and some other AIDS related conditions which also affect the brain and central nervous system. Targeting both family/carers and people with ADC, it contains info and practical suggestions about treatments and management of ADC. There are also chapters on support services, looking after yourself as a carer, legal matters such as living wills, and financial support. The booklet includes stories from a person with ADC and carers of people with ADC. Available from PLWH/A, ACON branches & other services.

● On November 18, ACON launched, "HIV Drugs + Life", a booklet which responds to the most commonly asked questions about treatments. It includes info about treatments, resistance, managing side effects, interactions with recreational and medicinal drugs, and suggestions about how to incorporate the drugs into your lifestyle. For more information or a copy of the booklet, contact ACON or call 1 800 816 518.

● On World AIDS Day, Glaxo Wellcome (UK) launched its HIV Care website. ([Http://www.hivcare.com](http://www.hivcare.com)). The site will provide a wealth of information on virtually every aspect of HIV/AIDS and is designed to be informative without being technical. Glaxo Wellcome is donating money to Great Ormond Street Hospital Children's Charity for every person who fills in the feedback form at the site.

● Doxil is a form of the chemotherapy drug doxorubicin, which has been available here only through a compassionate access scheme in Sydney and Melbourne. The drug has been shown in US trials to be effective for long term therapy against Kaposi's Sarcoma (KS) and was approved by the US FDA in November 1995. It's considered to be the first line chemotherapy for HIV-related KS. Schering - Plough, the Australian distributor, will be submitting the drug for approval in mid December. In Australia, doxil will be marketed as Caelyx.

● The indinavir Summer Care Kit was launched on World AIDS Day. The kit includes information and knick-knacks such as a key-ring beeper. Free to PLWHA on indinavir, ask your doctor. For more info about indinavir, call the Merck Sharp & Dohme info line: 1 800 645 712.

conomic costs in the future could be devastating."

"Apart from Thailand, Asia's epidemic is not long standing enough to have produced the kind of widespread impact already visible in Africa. Not only the painful personal and social consequences of AIDS but the high economic costs of treatments and care, prevention, testing of the blood supply, care for AIDS orphans, and the even more important indirect costs due to the loss of young adults of prime working age."

Meanwhile, some PLWHA and positive groups at the conference objected to a sculpture by a local artist which portrayed living with HIV in terms of pain and suffering. They made their protest heard by covering the sculpture with slogans of empowerment.

- Derek Hand

Women on kids

THE INTERNATIONAL COMMUNITY of Women Living with HIV and AIDS (ICW) made the following statement on the theme of World AIDS Day 1997: "Children Living in a World with AIDS".

As carers and mothers of children across the world, we are concerned about the situation of

children living in a world with AIDS.

The trends of HIV infection and the dilemmas, perturb us as HIV positive women, and we are alarmed at the risk factors that are accountable for children's vulnerability to HIV, in particular, vertical transmission, poverty, rape and defilement.

We therefore urge our governments, AIDS service organisations, non government organisations, communities and donors to observe the following:

- Women's reproductive health rights should be a key issue in AIDS interventions, incorporated with education and correct information to allow all HIV positive women options and informed choice.
- Research - both clinical and social, tied in with concrete strategies to reduce women's vulnerability - should be designed as this is a key factor in paediatric AIDS.
- In all our communities, women living with HIV must have access to appropriate paediatric care and support.
- Families living with HIV need support, including peer support, respect and guidance in planning for the future, as we know our needs best.
- Access to treatment and other alternatives should be expedited to reduce HIV infection in children, in particular, risks such as breastfeeding and the implications for poor countries, where the majority of HIV infections in children exist.
- Women living with HIV and AIDS have the right to self determination in decision making regarding the birth, the care, and the treatment of their children.

Adopted at the 8th International Conference of PLWHA and the 2nd strategic planning meeting of ICW, Chiang Mai, Thailand 1997.



CONFERENCE REPORTS: CHIANG MAI

"Basic Needs – Basic Rights"



by Luke Smith

I RECENTLY HAD THE HONOUR OF being a participant at the 8th International Conference for People Living With HIV/AIDS in Chiang Mai in November. It was my first international PLWHA conference.

The conference was organised by the Global Network of PLWH/A (GNP+) and the International Community of Women Living with HIV/AIDS (ICW). The aims of the conference were to: create a safe and supportive environment for PLWHA to meet and share experiences, knowledge and ideas; focus international attention on the needs of PLWHA, particularly in Asia; develop and support collaboration within the Asia/Pacific and other regions; identify and support appropriate PLWHA representatives for the various international committees and bodies such as the United Nations Program on AIDS (UNAIDS) and to identify the skills that PLWHA need to function in these roles; identify the ongoing discrimination and stigmatisation facing PLWHA and agree on strategies to counter this, particularly in Asia; and to support the development of PLWHA networks in the host country and regionally.

As a PLWHA of twelve years and a paid worker in the field for two years, I personally found that the Conference broke me out of my sometimes isolationist perspective. I don't feel guilty or selfish for being insular because I believe one of my greater survival strengths over the years has been my ability

to learn to put myself first – be it a decision to take or not to take treatments, leave work, be in a discordant relationship or whatever.

On the other hand, this isolationism did not allow me to connect with the fact that I belong to a global village of PLWHA and although some of us are better off than others we have all fought for or are fighting for our "basic needs", which *are* our "basic rights". Although globally the number of people living with HIV/AIDS and the number of children who will be orphaned because of AIDS is a chilling thought, I still found enormous strength and encouragement from my attendance at the Conference in knowing that I belong to this global family.

In the opening ceremony, a keynote speaker from UNAIDS expressed the need for PLWHA to be able to network, discuss and learn with and from other PLWHA, and to have forums like the Conference available in which to do this. Most PLWHA already recognise that they need to speak on their own behalf but the powers that be, such as society, governments, potential sponsors etc., do not always assist this process. As positive people we need to keep voicing the need for our involvement in the decisions that affect our lives and as positive people we need to fight for environments in which this can be made possible.

The conference was organised as two streams run concurrently for men and women. At times I found this frustrating as I would have learned from and valued the input of all delegates in some of the workshops. I found it strange that I was doing a workshop entitled "Understanding and Respecting Women's Issues" and yet there were no women present from

whom I could acquire knowledge – not even a woman facilitator.

Conference workshops varied from issues around sexuality and sex after diagnosis to men as caregivers, and HIV in the workplace. A parallel forum also ran during the Conference which was open to anyone who was interested in attending. I attended "The Role of Religion and HIV/AIDS in Thailand" which (although the English translation was bad) turned out to be an enlightening morning on how the Buddhist monks and temples have taken on the roles of caregiver and hospice respectively.

So that more people can benefit from the information that I obtained by attending the conference, I will be writing a report. This report, along with copies of papers from the plenary sessions, workshops and recommendations that representatives from the Asia Pacific region gave to the GNP+ will be available from the PLWH/A office. You can call me on Sydney 9361 6011 or Freecall 1 800 245 677.

*PLWH/A Finance/Administration
Officer*



CONFERENCE REPORTS: CHIANG MAI International Community of Women

By Vivienne Munro

THE INTERNATIONAL COMMUNITY of Women Living with HIV and AIDS (ICW), met for three days in Chiang Mai after the 8th International Conference for PLWHA in November. It was ICW's second strategic planning meeting of Key Contacts (and some country contacts) in its five year history.

The meeting reviewed ICW's strategic plan and brainstormed issues around communication between members (there are considerable obstacles in terms of access to equipment and translation of literature). Some time was also set aside to discuss the ICW Key Contact election and to update on ICW's involvement as one of the co-organisers of the 12th World AIDS Conference in Geneva next July.

The meeting was informed about ICW's reproductive rights project, "Positive Women - Voices and Choices". The project will focus on documenting women's choices around pregnancy, but will encompass the social and emotional aspects of our right of choice and will establish how women living with HIV and AIDS are treated differently. It will involve teams of positive women working alongside researchers and subject to funding, will be started in Zimbabwe, the UK and Thailand in 1998-99.

ICW has published the fourth issue of *ICW News* (in English, French and Spanish). The ICW leaflet and membership forms are also translated to Portuguese and Czech. Women at the meeting volunteered to translate ICW materials into Thai, Urdu, Swahili, Polish, Russian, Malaysian and German.

Since the development of ICW's strategic plan in Bangkok in 1995,

there have been some major achievements in this region, the most significant being the first regional Asia/Pacific meeting of ICW. Women returned from this meeting enriched and the networks among the women were strengthened.

ICW now has country contacts in India, Pakistan, Malaysia, and Guam. A support group of seven positive women has been established in Guam, where they are now advocating for patients in hospital, visiting each other and



Junsuda, Thai Key contact for ICW.

lobbying for access to better medical treatment.

In Thailand, Key Contact Junsuda has brought non-government organisations, AIDS coalitions, nurses and doctors from Government and private hospitals together with HIV positive women who have had negative medical experiences to talk about their needs. Abortion is illegal in Thailand but is done in 'certain cases'. This is supposed to be a voluntary act but there is unwritten policy on aborting pregnant women who have HIV. Women who are 'counselled' to have abortions are also requested

to sign documents authorising sterilisation at the same time. This is not happening as frequently now in Bangkok, as practitioners are aware there is an advocacy group prepared to expose the practice.

The first support group for women has now been established in Pakistan and has received private donations to assist with shelter and medical support. The woman who started this group is providing translations of educational materials on HIV and supporting women in safer sex practices.

ICW elections have previously been held at conferences or pre-conferences, and have not been wholly representative, as only those members attending were able to nominate or vote. It was agreed by all of the Key Contacts present that the next election would be held by post. A call for nominations will be sent out in the next quarterly newsletter and the February newsletter will have the voting papers and biographies of those nominated in each region.

Key Contacts can only stand for two terms running (each of two years). I will be finishing my second term at the close of this election and will therefore be unable to nominate again. I am happy to know that the Asia Pacific region is now well represented across Asia, whereas when I was first elected, only women from Australia were standing for election as we were the only positive women who were politically active outside of our own countries, out about our status and able to access funding to attend international conferences.

Vivienne Munro is an ICW Key Contacts for the Asia Pacific region. For info about ICW or the Geneva conference, call her on 9206 2000.

Issues

for HIV + people in NSW

PLWHA (NSW) SURVEY NOVEMBER 1997

PLWHA (NSW) is interested in finding out what HIV positive people in NSW think about this organisation, as well as what you feel are the important needs and issues for positive people over the next year.

This is your opportunity to tell the Committee and staff of the organisation your opinions about our work, and have direct input into the planning and direction of the organisation for 1998 and beyond. It is also a way you can identify what are priorities for you at this stage of living with HIV/AIDS.

Any information is strictly confidential, and will be handled by the Research project of PLWHA (NSW). The report will feed directly to the committee, and a report of the findings will be published in TALKABOUT in March 1998.

Take a moment to respond to our questions, and post back to us NOW.

The first letter opened after closing date - 31 January 1998 - will receive a dinner for two to the value of \$100, at the restaurant of your choice. A prize for being so supportive!!! To qualify for this prize please enclose your name and a contact number on a separate piece of paper.

Post to: PLWH/A Survey
Reply Paid 855
PO Box 831
Darlinghurst 2010

ABOUT YOU

- 1 What is your postcode? _____
- 2 What is your gender? _____
- 3 What is your age? _____
- 4 Are you HIV +? _____ Yes No
- 5 What is your Nationality or Indigenous group?

- 6 Do you have children? _____ Yes No
How many? _____
- 7 Are any children HIV +? _____ Yes No
- 8 Are you in paid employment? _____ Yes No
How many hours per week? _____
- 9 Do you volunteer for any group or organisation?
_____ Yes No

How many hours per week? _____

10 Are you a member of PLWH/A (NSW)?
_____ Yes No

11 Are you a member of any other HIV/AIDS group or organisation? _____ Yes No

List them. _____

ABOUT PLWH/A (NSW)

12 What do you see as the priority issues for people living with HIV/AIDS in NSW?

13 Are you familiar with the activities of PLWHA (NSW)? _____ Yes No

List which ones?

14 What do you think of the organisation?

15 The main focus of the organisation is advocacy and lobbying, what do you think are the most important issues to be working on today?

16 Would you like to see this organisation involved in any specific activities or projects?
_____ Yes No

17 Do you think that PLWHA (NSW) is still an appropriate name for the organisation - if not why not? _____ Yes No

Issues

for HIV + people in NSW

18 Have you any other suggestions?
 _____ Yes No

19 Have you visited our office, or made telephone enquiries?
 _____ Yes No

How often? _____

What were the reasons? _____

20 Were you satisfied with the assistance given?
 _____ Yes No

21 If membership fees increased during the next year, what type of extra membership benefits would you like to receive with PLWH/A (NSW)?

22 Are there any barriers which stop you from becoming an active PLWHA (NSW) member on one of the working groups or the Management Committee?
 _____ Yes No

23 If PLWHA (NSW) was to offer training so its members could become more involved in the organisation, what types of training would you find useful?

OUR PROJECTS

24 Do you receive the PLWHA (NSW) Annual Report?
 _____ Yes No
 Is there anything else you would like included in it?

25 Do you receive *TALKABOUT*? _____ Yes No

26 Are there any changes you would like to see in *TALKABOUT*? _____

27 Do you receive the Contacts Booklet?
 _____ Yes No

28 How regularly would you use it, or refer to it?

29 How useful do you find the listings? _____

30 Are you familiar with the Positive Speakers Bureau (PSB) project?
 _____ Yes No

31 Do you think that the PSB is an effective PLWHA (NSW) project, important for challenging the myths about people with HIV?
 _____ Yes No

32 Would you be interested in PSB training and work?
 _____ Yes No

33 The Research Project supports a large part of the PLWHA (NSW) working group activities.

- Treatment Working Group
- Complementary Therapies & Treatments Working Group
- Care & Services Working Group
- Legal and Euthanasia Working Group

Are there any specific issues or information you would like these working groups to be involved with?

34 The Community Development / Volunteer Project has different events organised throughout the year.

Are you familiar with

■ Mardi Gras Float _____ Yes No

■ Time out room (Sleaze and Mardi Gras)
 _____ Yes No

■ Fair Day stall _____ Yes No

■ Fundraising activities _____ Yes No

35 Are there any other activities you think PLWH/A (NSW) should support around NSW?

36 What do you think is the most valuable PLWHA (NSW) project for HIV+ people?

37 Is the PLWH/A (NSW) Freecall number useful to you?
 _____ Yes No

38 Are you on the internet? _____ Yes No

39 Are you able to access it anywhere?
 _____ Yes No

Where? _____

Poetry



Memorialised moments

AT
the bar in
the Midnight Shift
a man turns his head
and regards the beholder
with talkative eyes
and a warm smile
and then walks away
into the throngs
of the crowded bar

BUT
in the memory
of the beholder
this simple gesture
uplifts his spirit
from a melancholy moment
and has the power
of a remembered keepsake.

AND THEN
in a wistful moment
we remember
the warmth of the smile
and the language of the eyes
in our collective memories
and we wonder
if he's moved to Melbourne.

BUT THEN
in a commemorative moment
in these times of HIV
when the news of
another death
is met by
the shrug of the shoulders
we wonder
if he's even alive.

— Peter Mitchell

Olga's Personals

Hi, I'm a 17yo HIV+ female wishing to talk with other HIV+ people. I would like to know about methods of coping with HIV/AIDS and share experiences/stories of other people affected by HIV/AIDS. 971205

I am a 34yo, long term survivor of HIV. I am heterosexual, divorced with 3 children (not living with me). I don't smoke or drink. My hobbies are music (I play a guitar), tennis, squash, fishing, swimming, dancing and reading the Bible. I am looking for a HIV lady to share my life with, 25 - 35yo, who shares my interests. 971210

Mature (over 40) Chinese/Asian sought by MAG. Interests: meditation, Buddhism, & matters of heart, music, cooking, cinema, country trips, good restaurants, n.scene, n.smoke, sincere & genuine home person, quiet evenings & intelligent conversation. 971215

We all create scenarios then become convinced by them. I am convinced that with heartfelt love we could move the world. Interests: meditation, Buddhism, spiritual matters. Wo Hen Xiang Ni. Mature <40 special Asian friend sought by mature Caucasian. Let's not be lonely any longer! 971220

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, 2010 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.

Ooops!

APOLOGIES TO ANTHONY ADAMS, whose picture appeared on the November *Talkabout* cover. Anthony was wrongly identified as Gary, speaking at Board AID – in fact it was Gary who took the photo. Because of this case of mistaken identity, Anthony was not asked permission for the use of his picture. *Talkabout* unreservedly apologises.



People Living With HIV/AIDS (NSW) Inc.

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

Current staff:
Ryan McGlaughlin: **Co-ordinator**
Luke Smith: **Finance/Admin Officer**
Vacant: **Community Dev Officer**
Jo Watson: **Research Officer**
Robert Rogers: **A/Research Assistant**
Paul Maudlin: **A/Positive Speakers Bureau Co-ordinator**
Jill Sergeant: **Talkabout Editorial Co-ordinator**
Sandy Thompson: **Talkabout DTP/Advertising**
Vacant: **Talkabout Support Officer**
Tim Alderman, Phillip & Norman Last: **Volunteer Receptionists**

PLWHA Email: plwhagen@rainbow.net.au
Research Email: plwha@rainbow.net.au
Fax: 9360 3504
Office: Suite 5, Level 1, 94 Oxford St
Post: Box 831, Darlinghurst NSW 2010
Phone: 9361 6011
Talkabout: 9361 6750
Freecall: 1800 245 677

Editorial Working Group

The *Talkabout* Editorial Working group meets about twice a month to discuss the content of *Talkabout* and *Contacts*. If you're interested in joining, please call Jill on 9361 6750.

David Barton, Sarah Bergin, Vincent Dobbin, Bill Evans, Erycka Fars, Stephen Gallagher, Kim Gottlieb, Ryan McGlaughlin, Jill Sergeant, Sandy Thompson, Guy Taylor, Jo Watson.



1997 World AIDS Day Awards

Outstanding Achievement Awards



These awards acknowledge phenomenal effort in contributing to care, support or education in the HIV/AIDS pandemic in NSW.

Dr David Ellis

David Ellis was a founding director of the Mid-North Coast Division of General Practice. He continues to be an effective advocate for HIV/AIDS within that organisation. He was instrumental in establishing a monthly visiting specialist clinic for PLWHA in the area, which has markedly improved their treatment. He has been the major impetus behind Coffs Harbour AIDS Information Network, the major lobbyist of the Health Service to improve HIV/AIDS services in this area. David always shows great compassion, sensitivity and concern.

Richard Holland and Hands On Massage

Richard has been an active carer and member of CSN for as long as anyone can remember. In his early days with CSN he began to teach massage and established the volunteer massage project, Hands On, in 1987. He has continued to be a driving force behind Hands On. Richard has always given of himself and his time selflessly. As a CSN carer he has been known to do overnight shifts then go to work the following morning, or to spend his own money to buy small luxuries for clients. It's a common sight to see Richard doing the rounds of the Sydney AIDS wards, offering massage.

Rodney Junga

Rodney's contribution has been to raise, sometimes single-handedly, the profile of Aboriginal issues in the HIV/AIDS community. He has particularly been active in PLWHA organisations, especially as

a member of the NAPWA Executive. In this work Rodney has remained unpaid but this has not dimmed his commitment. He has continued to work in this area despite often being isolated as an Aboriginal person.



Rodney Junga.

PHOTO: GEOFF FRIEND

Sister Margaret Mines

Sister Margaret began her work in 1984 as a Pastoral Care Officer at St Vincents. During her time there she was significantly involved with many people with HIV/AIDS, their family and friends. After leaving St Vincents in 1995, Sister Margaret set up the Tree of Hope, a drop in centre for carers. She is also a regular volunteer each Monday at the Luncheon Club. Sister Margaret's service to HIV/AIDS started virtually from the outset and she continues to give physical, emotional and spiritual support as a Catholic nun and even more importantly, as a friend.

Drew Mollineau

Drew, a past volunteer for the AIDS Trust, BGF and the Luncheon Club, deserves particular recognition for his recent

volunteer work presiding over the transition of the Sydney PWA Living Centre from under the management of the Area Health service to that of a non government organisation. His sheer determination and lobbying brought about the agreement between community health services and programs, PLWH/A, ACON and the PWA Day Centre in November. The Living Centre's survival and growth can be greatly attributed to Drew's tireless work as President over the past year.

Nominated by PLWH/A (NSW) Inc.

Dr David Plummer

David has been involved in the area of HIV/AIDS since 1984, on a professional, personal and voluntary basis. His contribution has included stints with several Ministerial Advisory Committees on HIV/AIDS and the National Centre for HIV/AIDS Virology Research. David has worked on HIV/AIDS projects in Africa and Indonesia and has gained particular respect from Aboriginal communities for his work in developing HIV/STD education programs and clinics.

Sue Rodda

Sue has been involved with HIV/AIDS for over eight years. Currently responsible for care and support at ACON Northern Rivers, Sue has also worked in administration and as acting manager. She was instrumental in organising a positive retreat at Lennox Head several years ago. In the absence of a Positive Speaker's Bureau, she has taken high school students on weekend excursions with positive people. Sue regularly gives up her time to speak about AIDS to community groups and also to care for friends who are ill. She is always there showing love, compassion, understanding and empathy.



1997 World AIDS Day Awards

Service Awards



Service Awards are offered to individuals or organisations that have given above the call of duty in HIV/AIDS education, care or support. The following people were nominated by PLWH/A (NSW) Inc.

Kim Gotlieb

Kim, who has been a member of the *Talkabout* Editorial Working Group for about 18 months, has always played the important role of devil's advocate. He appears to subscribe to the anarchist philosophy "question everything" – a very healthy viewpoint to take. He has contributed many ideas



Kim Gotlieb

PHOTO: GEOFF FRIEND

and almost as many stories to the magazine and has gently but firmly raised issues and alternative perspectives – such as his article questioning the role of World AIDS Day in 1996, or suggestions about how to address the issue of poverty. Kim has been a constructive, sometimes dissident, sometimes controversial voice on the team behind *Talkabout* – and we wouldn't have it any other

way. *Talkabout* is not Kim's only commitment; he also provides massages at the Sydney PWA Living Centre and is a speaker with the PLWH/A Positive Speakers Bureau.

John Trigg

John has a long history of involvement with the community response to HIV/AIDS. In his stint as a PLWH/A Committee member, John helped establish the Complementary Therapies & Treatments working group and was also a key person in setting up the Positive Retreats, originally a joint project of PLWH/A and ACON. He continues to volunteer with the Positive Speakers Bureau and Time Out Rooms. John is also a volunteer at the ACON HIV Living Project. Where does he find the time to keep his hair nice?!

Vincent Dobbin

Vincent deserves recognition for his quiet and consistent work in the interests of all people living with HIV/AIDS. A PLWH/A committee member since November 1995, Vincent has been active on several working groups, especially the *Talkabout* Editorial working group and the Legal and Euthanasia working group. A Solicitor, Vincent is also a volunteer at the HIV/AIDS Legal Centre and a member of its Management Committee. We applaud the common sense, fairness and respect for others which pervade all of Vincent's work.

Jo Watson

In the relatively short period of time Jo has been the PLWH/A Research Officer, she has managed not only to forge strong community links on behalf of PLWH/A but also to create innovative new projects within the organisation. She co-ordinates the Treatments Officers' Network and was a dri-



John Trigg

PHOTO: GEOFF FRIEND

ving force behind the PLWH/A Treatments Working Group's recent publication "Getting The Most Out Of Your HIV Treatments". Jo also writes regularly for *Talkabout* on issues of concern for PLWHA such as up to date treatments information. We believe that Jo's invaluable contribution to the HIV/AIDS community has gone beyond that of an employee.



1997 World AIDS Day Awards



Posthumous Role of Honour Chris Hordern

Chris was an active member of the PLWH/A Committee and also participated in other significant organisations such as ACON and BGF, as well as volunteering for the Candlelight Rally. His support, both emotional and practical, was vital to the running of Time Out Rooms at major events and to PLWH/A fundraising activities. There is no doubt that his exceptional work as a volunteer was selfless, effective, and led to a better environment for positive people in NSW.

Dodge Traffic

Dodge, in a previous incarnation as Don Carter, was the first Co-ordinator of PLWH/A (NSW). PLWH/A in the early days was to many a voice at the end of the phone. That voice belonged to Dodge (pictured right). On a whim and a prayer he performed mini miracles for our

members, often spending hours of his own time hunting down some requested service. He didn't need to know you to care. Dodge also

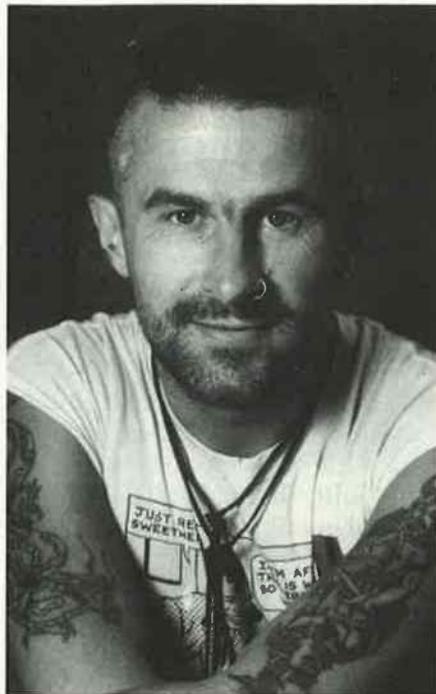


PHOTO: ELIZABETH OHLSON

had a long history of treatments activism, especially with ACT UP. He was a strong advocate for IDU and others on the fringes, who had difficulty accessing mainstream services. Dodge was full of fun and surprises, and had an intense, well thought out commitment to fighting for the rights and well-being of fellow PLWHA.

Robert van Maanen

Robert was a Committee member of PLWH/A for a number of years, during which time he was treasurer. He played a critical role in assisting the organisation in some very difficult times. Robert's clear headedness, focused commitment, fairness and quiet but determined manner are greatly missed. Some of us here at PLWH/A will always believe that his early demise was due not to AIDS, but to too great a predilection for brown sugar sandwiches.

- CHRIS, DODGE & ROBERT WERE NOMINATED BY PLWH/A (NSW) INC.

1997 World AIDS Day Service Awards

World AIDS Day Awards Steering Committee and Public Nominations

Patricia (Trish) Algate, Wayne Anderson, Wesley Badillo, Barker Howard, David Barton, Bethany Respite Centre, Marilyn Bliss, John Carrick, June Crawford, Des Doherty, Sisenanda dos Santos, Marion Dunn, Hani El Turk, David Ell, Jodie Evans, Lucy Falcocchio, Suzie Ferrie, Marie Fisher, Andrew Fraser, Evelyn Gardiner, Paul Gibbeson, Goodtime Committee, Tek Heang Ya, Heather & Doug Horntvedt, Paul Jacobsen, Peter Jarrett, Helen Jones, Jenny Jordan, Brian Kane, Suzette Kelly, Gary Keogh, Teresa Kovacs, Robyn Langlands, Jennifer Littlejohn-Jones, Peter Lock, Peter Longfield, Kendal Lovett, Macarthur Fun & Esteem Group, Carmel Martin, Kevin Martin, Joan Maxted, Ian McKnight-Smith, Greg Millan, Sr. Kristine Millar, Ross Moore, Mark Morris, Multicultural Health Promotions Project (Polly Purser, Mallin Wongthaveevatana, Panee Studdert), Stephen Oldham, Performance Positive, Victor Phillips, Dr. Peter Pigott, Kelly Quarmby, Elaine Rich, Evelyn Robinson, Paul Roberts, RUSH Editorial Committee, Agnes Ryan, Sacred Heart Hospice, Graham Saunders, Les Simmons, Connie Sinnott, Southern Highland AIDS Resources & Education, Bruce Strath, Sydney Conference & Exhibition Centre, Nancy Tam, Audrey Taylor, Gerry Tobin, Gary Trotter, Troy Lovegrove Foundation, Alex Vanderburgh, Romy Waterlow, Larry Wellings, Brian Wray, Matthew Young

Posthumous Roll of Honour

Michael Alexander Comaroff, Dodge Traffic, Michael Glynn, Paul Hill, Christopher Hordern, Rick Lansley, Robert van Maanen, Terry Patterson

Posthumous Service Awards

Malcolm Condran, Jeff Linich, Royce Sutcliff

You can't kill the SPIRIT

A year ago, the Talkabout Editorial Working Group decided that this December we would do a special issue on spirituality. The time approached and completely unsolicited, the stories started rolling in. Someone up there likes us!

Actually, the stories in this special feature are not specifically about spirituality. But what struck me, as one after another arrived on my desk, was that they shared a common theme: that individuals in this epidemic can draw strength both from within themselves, and from the love and support of their community, that transcends all difficulties. Even sometimes, as our lead story (p.18) shows, from unexpected sources.

In her acceptance speech upon receiving her World AIDS Day Award (an extract is printed below), Sister Margaret Mines from the Tree of Hope centre spoke a truth that many of us will recognise, whether we are Christians or not.

For me, her words define the spirit that is in the articles featured in this issue. And as our contributors show, no matter what happens to the body, you can't kill that spirit. It's what keeps us connected as human beings and no matter what the future holds in terms of drug therapies, vaccines, funding cuts or mainstreaming, with that spirit alive there is always hope.

Due to space limitations (it's a busy time of year) we weren't able to develop this theme as much as we'd originally planned. The wide variety of spiritual faiths held by people with HIV/AIDS is not fully represented. However, this is not, of course, the last word on the subject. Over the next few months – or as long as it takes – Talkabout will run an occasional series on the topic of spirituality. Your contributions are welcome.

– Jill Sergeant, Talkabout Co-ordinator

Sister Margaret Mines



PHOTO: GEOFF FRIEND

IN THE LAST MANY YEARS I HAVE been invited into the lives of a lot of wonderful people. They have enriched my life. I am grateful for all the ways they have shown me what true love and devotion is, what true compassion is, what courage is and that healing comes from laughter and tears.

We all have something to offer, some gift. We touch each others' lives with great respect, and in a way that preserves our own space and our own dignity, as well as the dignity of others. I thank all these people for their hospitality and welcome.

The gift that many people appear to value from all at the Tree of Hope is our spirituality. It helps us all to search for what gives meaning and purpose in our lives. I know this has helped people to be more in touch with their deeper

selves. Our role is different from that of Ankali or CSN or the other service providers.

We help people to discover spirituality and hope, a layer of ourselves that is God's Spirit within, holding a treasure of strength and wisdom, the source of courage, and the affirmation of a future that holds a promise. Not a hope for a future that is dependent on the success of a drug regime, or even that magic word 'cure'. This indomitable strength comes from acknowledging that there is a power, greater than ourselves, a power I call God, although there are many names for our greater power. This is the power of love and the source of our hope.

So let us go forward together, with great hope.

On behalf of all those who offer spiritual care, I thank you. ♥

'I love you Sisi'

In 1994, Susan Paxton was asked to support a young HIV positive African woman who was admitted to Fairfield Hospital with PCP (pneumonia). Jane didn't have anybody visiting her and was very isolated and depressed. Susan's visit changed both of their lives.

JANE SITS IN HER BED. A FRAGILE, beautiful, young woman with a gentle, noble bearing. She looks at me and smiles. It is the beginning of one of the most intense friendships I have had. Over the next few weeks I became Jane's sister – her carer, her organiser, her advocate, her bank signatory, her medical power of attorney, and her Sherlock Holmes. Before she died she gave me permission to tell others her story.

Jane's Tutsi mother and Hutu father had lived all her life as refugees in Uganda. After the death of her father, her mother brought up her four daughters and one son alone. She bred cattle – cows with the longest horns on earth. Jane and her siblings, as refugees, were educated by the Red Cross. When it came time to find employment the family struggled to raise the bribe necessary to obtain Ugandan identity papers. Nobody would employ a Rwandan refugee over a local Ugandan.

Jane's oldest sister, Frances, had died of an AIDS related disease two years previously. Her second oldest sister was alive but very unwell. Jane had adopted Frances' daughter, Fionna, and promised to look after and educate her as her own. After completing a diploma in accountancy, Jane started work with a large company. In Kampala

she met people who had travelled outside Uganda and done well for themselves financially. At the age of twelve Jane first read about Australia and had decided to go there one day. Australia or Sweden. Wherever she might be able to earn money and deliver her niece, her mother and her youngest and dearest sister, Mary, from the incessant poverty trap.

Jane arrived in Australia in January 1994 with a six month tourist visa, \$1,000 and the address of a Ugandan acquaintance. Within a few weeks of arriving, the acquaintance had moved interstate and Jane had unsuccessfully applied for dozens of jobs. She met somebody who owned a house in the country and who offered her a place to stay rent free. Jane moved out of Melbourne.

Each week she journeyed down by train to look for work. She applied for child minding, book-keeping, dishwashing, anything to stop her shrinking bank account from bottoming out. One day she walked the length of Lygon Street asking in each and every restaurant for employment. By now autumn had set in and the cold of Melbourne began to affect her health. She was diagnosed with bronchitis. But without employment she could not afford to rest. Doctor's visits were expensive and she needed to buy warmer clothes. In cotton dresses she continued to travel down to Melbourne seeking the elusive job. Her bronchitis would not respond to medication and the weight pressing on her chest was continual.

On June 9, with only \$11 left in the bank, she was offered a menial job in a local manufacturing company. Unfortunately her resources were depleted in every way. She collapsed a week later. That is when I met Jane. Just diagnosed,

not only with HIV but also with AIDS. Where Jane came from, AIDS meant death.

Jane was afraid. She was a strong, determined, resourceful young woman, but her fear was insurmountable. She absolutely did not want anybody from the African community to know that she was in Fairfield Hospital. As in most countries, the early warnings about AIDS in Uganda were full of moral blame. Prostitutes were seen as the vectors of HIV. Stigma was attached to an HIV diagnosis. Proof that you have had unsafe sex at some point in time and that you are therefore a bad person. Similar stigmatisation and fear were stimulated in Australia after the Grim Reaper adverts in the late 80's.

Despite the fact that HIV has spread into every echelon of society in Africa and one in three adults are HIV positive in some areas, messages about HIV/AIDS have been slow to catch up. Despite the fact that in countries like Uganda, Zambia, Zimbabwe it would be difficult to find a family that has not, by now, been directly affected by AIDS, there is still a wall of silence surrounding it.

It is no wonder that African who are diagnosed as HIV positive in Australia often take on the shame and stigma and cut themselves off from contact with others. This isolation results in HIV positive Africans being denied the support and services necessary for their emotional, mental, spiritual and often physical survival.

In Australia there are no many HIV positive people able to speak out about living positive with HIV. Such messages are inspirational to people newly diagnosed with the virus and have no doubt contributed to t

longer survival rate of Australians living with HIV. These messages have also contributed to the breakdown of discrimination against people living with HIV/AIDS.

Sadly Jane had not been here long enough to hear this. In hospital she responded to the medication. I visited daily and we spent hours sharing our stories. Sometimes I would take my young son, Tsari, who was very fond of Jane. We would creep quietly into the room to be welcomed lovingly and invited to sit up on her bed and talk. She loved company.

After Jane's discharge from Hospital in July she began to absorb the reality of her situation. Her diagnosis was shattering news. She soon began continuously vomiting, rapidly losing what little weight she had. She was readmitted to hospital weighing 37 kilos. By this time I was worried that I was the only person in the world who knew who Jane was, where she came from, or how she was coping (or not coping).

A close friend, Sonja, a woman also living with the virus, began to visit Jane as did her lover Lesley and their daughter, Zowie. Over the next three months we became Jane's family. She was again discharged but continued vomiting and losing weight. After two weeks Jane decided to have a stomach plug – a feeder tube directly into her stomach to enable her to build up her body weight.

Immediately after the long operation Jane had a brain seizure. I believe her mind could not come to grips with the invasive surgery she underwent. She sustained

short term memory loss which she never fully regained.

Shortly afterwards Jane turned to me and asked "I nearly died didn't I?". "Yes, you nearly did" I replied. "And were you going to bury me?". "Yes, I was. Well actually I wasn't sure if I would bury you or cremate you, but I would have organised it. Would it have mattered which?". (Jane was not a woman to put all her eggs in one basket. She was a Catholic, a Methodist and a Born Again Christian.) "No", replied Jane "it



GRAPHIC: ROSANNA SILVESTRO

would not have mattered". I knew we were both planning for the future at that moment.

Jane was now very confused. She was very uncomfortable and unhappy with the drip and the stomach plug and continually tried (sometimes successfully) to pull them out. Sonja, Lesley and I realised that Jane's survival was precarious. I was concerned that she could die without again speaking to her family or communicating her wishes. She was in a strange land and her family still did not know she was ill.

One day I suggested we make an audio tape to send to her family. Jane lit up at the idea. When she said she wanted to tell them she was well I told her I did not feel comfortable about that. We quibbled as sisters do and dropped the idea.

September was harrowing for Jane. She was tormented by fear and began to deny that she could be HIV positive. I felt she needed to speak in her language, and determined that I would find somebody who spoke Runyankore. With the help of Robert Wood at the Victorian AIDS Council we located a Ugandan Vet in the eastern suburbs who spoke Runyankore. He took a train into town the next day. I collected him and drove him straight to the hospital. He sat down and began to talk to Jane. She responded. I left them together.

The next day when I saw her she was utterly beautiful. She smiled at me calmly and told me that she had gone home last night and that everybody was very well. I had never seen her so peaceful.

Jane did not lose that aura of peace. When the Ugandan community heard about Jane, visitors flooded in, mainly at weekends. I had been visiting almost daily for over three months and was feeling somewhat exhausted. From the beginning of October I began to take off Saturdays and Sundays.

Because of Jane's short term memory loss we decided to keep a journal and asked visitors to write in it so Jane could read it and remember who had come. At times she would ask where she was and

exclaim surprisedly when we told her. At other times I would go out for a toilet break, return to her room and be chastised for not visiting her for weeks. One thing that was consistent throughout this time was her often repeated comment, "I love you as if you are my own sister".

Within a couple of weeks Jane's health again took a downturn and this time I knew we had to contact her family. Jane was unable to give any information other than the name of her sister. This is when I went into detective mode.

Only once before have I had the experience of rifling through somebody's personal, intimate papers. That was when my father died. It was a very strange experience. This was even stranger because Jane was alive, but unable to understand much of what was happening. I went through every scrap of paper, every letter, every bill to find clues to Jane's identity. She had kept a record of her life

by way of bus tickets, appointment dates and chemist bills. Her lonely, difficult time after her arrival in Melbourne was laid out for me to see. Endless job refusals, business cards, and bank statements with an ever decreasing balance. I found a postal address for her sister but decided that was far too slow a process. **Perhaps the embassy would have to help me. Then I discovered it – an old phone bill with four Ugandan phone numbers. Surely one of these numbers would link me in to somebody who knew her family.**

Over the next few days I tried each number continuously. Two were disconnected, two not answering. Eventually one answered – a friend of Jane's who had visited Australia and had been close to her sister Frances and knew Mary, her youngest sister. Within another couple of days he had contacted the sister, travelled with her to the rural area to talk to Jane's mother,

and brought her brother back to Kampala to talk to Jane. In mid-October Jane spoke on the telephone to her family in Uganda.

Jane died in the arms of Sonja, Lesley and me at midday October 31, 1994, at the age of 26. The African Community raised the money to bury her. Over seventy people came to Jane's funeral. Many who did not know her came to show their support and solidarity. They were people who would have given their support during Jane's life if she had been able to be open about her AIDS diagnosis.

After the funeral I asked a friend what was the point of Jane coming all this way to become ill, suffer so much and die in a foreign land far from her family. She replied "Perhaps it is to remind us Africans in Australia that we cannot run away from AIDS. It is with us everywhere and we cannot bury our heads in the hope that it will not affect us here." ♥

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Information, referral and support for women living with HIV by women living with HIV, call (02) 9206 2012 / 2083.

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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 (02) 9206 2026.

GLIDUP

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Treatment Officers

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Women and AIDS Project

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Aboriginal and Torres Strait Islander Project

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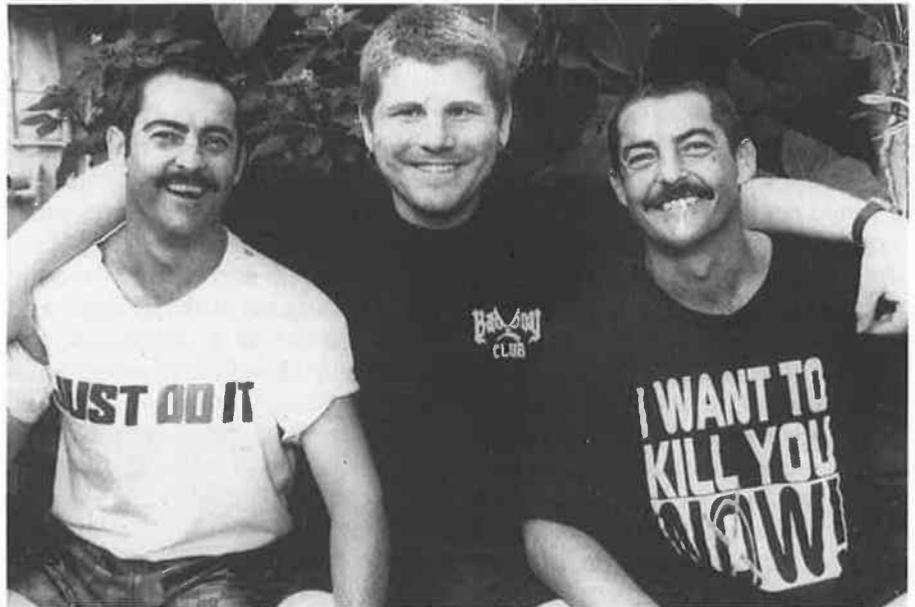
150 days OUT

Jon and Tim Vincent's story of a bone marrow transplant will be familiar to many readers. Several months on, Jon describes the process and the meanings it held for he and his twin.

HAVING LIVED WITH HIV FOR over 15 years, I was faced with my first AIDS defining illness, an aggressive Non Hodgkins Lymphoma, in September 1996. With a worst case scenario of eight weeks to live, my doctor and I (and the staff of Royal Prince Alfred Hospital) moved quickly and a six month course of chemotherapy followed. Radiation therapy in November seemed to have stopped a relapse but then in March of this year we found more holes in my bones, which meant that we were loosing the battle.

The next step was to take on a couple of courses in the heaviest duty chemotherapy, which would require me to have a Hickmanns dual line catheter inserted in my chest. It is a strange feeling to gaze down and see a couple of plastic tubes extending about 18 inches from a point on your skin which you can trace with your hand up your chest, where it is attached to a clave that leads to your heart. The procedure itself was no big deal, but the daily sight of it in the mirror as I followed a strict cleaning protocol was something that I never got used to.

Next was the biggest step of my life in the battle against HIV. The two doses of chemotherapy would not only eradicate my immune system, but also the bone marrow where the immune cells were made. I needed to substitute the obliterated marrow with that from a donor – not just any donor but my HIV negative identical twin brother, Tim.



Jon Vincent (left) with partner John Holmes and brother Tim.

PHOTO: MAZZ IMAGES

This had never been tried before in the world, for the treatment of Non Hodgkin's Lymphoma, so the hospital was naturally nervous. It was a live or die situation but it seemed to me that given the medical knowledge that could be acquired from this experiment, I had no choice but to give it a go.

Fifteen years plus of living with HIV, the loss of a brother, partners and hundreds of friends had somehow brought Tim and I to this crossroad. The torch it seemed had been passed onto us and as much for a legacy for our HIV descendants as ourselves, we had to spread our wings and fly into the unknown.

As a person who has lived with and through the post combination therapy blues, it seemed to me that the push to find a cure had somewhat stalled. Not everyone I knew was doing well on the new cocktail, but this seemed to have been forgotten by the gay community and onward they partied. The opportunity that was presented to Tim and I was therefore also a means to bring the bigger picture back into focus, and to offer that

intangible ingredient: *hope*. For that reason we needed to engage the services of the media so that the message could be amplified to the broadest possible audience. I mention this in response to criticism levelled at us for going public on this story.

Three things could never be compromised, if this story was to be truly told. We could not betray the love the community had shown us. We could never shy away from the truth or reality of the situation, and at times there were moments that were full of fear and required great courage. Finally, we could never let ourselves stray from the integrity of the process. It had to be defined clearly from the start and we couldn't compromise our aims and objectives. Many lively discussions with the hospital resulted in a clarification of our position. In such a situation my HIV specialist outside the hospital was a major ally and I have much to thank Dr Cassy Workman for. The hospital came to realise that this patient had the power to manage his HIV treatment outside the

hospital and I always felt this to be empowering.

So eight million of my brother's stem cells (immune system) were transplanted into me through those plastic tubes and we waited and hoped that the transplant would take. If it failed then there was a good chance that I would not survive. Having wiped out my immune system, I had to hope that my body would 'accept Tim's and it could set up shop in me.

A period of isolation followed the transplant and for me this was a most revealing time. Rarely in our lives do we have the opportunity to be still and to listen as our body speaks to us. An isolation situation is one of those arenas where we can learn so much about ourselves. We are stripped down to our barest humanity. Despite all the love that is sent to you, you are on your own.

Meditation and a more Eastern approach to the protocol was a great complement to the experience and a great balancer. Other

knowledge acquired in this time is of such an intrinsic and personal nature that even now I am respectful of its power. It will take much time and contemplation to assimilate it into my psyche and some of it may never be addressed, at least in the near future. There is certainly a book that needs to be written on the experience and this I have in mind. I have found the need to externalise the experience to be ultimately healing, no matter how compromising that may be.

I managed to compose a song cycle during my isolation stay, and maybe there is a composer out there who would like to set it to music. Poetry seemed to flow from my pen and a daily journal written last thing at night recorded the day's events.

One hundred and fifty days ago my brother and I took a bold step. We have both experienced such tremendous love and support from the gay and straight communities as to have been forever changed. Special mention needs to

be made of the CSN drivers who ferried me to and from the hospital on the visits that followed my release from hospital, along with the Luncheon Club members who embraced our experience. The Bobby Goldsmith Foundation kept our heads above water many times. The love of these organisations is ongoing and cherished.

The latest count has my CD4s at 420 and rising and yesterday we had a confirmation of the absence of any recurring cancer. Now the long term focus is to see how this experiment can impact upon my HIV. We still take it day by day just like everyone else who lives with HIV and continue to resonate those greatest feelings of love and hope – love of self and others – and hope for a better future.

Finally I must pay tribute to my partner John Holmes for his steadfast love. I have not walked this path alone, but his presence, the gift of life from Tim and the love of the universe have been an integral part of this process. ♥

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My journey with YOGA

by Blair Silverlock

I WAS INTRODUCED TO THE PRACTICE of yoga some 20 years ago as a young teenager. My mother began yoga about then and would show me the various postures from her yoga lessons. I gleefully copied them.

I have had many yoga teachers since. Each teacher and each lesson in yoga is truly a learning experience. The 'essence' or the 'spirit' of life is often overlooked in today's world. If it can't be looked at with a microscope, x-rayed, measured by a sensitive instrument or chemically analysed then it doesn't exist according to today's science. Yoga has taught me to look inwards and discover the life essence in my physical body. The Chinese call this energy 'chi' - in yoga the word 'prana' describes it.

Prana is said to be a cosmic energy that is highly concentrated in air and can be converted into psychic or spiritual force within the body by combining controlled respiration and meditation. Directed prana carries healing power.

Yoga is made up of breathing exercises usually combined with physical postures (also called 'asanas'). The asanas have such fantastic names as 'fish pose', 'child's pose', 'camel pose', 'the bridge' and 'the wheel'. I particularly enjoy the challenge of the 'reverse triangle pose'.

Yoga is good for the back, legs and arms, strengthens the abdomen, reduces tension in the neck and shoulders. Several yoga poses are beneficial for the immune system and others assist the lymphatic system. I have used yoga to help me deal with many of the physical symptoms of AIDS and anti-viral medication. Yoga has helped me pass through times

of grief and confusion. Yoga has helped me to relax and to sleep well.

You don't need to be incredibly supple or young or fit to do yoga. A good yoga teacher directs each student in such a way that they do the posture within the limits of their ability.

The end result of a yoga class, which usually lasts 60 - 90 min-



PHOTO: JOHN TRIGG

utes, is relaxation and a heightened sense of living. There is no competition in yoga, there is no 'World Championship' for yoga: for yoga is related to the self (the metaphysical, the spiritual, the emotional). Standing in front of an audience and performing yoga postures and being applauded by an audience has no meaning in true yoga.

Yoga, for me, is about discovering the life and strength that comes with each breath into my body. It is also about discovering

the point where the physical connects with the 'self' (or 'ego' or 'mind').

Since earlier this year I have been attending the yoga classes of Acharya at his yoga room in Pitt Street. Acharya, a yoga teacher some 30 years, has been teaching yoga to people living with HIV/AIDS for the last few years. He generously donates free yoga lessons to any person with HIV/AIDS who turns up to his lunchtime (12:30-1:30pm) classes Monday to Thursday. (See *Contacts*)

Upon entering Acharya's yoga room a certain peace and quietness descends upon me as I lie down to prepare for the class. The yoga mats are laid out ready for the six or so other people to join the class. Acharya directs me verbally through the postures, always providing cues to remind of the various nuances. Every now and then he will tell a brief anecdote, from which I gain extra insight into my life and emotions.

Yoga is about yourself as an individual, you and your own body and mind and 'Self' and breath. You do the poses within your capacity, you let the breathing become relaxed, you allow your mind to become quiet. It is the breath alone that can give us early enough warning that we have pushed ourselves too far. As long as we can quietly follow our breath we will remain within the limits of our own physical abilities.

*The Self is not my Self or your Self,
But it is 'one' Self.*

*Life is not your life or my life
But it is 'one' life.*

*We are all parts of this stream of life,
All particles of dust floating in space,
One non-difference from the other.*

- Swami Venkatesananda

Finding the courage to DREAM

by Douglas Barry

*"I gets weary,
An' sick of tryin'.
I'm tired of livin',
An' scared of dyin'."*

— "OL MAN RIVER", FROM SHOWBOAT
BY KERN & HAMMERSTEIN II

AT TIMES, LIVING WITH HIV/AIDS has been, not so much like floatin' down Ol' Man River, but like being totally at sea — a sea of pain, misery and uncertainty. Not being able to work is just one of those lingering shards of pain. Many feel a sense of isolation and suffer a loss of income and status. Others lose their source of creativity and involvement and are no longer masters of their daily lives. Self esteem plummets. Many of us have made irrevocable life decisions, based on realistic assessments of our longevity.

But what's this . . . a life raft? With multi-drug therapy, there is now, for an increasing number, hope and the prospect of a return to the work force, to be creative, productive again. But, milking the metaphor, some of us may need help navigating.

I write from the experience of a middle aged male, a long-term survivor, exhilarated by the impact of multi-drug therapy. Feeling a need to get back into it all, but not wanting to return to my law career, I had been feeling my way through an emotional and practi-

cal maze. When I learnt of my undetectable viral load, a whole new life spread out in front of me. What could I do with this gift of a future, not wanting to go back to the past? What steps could I take and in what direction? Who or what was there to guide me? I want to relate how I have drawn upon my life-altering experiences with the virus, tried to make some sense of them, and so feel my way along a new path.

Imagine that living with the virus is like being forced to cross a vast field, sown with mines of

tuned, as if your life has been spent in an endless loop of disaster movies. And now, with combination therapies offering a path through that field, there are new feelings of relief, exhilaration and optimism.

I have pictured my past thirteen years of living with the virus, my memories, my experiences, the recollected feelings and sensations, as being my emotional baggage. I decided to unpack that baggage and to rummage right through it all and doing this, I have found myself taking hesitant steps along

that new path. I call this process being gently radical with myself and my way of living. By "gently", I mean taking my time, resisting the impulse to achieve now. Finding new activities, or new ways of doing old things, is what I mean by "radical".

A few examples: with the radio, I listen to more "word programs" — not just talk-back, but interviews and discussions; I often tape them

and listen to them again, perhaps when I am out walking. I try unfamiliar music, exploring the sensations it triggers. Going to a movie or a play can involve my thoughts and feelings for hours, even days, afterwards. And above all, there is reading. Sometimes, it takes ages to finish a book or a magazine article, because I allow my mind and feelings to go rabbitting off down some avenue I want to explore.

I have the time to do this. I live on the Disability Support Pension.



GRAPHIC: PHILLIP McGRATH

varying sizes. Agonizingly, you have tried to plot a course; you have made some progress and then, an explosion. You suffer; you change course and, somehow, you start again. And so it has gone on. For some, the hurts and the injuries have been too great to continue. This way of life, this journey of hazards can be like nothing you have ever experienced. And what impact must this have had on the emotions, the feelings, the senses? Every point of your being can seem razor-

I spend more time by myself, and my social life has taken a beating. But I enjoy a full solitude, in which my 'aloneness' is a rich and valuable ally in helping me to examine that emotional baggage. I remember being lonely, when a painful necessity drove me to fill a vacuum. This is different.

I overcame my long-held and pride-based resistance to counseling, and spent four months rummaging around the origins of some earlier inappropriate behaviours. I discovered the joys of regular meditation and came to terms with my past denial of issues related to living with the virus. I became better acquainted with my emotional responses, learning to interview them with affection. I discovered the value of experiencing a moment, by exploring the colour, shape or sound of things; putting in their appropriate place all the pressures and concerns of my life.

A practical way of doing these things was to devise a simple routine. I started gradually, about four hours a day, with a number of set activities. When it felt right to do so, I increased the hours. For me, the routine has two benefits: first, it gives me the answer to

'What am I going to do now?', or 'What'll I do tomorrow?'; secondly, it returns me to the discipline of working regular hours. If I feel my routine doesn't work, I change it. And I love taking 'sickies' - it's guilt-free and there's no boss to worry about.

I have been doing this for some months now. I am not back in the work force, but I don't feel I have been wasting my time. For one thing, my emotional antennae seem better, more finely tuned. I have lost some of the old fears and hang-ups. I ask myself, "What can anyone do or say to me that could be worse than living with this virus?" And I keep having *ideas*. Not about jobs, or career paths or CVs, but about people and living and society. I start to be confident that I need not be mired in the market place when considering my future, nor captive to conventional conditioning.

Enjoying my discoveries and ideas, I have urgently, at times passionately, wanted to share them with someone. Since I bask in that solitude of mine, there may be only a few friends and captive relatives on hand. The way to resolve this dilemma was to write about my discoveries. And so...!

You see if anyone had said, twelve months ago, that I would be writing this essay, I would have laughed in their face. I may be undecided about my future still, but I am enjoying writing about my indecision.

For those of us living with the virus and experiencing a present confidence, now could be the opportunity to explore and discover whether there is something we have always, really wanted to do with our lives - some treasured secret dream of ours. Equipped by my past and present experiences with the virus, I believe I can throw caution to the winds, take risks and find the courage to dream. For someone in middle life, this is vital. How wonderful it would be to hold a dream, to lose it, and then, as only a child can do, to dream again, and again and again. This would be courage indeed.

So instead of "Ol' Man River", why not the words of Annie Lennox from the "The Preacher's Wife"?

*'I'm takin' it,
Step by Step,
Bit by Bit,
Mile by Mile.*



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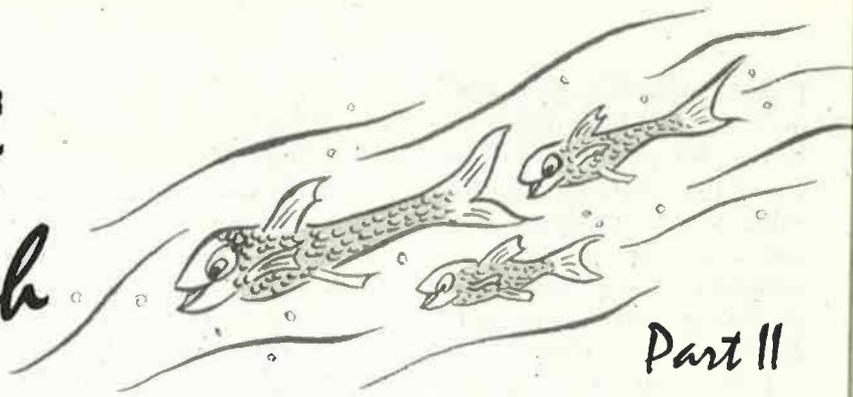
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A different school of fish



Part II

In the August Talkabout, Paul wrote about the reasons he became HIV positive. Now, a bit further along the track, he tells us what's changed for the better.

I HAVE BEEN LIVING VICARIOUSLY through the HIV alcove in my life for the past twelve months. It has propelled me into a journey of self discovery. The space created for a viral load in my body pushed out a lot of dormant emotional pain. And as my viral load abates, love is beginning its eternal reign in my life.

I have stumbled and I have fallen in life, but HIV is not attached to me like a ball and chain. I'm not a prisoner to HIV. But conquering the blues is a tough nut to crack sometimes. Despite all the generous love available in the HIV community, I have found that loneliness weaves its way into my bed every night when I go to sleep. There is something to be said for the love and intimacy lovers share with each other. Not to mention sex and affection. But I'm beginning to take hold of my circumstances and realities in life and live with them. It's hard letting go of your dreams and intentions and replacing them with new ideas that are a little unfamiliar to your previous way of thinking.

I lived through the pressure weighing in on my life to begin drug therapy. The timing isn't right for me. And also I do feel absolutely fabulous. It is a very informed decision. My viral load is hovering around the 50,000 mark with a strong constitution of CD4 and CD8 cells. One of the therapies I'm delving into between

now and my next blood extractions is DHEA.

I believe it's important to be at the helm of your health care. It is your body. Even though through default HIV was invited into my life, I've put my foot down on the substances and chemicals being poured into my body. More than anything else now, I'm receptive to love.

More and more I'm starting to accept the attraction to men that I



GRAPHICS: PHILLIP MCGRATH

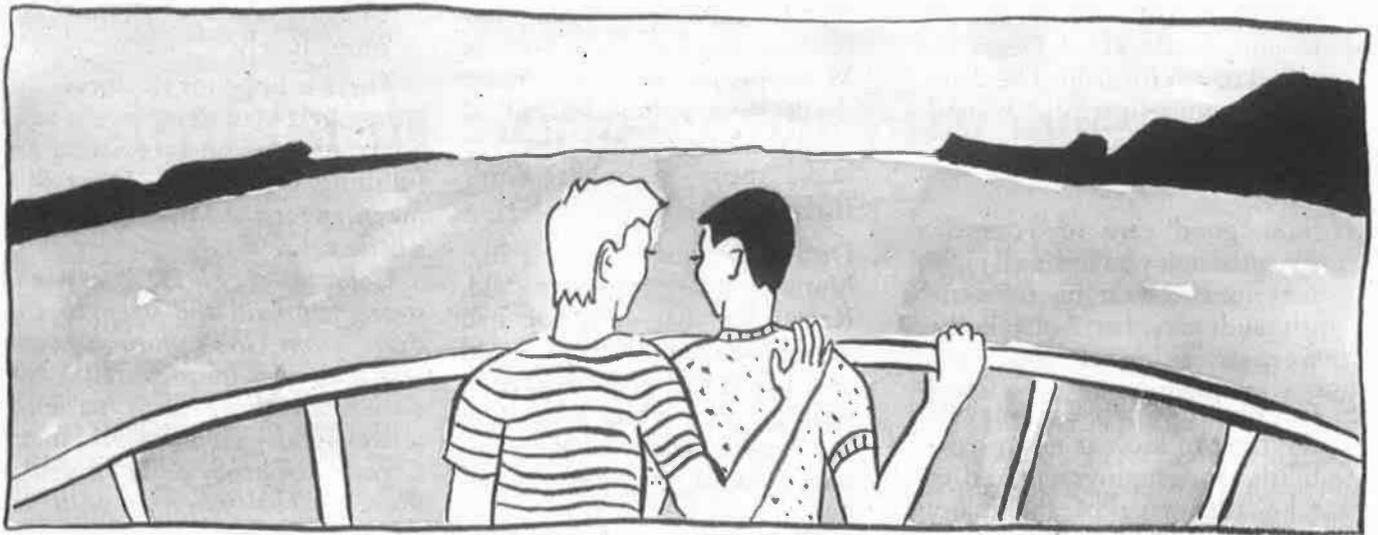
have been blessed with in life. And not confuse it with the paternal affection I crave. HIV has assisted me in asserting my desires and wants with humanity without being ashamed. No longer is sex an emotionless experience in the dark with strangers.

The sexual abuse reigned with waves of destruction for 20 years in my life. It hit its zenith with HIV, but through HIV I've been able to clamp down on the stranglehold it had over me. I am a child sexual abuse survivor, but it's an ongoing journey. It may have taken me longer than usual to understand the world, being fatherless, but now that I do I'll never let it go. And if we're all cured of HIV or live a respectable lifetime with it, the world really is our oyster. Mine for the first time.

There is no easy road to travel with HIV. Each avenue is fraught with anxiety and a quest for knowledge. The best thing created out of the HIV experience is the capacity and desire for love that we all share. Love of yourself and love of others.

I want to be aboard Earth for as many colossal cruises around the sun as possible. And forever more I want life to contain a Fair Star level of love and fun. We're all different, but we're all progressing to similar destinations with recognisable commonalities in our journeys.

Sharing is precious. We all carry pain but also we carry the capacity to love. A viral load does not reduce your skill to love. So make your choice. Take a stand for yourself. And make out of this life everything that you dream. There is no time like the present. Keep healthy. ♥



GRAPHIC: PHILLIP McGRATH

Ten tips for LIVING

By Rev. Greg Smith

MANY PEOPLE LIVING WITH HIV/AIDS are experiencing a profound and positive change in their conditions and life expectancy. With the many new drugs and 'cocktail' therapies, many who were once facing an uncertain and short future are now looking at the prospect of living a long, healthy and active life. For many of us this is an answered prayer! It is a source of hope for those who can access and tolerate the new treatments.

However, many people have mixed feelings about their new hope of living long and well with HIV. This often comes as a surprise to many who experience it and to those who love them.

There's an expectation that people in this situation should be relieved, grateful, and joyful. While many do feel this way, the reality for some who are suddenly facing life after facing death is a deep depression, profound anxiety, or simple fear. If you're in this situation and feeling this way, you're not alone!

There are many people living with HIV/AIDS who, believing their life span was about to be cut short, cashed in their superannuation, quit their jobs, went onto the pension, overspent on their credit cards and made their 'final arrangements'. The prospect of turning all this around and getting back into life can be quite overwhelming, and can have a strong emotional impact.

Many people, in realising they are going to survive, are amazed at how much they had grown to accept their imminent death. For many, the joy of getting well can be overshadowed by the fear of the future and the changes needed to start a new life. Many who were unable to do tasks for themselves are now well enough to become actively involved in the community again. Making decisions about running the house and shopping can be overwhelming if you have grown used to someone doing these things for you.

Many people go through a form of 'survivors guilt', wondering why they have been spared when so many others have died. To top

this off it often seems that some friends are actually angry with you, as if they had done all their anticipatory grief work for nothing. It is difficult to stop worrying that a time bomb inside you is just waiting to explode.

A common question asked these days is "OK, I'm going to live . . . now what do I do?"

Maybe the following ideas can be of some help.

1. Be grateful. Give God thanks and praise! Celebrate life! Remind yourself every day that you are going to live. This is not only a good thing, it's a miracle. You are God's precious creation. You deserve to live and you are going to live and you have a lot to be grateful for.
2. Don't stop your medication. Many of the current medications require strict compliance. Your survival may depend on how well you are able to follow your doctor's directions.
3. Reach out for help. Realise that it isn't easy making the >

transition from chronically ill to chronically alive! Don't be afraid to ask for help. There are many counsellors, clergy and therapists just waiting to help you.

4. Take good care of yourself. Even though you feel well now, you need to continue to nourish and care for your body. Keep practicing safe sex.
5. Get back to work. This may be the time to look at new possibilities for employment, and to take advantage of the many training courses available.
6. Resolve financial problems. Many of us have let our financial house get out of order while we were ill. Although it may seem impossible, even small changes could help get things back on a even keel.

7. Plan for the future. Make plans to enjoy life. Live your dreams. Many people who have faced death have a long list of 'if only's'. Now is the time to make those 'if only's' come true.

8. Deal with your fear of ageing. Many people fear growing old. Remember that once you had very little chance of seeing old age. Learn to see the beauty in wrinkles and white hair. Find out for yourself what the positive sides of growing old can be.

9. Incorporate the lessons of dying into living. Live what you learned when you thought your time was short. Celebrate every moment of your life.

10. Don't get frustrated. It will take time; be gentle on yourself and don't get frustrated when

things don't fall back into place immediately.

There is hope for the future and although it may never be the same as the past, it can be exciting and fulfilling. Please feel free to talk to me or anyone at MCC if you need a little help.

Colossians 1; 11-12: May you be strong with all the strength that comes from God's glorious power, and may you be prepared to endure everything with patience, while joyfully giving thanks to our Creator, who has enabled you to share in the inheritance of the saints of the light.

Many thanks to Rev Steve Pieters, Director of AIDS Ministry UFMCC, for the ideas in this article.

Rev Greg Smith is the Pastor of the Metropolitan Community Church, Sydney

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Conference report

Australasian Society for HIV Medicine

Adelaide, November

by Jo Watson

ASHM 1997 WAS MARKED BY AN obvious swing in mood. Although the past 18 months have seen a significant change in the hiv treatments outlook, this is accompanied by the reality check of the complexities of treatment regimes and the adjustments that confront people living with hiv/aids.

The conference discussed the developments in our knowledge about the potential long term effects of combination therapies, as well as the importance of considering the many variables of an individual's case history and lifestyle, before choosing the most beneficial treatment option.

The program included a range of papers from both Australian and international speakers. Of particular interest were presentations covering the following topics.

Lipodystrophy

Lipodystrophy is the term used to describe a redistribution of body fat, with wasting of the face and limbs, but development of a fat belly. It is a disturbance of the way the body produces, uses and distributes fat. While there were only a small number of presentations ready for this meeting, there was a great deal of discussion about the anecdotal reports which have been appearing both here and overseas. The Treatment Officers Network (TON) meeting held just prior to ASHM also discussed this topic at length, and considered the information we have to date.

Some people who have been using combination therapy for a period of time can experience wonderful results but are also noticing some lipodystrophy, which may be a long-term adverse effect of protease inhibitors.

The consensus of opinion at TON, and from many at ASHM



itself, was that a small number of people appear to be experiencing significant features of lipodystrophy, but there is a need for more research and study data to establish the actual cause. Certainly in the US and Canadian reports there is agreement that the cause or causes are still unclear. Other factors that could be causing these responses are being discussed, including diet, exercise, hiv disease patterns, and hiv therapy responses in general.

Research centres here and in the US are collecting more information and at an upcoming meeting in Chicago in February, there will be eight major presentations discussing the issue in more detail. In the meantime, if you would like to have more information, or discuss this further, read the August/September issue of the HIV Herald, which discusses body weight and body image in length, and contact your doctor or Treatment Officer.

Virological relapse

There is now clear information that a number of people using combination therapies are relapsing or becoming 'detectable' again. While we have heard a lot of evidence that not taking the drugs at the prescribed times can cause the virus to become resistant to the drugs, it is now better understood that there are cases where anti-retrovirals are failing patients even when they stick to their dosage regimes. The reasons can be com-

plex, but include inadequate or "sub-optimal" treatment regimes, individual differences in absorption and metabolism, drug interactions, and differences in tissue penetration of the drugs.

As I said before, the progress that has been made in hiv medicine is throwing up the complexities of long-term management for prescriber and plwha alike. In any case where drug failure has occurred, all possible contributing factors must be considered. If a person is having trouble taking their drugs at the right time and is missing doses, that will require a very different therapeutic approach than that for someone who has relapsed for other clinical reasons.

Social science

In the social science stream there were many presentations discussing the challenges faced by plwha when discussing treatment information and options with their doctors, or using other sources of information. There was acknowledgment that people who facing specific health and life decisions can feel intimidated and disempowered by the technical language of treatments information. This can drive people away from treatments and therapies.

It has to be underlined just how complex the everyday becomes, when your attitudes to disease, the banal monotony of being tied to a large number of pill dosages, and the tensions of who has control over your life, come into play. For plwha who have chosen to take treatments and monitor their health, the future has indeed changed with the exciting developments, but ASHM 1997 emphasised for me just how that excitement is tempered with a range of reality checks and quality of life factors.

Service Update



OUT OF THE CLOSET EMPORIUM

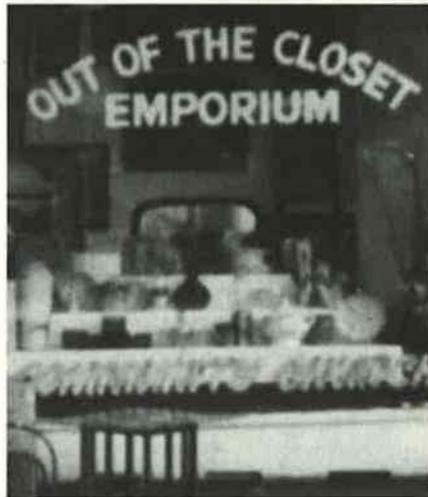
FROM SMALL BEGINNINGS ALMOST four years ago Metropolitan Community Church Sydney's Out of the Closet Emporium has become the key source for funds and goods for the various welfare services of MCC Sydney.

The emporium began as a result of the increasing awareness of problems experienced by many people living with AIDS when they approached other welfare organisations, many of them run by mainstream religious organisations, for assistance. Often members of our community were told, or it was implied, that they were not welcome, as they didn't fit the 'normal' family model. Although some agencies were somewhat understanding, PLWHA's general experience was of judgement or in some cases outright rejection.

MCC recognised the need to provide assistance to people who were in the process of setting up home and who had little or no household furniture. In an attempt not to duplicate services MCC began to look at the areas that were not covered by organisations such as the Bobby Goldsmith Foundation (BGF). There was an obvious gap in the provision of beds, lounges, tables and chairs and other basic non electrical goods. Using the pastor's old Valiant and a hired trailer, a small band of volunteers began to pick up donated goods and distribute them to those who were in most need. Many thanks must go to Mark and all the folk at BGF

for assistance in those early days and for the use of their van on occasions.

Eventually it became obvious that there was a great demand for assistance and MCC opened its shop on Broadway called Out of the Closet Emporium. The Emporium enables MCC to raise the funds needed to purchase much needed items such as beds etc. It also serves as a depot for the



receipt and redistribution of goods and is a cheap source of other non-necessities that provide comfort for those struggling on a low income. The Emporium is fully staffed by volunteers, many of whom are PLWHA, and operates its own truck for pick up and deliveries.

Out of the Closet is also a great place to shop for those people who are looking for that special or unusual bargain. In an article in the Good Weekend last year, Out

Of The Closet was listed as one of the best thrift shops in Sydney so it is worthwhile dropping in occasionally to see what we have in stock.

Since the opening of the Emporium MCC has been able to assist over 550 people to move into new accommodation. Although the Emporium continues to be a source of goods and funds, the increasing demand continues to stretch our limits. We are in constant need of good quality furniture and bric-a-brac and would greatly appreciate any donations. Pick-ups can be arranged by calling 9281 8928 Wednesday to Saturday.

To be eligible for assistance PLWHA who are on low income need to meet the basic requirements of eligibility laid down by BGF. You will be required to have an interview with the pastor, Rev. Greg Smith. This can be arranged by calling 9211 9119 during business hours. It is our aim to make this process as easy and comfortable as possible. Because of MCC's belief that our sexuality is a gift from God, you will find an atmosphere of acceptance rather than judgement in all of your dealings with the Church.

Out of the Closet Emporium
147 Broadway, Ultimo
Tel: 9281 8928
Open Wed - Sat: 10am - 2pm
Thur - Fri: 10am - 4pm
Closed Public Holidays

Talkabout

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Join PLWH/A in the fight against AIDS!
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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.

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

- Full member (NSW resident with HIV/AIDS)
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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!
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 I am an individual living overseas **A\$70** per year

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