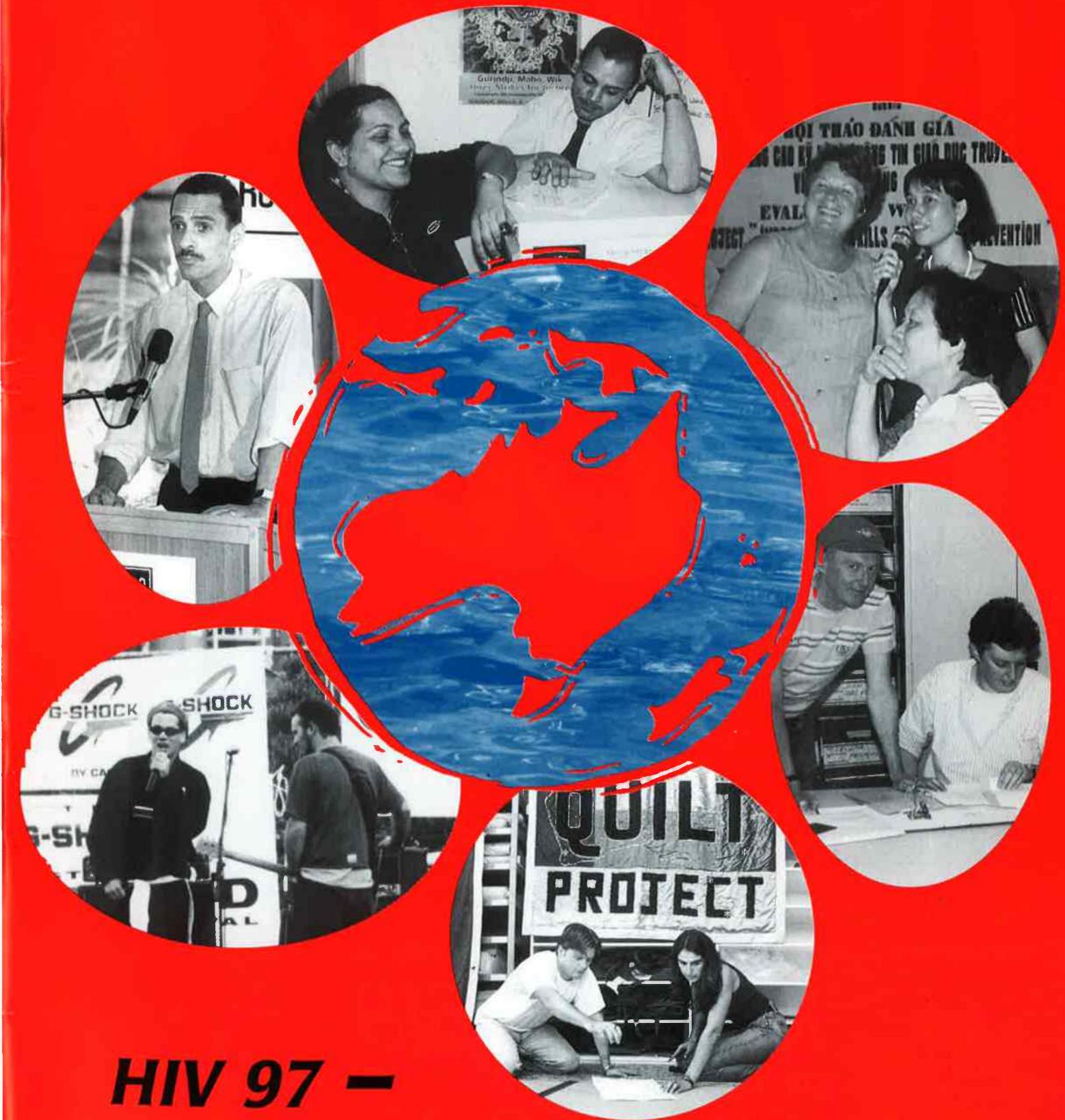


No. 81 November 1997

Talkabout

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

◆ Where We Speak for Ourselves ◆



HIV 97 -

THE BIG PICTURE

lighten your load

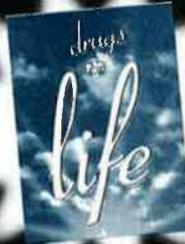
Nowadays by lowering your viral load, it's possible to control HIV for longer than ever before. But to ease your viral load takes more than sheer determination. It also takes practical support. A free booklet is now available to help you get the most from your treatment. It has information on how to manage side-effects and tips on making the drugs easier to take. Pick up this booklet and reduce your load.

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This month's cover



by Sandra Thompson. Photos by John Trigg, C.Moore Hardy, Geoff Friend, Gary Spencer & Mazz Image. Some people think the AIDS crisis is over. We don't. Neither do the people pictured on our cover, all of them volunteers or paid workers in HIV/AIDS. And without fanfare or fireworks, they're making a difference. Clockwise from top: Equity: ACON's new Aboriginal workers Keith & Sue. Australian aid: APHEDA's Di Butler at a Thai conference on HIV with Ms Lan & Ms Phuong. Meetings and lobbying: Bill and Jo of PLWH/A's Treatments Working Group. Remembering: volunteers planning a new Quilt panel. Telling our stories: Gary, a positive speaker at BoardAID. Speaking out: Andrew Little at the '96 AFAO Media Awards. Thanks to Colin Clewes for planting the seed of an idea for this issue's theme, in his article "Complacency is not the cure" in the July *Talkabout*.

Talkabout

Talkabout is published every month by People Living With HIV/AIDS (NSW) Inc. All views expressed are the opinions of the respective authors and not necessarily those of PLWH/A, its management or members. **Talkabout** is produced by the Newsletter Working Group of PLWH/A (NSW) Inc. Copyright for all material in **Talkabout** – text, graphics and photos – resides with the respective contributor. Contact Jill Sergeant, the editorial co-ordinator, for information on reproducing articles or illustrations.

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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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B r i e f s

● A new report from Ireland's Department of Health says that Irish physicians will not be required to be screened for HIV or the hepatitis C virus because there are no available vaccines against these viruses and testing would be "impractical." The report also suggests a plan to require all health-care workers to sign a document certifying their awareness of the need to inform authorities should they become infected with a blood-borne disease or become at risk for infection. Doctors' groups plan to meet with the health department to discuss compensation for doctors unable to practice because of HIV, HBV, or HCV infections. (*CDC Daily Summaries*)

● Trials of AZT on HIV+ pregnant women in Africa, the Dominican Republic, and Thailand, have attracted widespread criticism from AIDS activists in the West because some of the women on the trials will be given a placebo. In the latest episode in the controversy, AIDS experts Dr David Ho and Prof. Catherine Wilfert have resigned from the editorial board of *The New England Journal of Medicine* to protest an editorial published last month that criticised the ethics of international trials of AIDS drugs.

In an editorial published on September 18, the journal's executive editor, Marcia Angell, compared such trials to the infamous Tuskegee study, which left black men who had syphilis untreated even after penicillin became available. A response to the editorial, written by the heads of the National Institutes of Health and the Centers for Disease Control and Prevention, was published in a subsequent issue.

Critics of Dr. Angell's editorial have said that her comparison was unfair, because the 12,000 participants in the AIDS drug trials are aware of the potential treatments and know that they might be taking placebos. The men in the Tuskegee study, by contrast, were not told that an effective treatment was available.

The scientists who are conducting the trials want to find a cheaper way of preventing the transmission of the AIDS virus from pregnant women to their babies and are using shorter regimens of the costly drug AZT than are used in the richer industrialised countries. The researchers say that they need to compare the short regimens to placebos if they are to find out whether the treatments work. In her editorial, Dr. Angell argued that ethical standards require that the best treatments be used as a basis for comparison in drug trials, not just the locally available treatments. (*Chronicle of Higher Education website*)

PLWH/A news

THE PAST MONTH HAS SEEN THE beginning of hype and activity as the year draws to a close.

PLWH/A has been invited to nominate a delegate at the upcoming Positive Information and Education (PIE) summit in Sydney on December 6/7. This will be an opportunity for this organisation to have input into the national strategy for the delivery of information and education to PLWHA.

The PLWH/A Annual General Meeting is set for December 15, and details will be sent out to all members in the next few weeks. Membership renewals and new membership applications close 4.00pm, Friday December 12. The Committee and staff are busy getting the Annual Report organised, and look forward to seeing as many people as possible at the AGM. Mark that date!

PLWH/A is making plans for a survey of PLWHA in NSW. We will be asking for feedback about priority issues that affect your daily lives, and the areas that need attention and advocacy from HIV/AIDS organisations and service providers. It is timed to go out in the next issue of *Talkabout*, and you will have the opportunity to make suggestions about the organisation's priorities over the next twelve months. This organisation is the representative advocacy organisation for PLWHA in NSW, so we need your thoughts and opinions. Look out for the survey, and there will be a prize offered for the first survey drawn out of the mailbag after the closing date at the end of January. You've got to be in it to win it!

At the time of reading this, the international conference for people living with HIV/AIDS will have been held in Chiang Mai, Thailand. This organisation has two staff attending, Luke Smith and Ryan McLaughlin, and we look forward to their reports when they return.

Staff numbers will be low during November due to this conference, the annual Austral-

asian Society for HIV Medicine (ASHM) Conference and Treatment Officers' Network meetings, which Jo Watson will be attending in Adelaide, and some other staff leave.

By the beginning of December we will have a full office again, ready for the AGM and the end of year review meetings. All our working groups will have their final meetings for the year, and all our volunteers will be ready for a well earned break.

Some of these volunteers have been nominated by PLWH/A staff and Committee for World AIDS Day Awards this year. We wish them luck, and acknowledge that without the efforts of so many people, organisations like ours could not achieve the results we aim for, on behalf of all PLWHA in Australia.

- Phillip Medcalf

Treatments roadshow

"HOPE OR HYPER?" IS THE TITLE OF a series of forums conducted by the National Association of People With HIV/AIDS (NAPWA) as a travelling treatments 'roadshow'. The roadshow aims to bring the very latest news on where we're at with HIV treatments to people with HIV/AIDS in Cairns, Adelaide and Melbourne. At each location expert speakers will be discussing issues such as: new understandings of HIV, treatment issues for women, viral load, drug resistance, how to get the most out of your treatments and more . . .

The speakers are: Bill Whittaker (Committee Member, NAPWA), Dr Cassy Workman (general practitioner specialising in HIV medicine - Sydney), Dr David Bradford (Director, Sexual Health Program - Cairns), Dr Jo Thomas (general practitioner with a strong interest in HIV medicine - Adelaide), and Dr Anne Mijch (infectious diseases physician, head of HIV Clinical Services, The Alfred - Melbourne).

The dates are: Monday November 10, Tradewinds Esplanade

Hotel, Cairns; Thursday November 13, The Richmond Hotel, Adelaide; Monday December 8, Melbourne – venue still to be determined.

Stock the larder

SATURDAY, NOVEMBER 29 IS YOUR opportunity to help the Luncheon Club Larder stock its shelves. After you've enjoyed the AIDS Trust Food & Wine Fair in Hyde Park, saunter up to Oxford Street, where many of the hotels will be supporting the Larder by having entertainment, food bins, chocolate wheels, lucky dips, and chook raffles. All the shops are being approached to take a money tin and maybe even decorate their windows. If you'd like to help out in one of the venues, please call Ken Holmes on 9360 7011.

The Luncheon Club has decided not to have a picnic in the park for World AIDS Day this year, because of the financial risks of bad weather. "Our need for help for the Larder, both financially and with food, is far greater", said Carole Ann King in a media statement. However, there will be a "very special luncheon" on Monday, December 1 – which just happens to be World AIDS Day.

The Luncheon Club will be releasing a 'shopping list' of essential food items and the food bins will stay in the venues until December 14, giving everybody an opportunity to help. During that time, there may be some more benefit nights.

Bouquets

THIS YEAR FOR THE FIRST TIME, NorthAIDS instituted an Award for Outstanding Achievement. The Awards were made at NorthAIDS' Annual General Meeting in October to Joan Maxted, Elaine Rich, Romy Waterlow and Guenter Plum.

Joan has been involved with NorthAIDS for several years and her most well known contribution has been as cook for the Friday hot lunches. Her meals reflect her



Children living with HIV/AIDS painted this banner on October 18 & 19. The banner was displayed at Performance Positive VII: "Hope", which took place at the PRIDE Centre on October 24 & 25.

PHOTO: C. MOORE-HARDY

style: straight forward and prepared with love. Elaine, also a long term volunteer, has served on the House subcommittee, written the DKL volunteer newsletter and regularly done the unglamorous task of twice weekly food shopping for the House. Her gift to NorthAIDS is a calm, loving stability that all guests have benefited from.

Romy facilitated a support group at Royal North Shore Hospital which was the original base out of which NorthAIDS grew. Through fundraising activities, balls and raffles, Romy worked tirelessly to ensure that the dream of a centre for positive people on the North Shore finally became a reality.

Guenter and his partner, the late Allan Kingsford-Smith, were involved in early discussions about a service for positive people based in the Northern Area and Guenter served as first chairperson of NorthAIDS for four years until his resignation in July this year. His thoroughness, eye for detail and respect for appropriate processes ensured NorthAIDS has

grown into a respected community-based service. Perhaps the greatest tribute to his stewardship is that he has shaped an organisation that has the ability to continue without him.

(NorthAIDS Annual Report)

Northern retreat

POSITIVE PEOPLE LIVING ON THE Mid-North Coast, their partners and carers, can spend a relaxing couple of days at a positive retreat on the weekend of November 28 - 30. The retreat will be at a peaceful beachside setting at Stuart's Point, about 70k south of Coffs Harbour.

You can look forward to massages, natural therapies & treatment advice, swimming, bushwalking, games, rest and relaxation. Most meals are provided and there's private home-style accommodation. Transport can be arranged if necessary. The retreat is free, although a \$20 donation would be welcome if you can afford it.

The retreat is supported by MNCAHS, ACON, Coastal Lynx

B r i e f s



- In early October, ACON Northern Rivers branch moved to new premises at 27 Uralba St, Lismore (just up from the shopping square). The new location will contribute to an all round improved service. One of the major benefits from the move is that we are able to allocate an independent Positive Space in our building. The free lunches that ACON has been providing for the last few months will stop until a committee of positive people is formed to establish and manage the positive space.
- If you missed out on AIDS Impact, the international Biopsychosocial conference on AIDS in June, you have a second chance. Tune in to ABC's Radio National for a 40 minute documentary which captures the highlights of this event, on the program "Radio Eye", Sunday November 30 at 8.20pm and Saturday December 6 at 3.30pm. Voices from the conference include Dr Peter Piot, director, UNAIDS, Marina Mahatir, Chief of the Malaysian AIDS Council and Rodi, a young HIV+ woman from Northern India.
- Health In Difference, the Second National Lesbian, Gay, Transgender and Bisexual Health Conference, will take place in Melbourne, January 22 - 24, 1998. The conference will cover all aspects of health and service delivery as well as sexual health. For more info call Feona on (03) 9286 2071.
- Art From The Heart, an exhibition in association with the AIDS Trust of Australia, opens at Bondi Pavilion Gallery on November 23 for AIDS Awareness Week. Works will be exhibited by people whose lives have been affected by HIV/AIDS. Entry to the exhibition is by donation and all proceeds go to BGF. It's not too late to exhibit, call Grant on 9331 5559. The Exhibition is also sponsored by the Stonewall Hotel.
- ACON Western Sydney is developing a needs assessment survey. Guided by a steering committee made up of carers, counsellors, educators and positive people, the project's aims are to develop an appropriate picture of the educational, health maintenance and support needs of positive people living in the Western area of Sydney. Scott Parker, the HIV Positive Community Development and Education Officer, is the convenor and creator of this project. Scott will develop the survey and hopes to interview, via telephone or face to face, 100 positive people. The results will be widely reported to all service providers in the Western Sydney area. To participate contact Scott Parker ACON Western Sydney: 9204 2400 or Gregory Allen at PLWH/A (NSW): 9361 6011.

and Chaps Out Back. For more info, or to book, call Kevin (02) 6583 5722, Craig (02) 6562 6066 or Damien (02) 6564 8037.

A new Bill

OUR BIG NEWS IS THAT WE HAVE A new co-ordinator at Des Kilkeary lodge. Bill Paterson has taken up the position and we're glad to have him on the team. Bill may be familiar to some *Talkabout* readers as the charge nurse at St Vincent's Ward 17 throughout some of the early days of the epidemic. He's been living quietly in the country with his partner for a few years, and is glad to be re-entering the field of AIDS work, this time with a community organisation.

Bill wants to make sure that the high reputation of our supported accommodation centre in Dee Why is maintained and to ensure that we face the future and respond to the changing needs of the epidemic. He'll continue to be supported by Belinda, our unflappable part-time admin assistant and new mother, and Andrew, still acting as live-in Support Worker, student and surfer.

- Bill Evans

Call for carers

THE COMMUNITY SUPPORT Network (CSN – part of the AIDS Council of NSW) relies on 247 volunteer carers to provide practical home based care and support for people living with HIV/AIDS. However, CSN still requires 15 new volunteers each month to meet the needs of clients.

The relative success of new treatments has not reduced the number of CSN clients but it has meant a change in the kind of care provided. Volunteers are doing less palliative care and providing more assistance with simple, practical activities of daily living, such as cooking, cleaning and shopping. Assistance with these tasks may mean that a client who is improving on new treatments has a chance to return to work.

Since 1984, CSN has trained over 1,600 volunteer carers. During

1996/97, CSN carers provided a total of 21,229 hours of care. For more information about becoming a carer, call CSN on 9206 2032.

Prisoners' victory

ON OCTOBER 3, THE ANTI-Discrimination tribunal found that the Queensland Corrective Services Commission (QCSC) discriminated against prisoners with HIV, ordered compensation to be paid, and gave the QCSC until February 1998 to alter its custodial practices so that it no longer breached the Anti-Discrimination Act 1991.

The decision was handed down following a number of complaints under the Act brought on behalf of a number of HIV positive prisoners by the Prisoners' Legal Service, the Queensland AIDS Council (QAC) and Queensland Positive People (QPP), who had been advocating for the past four years for the desegregation and equal treatment of HIV positive prisoners.

The prisoners claimed discrimination on the basis of an impairment (i.e. their HIV status) in relation to:

- accomodation, in that inmates were segregated and subjected to restricted mobility;
- goods and services, in that they did not have access to same quality of facilities; and
- limited choices of work opportunities.

President of QUAC, Adrian Lovney, said that the outcome was an obvious one. "For a long time, our organisations have been concerned about the treatment that HIV positive prisoners receive in the Queensland prisons system. [They] are doubly penalised – once for their crime, and twice for their status", said Lovney.

QPP Convenor, Kerry Shields, said that the decision was a fantastic one which recognised the absolute right of HIV positive people, regardless of their situation, to be treated equally. She also acknowledged one of the complainants, DM, who died before

the decision was handed down. "If it were not for his courage and determination to fight what he perceived as unfair treatment, and encouraging other HIV positive inmates to come forward, we might not be in this position today", she said.

Human rights in Asia

ON SEPTEMBER 22-24, THE UNITED Nations Development Program and the UN program on AIDS (UNAIDS), organised a joint meeting on Human Rights and AIDS with representatives from the Asia-Pacific Coalition of AIDS Service Organisations (APCASO) and the ASIA Pacific Network of PLWHA (APN+) in Denpasar, Indonesia. This was a follow up to the July Stocktake and Planning Meeting for HIV, Ethics, Law and Human Rights Activities in Asia and the Pacific.

The meeting proved to be an invaluable opportunity for APN+ to strengthen its recently funded Human Rights Peer Education & Documentation Initiative and broaden the scope of the project. The APN+ and APCASO reps met to determine ways of working collaboratively to strengthen the overall response to human rights in the region. The focus was areas of overlap and ways of assisting the APN+ Human Rights Initiative, a peer education project to document human rights violations, which started on October 15.

Since the advent of HIV/AIDS many people living with HIV/AIDS have experienced violations of their human rights. Prevalent social attitudes deprive most PLWHA of support, social integration and a sense of well-being. The critical human rights concerns affecting PLWHA include mandatory testing, confidentiality after testing, discrimination by health workers, dismissal from work/school/social group, medical insurance, access to treatment and care, women's rights within marriage, children's rights



Lavish entertainment by Bunny at the Parramatta Golf Club on October 25 when Western Sydney's gay and lesbian social group, Castaways, partied. The night raised \$3,810 for a new drop-in for local PLWHA, Western Suburbs Haven.

PHOTO: MAZZ IMAGES

to attend school, sexual rights, social isolation, and preparing for death.

The APN+ Human Rights Initiative aims, by training PLWHA to document cases of human rights violations, to build their ability to respond to human rights issues, and identify ways of working more effectively with non-government organisations (NGOs) in the Asia Pacific region on human rights concerns.

The initiative aims to:

- increase awareness and understanding of human rights issues amongst PLWHA and NGOs by producing accessible and action-orientated information;
- identify the gaps in current awareness and develop mechanisms for addressing these gaps in order to assist towards a comprehensive regional human rights response; and
- build the capacity of APN+ members and others affected by HIV/AIDS to prevent, as far as possible, and respond effectively to human rights violations of PLWHA in the region.

The initiative, a twelve month project, has found a welcoming

home in Hong Kong with AIDS Concern, a local NGO who have pledged their support. The project is managed by the APN+ Human Rights Working Group.

People living with HIV/AIDS in APN+ member countries will be trained in human rights and recording human rights violations.

It is expected that the information gathered at country level, coupled with the training provided to PLWHA, will build their capacity to advocate for change and respond effectively to violations.

Within NGOs the information will stimulate debate around the human rights of PLWHA, change attitudes to PLWHA, and mobilise community interest.

With increased involvement of PLWHA the process should become self-sustaining and ultimately lead to legal reform and more enlightened public health policy.

— Susan Paxton,
APN+ Human Rights Convenor

NO Minister

NSW COMMUNITY SERVICES Minister Ron Dyer has been condemned for "failing to show" at the launch of a report into access

B r i e f s

● Viral load tests were under a temporary funding scheme until November 1, when the Federal Government was scheduled to put in place a permanent funding arrangement. The Government announced on October 29 that the interim arrangements will continue, as it is still considering the final details of a report from the Australian Health Technology Advisory Committee (AHTAC). AFAO and NAPWA have been monitoring the situation and urged that permanent funding arrangements be finalised soon. Shortcomings of the interim arrangements include the costs borne by labs that process the tests, as well as the concern that there will be a likely increase in costs when the new generation of viral load tests become available in Australia.

● DMP266 is an NNRTI, in the same class as nevirapine and delavirdine. It is to be marketed in Australia by Merck, Sharp & Dohme (MSD). A community dialogue group, comprised of HIV/AIDS treatments activists and workers, has been established to start meeting with MSD at the end of November. These meetings will inform MSD about community expectations and needs for access to this new drug, including compassionate access. PLWHA (NSW) will be represented and keep members informed of developments.

● A nationwide consultation conducted by the Positive Information and Education (PIE) project, a joint project of NAPWA and AFAO, has signalled new directions for HIV education and services for positive people. A number of recurring themes appeared in the national consultation, including that the particular needs of positive people have drastically altered due to the successes of combination therapies, and that there was now a shift in thinking about notions of future for PLWHA. It was also noted that outside of metropolitan Sydney and Melbourne, basic information was not always easily available. Copies of the "Phase One Consultation Report from the PIE Project" are now available from AFAO.

● An independent advisory committee has been established to oversee the content and evaluation of the Colao Project, a free support service for HIV positive people. The committee membership includes HIV prescribers, nurses, and community treatment representatives, and will be providing clinical and community feedback to the project workers, as well as monitoring the performance of the project. The project aims to support people with treatment issues, and has commenced workshops dealing with issues such as stress management, and goal setting.

for people living with HIV/AIDS to Home and Community Care (HACC) services. (See story p10)

The Minister's department had indicated that a representative would attend, however launch organisers were told at the last moment that no representative "senior enough" could attend.

"The failure to attend speaks volumes about how the issue of HIV/AIDS is still denied, ignored, excluded, and rejected by governments and the community. We continue to have a problem with the Minister's lack of leadership on this issue," said a spokesperson for the report's Steering Committee.

A last-minute fax to the launch organisers stated that Mr. Dyer has "directed the Department to address the issue of discrimination against people living with HIV/AIDS... across all funded projects." However the spokesperson warned that, "this is not enough as a commitment to implementing specific access and equity policy for PLWHA using HACC services and funding training and information strategies across the sector that will improve and enhance the quality of life for PLWHA."

A copy of the entire report is on the World Wide Web at this address: <http://www.geocities.com/WestHollywood/Heights/5227/access-equity-report.htm>

World AIDS Day events

NSW AIDS AWARENESS WEEK will be launched on November 23 at Manly Warringah Leagues Club by Jeannie Little as part of NorthAIDS "Red Ribbon Blue Notes" concert, featuring James Morrison and Jenny Morris. For details call 9929 4288.

On November 25 at 7.30pm, the second annual HIV/AIDS Ecumenical Service and names reading will take place at St Patrick's Church, Kogarah. Call 9545 6331 for details of this service and the Memorial Mass of Thanksgiving and Remembrance at 7.30 on World AIDS Day.

Indulge yourself at the AIDS Trust of Australia Food & Wine Fair at Hyde Park North on November 29 from 11.00am - 5.00pm. This annual fundraiser for the Trust showcases some of Australia's top restaurants and wines.

A partial display of recently presented panels and blocks of the Australian AIDS Memorial Quilt will take place in Hyde Park on November 29. Throughout AIDS Awareness Week, blocks of the Quilt will be on display throughout the State.

On November 30, memorial services will take place in Orange, (Botanical Gardens, 2.00pm) Parramatta (MCC Good Shepherd, 6.30pm) and Darlinghurst (MCC, 7.30pm).

The HIV Continuing Medical Education project will be holding a medical update for practitioners with an interest in HIV. The update, on Sunday November 30, will address developments in treatments and review material presented at the ASHM Conference in early November. More detailed info and registration forms are available from the project Co-ordinator Levinia Crooks on 9382 3702, fax 9398 8296.

On December 1 there will be stalls and entertainment in Martin Place from 11.00am - 3.00pm. The Quilt Project will also be launching their display package and new education package.

The Annual World AIDS Day Awards will be presented at the Seymour Centre in Chippendale on Sunday November 30 at a spectacular awards ceremony and thank you party. The Awards recognise some of those people who have worked tirelessly and unselfishly in the fight against AIDS.

For more information about any of these events, call Douglas on 9382 8356.

Children Living in a World with AIDS



Fund delavirdine now

Representatives of a number of organisations, and including PLWH/A and the Australasian Society for HIV Medicine have been lobbying Michael Wooldridge, the Minister for Health & Family Services, regarding the Pharmaceutical Benefits Advisory Committee's (PBAC) recent recommendation that delavirdine not be listed on the Pharmaceutical Benefits Scheme (PBS).

The PLWH/A Committee urges Talkabout readers to support this campaign by sending the following letter to Michael Wooldridge. Photocopy or tear out this page, sign it and post to The Hon Michael Wooldridge, MP, Parliament House, Canberra ACT 2600.

Dear Minister,

I/we write to express our strongest possible concern at the decision by the PBAC to recommend to you not to list on the PBS an anti-HIV drug, delavirdine (Rescriptor).

The decision to deny listing to the PBS by PBAC was not made in the context of current management of HIV. We understand that it is the policy of the government to fund drugs on the basis of their medical need and cost effectiveness. We feel that delavirdine meets the government's policy guidelines.

This drug was first approved by the US Food and Drug Administration and was approved later for use in Australia by our regulatory authorities after the most stringent analysis of the clinical trial data.

At present there are around 200 HIV positive people on this drug in Australia. Delavirdine is currently being made available free of cost to these people by the manufacturer, Pharmacia & Upjohn.

Delavirdine is one of two new non-nucleoside reverse transcriptase inhibitors (NNRTI) that are being used in combination with other anti-retroviral drugs to suppress HIV replication.

Delavirdine has a place in the pharmacopoeia for the treatment of HIV. It has clear value as an anti-retroviral for people who are unable to tolerate nevirapine (Viramune), and it has the ability to boost the drugs levels of the protease inhibitors when used in combination therapy.

PBAC ought to have taken into consideration the need for therapies to be tailored to the needs of patients, and that drugs like delavirdine, whilst not as potent as other drugs used in HIV combination therapy, still have a role to play in suppressing HIV replication.

The failure of the government to list on the PBS this important addition to HIV therapy raises the general issue of reform of the funding arrangements for drugs approved for marketing in Australia by the Therapeutic Goods Administration.

Other than the Australian National Audit Office's current review of the PBS we have been given no undertakings that the Commonwealth government will act to get Australia's drug funding system functioning in step with its drug approval processes.

I/we are seeking such an undertaking from you in this correspondence.

The failure of the government to set a rational, streamlined drugs funding policy will send confusing messages to all stakeholders in HIV/AIDS. People who desperately need the new drugs will not get them. People will die as a consequence of this preventable bureaucratic paper train.

There are a number of new drugs about to enter Australia for the treatment of HIV. I/we urgently request that you implement reform of the drugs administration. This is particularly important in the case of drugs that are used to treat terminal illnesses. I/we would ideally like to see an administrative mechanism in place that allows for priority processing of drugs used to treat illnesses and diseases such as HIV.

Yours faithfully, _____
signature

address

name



HACC Report released

ON OCTOBER 31 'Us & THEM', the report into Home and Community Care (HACC) services was launched at the PRIDE Centre. Speakers included Gabe, an HIV positive HACC service user, BGF's Mark Tietjen, HACC Review project worker Bill Rigney and HACC Development Officer Fay Williams. The audience of over 60 people was also entertained by songs from Alex Harding. NSW Community Services Minister Ron Dyer was condemned for not attending the launch. (See news pages).

This significant report is the result of an extensive community consultation into the experiences of PLWHA when using – or trying to use – HACC services, such as Meals on Wheels, in the Eastern Sydney Area. (The report notes that this area has been home to 33% of people with HIV/AIDS in Australia).

The consultation came about as a result of the "Poverty Sucks" campaign, initiated in 1996 by the late Michael Glynne and others. At "Poverty Sucks" community meetings, HACC services were identified as a problem for positive people. A review of the services was suggested and the resulting consultation, which was funded by HACC and auspiced by Botany Neighbourhood Centre, took place over several months earlier this year. A steering committee with representatives from a range of organisations including the Bobby Goldsmith Foundation, PLWH/A (NSW) and Home Care Services of NSW, guided the project.

The project worker, Bill Rigney, spoke with community representatives, service providers and concerned individuals. He discovered that many positive people and HIV/AIDS organisations were not aware of the services HACC provided, or were not aware that PLWHA were eligible for them.

Individuals who had used them, were frequently dissatisfied for a range of reasons including the cost, inflexible times, modes and quality of services, lack of confidentiality and insensitivity on the part of workers.

The report states: "Specific concerns were raised about food services, personal care and cleaning services . . . Many PLWHA believed they had been confronted with "offensive" service delivery and felt disempowered and angry about the experience. Some felt their human rights had been breached in some instances."



Bill Rigney, HACC Review Project Worker

PHOTO: C. MOORE-HARDY

The report has made a number of recommendations to address these concerns, including:

- to achieve a clear statement of entitlement to HACC services for people living with HIV/AIDS;
- to ensure that HACC Policy, Procedures and Services Standards uphold the access and equity rights of PLWHA;
- to achieve flexible, responsive and appropriate service delivery

that meets the complex and special needs of PLWHA;

- to address the issue of chronic under funding and under-resourcing of the HACC program;
- to set up networks and linkages between HIV/AIDS specific service providers and HACC service providers regarding existing and potential service delivery to PLWHA;
- to produce appropriate information for PLWHA on HACC Services in the Eastern Sydney Area;
- to request that the Minister for Ageing and Disability immediately investigate all food services operating in the Eastern Sydney Area, in relation to the needs of PLWHA;
- to fund fresh fruit and vegetable services, similar to the model and operation of the Food Distribution Network, to meet the needs of PLWHA across the Eastern Sydney area;
- to call for the immediate release of the NSW Draft Fees Policy and to ensure that the special needs of PLWHA are addressed by full implementation of a policy on waiving of fees that does not compromise entitlement rights and meaningful access to services;
- to ensure that changes resulting from the Review into Home Care Services will address the special needs of PLWHA and that any recommendations relating to PLWHA are implemented; and
- to request relevant government departments . . . formulate policy for the delivery of services to PLWHA.

A committee has been set up to implement these recommendations and ensure that HACC services statewide also recognise the report.

Blackfellas at ACON

Welcome to the new workers at ACON's Aboriginal and Torres Strait Islander (ATSI) program. Women's Officer Sue Fowles started in August and now that she's been joined by Gay Men's Officer Keith Ball, the new project can steam ahead.

KEITH, WHO IS POSITIVE himself, has a background in adult and health education and outreach. Sue, whose varied history includes refuge work and most recently, work in the film industry, has been a carer for a close friend with AIDS.

The aim of this new project is to get more ATSI people aware of and making use of the HIV/AIDS services that are available to them, in particular the ACON branches, but also other services throughout the state. The project will be targeting positive Aboriginal and Torres Strait Islander gay men, women, lesbians and transgender people as well as those at risk of getting HIV.

The new project workers confirm that the main problems facing positive Aboriginal people are lack of confidentiality and lack of support within communities, ostracism of positive people and their families, difficulty accessing services, indirect racism and lack of resources.

Keith and Sue's first step will be a needs assessment – a fancy title for just getting out there, with questionnaires, meetings and interviews, to find out just what

people are wanting and needing from the services, what they know about them, and what is stopping them from using those services now.

As part of this process they'll be contacting Aboriginal sexual health workers around the State. These workers, who are currently responsible for HIV/AIDS prevention education, often have little

They'll also be looking at ways to support families and volunteers in Aboriginal communities, such as CSN and Ankali training.

Another important part of Keith and Sue's work will be cross cultural training projects to make non-Aboriginal services more culturally appropriate – for example, to make sure that pamphlets produced by a service include some indigenous content, or are written in a more appropriate style of language.

Sue and Keith have already started networking with Aboriginal organisations and liaising with non-Aboriginal HIV/AIDS services. Later this month they will be visiting Aboriginal communities on the south coast and cheering on the teams playing at the Rossy Smith Memorial Knockout at Narooma.

While various people have been predicting an explosion of HIV among ATSI people for several years, we still don't have accurate, comprehensive figures for the number of infections. Sue is of the opinion that it's not important. "Gathering statistics isn't useful, Aboriginal people have had so many studies done on them, it's an approach that doesn't work," she said. There are ATSI people who are HIV positive and affected by the epidemic – that's reason enough to, "just do it [work on the problems we already know exist]."

ATSI readers of *Talkabout*, Keith and Sue would love to hear your ideas about what the issues are and what should be done. Give them a call on 9206 2000.



PHOTO: JOHN TRIGG

support and low resources, although they may be covering vast areas of the State. Sue and Keith will be looking at ways in which these workers can be better supported. Following on from the needs assessment, which they hope will be finished by the end of June '98, Sue and Keith plan on organising workshops in communities around the State.

More than words



I made love with love every time I felt love. One day an undesirable sneaked in - crept in without a noise.

The blood reading Professionals say that this strange cohabitation is for life. I now have a cute nickname: Positive . . . Positive, to my friends of course, for the others I'm labelled HIV+.

This sort of news is a bit like a friend's death, between the ears and the conscience there is a long journey. And then when you think you've finally realised, you are torturing yourself with a false reality. No, HIV does not rhyme with hell - in fact it changes nothing.

If you would have said that to me at the beginning of this cohabitation I would have surely answered "Fuck you!" - 'cause to be aware that death is snoring in you is a kind of hell.

To find out that there is a contagious death hiding between your legs is a form of hell.

You get the flu and you worry.

You fall in love and you cry.

And some days this virus makes you so sad that you wish to die.

Death, what other ending is there?

Condoms, is it really a big deal? - in our decade you have to use them anyway!

There is one thing I know now: Life is an amazing trip and no one should waste a bit. That's it.

Erycka, 1996

Olga's Personals

Guy, 35, HIV+ since 1984. Very healthy, full time work, gym regular. Taking combination therapy including Ritonavir. Interested in meeting others for o/s travel (Asia? Europe?) or hearing from anyone who has travelled o/s with antivirals. ALA. 971105

Intellectual, passive, quality CBD guy, 39, epicure, wine buff, newly divorced. Seeks dom 1-1 r/s, affectionate, gentle, horny older guy to 65, carnal likes 'green horns', erotic videos, games, b/d, role reversal, kinky toys, submissive plays. Photo/ph please. 971110

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.



People Living With HIV/AIDS (NSW) Inc.

Current committee:

Philip Medcalf: Convenor
Claude Fabian: Deputy Convenor
Vincent Dobbin: Secretary
Erycka Fars: Treasurer

Chris Holland, Andrew Kirk, Bill Whittaker, Ed Moreno, Les Szaraz, Shane Wells

Current staff:

Ryan McGlaughlin: Co-ordinator

Luke Smith: Finance/Admin Officer

Greg Allen: Community Dev Officer

Jo Watson: Research Officer

Robert Rogers: A/Research Assistant

Paul Maudlin: A/Positive Speakers

Bureau Co-ordinator

Jill Sergeant: Talkabout

Editorial Co-ordinator

Sandy Thompson: Talkabout

DTP/Advertising

Paul Roberts: Talkabout Support Officer

Tim Alderman, Daniel Conlon, Phillip &

Ross: Volunteer Receptionists

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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 Gotlieb, Ryan McGlaughlin, Paul Roberts, Jill Sergeant, Sandy Thompson, Guy Taylor, Jo Watson.

Talkabout is your magazine

Have your say about what should be in it over the next year at the

Talkabout planning day

Tuesday, December 9

at North AIDS, Myrtle Place

Some funding is available to subsidise people from rural areas.

For more info call Jill on 9361 6750

HIV 97 – THE BIG PICTURE

Complacency is not a cure



Is the AIDS crisis over? Ian Rankin, President of the National Association of People with HIV/AIDS, doesn't think so. And he's not the only one. Ian kicks off this special issue, which takes a look at the big picture: what it's really like for people to live with HIV/AIDS in 1997, both in Australia and around the globe.

THE HIV EPIDEMIC IN AUSTRALIA is a human crisis, not just a medical challenge. While science and technology have recently delivered many astounding benefits for many people living with HIV/AIDS, AIDS will not be 'cured' until we address all of the ramifications of this most powerful of diseases.

The history of AIDS in Australia is one of remarkable achievements. Advances in the understanding of the human body and how it deals with viruses, means of measuring levels of virus activity, understanding of the courses of disease and importantly, chemical strategies to combat the progress of HIV have all developed over the last decade and a half.

This is incredibly quick science, which has occurred due to the passions and commitment of scientific and medical communities and particular individuals. Health system advocacy within the AIDS movement has had a significant impact on the models of health care delivery in Australia. The primacy of the individual and the empowerment of people in relation to health service providers has been a hard fought and worthwhile battle. This movement developed in an environment

where there were few, if any, medical solutions for people with HIV/AIDS. It will be important to monitor who holds the power now new and complex medical therapies are becoming so important.

Even though we have made great advances we are still only a short distance from the starting line in terms of a medical cure for AIDS. We have no vaccine. We have highly toxic drug regimes that combat the virus in the relatively few people (in global terms) who can afford and tolerate the drugs. We have a long way to go.

My doctor challenged my life view recently by asking if I now considered that I have a future. It was an unresolved discussion. I thought that the currently available drug regimes might mean a five to eight years life extension, and his "extended hope" was that over the next five years we will have therapies available that will



GRAPHICS: PHILLIP MCGRATH

afford at least a 30 year life extension. I am encouraged by his hope but I'm not going to join him until there is evidence that what is being talked about will be actually delivered.

The virus invades all of the body's systems; so too has it invaded all of society's systems. It has had a dramatic impact on Australians' willingness to discuss sexuality, reform laws, acknowledge diversity and provide means for marginalised individuals to empower themselves. Once again we are not far from the starting line in many of these reform processes.

We have made significant gains, have been involved in one of the world's best responses but from the vantage point of the human rights of people living with and/or affected by HIV/AIDS, there are still significant problems to be resolved. The increasing conservatism of the political land-

scape may jeopardise advances made in our response to HIV to date. Increasing levels of censorship in relation to explicit prevention initiatives, scurrilous debates about the provision of needle and syringe exchange programs and tougher immigration restrictions are all significant markers of the direction of politically led public opinion. There has been an indication of a drop in the level of volunteer involvement in the AIDS movement and a drop in the level of financial support for AIDS charities. If these trends continue, the quality of life of people with HIV/AIDS will decline and the rate of HIV infection will increase.

Reductions in the level of government services are coming at a time when people with HIV want to use a more diverse range of these services. Cuts to the Human Rights and Equal Opportunities Commission and reduction in the level of labour market program as-

sistance will have a negative impact on positive people.

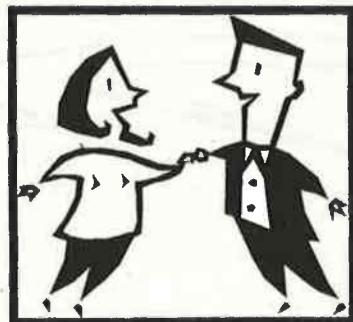
I identify as part of the Australian response to HIV/AIDS. I'm pleased to be able to be an openly positive person contributing to the effort. However, there is a malaise in the AIDS effort. Many people are 'over it' either in relation to their personal behaviour, or their involvement in organisations and activities. We are probably suffering some success fatigue. We have done well, but still people are infected and killed by this disease.

Until we can deliver a good quality and extent of life for all people with HIV and we can prevent any further transmission of the virus, we cannot afford complacency. The cost of complacency will not be measured today but in five years time. The strength of our efforts today will determine the level of disease and despair in our communities tomorrow. ♦

LIVING HETEROSEXUALLY WITH HIV/AIDS

Second Annual Workshop

Saturday 6 December 1997
9.30am - 5.00pm
Surry Hills
Sydney



A free one day workshop where HIV+ heterosexuals and partners get together to share the latest information and ideas on health and self care practices.

Places are limited! For workshop details phone (free call) 1800 812 404 or write to the workshop coordinator, PO Box 1311, Darlinghurst 2010.

An initiative of Positive Heterosexuals Support Group funded by ACON Hand in Hand Community Disbursements.

Helping each other, helping ourselves. Heterosexual men and women with HIV/AIDS.

THE BIG PICTURE

voice of the people



PHOTO: KATE GOLLINGS

Kim Davis

As NAPWA's International Spokesperson, Kim's role is to establish links with PLWHA in other countries and find ways Australia can assist those in our region. Kim, who is based in Melbourne, is also active with Positive Women and PLWH/A Victoria. An avid traveller, she has worked and lived in Europe and developing countries.

Is the AIDS crisis over?

No, I personally think it's probably worse than it was in the beginning because people have become quite complacent about the situation. I do Speakers Bureau, and it keeps me on the ground and lets me be aware of what's actually going on in the community where I'm living. The awareness of the kids is just – it's naive, it's sad. Fifteen years down the track and they're still completely oblivious to how dangerous the situation is.

What about in developing countries?

I think [people in Australia] aren't even thinking about what's going on overseas. I don't think they're even keying it in to the fact

that what affects someone in the country next door to us, or in Africa, will eventually impact on us and vice versa. There are no boundaries on this virus whatsoever so we've got to start looking at this as a global situation instead just looking at our own backyard. We've got to really broaden it right out.

How dare it be that in certain developing countries, people earn \$20 a month and it costs \$13,000 a month to get medication – it's not feasible, it's just disgusting.

Recently, 13% of the Australian aid budget for Asia's been cut. Papua New Guinea (PNG) and Irian Jaya are probably one of the biggest hubs of new infections happening at the moment and people just aren't aware of what's happening. They've got a higher rate of infection in PNG than they have in Africa, it's on such an increase, and 90% of all new infections are females. In Irian Jaya, the Indonesian Government is taking the attitude that it really isn't happening.

What do you think should be done?

I think we need to have more communication between them and us. Western countries already have programs in place there, and I think there should be a lot more input from developing countries themselves.

Interview by Jill Sergeant

Ross

31, Koori gay man

How does HIV/AIDS affect your life?

I work in the field and also had a really close friend, brother type, who passed away three years ago –

best friend I ever had. Our friendship was so strong, I didn't need to make other friends. Now I can't get close to anyone. I also work in a place where people are either living with Hep C or at risk.

Is the AIDS crisis over?

Definitely not. Where I work I see lots of recently diagnosed positive people. Also the statistics on STD's are increasing, showing that some people are not practising safe sex. I also heard that the number of rural women that are positive is increasing and that blows me out, and then there are people that are infected and don't know it.

What should be done?

Lots more education, there's no other way to combat it. We need larger scale campaigns, more grassroots approaches so that you get right into communities. I know of people who are still having unsafe sex. I had someone tell me the other day that he did. When I asked him why he said he thought it was okay because positive people don't have unsafe sex. I thought, it's '97 and someone still thinks that.

Interview by Sarah Bergin

Douglas Knox

World AIDS Day Co-ordinator

Over the past 25 years the majority of my close friends have been gay. When I reminisce about many of the important, significant and happy times in my life I find that I can't do it with rose-tinted spectacles. Too many of the significant people in those memories are now dead or are living in the shadow of HIV/AIDS.

When I came to Australia four years ago I decided it was time I put something back into the com-



**"Are the good results
and improved therapies
of the past 18 months
making us complacent?**

**Complacency is not
the cure!"**

- Douglas Knox

munity which I had been enjoying for all of my adult life. Partly to ease the pain of losing friends, partly to ease my guilt feelings at not being infected, I offered my services to ACON as a volunteer. I got roped into helping with the Quilt Project and three years later became the convenor of the Quilt Project in Sydney. At about the same time I was successful in applying for the position of World AIDS Day Co-ordinator for NSW. This position has given me the opportunity to try to raise awareness in the wider community through several of the projects which we run.



PHOTO: GEOFF FRIEND

My sexual lifestyle has also changed. I'm still the same old slut that I've always been but I am much more aware of the activities I get involved with. I don't allow myself to get off my face any more because I know that I couldn't and wouldn't control my actions if I did.

Working in the World AIDS Day project I have to be aware of the world-wide picture and that is horrifying. The statistics coming out of Asia and Africa, the negative action or inaction of governments in too many countries show me all too clearly that the AIDS crisis is far from over. On

a world scale it is still a rapidly growing problem.

Closer to home things may appear better: people are living longer, new drugs, lower diagnoses of AIDS. But these are the results of concentrated, systematic, long term lobbying and education by a host of dedicated workers and volunteers.

If the levels of support in the fight against HIV/AIDS are allowed to fall, will this all be in vain? Unsafe practices seem to be on the increase. Support for the Quilt, Candlelight etc. all seem to be on the decline not just here in Sydney but in all the centres where the fight has been strongest. The US and the UK both reflect the falling numbers involved in supporting these initiatives.

Are the good results and improved therapies of the past 18 months making us complacent? I have a terrible fear that we are only going through a lull, a short respite and that things are going to get worse again. If this proves correct, and I sincerely hope and pray that I am wrong, then it is going to be much more difficult to revive the education, advocacy and support strategies which have been successful in the response to HIV/AIDS in Australia.

Michael

HIV positive gay man

How does HIV affect your life?

Probably every aspect of it. My living, my own mortality is affected by HIV, so all aspects of my life are touched. I'm positive so I've had to make changes to my life, I've had to think about death.

Is the crisis over?

No, definitely not. I think it's going to get worse as it becomes compounded with things like Hep C. I can't see it being over when I see so much casual sex and so much drug use happening. From what I understand new infection rates are still occurring between men who have only been in relationships for a short while, so how can it be over?

Interview by Sarah Bergin

THE BIG PICTURE



AIDS activists: Do we still exist? What do we do?

By Andrew Kirk

SOME PEOPLE WONDER WHETHER AIDS treatment activists still exist, and if they do, what are they doing?

The short answer is that we do exist and we are trying to get immediate compassionate access for all the new drugs that are being developed to treat HIV infection. We also work to ensure that accurate and timely information about treatments is widely available.

So why aren't we out on the streets demonstrating, like in the ACT UP days, when the government or the drug companies screw us over? Good question.

I think the reason for this is that over the years the relationships between the players in HIV/AIDS have reached a more, how shall I say, refined level. To a large degree, now we are able to pick up the phone and discuss rationally our views and needs with the relevant company representative or ministerial advisor. Meetings are mostly conducted in a civilised and decorous fashion: tea and sandwiches are often served. It is all so Lady Bracknell in drug high society nowadays.

This method has worked fairly well. We have been able to secure rapid open access to all the new protease inhibitors (PIs) and non-nucleoside reverse transcriptase inhibitors (NNRTIs), but we have recently come quite unstuck with Glaxo Wellcome over their new nucleoside RT inhibitor, 1592.

This truly huge corporation (Market capitalisation: US \$52,300,600,000. Profits last year: US\$4,229 million.) has decided to fuck over people living with AIDS in a major way by refusing to increase the number of places for compassionate access until sometime in 1998. Meanwhile, one out of two Australians with AIDS who need access to this drug for a combination switch are told to *wait!* It's tough if you can't live long enough to wait.

I'm sorry but Glaxo Wellcome is off my Sunday sherry social circuit with this sort of uncouth behaviour. I must add that AIDS activists all over the globe have been unable to get any satisfaction from Glaxo Wellcome (do recall this is the company that markets AZT, a big profit spinner considering it was a 1960s cancer chemotherapy that was "too toxic" to be used for that purpose).

Can't we do more, I hear you ask? Well, my dears, what leverage do we have? Look at the big picture: we've all been such good positive people over the years that infection rates are half what they were in the days of ACT UP, our numbers are down because of illness and death, and no new people have replaced this unnatural attrition. There is widespread belief in government circles that the AIDS community organisations have been on a fabulous gravy train at the taxpayers' expense – not that HIV positive people have seen all, or even most of, the benefits of this. Finally, the companies know that we desperately need the drugs, so they are prepared to wait till they are ready to market them to us.

We are not assisted by the fact that the bureaucracy in Australia, in terms of approving drugs for inclusion on the Pharmaceutical Benefits Scheme (PBS), is totally bereft of rationality. It is a cumbersome and slow mechanism that has recently delivered a body blow to delavirdine by refusing its listing. (Fortunately the company in this case, Pharmacia & Upjohn, has guaranteed that all the people on delavirdine will get it free of

ACON VITAMIN SERVICE

Stock Clearance Sale

We are clearing stock of selected nutritional supplements and vitamins.

Starting: Monday 3rd November

For more information please call 9206 2043 during ACON business hours.

NOTE: Offer only available to vitamin service members with current script. Please call to join.

charge until the company submits more data and the government bureaucrats get their act together. Delay: more than eight months).

Other companies keep a close watch on these bureaucratic stuff-ups and delays, and are consequently cautious about bringing their products into Australia if this is the way they are going to be handled. Delays in PBS listing after we have negotiated compassionate access from the company can cost plenty. Being in business, as they are, it is logical for them to attempt to narrow the time-frame that they will have to provide free product to the marketplace, viz, us.

So, what do we do about this travesty? We lobby HIV/AIDS organisations like AFAO and ACON, which are meant to be very powerful and well-resourced (1,500 times the funding of PLWH/A's Treatment Working Group), into getting fundamental change in the way things are done at the highest levels of government.

Has this been a success? Er, how can I put this politely – well, not so



Top: On June 6, 1991, Lois did something about AIDS. She demonstrated in Canberra on D-Day, a nationwide ACT UP demonstration urging the Minister for Health to speed up the drug approval system. In 1997, treatments activism is less spectacular, with meetings and behind the scenes lobbying the main activities.

Above: A PLWH/A Treatments Working Group meeting. PHOTO: C. MOORE-HARDY

PHOTO: JAMIE DUNBAR

far. The people in those community organisations are just so very busy, they have so many other things to think about that often these little things just slip into the 'too hard' basket and are conveniently forgotten. I do keep reminding them every now and then, as do other members of the treatments activist group, but frankly I am not overly confident of quick action. Perhaps readers could write in with their suggestions on reform of the AIDS community organisations. (I've already recommended Semtex.)

I might harp on this point for a while, because it is important to our survival.

People with HIV need access to drugs as soon as they are approved for human use by the US Food and Drug Administration. (Why the US FDA? Because that's where all the companies go first to get their drugs fast-tracked for marketing. AIDS activists in the US have been very successful in getting change in their bureaucracy to ensure that HIV drugs are given the very highest priority through the regulatory processes. I should add that these changes took place under the old conservative Republican administration.)

In Australia these FDA pre-approved drugs are approved by the Australian Drug Evaluation Committee (ADEC) and then move slowly through the system to be approved by the Pharmaceutical Benefits Advisory Committee (PBAC) for listing on the PBS. This process can mean that drugs approved in the US are finally approved and listed in Australia two years later. Pretty fucking bloody

hopeless, if you'll excuse my French.

I have often racked my brains to think of a higher lobbying priority for immediate reform in HIV/AIDS. Other than continuation of funding for the community-based organisations, which of course is right up there, I can't think of anything currently more important. Again, perhaps I am missing something; readers can write in with their suggestions.

I have personally raised these issues with Chris Puplick, Chair of ANCARD, and with the senior advisor to the Federal Health Minister on HIV and AIDS. I have been given no commitment of movement from the Minister. It would appear that the Minister does not have the political will-power to tackle these questions within his own Department.

We must therefore consider using more forceful methods and even subtle, innovative methods.

The National HIV/AIDS Strategy is meant to be a partnership, but positive people are the ones who have to take all the responsibility for preventing transmission by telling every potential sexual partner our serostatus (the law in NSW) and by using a condom for sex (AIDS Council guidelines). In return for this what do we get: ignored. Ignored when it comes to the essential needs of HIV positive people: equitable access to adequate treatments.

We were ignored when we demanded money for research into a cure in the 1980s and we were ignored when we called for reform to the PBS listing bogdown in the 1990s when the foreign drugs finally arrived.

Maybe it's time to ACT UP.

Andrew Kirk is a member of the PLWHA (NSW) Treatments Working Group.

LET'S TALK ABOUT SEX

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& info phone 9382 7440
For recorded information 11646

- * HIV/AIDS tests and care
- * HIV eye clinic
- * STD tests, treatment and information
- * Hepatitis B tests and vaccinations
- * Counselling
- * Free condoms, dams and lube
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- * Needle syringe exchange
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SYDNEY SEXUAL HEALTH CENTRE Sydney Hospital, Macquarie St

(near Martin Place Station)

No medicare card required



PLWHA
New South Wales
People Living with HIV/AIDS

People Living With HIV/AIDS (NSW) Incorporated

ANNUAL GENERAL MEETING

will be held on

**December 15 1997
at 7.00pm**

**Terrace Room
Australian Museum
William St, Sydney**

Light refreshments will be served

Only full financial members are eligible to vote at the AGM. Membership renewals and new memberships close at 4.00pm on 12 December 1997.

For further information call PLWHA (NSW) Inc.,
Sydney 9361 6011 or freecall 1800 245 677.

THE BIG PICTURE

voice of the people



Grahame Monteith

How does HIV/AIDS affect your life?

Diagnosed in '85, for the first eight years it had no effect at all then in 1993 I started treatment as the result of a drop in CD4 count and weight-loss. My response to treatment (AZT, ddC) was excellent and for two more years, apart from the need to take medication every day, my health was restored and life continued pretty much as normal.

A bout of PCP two and a half years ago saw me stop AZT, ddC and then go on the Merck trial after three months of no treatment. I was on indinavir only and the response was good for about ten months, then I had a significant fall in CD4s and weight loss. This coincided with the advent of triple therapy and I was put on indinavir, 3TC & d4t.

After an initial few weeks of side effects I responded well, viral load down from 770,000 to 30,000; CD4 up from 140 to over 300 and once again I was well. However, after only six months my viral load began going up again and my CD4 count dropping. As a result I went on a quadruple therapy of ddI, ritonavir, saquinavir & nevirapine. Once again after weeks of unpleasant side effects (nausea, headaches, diarrhoea) my viral load fell from 750,000 to only 2,700 and CD4's went from my lowest ever of 120 back to 360. I felt good, went back to the gym, put on twelve kilos and felt great.

After seven months a repeat of the last time. Viral load is back up around 700,000, CD4s down to 185 and I'm feeling a lack of energy and a pattern of 'good days and bad days'. So at present I'm still taking the four drugs, which ap-

pear to be giving me almost constant diarrhoea (pathology tests have shown no gut infections), and it would appear that I've developed resistance and things are not working anymore. I was almost religious in my 'compliance' so I do not regard that I have failed. The drugs are failing for me and I am running out of options.

Is the AIDS crisis over?

Most definitely not. Treatments and options are greatly improved in the last few years and the prospects look to be improving all the time.

What does the future hold?

The options for treatment are greater than ever before and should get even better. However, it should be recognised that people may respond well to treatment and then begin to slip back. Changing treatment may again reverse the process so it is possible to prolong periods of good health and this will probably vary from person to person. Individual responses will vary greatly but I feel the future is quite positive – no pun intended!

Interview by Guy Taylor

Zara Thompson

Age 12

How does HIV/AIDS affect your life?

I've had a lot of friends with HIV/AIDS & it's hard because they get sick & they just get sicker because if they catch anything like the flu, they get sicker than other people.

It's hard for me because I know they're going to die sometime. Some of them stay well for a long time but . . . I just lost Jonnie.

Is the AIDS crisis over?

No, because people are still getting it and people are still sick with

it. Even if there's treatments and medicine, people are still sick with it. Until we find an absolute cure and you can cure it quickly, it's not over.

What should be done?

I think people have got to be more careful and try harder not to get HIV and I think we should work harder to try to find a cure and a medicine so it's easier for people with AIDS.

I think people with HIV and AIDS should get immunised for things like the flu. This is dangerous because they can get sick from the immunisation, but maybe they could have a lower dose, because if they get the flu they're more likely to deteriorate sooner.

Interview by Jill Sergeant

Paul

How does HIV/AIDS affect your life?

Being HIV positive has made me a more private person because I've had to hide my status. I've had to spend time alone researching the virus. It has drawn me in closer to myself and taken me away from society for a little while. It's a private responsibility.

Is the AIDS crisis over?

No, it won't be over until a cure is found. It may seem to be over at the moment because of the success people are having with the new treatments but no-one knows enough about the side effects or about how long they will be effective. We could be back at square one in five years time.

What does the future hold?

A lot of fun and hope! I'm taking the future one day at a time.

What can be done to end the AIDS crisis?

There needs to be more mainstream comment, more discussion and acknowledgment of AIDS, rather than regarding it as a gay problem. It's a world problem. There needs to be a lot more love from people of all sexualities.

Interview by John Cumming

Bobby Goldsmith Foundation



Is the AIDS crisis over?

In BGF's view, whilst the environment has changed considerably, the crisis is clearly not over. BGF is busier than ever before, currently providing some form of assistance to approximately 750 people throughout NSW.

There is considerable optimism with the development of new treatments, but there is also considerable anxiety and uncertainty about the future effectiveness and the side effects of combination therapy. Although many positive people have experienced signifi-

cant improvements in their health and well-being, many (for many reasons) are choosing not to take up or continue with combination therapies and treatments are not proving successful for everyone.

Even for those who are benefiting from treatments, a return to full-time work may not feasible or appropriate. For example, how do you explain to a prospective employer that you have been on a pension for three or five years because of an AIDS diagnosis? Therefore, as the recent study (see p10) has shown, 45% of PLWHA continue to live in poverty without enough food, with poor nutrition, and less able to pay for treatments and therapies.

Until such poverty no longer exists, until every positive person has affordable and appropriate accommodation, until there are effective and appropriate treatments for all, until there are no new infections, until HIV-related discrimination no longer exists, the crisis is not over.

What should be done?

BGF has two principal tasks:

1. To work to reduce HIV-related poverty and its impact on the health and well-being of positive people;
2. to ensure a range of appropriate and affordable housing options are available to positive people – housing which is responsive to changing needs.

As a community organisation, we need to work effectively with other organisations both on service delivery matters and in advocacy and lobbying. We need to respond rapidly and effectively to changes in treatments, recognising the complex impact these changes are having on people's lives. In doing so, we need to make sure that positive people play a central role in the organisation's decision making and in developing or adapting services.

**- Alison Cunningham & Mark Tietjen,
Bobby Goldsmith Foundation**

Women

Support and information for women and families living with and affected by HIV/AIDS.

HIV Positive Women's Support Project

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

Family Support Project

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

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

Information for lesbian drug users on being positive and using, safe injecting information, needle exchange service etc, call (02) 9206 2074 / 2096.

Treatment Officers

Information about the latest treatments available 1800 816 518.

9 Commonwealth Street
Surry Hills NSW 2010



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Toll Free 1800 063 060

HIV '97 - THE BIG PICTURE

The Challenges for governments



By Justice Michael Kirby

LIKE MANY OF YOU, I HAVE BEEN A participant in this journey for nearly two decades. I remember the early sense of astonishment and puzzlement when AIDS first came swimming into consciousness. I remember the anger I felt as people I loved and respected became caught up in this global epidemic. I still feel that anger. I remember the frustration at the slow response. Rage at the huge expenditures on armaments and the tiny trickle of the world's capital spent on the scientific endeavour to cure or arrest HIV/AIDS. I still feel that rage. How often our hopes have been lifted with the word of new drugs to treat the condition or palliate the suffering. I still feel that hope.

I am here [at the 4th International Congress on AIDS in Asia and the Pacific in Manila] because of the determination which I share with you to do everything that can properly be done to prevent the further spread of the epidemic and to respond with energy, protection and support for those already infected and their carers. We are all here because of solidarity that seeks out part-

nerships across national and regional borders; that seeks to learn from the strategies which appear to work and to avoid the strategies that seem to be just rhetoric and to fail.

The Aboriginal poet, Jack Davis, wrote of the need to cross boundaries and to form new partnerships:

*"Let these two worlds combine,
Yours and mine.
The door between us is not locked,
Just ajar.
There is no need for the mocking
Or the mocked to stand afar
...
It is time to learn.
Let us forget the hurt,
Join hands and reach
With hearts that yearn"*

He said this to his non-Aboriginal fellow citizens in Australia. I say it to you. It is time for all of us to learn. Let us join hands and reach out.

But how do we do this? The answer for our region, clearly enough, is pretty poorly. The United Nations Development Programme (UNDP) has declared:

"The HIV/AIDS epidemic in Asia and the Pacific is growing as fast or faster than anywhere in the world. By the year 2010 Asia and the Pacific is expected to have the largest cumulative number of people with HIV infection... In most countries of Asia and the Pacific the epidemic is still not very 'visible'. The rhetoric of... the need for a multi sectoral response to the epidemic is sometimes present but there is not a strong body of work to represent what this means in practice."

It all stands to reason. This is a region of the world with great concentrations of population. It is a region which, despite recent eco-

nomic advances, still has an awful lot of poverty... where, more than most, there are impediments in cultural factors and still inadequate educational opportunities, disempowered women and minority groups, including some at special risk of HIV/AIDS. It is a region with its fair share of unresponsive, centralised, out of touch governments.

Good governance - with its emphasis on decentralisation, grass roots, contact with community organisations and involvement of people on the frontline - is an essential prerequisite to an effective response to the HIV/AIDS pandemic. Yet throughout our region, governments are over-taxed with problems. Their distracted, overburdened central administrations focussing so sharply on necessary economic advance, working political machinery all too often inherited from colonial times, creaking and straining under unprecedented pressures, fail to respond properly to HIV/AIDS. The rhetoric may be there. But effective responses are not. That is why, although only 7% of the total AIDS cases in the world are presently reported in Asia, there are very worrying epidemiological trends:

- An increasing spread of HIV infection.
- Changing patterns in the spread of HIV infection.
- Particularly rapid spread of HIV in Thailand, India, Cambodia and Myanmar/Burma.
- One million of the 2.7 million estimated new HIV infections in the world in 1996 were in South East Asia. In the same year, 30% of the new HIV cases in children occurred in that part of the Asia-Pacific region.

The reasons for these discouraging trends, which have to be

spoken of quite bluntly, are not difficult to find:

- AIDS programs generally have a low governmental priority;
- national AIDS committees are all too often inactive;
- there is limited manpower available to work on AIDS programs;
- budget expenditures on health programs generally are low;
- there is a limited involvement of the non-health sector; and
- there is poor or limited coordination of HIV strategies.

Of course, there are exceptions to this melancholy tale. The clearest exceptions show that progress can be made, including in our region. The best examples of what can, I think, be done can be found in Australia and New Zealand (where sero conversions have plateaued) and Thailand (where there has been a big fall in the HIV positive incidence amongst young men performing military service and young women: previously both high risk populations).

What are the features which have marked the early responses of these three countries from which other countries in the region can learn? They are, I believe the following:

- political appreciation of the importance of the epidemic, not only in human terms but in economic, developmental and social costs;
- mobilisation, despite all the difficulties, of politics and government to come to grips with the realities, not the myths, of the epidemic;
- involvement of the people most at risk in planning strategies to combat the spread of HIV/AIDS – commercial sex workers, intravenous drug users and homosexual/bisexual men;
- close involvement of NGOs/CSOs in the grassroots communities, including people living with HIV and AIDS;
- active involvement of the mass media in bringing accurate mes-

sages about HIV/AIDS and recognising that it is an epidemic of waves and not linear in its shape.

- a willingness to adopt bold and controversial strategies: the needle exchange program in Australia; the widespread free distribution of condoms in Thailand; and
- a readiness to offend the sensibilities of those who yearn for the days before AIDS and to challenge even religious and cultural modesties in an overwhelming passion to save precious, irreplaceable lives.

One cannot wave a magic wand. One cannot wish away the impediments that exist to the successful strategies to contain this epidemic. At least, one cannot do so in the early stages of the epidemic when the reported cases are few, hidden away in embarrassment and when officials, facing many other challenges, hope that the problem will disappear.

Giving and reinforcing information to prevent the spread of HIV is difficult enough in the wired societies of the developed world. Even there, the expenditures on prevention are typically contemptibly small. In the United States, in 1994, national expenditure on treatment for AIDS was \$9.4 billion.

On research, it was \$1.6 billion. But on prevention it was only \$0.6 billion. If this is the attitude in a sophisticated media obsessed polity such as the USA, can we really expect better in the struggling, often disadvantaged, problem ridden, diverse, usually poor societies of Asia and the Pacific?

The human rights paradox

Paradoxically enough, the only way in which we will deal effectively with the problem of the rapid spread of this epidemic in our region is by respecting and protecting the human rights of those already exposed to the virus and those most at risk. It is a paradox because convincing ordinary citizens that you need to protect the basic dignity of commercial sex workers, 'promiscuous' people, injecting drug users, gay men and other marginalised individuals, is very hard to achieve.

Yet this paradox must be consistently and forcefully brought home to everyone who has influence in the design of the programs for dealing with HIV/AIDS. The riddle is quite easily explained. Without a cure and with no vaccine yet in sight, the only truly effective strategy for prevention is non-infection. Yet that will not occur without knowledge about



Women's community health workers at an HIV/AIDS training course in Kanaky (New Caledonia). Photo Courtesy of APHEDA.

the virus, awareness of its modes of transmission and a constantly reinforced effort at community protection.

Protecting the groups and individuals at risk is a moral obligation, a priority strategy – owed to brothers and sisters because, like us, they are human. They feel. They suffer. They and their families are cruelly burdened when this infection takes hold, and nowhere more so than in poorer, developing countries where palliative drugs are generally unavailable, social support, outside the family, is negligible and where stigmatisation based on ignorance and prejudice is rife.

Prevention is not the only strategy. Help, support and protection for the infected and their carers must be the second strand. Scientific research must be the third strand. But in terms of macro policy, prevention should be the first.

These are conclusions which have been reached by so many AIDS conferences that it seems superfluous to repeat them. Yet sometimes simple messages are the most important ones to repeat. To say them again until they sear the intellect of those with the power to act. In the great struggle against HIV/AIDS, respecting the basic human rights of those infected, those at risk and their carers and families is the duty of all governments.

In the consultation on this topic held by UNAIDS and the Centre for Human Rights in Geneva a year ago, twelve strategies were endorsed. Space does not permit the elaboration of all of them. However, they present a checklist for how we are dealing with the problem. The Secretary-General of the United Nations has been invited to convey them to the Heads of Government of UN member countries. Here are some of them.

- States should establish an effective national framework for the response to HIV/AIDS which ensures a co-ordinated, participatory, transparent and accountable approach: integrat-

ing HIV/AIDS policy and program responsibility across all branches of government (Guideline 1).

- States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights . . . (Guideline 4).
- States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups [and], people living with HIV/AIDS . . . ensure privacy and confidentiality . . . [and] emphasise education and conciliation . . . (Guideline 5).
- States should enact legislation to ensure . . . widespread availability of . . . adequate HIV prevention and . . . information and safe and effective medication at an affordable price (Guideline 6).
- States . . . should promote a supportive and enabling environment for women, children and other vulnerable groups . . . (Guideline 8).
- States should promote . . . creative education, training and media programs explicitly designed to change attitudes to discrimination and stigmatisation associated with HIV/AIDS . . . (Guideline 9).
- States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights (Guideline 11).

These proposals were adopted by the United Nations Commission on Human Rights on April 11, 1997. But passing resolutions is an easy thing. Ensuring that their noble suggestions permeate down the cumbersome line of bureaucracy into the smallest village of our region, is much more difficult. Getting such brave ideas into the hearts and minds of ordinary people so that they will change their attitudes and conduct is still more difficult.

So if we ask how are we dealing with the problem of HIV/AIDS, and

measure the responses of governments against the trends of the epidemic, the best practices that have been delineated and the guidelines I have just mentioned, I think you will agree that the answer is: we are not doing very well. There is a basic lack of commitment. A lack of resources. Often a lack of essential sympathy for the fundamental human dignity of this class of person. There is stigmatisation and prejudice, until HIV/AIDS comes knocking on your own door. Then, those who know realise that it is just another microscopic human virus that is the enemy of the whole human family.

But how we enliven the sense of urgency, the appreciation of the HIV paradox, the commitment of resources and the fundamental determination to tackle this virus in Asia and the Pacific whilst there is still time – that is the challenge. Some countries have done better than others. We are here to learn from them by partnerships across borders. And if we do, eventually, HIV/AIDS will be consigned to a footnote to human history. Until that happy day we, the knowledgeable ones, must be galvanised as evangelists to replace discrimination with understanding, ignorance with knowledge and indifference with commitment.

Jack Davis finished his poem with these words:

*"Your world and mine
Is small.
The past is done.
Let us stand together,
Wide and tall
And God will smile upon us each
And all
And everyone."*

The Hon Justice Michael Kirby AC CMG, is a former member of the WHO Global Commission on AIDS. Justice Kirby gave this speech at 4th International Congress on AIDS in Asia and the Pacific in Manila, the Philippines in late October. It has been edited for length.

THE BIG PICTURE

voice of the people



Erycka Fars

HIV Women's Support Officer at
ACON



How does HIV affect your life?

It doesn't really! Except the fact that my husband always has to use condoms, and also when it comes to thinking about pregnancy it takes more "wonder" that's all. And of course it makes me take better care of my health.

Do you think the AIDS crisis is over?

No, I don't think so. I think it's very difficult because most people say to positive people, you're fine now, you've got drugs and why do you worry. I think that's pretty dangerous because treatments don't work for everyone and they're not a miracle either. I don't think it's the end at all. Different issues, different problems, but I don't think it's the end.

Some people like to believe it's over, it makes them feel really good. Are they being realistic? I don't think it's over.

It might be more difficult for women to believe it's over because there's so little research that has been done in terms of treatments and things like that, there seems to be more doubt for them.

What do you think should be done?

I think drug companies should think about finding drugs that have less side effects and that are more efficient. Maybe people should be more educated to help people with HIV to cope better or be more supported. I've heard it so many times lately that positive people still worry about being positive and I think they've got less support since the new treatments are there. They don't take the issue as seriously. I think it's not a very good time emotionally. Complacency is a big danger.

What everyone needs who's positive, is to be supported in their decisions with drugs, to be supported in their decisions with having babies or not having babies, to be supported when they get into relationships, maybe help positive people to talk more freely about their status and try to make them understand that it's okay to be positive and you don't have to hide. But that comes slowly, slowly. I think what ought to be done is all on emotional levels. Drug companies and activists are taking care of the rest.

Neville

Hi, I am Neville Fazulla and I currently work at the Queensland AIDS Council in the Education team of the Brisbane office. My role is to provide relevant information to the Indigenous community on HIV/AIDS and sexuality. I am an Indigenous man from

South Australia. I have been involved in HIV/AIDS for a period of eight years in all areas from volun-



teer to paid staff and from local to national committees and working parties.

How does HIV/AIDS affect your life?

I think I should start by saying that HIV/AIDS affects my life in many different ways, but I think the greatest effect that it had was the simple fact that it caused me to mature and to become more aware of myself as an individual, and as a person.

I guess that it is fair to say that it plays an integral part in my everyday life and has done so in a greater dimension since August 1994 which was when I was diagnosed. This took a great toll on my life personally, professionally, socially and economically, not forgetting physically.

I'm not saying that this does not still happen, it just shows how we can gather the strength to address



"The suffering of millions of people is private, silenced, unreported, and insignificant in our globalised economy."

— Ken Davis

the issues we face on a daily basis and having a positive mind for a positive lifestyle. I feel that I have become an even prouder person in relation to my sexuality and lifestyle and I do not feel ashamed of myself for being an Indigenous positive gay man. I think that working in an education team of an AIDS council can constantly remind you every single working hour of the effect HIV can have on your life. This has both its pros and cons.

Is the AIDS crisis over?

No!

What should be done?

I think we need to accept that the community needs to be even more receptive of the HIV/AIDS crisis and that the style of education materials needed must be inclusive of the particular needs of the diversity that exists in our community/s. HIV/AIDS health service delivery needs to become a part of the everyday health service delivery and health maintenance and enhancement.

Neville Fazulla is Alternate Indigenous Spokesperson for NAPWA.

Hamish

Gay male, "30ish"

How does HIV affect your life?

Well I'm actually HIV negative myself, but when I think in terms of the way it has affected my life it's really about the relationships I have with positive gay men, both sexually and socially. It's very hard to establish relationships with HIV positive gay men; and socially I think there is still a stigma associated with being HIV positive. Whether or not we want to subscribe to that, it still exists and I think it does affect our relationships with positive gay men.

Do you think the AIDS crisis is over?

I know people who would certainly say it isn't over, but I think it is changing in the sense that HIV is much more manageable. But some people really do still feel a sense of crisis when they sero convert now in the 90's and it's becoming much less acceptable to sero convert in the 90's. And also for people who are still getting ill and dying it is obviously still a crisis. But I don't think it is a crisis in the sense that it was ten years ago, I think it has changed remarkably in the last two years with new treatments but I don't know what that will mean in another two years or so when some of those treatments start to fail for people.

What do you think should be done?

I think there needs to be continued HIV prevention education. We need to address gay men's relationships and risk management for people in sero-discordant relationships. I think that there needs to be a lot of education around treatments, and access to treatments, and giving gay men the choice about taking those treatments up. They need education about what the implications are. But I also think there should be a lot more discussion in the community about the way that gay men who are HIV positive and gay men who are HIV negative relate to each other, and how we can start dealing with that in the near future.

Interview by Guy Taylor

Ken Davis

For a dozen years, when I was living in inner Sydney and working in ACON, so many of my friends died. Until the mid 80s, I'd thought we'd all still be around through the start of the next century, wasting middle and old age

together, 'cept for the odd murder or overdose.

At least now several of my friends here are going well to varying degrees with the new combination therapies.

But I have been working on projects in Viet Nam, Cambodia and Southern Africa for three years now, with APHEDA, the overseas aid agency of the ACTU. Now my friends in South Africa are dying. On Sleaze Ball weekend Niall died with his Muslim/Catholic/Hindu family in a coloured township in kwaZulu-Natal. He had been very sick for three weeks. The local doctor and nurse did everything they could to treat his thrush, diarrhoea and TB, but without access to some of the expensive and more effective drugs you can get here. Niall had lived for ten years outside South Africa; if he had stayed away, he would have had access to better drugs and still be alive.

Niall was only one of about three million people with HIV in South Africa, most of whom were infected very recently. The epidemic there is much newer than the countries to its north. In Winterveld, where APHEDA supports a local AIDS education and care project, infection rates among young women have risen from eight to 25% in one year. For southern and western Africa, and for the southern Asian countries the crisis is just beginning.

In most African and south Asian countries, there are very few resources for health for the majority of people. With aid money from the imperialist countries drying up, penalties for countries that do not pay their unjust but still skyrocketing debts, and imposed 'structural adjustment' plans, there's actually very little money for implementing grassroots AIDS care or prevention programs in the

'developing' countries where 95% of people with HIV live. In many countries, people have much less access to health care or education than in the 1960s or 70s.

You don't even become an AIDS statistic, if you know there is no point going to the local clinic, because you can't afford it, and there will be no treatments available. You may go to a traditional healer, or go home to die from TB or wasting, with whatever shelter and care your remaining family can provide. If there is money for a funeral, no one will openly say you died of AIDS. The suffering of millions of people is private, silenced, unreported, and insignificant in our globalised economy.

Much of the AIDS funding from donor countries goes to pay for technical advisers, planners, researchers, evaluators, and for the profits of the development consultancy companies. In the Australian overseas aid budget, for example, about 90% is spent in Australia, on payments to Australian consul-

tants and companies. But it is not talent or knowledge that is lacking in Africa and Asia, it is resources to provide support for people with HIV and educate communities.

gious and political leaderships, lack of democratic space, wars and civil conflicts, the oppression of women. But people work on in whatever way they can, with hope and/or compassion.

The crisis will only get worse through the early years of next century, and the impact on individuals, households and communities will become more and more unbearable, until there are widely available and very cheap therapies and vaccines. Yet that would require an unprecedented assault on the profits of the international pharmaceutical companies.

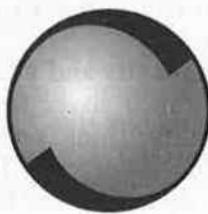
"When the history of our time is written, it will record the collective efforts of societies responding to a threat that has put in the balance the future of whole nations. Future generations will judge us on the adequacy of our response."

Nelson Mandela, AIDS: facing up to the global threat, World Economic Forum, 3 February 1997.



PHOTO: C. MOORE-HARDY

Of course there are other local barriers to effective responses to HIV: the power of reactionary reli-



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Legal Update



Insurance

by Benita Glaser

Can insurance companies require me to take the HIV antibody test when I apply for insurance?

Yes. Most importantly, the law states that both parties must observe the utmost good faith in their dealings with each other. The person seeking the cover must ensure that all details provided to the insurer are true, not misleading and an accurate reflection of the person's circumstances. Similarly, s/he is under a duty to disclose all relevant (material) information to an insurer before a contract is made.

Life and disability insurance companies will want to know if you are in what they consider to be a "risk group" or engage in any risk activities. If you have a history of any activity that means you might have HIV, they will require you to have an antibody test and a negative test result before they insure you. For life and disability insurance above a certain amount, a test must be taken regardless of any risk activity.

Can insurers refuse me death, disability or life insurance because I have HIV, HIV illness or AIDS?

Yes, you will almost certainly be denied insurance. Alternatively, you may be offered insurance that ensures that you would receive the benefits only if death or disability was not related to HIV or AIDS, by excluding HIV-related conditions. There are investment policies available without restrictions.

I already have insurance. Can my

insurer refuse to pay AIDS or HIV-related claims?

Your insurer cannot refuse to pay, unless you were untruthful on your application or your policy excludes all sexually transmitted diseases or specifically AIDS or HIV-related conditions.

What cover can I get with private health insurance?

Usually, cover is not provided in the first twelve months of membership for conditions that exist prior to taking the cover. After that time however, you would be covered unless the insurance specifically excludes illnesses related to HIV.

How can I protect my rights when it comes to insurance and superannuation?

You will need to check whether you can continue your group or individual cover when you transfer jobs or leave your present job. If you have HIV/AIDS you should continue or change over your cover because you will be unable to get a new individual policy and probably will face a two year exclusion period for HIV or AIDS claims in a new group scheme.

Think carefully before dropping your present coverage. If you have HIV or AIDS you will be unable to replace it, or you will only be able to replace it on less favourable terms with exclusions.

Life insurers may ask your doctor for information about your medical history. If you are concerned that information recorded by your doctor may influence the insurer's decision to accept your

proposal, your doctor should be contacted to discuss the information that is to be provided. However, life and disability insurance can only be issued on the basis of full disclosure of all relevant medical information.

Be careful about choosing an insurer as not all of them ask the same questions or treat answers to them in the same way. Read the proposals, policy forms, terms and conditions very carefully, especially the fine print and if in doubt seek legal advice. Find out if there is a waiting period after you start making contributions during which you cannot make an HIV or AIDS-related claim.

If you do not have HIV and you do not have insurance cover for sickness or disability, think seriously about getting cover now. If you do have HIV, you will have to look at other forms of income security. Check with a financial advisor.

What if I have a complaint about insurance or superannuation?

Seek advice. There is a Life Insurance Code of Practice on AIDS, as well as HIV/AIDS Superannuation Industry Guidelines. The HIV/AIDS Legal Centre can assist you.

The key in relation to insurance and superannuation issues for people with HIV/AIDS is to stay informed in this complex and difficult area.

Benita is a student volunteer at the HIV/AIDS Legal Centre. The text is based on information contained in the "HIV/AIDS and Your Rights" pamphlet produced by AFAO.

Service Update



CONSUMERS' HEALTH FORUM of Australia Inc.

IT IS AN OFTEN OVERLOOKED FACT that health consumers have considerable expertise when it comes to their own health. Consumers do have very clear ideas about what constitutes good quality health care for them. And, people with chronic health conditions and who have high health care needs have a particularly unique and valuable view of what a good quality health care system for Australia looks like. The Consumers' Health Forum (CHF) aims to promote the important role of these perspectives and to translate them into policy advice for governments and health care providers.

CHF is a national peak body of consumer and community groups with an interest in health care issues. Over 100 groups and organisations are voting members of CHF, and these members elect a General Committee every two years to govern the work of the or-

ganisation. Voting membership is open to consumer organisations which support CHF's work, and currently ranges from large national organisations such as ACOSS and the Council on the Ageing, through to state-based organisations and local level self-help groups including PLWH/A (NSW). Associate membership is available to interested individuals and other organisations such as divisions of general practice and pharmaceutical manufacturers.

CHF celebrates ten years of providing a voice for health consumers this year, as well as a balance to the views of health care providers, governments, health care industries and other players in the health care arena. CHF is currently undertaking policy work on issues such as health financing, the reforms to general practice, pharmaceuticals, and information and privacy, as well as continuing its

core activities of publishing a quarterly journal, *Health Forum*, and co-ordinating a consumer representatives' program.

CHF has consistently articulated the need for health care that recognises and incorporates consumers' views and a culture of health care provision which regards consumers as active and equal participants in decision-making about, and the management of, their health.

CHF's recent work on the issue of consumer access to health records, on the development of a 'report card' for hospitals and on the Commonwealth Government's move towards 'strengthening the evidence base' of health care all reflect this belief in the contribution that consumers can, and should be encouraged and supported, to make.

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Service Update



HIV/AIDS International Development Network of Australia

HIDNA IS A JOINT PROJECT between the Australian Council for Overseas Aid (ACFOA) and the Australian Federation of AIDS Organisations (AFAO). It is an informal association of agencies and individuals concerned with lessening the impact of HIV/AIDS in developing countries.

While most members are Australian based, HIDNA has links with many international agencies, including the United Nations Program on AIDS (UN-AIDS). HIDNA nominee Bill O'Loughlin is one of the representatives for the Asia-Pacific region on the management board of UN-AIDS.

HIDNA does not provide direct development assistance, its role is to strengthen the capacity of the agencies that do, through information exchange, education and training, and advocacy.

HIDNA objectives are to provide a forum to address the global implications of HIV through:

- collaboration in development co-operation activities;
- exchange of information and strategies which will facilitate greater understanding of, and appropriate response to, the epidemic;
- strengthening the capacity of agencies and individuals to respond to the epidemic; and
- raising public awareness of the global implications of HIV/AIDS.

Major achievements for HIDNA in the last year include:

- developing and running, with Family Planning Australia, in Sydney and Brisbane, two multi-day seminars: Training in Sexual and Reproductive Health for Pacific Island Community Workers; also a series of regular seminars on Development Education for Sexual and Reproductive Health Professionals;
- co-ordinating a one-day seminar, Emerging Issues: Women and Children at Risk;
- bringing together a wide range of aid and development and HIV/AIDS organisations through training seminars and information exchange;
- co-ordinating a series of shorter seminars/workshops including: The Shalom Project, Evaluation Workshop, Peer Education and Sex Work in a Developing Context;
- publishing a bi-monthly newsletter *Echidna*; and
- providing input to the Government on issues such as the AusAID ANGOP Guidelines for HIV/AIDS and the development of Australia's 3rd National AIDS Strategy.

Join HIDNA and you receive:

- the newsletter – several copies if you are an organisation;
- opportunities to attend network meetings, training courses and

seminars which are heavily subsidised;

- the opportunity to have input to working groups and committees;
- access to information on policy and program issues; and
- access to a group of highly skilled, dedicated individuals and lively professionals.

HIDNA is funded by the Australian Government through the Australian Agency for International Development (AusAID) and the Commonwealth Department of Health and Family Services; additional funds come from member contributions.

HIDNA is based in Canberra at ACFOA. It has a small management committee and an advisory group and is staffed by a Co-ordinator and an Information-Project Officer.

Membership Costs 1997-98

Individual – waged	\$30
Individual – unwaged	\$20
Organisation	
– ACFOA member	\$100
Organisation	
– non-ACFOA member	\$150

Contact Details:

Co-ordinator, HIDNA, ACFOA,
Private Bag 3, Deakin ACT 2600
Email: hidna@acfoa.asn.au
ph: (02) 6285 1816
fax: (02) 6285 1720

Talkabout

WHERE WE SPEAK FOR OURSELVES

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

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

PLWH/A Membership

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

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

Talkabout Annual Subscription Rates

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

All NSW *Talkabout* subscribers also receive *Contacts* – the directory of services for people living with HIV/AIDS in NSW – quarterly.

Individuals

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

Organisations

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

Donations

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

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

Method of payment:

Cash Cheque Money Order
 Mastercard Visa Bankcard Card number _____

Expiry date _____ Signature _____ Date _____

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

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

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

First name _____ Last name _____

Postal address _____ Postcode _____

Phone (h) _____ (w) _____

Mobile _____ Fax _____

Please forward this completed form to:
Subscriptions, *Talkabout*, PO Box 831, Darlinghurst NSW 2010.

Thank you!





events

Launch • NSW Official launch of AIDS Awareness Week and World AIDS Day on Sunday 23 November 2.00pm at NorthAIDS Inc's "Red Ribbons Blue Notes" concert at Manly Warringah Leagues Club. Starring James Morrison and Jenny Morris.

Quilt • Australian AIDS memorial Quilt Regional Tour. The Quilt will be displayed throughout the state during AIDS Awareness Week (23 November - 1 December).

Awards Night • University of Sydney's Seymour Theatre Centre, Sunday 30th November. Invitation only event to honour the outstanding work of those involved in the advocacy, care, education and support of HIV/AIDS in NSW.

For more details of the 200 plus events happening across the state during AIDS Awareness Week, please contact;

NSW World AIDS Day Project
RSSCHC
Joynton Avenue
Zetland NSW 2017
ph: 9382 8356
fax: 9382 8158
<http://home.rainbow.net.au/wad>

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