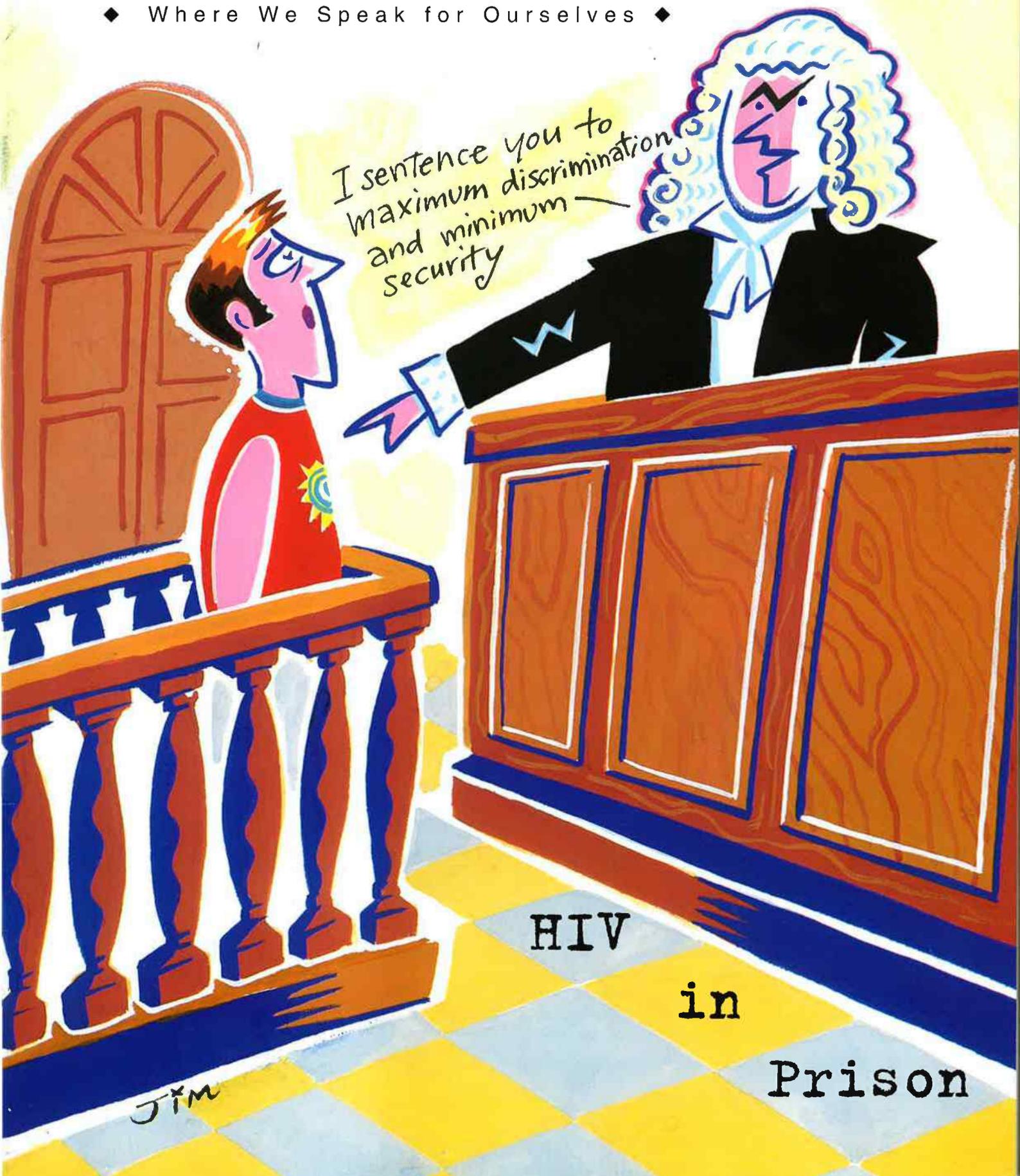


No. 79 September 1997

# Talkabout

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

◆ Where We Speak for Ourselves ◆



I sentence you to  
maximum discrimination  
and minimum  
security

HIV

in

Prison

JIM

# Convenor's Report



AUGUST 18 SAW THE LAUNCH OF our new booklet: "Getting the most out of your HIV Treatments". The launch at the Lizard Lounge was attended by over 150 health workers and community representatives.

Part of this organisation's advocacy work is communicating with our own constituents – and there is surely nothing more important at this time, than sharing constructive ideas about how to get the best out of the new treatment options.

The idea for the booklet came from the PLWH/A (NSW) Inc. Treatments Working Group. The

booklet moves away from debate and does something really practical to help positive people deal with the issue of taking their treatments correctly and getting the most benefit from them. For more information see the news pages.

We invite your feedback on the booklet and any suggestions you have for improving it. A big thank you must go to all those who worked on the success of this campaign.

PLWH/A is currently applying pressure on the NSW Minister for Health to release the findings from the Review of HIV-related poverty in NSW, which was finished in January 1997. We are also working with other community agencies to pressure the Minister for Community Services, Ageing and Disability to sign off on the report into Access to & Equity in Home and Community Care (HACC) services for PLWH/A in the Eastern Sydney Area, which was completed in July.

The July *Talkabout* women's special edition has proved to be one of the most popular issues we've done, with returns the lowest on record.

## Bye Bye John



EDITING *TALKABOUT* WAS MY first paid employment after retiring a year ago because of ill-health. When I think about the personal changes I've experienced

in the last 12 months – retirement, my health bouncing back, and then finding myself editing *Talkabout* and working in a community organisation – the last year seems more like three. On a day-to-day basis, my experience of PLWH/A (NSW) Inc is of incredibly hard work from everyone involved – the contrast with my old career in the public service is amazing! The four months I've spent here have been very exciting because of the rapid changes in the positive community and I'm pleased to have reflected these changes in *Talkabout*. My thanks go to everyone I've worked with.

– John Cumming

This issue marks the departure of acting Editorial Co-ordinator John Cumming. He has done an excellent job filling in for Jill Sergeant, who is returning from leave. We wish him well for the future and thank him for his hard work. Also, of course we welcome Jill's return to the team.

This month we say goodbye to Norman Last, who has been a volunteer receptionist in our office since last November. Thanks Norman, for your cheerful face and the support you gave to staff. Welcome to our new receptionists, Jamie, Tim and Daniel.

Finally, our congratulations to Bill Whittaker, PLWH/A committee member and national treatments spokesperson, for being selected on the Clinical Science Track committee for the 12th International Conference on AIDS.

– Philip Medcalf



**People Living With HIV/AIDS (NSW) Inc.**

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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

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### This month's cover

**By Jim Chan.** It's been said that being deprived of liberty is punishment enough – there is no justification for depriving prisoners of other rights once they are in gaol. But HIV positive prisoners are especially vulnerable to discrimination, exposure and abuse. In this issue, as part of a special feature on prisons, we publish stories about what it's like for those inside. The feature starts page 12.

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

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● Young women in Papua New Guinea account for 90% of infections according to Ludger Mond, PNG's Health Minister. The first recorded case of HIV infection on PNG was in June 1987; 745 people are now infected, 389 of them female. Mond estimates that the current rate of infection is just the "tip of the iceberg" and that the rate of infection could be as high as 10,000. A national strategy geared toward HIV education, prevention, community care, research and technology will be launched, said Mond. (Reuters)

● The Israeli army reported in August that it routinely tests its Ethiopian Jewish soldiers and known homosexuals for HIV without their consent. Ari Eldad, the chief army medical officer said in regards to the matter, "There is no issue of discrimination or relating negatively to any sort of group here. We relate to risk groups." Ethiopian parliamentarian Addisu Messele said the revelation indicated that the Israelis had learned nothing from the incidents last year when it was discovered that hospitals were secretly dumping blood donated by Ethiopians for fear of HIV contamination. Of the 1,400 cases of AIDS reported in Israel last year, 550 were in Ethiopian Jews. (Reuters)

● In the USA, A federal jury began deliberations in late August in the case of Michael Blucker, a former state prison inmate who claims he was infected with HIV after repeated rapes by fellow prisoners. Blucker filed suit against seven employees of the Menard Correctional Center, alleging that they did not attempt to stop the sexual attacks. The defense argued throughout the week that Blucker was not a rape victim, but instead contracted HIV through consensual sex. (CDC Daily Summaries)

● The ashes of Lt. Col. Charles William Slack III, who died of AIDS in 1995, went into orbit in April on the Spanish Pegasus rocket. Slack's family paid \$4,800 for space on the starship because, his sister said, he "belongs out in the heavens." (Poz)

● According to the Interior Ministry, the total number of IDU in Russia now hovers around 2 million people. Some 75 percent of the approximately 5,000 officially registered HIV-infected Russians are also drug users, health experts say. (CDC Daily Summaries)

● Many island and Aboriginal communities in Northern Australia may be at risk for HIV infection spread by Thai trawler crews working in the Torres Strait, according to Australian Health Minister Michael Wooldridge. He noted that "in Indonesia, the place with the second highest level of HIV is Merauke, a fishing village in south-east Irian Jaya." (AAP)

## Special lady

PEOPLE LIVING WITH HIV/AIDS have joined the world in mourning the death of Diana, Princess of Wales on August 31.

Announcing the launch of a joint AIDS Trust of Australia and AFAO "Diana, Princess of Wales HIV/AIDS Appeal", Chris Puplick, Chair of the AIDS Trust, commented: "through direct action, Diana did more than almost any public figure of her time to overcome discrimination, prejudice and ignorance. This is particularly so in the case of HIV/AIDS. Her kindness and compassion will be remembered, especially by those who met her on her frequent and often unpublicised visits to people in hospitals and hospices."

Peter Grogan, President of AFAO, summed up Diana's impact: "The images of the Princess of Wales visiting people with HIV and AIDS during the late 1980s, when fear and discrimination were rife, remain with us," he said.

Luncheon Club volunteers and diners made a unanimous decision, on the Monday following the Princess's death, to remember that "special lady", as Carole Ann King described her. Luncheon Club Committee member Audrey Taylor spoke to the Club about Diana's commitment to people living with HIV/AIDS. This was followed by a minute of silence. "We have lost one of the greatest crusaders HIV/AIDS could ever have, so it was a mark of respect for that reason", Carole Ann told *Talkabout*. It is the first time that the Luncheon Club has acknowledged a death.

The "Diana, Princess of Wales HIV/AIDS Appeal" was launched in response to inquiries from many people as to how they could support causes championed by the Princess in memory of her life and work. Fifty percent of the funds raised will be directed to State based AIDS Councils and other community based organisations in Australia, and 50% will be directed to community based responses to HIV/AIDS in the Asia Pacific

region with which AFAO already has links. Donations can be made to the AIDS Trust, call 9281 6000.

## New HIV/AIDS treatment booklet

ON AUGUST 18 PLWH/A (NSW) Inc. launched an innovative new treatment resource; a booklet entitled "Getting the most out of your HIV treatments". The booklet, the first of its kind produced in Australia, aims to give really constructive ideas to people with HIV/AIDS about how to get the best results from the new HIV/AIDS treatment options.

"The idea behind this booklet was to move away from debates about words like 'compliance' - and do something practical to help positive people deal with the crucial issue of taking their treatments correctly," said PLWH/A Convenor Phillip Medcalf.

The need for the booklet arose from the important advances in new antiviral treatments that have occurred over the past two years. These advances have dramatically changed the AIDS treatment picture.

However it has also become clear that if these treatments are to work properly, it is essential that the treatments are taken correctly and that doses are not missed. In medical circles this issue has become known as "compliance", with other words like adherence and concordance also being used. "The booklet provides information to help people with HIV, in partnership with their doctors, work through the different treatment options available to them, and come up with the best antiviral treatment strategy to fit individual lifestyles," explained Mr Medcalf.

The booklet was produced by the Treatment Working Group of PLWH/A and will be distributed around NSW to people with HIV, doctors, community groups and others involved in providing HIV care.

## Priority to poverty

PLWH/A (NSW) Inc. welcomes the Review of HIV-Related Poverty Report, which was released in late August. The Report was proposed by this organisation in 1996, and commissioned by the NSW Department of Health.

"Quite clearly this review has identified what we have been saying for some time, that HIV related poverty in NSW is a significant problem", said the Convenor of PLWH/A - Phillip Medcalf.

Insufficient food and poor nutrition were seen as two of the major impacts of HIV related poverty, and it was also emphasised that poor health leads to an inability to earn an income.

"The recommendations to address these major concerns have implications for a number of community based organisations and services, as well as a number of government agencies, and we will be looking forward to working with such groups to ensure that action begins quickly and effectively", Medcalf stated. He warned, "This report is a valuable tool in addressing HIV-related poverty in NSW and PLWH/A does not want to see it collecting dust on a shelf. This report cannot be ignored, nor the plight of those most affected by these findings."

The report sets out 23 recommendations and PLWH/A has urged the AIDS and Infectious Diseases (AID) Branch to mark these for action, and institute a meaningful time frame for reviewing the implementation of these recommendations. The Branch has also agreed to convene a representative group to oversee these actions.

## NAPWA AGM

THE NATIONAL ASSOCIATION OF People Living with HIV/AIDS (NAPWA) has announced its Annual General Meeting to be held on Friday September 12 and Saturday September 13 at the Victorian AIDS Council, Claremont St, South Yarra, Melbourne.



Some of the new PLWH/A Treatments Booklet's proud parents, L-R: Phillip Medcalf, PLWH/A Convenor; Jo Watson, PLWH/A Research Officer and Sandra Thompson, DTP Officer. The booklet was launched on August 18, see story opposite page.

PHOTO: MAZZ IMAGES

Further information about agenda items and workshop topics will be distributed closer to the date. For more details please contact Russell Westacott Monday to Wednesday, or Andrew Little Thursday to Friday on (02) 9281 1999.

## ACON travel forum

ACON'S HIV LIVING UNIT HAS been receiving increasing reports of HIV positive Australians being refused entry to many overseas countries. To update HIV positive people about international travel, concerns about entry restrictions and about travelling across borders with treatments, ACON is hosting a forum.

The forum will also provide information about where to go if you need assistance overseas, how to reduce stress and worry caused by travelling with treatments and how to fit them into your changed daily pattern. Information will also be provided about which vaccines are safe, travel insurance, foods which are safe to eat and what to do if you get sick. The forum will be held on September

10, 6:30pm, at ACON, 9 Commonwealth Street, Surry Hills.

## PLWHA on video

SYDNEY BASED INDEPENDENT production company 21A Multimedia has produced what it describes as the world's first two educational videos covering new treatments for people living with HIV/AIDS.

Titled "An Educational Video for People Newly Diagnosed with HIV/AIDS", the videos feature interviews with HIV positive men and women who explain why they have opted for their particular treatments regimen. Funded by a multinational pharmaceutical company, the video informs HIV positive people of the treatment options available to them. The people on the video also speak openly about discrimination they have encountered and the emotional impact of having HIV.

"The availability of new combination therapies is offering new hope for thousands of Australians", said associate producer Malcolm Griffith, "and to see

## Briefs



● Mr Peter Grogan has been elected unopposed as the President of the Australian Federation of AIDS Organisations (AFAO). Peter has acted as President since Bill O'Loughlin resigned from the position in April. AFAO constituent members welcome his appointment. Peter has a proven track record of working fairly and constructively with communities affected by the HIV epidemic.

● PLWH/A (NSW) will host a Time-Out Room for people living with HIV/AIDS at Atlantis, the 1997 Sleaze Ball on October 4. It will be located in the Hordern Pavilion.

● The Sydney PWA Living Centre is open for Saturday lunch from August 30. If you're in the neighbourhood, drop in and say hi! The Centre will be open from 10.00am - 3.00pm. Lunch & drinks served at 12.30pm followed by free Bingo (Housie) at 2.00pm. For safety & security reasons access will be restricted to the dining floor & toilets only. A stair climber is available for anyone with mobility problems, but please call Gary before you come on 9357 3011.

● Corroboree Three, a gathering for gay and lesbian Aboriginal people, their friends and lovers is being hosted by the PRIDE HIV/AIDS Community Development Project at the Imperial Hotel (downstairs) 35 Erskineville Rd, Erskineville on Saturday September 27, 7.00pm till midnight.

● Performance Positive 7, the next in the series of successful performance events staged at the PRIDE Centre, has been postponed till October 24 and 25. Proposals for the event are invited from performers. Contact Paul Canning (9331 1333) or Victoria Spence (9557 4332) with your proposal and details of your past experience. PRIDE is located at 26 Hutchinson St Surry Hills NSW 2010.

● "No Matter What!", a CD of original songs by musician Michael Harris, has been released in NSW. Michael has been HIV+ since 1985 and the songs on the CD deal with his experiences since then. He has been a professional musician since 1988 and earlier this year sold everything he owned to finance production of the CD. Members of Gangajang and the Wendy Matthew's Band perform on the CD, which can be ordered through any music outlet. 10% of the proceeds will go to the Troy Lovegrove Foundation, which works to increase the quality of life for children living with HIV/AIDS in Australia. The album can also be ordered direct from Michael Harris, PO Box 116, Hardy's Bay NSW 2257. The cost of \$24.95 includes postage and handling.

first-hand how people are dealing with the medical choices now available goes a long way towards helping HIV positive people realise that their status doesn't mean an imminent or automatic death sentence."

One half hour video features interviews with HIV positive men and women in Sydney, Melbourne and rural Australia. Also featured are medicos working in the HIV/AIDS field. "It is interesting to see that while many people are choosing to go onto combination therapies, others are opting for a more alternative approach," said Mr Griffith, "and this video allows them to see advantages being made in the treatment of HIV/AIDS. Information overload is a major problem for a lot of people at the time of their diagnosis and the video allows them to access information at their own pace, in their own home."

The second video is forty minutes long and aimed specifically at women.

An initial run of five hundred videos has been distributed Australia-wide to doctors with a high HIV caseload. It is also available through medical centres, AIDS councils and similar organisations. Enquires about the videos should be directed to 21A Multimedia; 9519 3008.

## SMASH study appeal

OUR COMMUNITY IS UNDERGOING dramatic changes at present with regard to both new treatments and possible increases in unsafe sex. In the context of these changes the next two years are vitally important and data from the SMASH (Sydney Men and Sexual Health) study will help us understand what is happening.

Much of our community's response to HIV/AIDS in recent years has relied on the SMASH study. SMASH has shown that there are rapid changes in treatment strategies among positive men but it is unclear how this will affect their health and situation in

the coming months. Also the results of the regular Sydney Periodic Survey from last February indicated an apparent increase in unsafe sex among gay men but the data was not clear on this and no-one is sure whether it is a long-term trend.

What do these apparent changes mean for our community? The findings from follow-up interviews for SMASH over the next few months will be crucial to helping understand these developments in our community. SMASH interviews are an especially important component in the tools available to organisations like the AIDS Councils and the PLWHA organisations, when considering what actions they should take.

There is, however, a major problem of trying to keep in touch with everyone in the study and ensuring that these interviews are conducted with as many men as possible. Few men formally discontinue, but many men are lost through changes in address. The study needs the continued participation of every man. This is an urgent problem now because the number of men who have lost touch with SMASH has become quite large, while the issues our community is dealing with have become more pressing.

An appeal is being made to all former SMASH participants to contact the project. If you or someone you know have ever been interviewed by SMASH and have moved or changed phone number but forgotten to tell us, please contact us now. If you haven't been interviewed for a year or more, now would be the ideal time to call and arrange to do your interview.

If you've dropped out of the study for whatever reason, but would be willing to do another interview at this time, please contact us. If you cannot spare the time, or you have moved out of Sydney, SMASH can make other arrangements for interviews, such as doing it over the telephone.

Contact either Hardy Ernst or Garrett Prestage on (02) 9332 4648

or by email [smash@ncheccr.unsw.edu.au](mailto:smash@ncheccr.unsw.edu.au)

– Garrett Prestage  
SMASH Co-ordinator

## Friends of Waratah news

FRIENDS OF WARATAH INC. HAS A new address and phone number:

PO Box 516  
Sutherland NSW 2232  
ph: 9545 6331

Office hours have changed to: Tuesday, Thursday, Friday 9.00am - 3.00pm.

Friends of Waratah Inc. is a support, social and fundraising group for people with HIV/AIDS and their carers in the Sutherland Shire and St. George District. The group was established and is managed by people with HIV/AIDS and all work done is on a volunteer basis. We receive no Government funding to date.

We are the first and only PLWHA support and social group operating in the southern suburbs. We have embarked on a project to promote our services and those of the Waratah Clinic and the new South Sydney Carers Group to PLWHA. With a grant from the ACON Hand in Hand Disbursement Fund we have purchased a photocopier/printer and scanner which will be used to further communicate our needs to our present and future membership and to the HIV/AIDS community. We wish to thank ACON, the gay and lesbian and HIV/AIDS communities for this money.

During the past two months we have had social dinners, information nights on: new treatments and on the Health Complaints Commission. Each fortnight at the St. George Hospital we have had raffles to raise money for the services we offer. We are now trying to raise funds for a computer as the project will generate more administrative work.

We will be holding workshops on issues such as sexuality, spirituality, support for partners of people living with HIV/AIDS, living with HIV/AIDS in the 90's,



**Bobby Goldsmith House, the long awaited supported accommodation for PLWHA, has opened its doors. Pictured at the launch on August 21: NSW Health Minister Andrew Refshauge with Alison Cunningham, BGF Housing Project Manager. See our story from a new BGF tenant on p.29.**

PHOTO: MAZZ IMAGES

safe sex practices, complacency, compliance/scheduling of medication and preparing to re-enter the workforce.

– Marc Smith, President

## NT euthanasia legislation delayed

JOHN BAILEY, THE DEPUTY leader of the Opposition in the Northern Territory, has introduced a private member's bill which effectively decriminalises euthanasia. Although the proposed legislation would make it illegal to carry out voluntary euthanasia, a doctor who assists a patient to die would only be subject to a \$50 infringement notice, and would not be charged for manslaughter or murder. The bill has been tabled in the Northern Territory Parliament. However on August 12, the Northern Territory Government announced a state election to be held on August 30. Further progress of the bill now depends on the re-election of John Bailey.

## BGF awareness campaign

ON AUGUST 12 THE BOBBY Goldsmith Foundation (BGF) launched a campaign to promote its financial and welfare services for people financially disadvantaged as a direct result of HIV/AIDS. The community based charity provides direct financial assistance, welfare services and supported housing to people in NSW who are financially disadvantaged as result of HIV/AIDS.

BGF is concerned that there may be people who are eligible for BGF assistance but are not aware of its services. This is the first time that the charity has conducted such a public outreach campaign.

In May 1997 BGF reported its busiest month in its 13 year history, helping 337 people and distributing \$33,000 to clients. July 1997 surpassed May with a record \$38,000 going to 346 clients. The campaign will also reiterate to the community in general the role of BGF and determine the untapped demand for BGF services.



● Delavirdine, a non nucleoside reverse transcriptase inhibitor (NNRTI), has been granted marketing approval in Australia.

Over the past year the drug has been available through a Special Access Scheme. Pharmacia & Upjohn has made an application for listing of the drug on the PBS, and in the meantime will provide the drug free to existing and new patients.

● Recruitment has started for the Adult Compassionate Access Program for the new Glaxo Wellcome drug 1592 (a nucleoside analogue, in the same class as AZT). The program has been established in consultation with community representatives from NAPWA, PLWH/A (NSW), and the Treatment Officers Network. There have been intensive negotiations because of the world wide limitations on supply. HIV/AIDS practitioners around Australia have received notification of the start of the program and the limited access criteria. Places will be allocated randomly to people who meet the criteria, and increased places will be phased in until the Expanded Access Program is able to commence in early 1998. For more info consult your doctor or Treatment Officer.

● PLWH/A (NSW) has launched a new treatment booklet that discusses the different options for antiretroviral combination therapy and offers helpful tips for choosing a combination which best suits your lifestyle. The booklets are available - (with male or female covers!) from the usual sites, or call PLWH/A on 9361 6011.

● AFAO has started distributing its new and updated "HIV Tests and Treatments" booklet. Based on the successful ACON resource of the same name, it has a new look, some updated information, and will be available through HIV/AIDS organisations and health facilities. For more information call AFAO on 9281 1999.

● The International Association of Physicians in AIDS Care (IAPAC) is challenging physicians and advocates to be the first human subjects for a vaccine trial in which volunteers will be injected with an attenuated or weakened strain of HIV. Citing a compelling moral mandate to find a preventative AIDS vaccine, leading doctors in the Association have already registered as potential volunteers for the pilot human study.

(*IAPAC Journal, August*)

● Liver damage in people infected with both HIV and Hep C is directly related to the Hep C infection, according to a report from Spain. However, the researchers noted that as people with HIV are now living longer, it will become more important to keep tabs on the effects of HIV on the course of the Hep C infection. (*Hepatitis Weekly*)

If you are experiencing financial hardship because of HIV illness phone the Foundation on 9360 9755 or 1800 651 011.

## Hepatitis C threat

RELEASED THIS AUGUST WAS THE Surveillance Report of HIV/AIDS and Related Disease in Australia. The country's first comprehensive report on HIV/AIDS, sexually transmitted diseases, hepatitis C and contributing behaviour patterns, confirmed that the incidence of AIDS is declining steadily. Diagnosed cases of AIDS have dropped from a peak of 962 in 1994 to 706 in 1996 and are expected to fall steadily to 600 by 2000.

Professor John Kaldor, deputy director of the University of NSW's National Centre in HIV Epidemiology and Clinical Research, which edited the report, said that hepatitis C is going to represent a major cause of illness and mortality in Australia for many years. He also warned that there was evidence that unprotected sex was still high among gay people and heterosexuals.

## NorthAIDS news

MYRTLE PLACE, NORTHAIDS' support and information centre, needs another representative for the Centre Subcommittee. The committee is involved in choosing priorities and contributing to policy decisions made by the Management Committee. Anyone interested can phone Bill or Malcolm on 9929 4288.

Upcoming training and information sessions: a volunteer training day on Saturday September 20; a visit from Paul Maudlin, the Positive Speakers Bureau Co-ordinator on September 12, an information session on Nutrition on Sunday September 14 and a complementary therapies expert on September 26. Myrtle Place is located at 349 Pacific Highway Crows Nest.

## AIDS trust funding

ON AUGUST 8 THE AIDS TRUST, Australia's only national HIV/AIDS charity, released details of 18 projects it will fund this year. Community projects Australia-wide benefited from a total disbursement of \$193,3522.

NSW organisations that received funding included BGF, which received a grant of \$10,000 to assist PLWHA to pay their gas bills. The Quilt Project received \$5,000 to develop educational materials for when it is being displayed without Quilt personnel. ACON received \$20,000 to address the need for stronger advocacy concerning treatment access and availability.

## KM1 Herbal Trial suspended

THE KM1 Herbal Formula Trial has been temporarily suspended.

According to Trial Director, Jan Kneen-McDaid, results from the trial are being entered onto a database for analysis. She is calling for volunteers to help with this task. Anyone interested in helping should phone Jan on 9552 2243.

## STOP PRESS

*Talkabout* needs a driver to deliver *Talkabout* once a month and *Contacts* every three months.

The job takes a whole day and you must have your own vehicle, preferably stationwagon size or bigger.

Would suit someone on a pension and we pay.

If interested call Paul on 9361 6750.

# Talkback



## 1592

I WROTE THE FOLLOWING EMAIL to Glaxo about lack of access to their new drug, 1592. I am not personally affected by their withhold, and I do not have all the details. However, I am increasingly compelled to have a voice and speak out against things that I disagree with.

To [feedback@glaxowellcome.co.uk](mailto:feedback@glaxowellcome.co.uk).

*I have been dealing with AIDS for 11 years, and worked with many friends – many who have, of course, died. But there are some I know who have exhausted the current repertoire of drugs and still experience very nominal level of health. Surely these people deserve compassionate access to 1592. If it is a good one, you will surely reap the financial reward in the long term. Are you so frightened that perhaps this particular drug will only have a short product life before another new drug sweeps it into obsolescence? I encourage a more adult, broad based approach. The race is always on, and the competition stiff, I agree.*

*But I implore you to play fair with the people you have a vested interest in helping: people with HIV/AIDS.*

– **Kim Gotlieb**

Ed: See Treatment Briefs for an update on 1592.

## HIV futures survey

THE RESPONSE TO THE HIV Futures survey, which *Talkabout* subscribers received as a special mail-out, has been extraordinary.

By mid-August, over 670 completed surveys had been returned from around Australia. With the close of the survey we'd like to extend our thanks to the many people who took the time to fill in the survey and return it to us. We believe the results of this research will be an important tool in the advocacy work of the organisations such as PLWH/A (NSW) Inc.

We'd also like to acknowledge the hard work of the team at *Talkabout* and PLWH/A who went the extra mile to make the special mail out happen. The team's work was a vital part of the success of the distribution strategy. Thanks again.

– **Dr Doug Ezzy**  
**PLWHA & Carers Program**  
**National Centre in**  
**HIV Social Research**

## Trial concerns

THE "NOT YOUR AVERAGE Trial" story in *Talkabout* No. 78 contained serious misrepresentations that conflict with the information I received from the trial co-ordinator when the KM1 herbal trial started recruiting. The article stated the trial "doesn't restrict entry to people with a certain number of CD4 cells." This is blatantly untrue. The criteria for entering the study states "You have a CD4 count of 400 cells/ml3 (T4 cells) or less".

The article stated "it (the trial) allows participants to use any other drugs they like." This again is blatantly untrue. The trial criteria I received state: "Participants on an established treatment/no treatment regiment at the start of

the trial shall neither institute new treatment, terminate nor in any way alter their existing treatment status throughout the trial."

The article also said: "The lack of restrictions on trial participants means . . ." This again is untrue. The trial criteria I received state that participants must have been diagnosed with HIV for at least six months and have an AIDS defining illness.

In view of the information I received as an interested party to the trial I believe the story is unbalanced. Further and most troubling, I feel that PLWHA reading the article would be given a misleading view of the trial by the use of the sentences that I have demonstrated above to be inaccurate and I feel that these inaccuracies need to be addressed. I look forward to *Talkabout's* response to these issues.

**Name withheld by request**

*A pre-publication copy of "Not Your Average Trial" was shown to the trial co-ordinator to ensure there were no inaccuracies. After receiving the above letter acting *Talkabout* Editorial Co-ordinator John Cumming asked the trial co-ordinator to comment on it. She agreed that the trial criteria had changed after the trial started and referred *Talkabout* to Dr Don Smith of the Community HIV Research Network, who provided the following response:*

"TO ALLEVIATE SOME OF THE confusion that seems to surround the KM1 herbal trial's criteria: the Community HIV Research Network's role in the study started when Jan Kneen-McDaid approached us to see if we would

undertake a formal evaluation of herbal therapies. We were not in a position to fund such a study but we agreed to advise her on how best to undertake such an evaluation herself. We suggested that it would be best to concentrate on those individuals likely to have symptoms of HIV disease. This was the reason why her group selected the CD4 count restriction of less than 400 and the need to have symptomatic HIV disease. My preference was not to restrict this just to AIDS but to all early symptoms of HIV disease. However Jan's group decided to look at those people with a prior AIDS diagnosis.

I also pointed out that the new antiretrovirals about to become available could significantly confound any herbal treatment effect. Jan's group went away and wrote a protocol and set about commencing the study. We have had only occasional contact since then but to the best of my understanding the trial criteria has not changed.

I believe that the CD4 count criteria remained unchanged and thus one of the concerns raised by the letter to Talkabout is valid. I spoke with Jan Kneen-McDaid on August 18 about this and she confirmed that the medication changing criteria were relaxed but neither the protocol nor the patient information was amended to reflect this.

I believe that the predominant rationale for relaxation of trial criteria was in recognition of the large number of people taking up therapeutic options and allowing these people to enrol in the trial."

## Request

"CONFIDENTIALITY IS BULLSHIT in gaol. Everyone knows you're positive whether you want them to or not. You can tell that they know just by how they look at you and talk (or don't talk) to you."

"You're playing with fire when others inside know you've got HIV. Sometimes you get burned real bad. Others are scared of you.

Education is one thing, believing it is another."

"I remember when my partner was dying, the prison wouldn't let me visit because it was against 'regulations' . . . I'd had my quota of visits that week."

These are but three of the many stories told to me during my years of counselling in the general HIV/AIDS community. Stories that I have heard often enough to concern me about what is happening for HIV positive people in our prisons. Despite sero-status, drug use history or sexual orientation, inmates have the basic right to appropriate, adequate and non-judgemental medical care and to confidentiality. However, what is the experience of the HIV positive prisoner and/or their family?

At present I'm preparing a paper for my Masters degree in the area of criminology. Clients' personal accounts (such as those above) have steered me towards studying HIV/AIDS and NSW prisons.

More specifically, I'm aiming to research the nuts and bolts experiences of HIV positive prisoners - good and bad. My research thus far shows me an extensive library of research about how to prevent the further transmission of HIV within our prisons. I have, however, found little information that describes the experiences and perceptions of HIV positive prisoners.

So . . .

- Are you HIV positive and currently in prison?
- Are you HIV positive and have been in prison while sero-positive?
- Do you know someone who is HIV positive and been in prison while positive? or,
- Are you someone who works within this field?

If so, I would like to hear what you have to say. For, while held in the strictest confidence, the information you possess will be integral to determining the direc-

tion in which this proposed research will travel. So get in touch by writing to me C/O PO Box 350, Darlinghurst NSW 2010.

- Sheelagh Daniels, Counsellor

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



Talkabout, PO Box 831  
Darlinghurst 2010

## Olga's Personals

Guy 35 HIV+ and healthy. Have been carer now my skills are redundant. Current skills are client service, typing, public speaking. Previously worked in administration and catering. I am willing to retrain and am optimistic and enthusiastic. Training wage considered.  
970905

### How to respond to an advertisement:

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

### How to place your advertisement:

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

## Work Wanted

HIV positive man 39 years wishing to return to the workforce part-time. skills include PC support, system design, computer audit, debtors & creditors, data modelling & WP training, customer service & sales. Looking for 25hrs Mon-Fri. Ph 9516 1551 Mark.



*Diana*

*Thank you*

for all you have done for  
people living with HIV/AIDS world-wide.  
You will be sadly missed but not forgotten.



# We are human beings



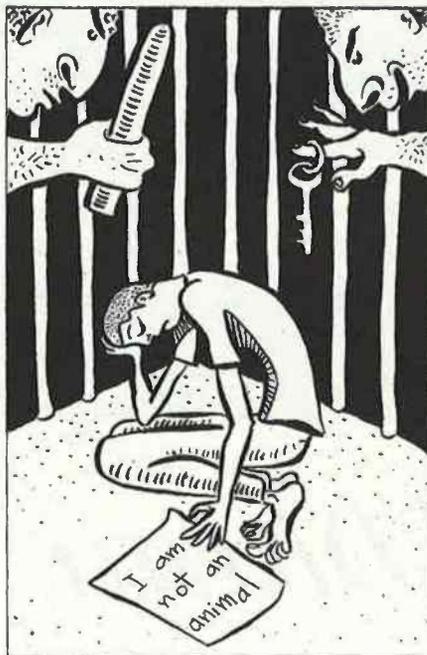
*In 1990 Les entered Fremantle Prison in WA to serve a short sentence. The treatment he received there as a HIV positive prisoner prompted him to make a claim of discrimination to the WA Equal Opportunities Commission. In an outcome that set a legal precedent, the Corrective Services Department settled his case out of court. Les spoke to John Cumming about his experiences.*

I'VE BEEN HIV POSITIVE SINCE August 1985. The prison officials knew I was HIV positive because the Health Department notified them. When I went into prison in 1990, although I was classified as minimum security, because I was HIV positive, I had to remain in the Infectious Diseases Unit (IDU) of the maximum security facility because they didn't have anything else for HIV prisoners.

Most of us in the IDU were physically well at the time but if anything, being in the confinement of the maximum security unit made us unwell. You weren't just classified as HIV – you were classified as deviant and promiscuous. This impression was conveyed by the guards and the medical officers, who should have known about HIV. The head medical officer even said we should be taken out to an island and shot.

Other prisoners can go around by themselves but because we were HIV we were escorted everywhere and only at certain times. It was supposed to be for our own protection. Officers would say to us "you do what you're told – or we strike".

Adjacent to our unit we had contact with the other guys and we got letters of support from other guys saying they didn't mind having us in their block. When we protested at being in maximum security the guards threatened to put us into the section where the child molesters were kept. But we didn't want to be placed with dogs. One guy slashed himself up a bit and they made him clean his own mess up.



GRAPHIC: PHILLIP MCGRATH

## Solitary Confinement

At one stage of my eleven months I spent six months by myself because there were no other HIV positive prisoners. So not only was I confined, but I was in solitary confinement. Most of the time I spent just lying down. I did some stupid things like swallow bleach. The only time I had contact with the staff was at medication time, in the evening. Some guards would walk past and

bang on the windows and say "You're nothing but fucking dogs." There was a medical emergency bell, but that would light up the whole prison. The best part of the day was the end, because that was another day over. We didn't get education officers, supposedly because they couldn't spare one. If there weren't enough staff to look after us sometimes we would be locked in from 3.00pm till 7.30am the next morning.

## Discrimination

At Fremantle we were able to go into the library, but no-one else was allowed to be in the library at the same time. They'd be wiping the books down after we'd used them. Or the books were not to be returned after they'd been in the IDU.

We had to do our own washing. When you were released, your blankets and sheets would be burnt. When there were more than four residents in the IDU, it became barbaric. We had to use Port-a-loos. We weren't given the opportunity to work. I'd make cups of tea for the medical staff – they didn't mind, but if the officers saw me doing it they would go on strike.

To get anything extra off the guys in the kitchen a lot of the guys would try to get blow jobs from us because we were gay, but I never did. I'd rather drink my own urine than have sex with someone for an extra piece of meat.

No-one gave me the idea to approach the Equal Opportunities Commission (EOC). I read a couple of articles. I knew we had rights, like access to the library. And I'd heard stories about how you could further your education.

The Education Officer said to me, "You have rights." I knew there were three people I could

write to: the Human Rights and Equal Opportunities Commissioner, the Premier – Carmen Lawrence at the time – and the Ombudsman.

I wrote to Carmen Lawrence, who referred it to the EOC. Someone from the EOC came out to see me and said, "Yes you do have a case. What they are doing is illegal." It took forever to get a hearing date.

Then I was moved to Casuarina prison, where I got the same treatment, but we were more humiliated. They used to treat us like dogs. We weren't allowed to use the gym. We were offered a job, working with the pedophiles, folding pamphlets. I refused because I didn't want to associate with child molesters.

I thought, they haven't learnt from the first time, so I made an-

other claim to the EOC and went through the whole business again. I said to everyone else, "Just keep on doing it, this is the only way we're going to get things changed. We are human beings, we shouldn't be in a maximum security prison."

While I was waiting for a hearing date I was released and I felt like the police were harassing me even more, so I moved to Sydney to get a new start, I wanted to get on with my life. I had tried to get involved with PLWH/A in WA, to go and educate prisoners and officers but they wouldn't let me sit on the Board because of my criminal record. Services are a lot better in Sydney. By the time I moved to Sydney the Department had made an offer to settle out of court on the first claim – for \$311. That amount was supposed to

cover loss of wages, because they wouldn't let us work. We negotiated until they offered \$4,500, which I accepted. The settlement I got for the second claim was \$3,500.

### Today

This kind of discrimination is still going on in Perth, as far as I know. There's still the phobia – the officers rule the roost. I heard that one guy's parents were visiting him in prison and the parents didn't know he had HIV. The guards were explaining to the parents how they would have to go and bring their son to them from the Infectious Diseases Unit, "because he's got AIDS." They can't be trusted. I've wanted to put it all aside. I still have dreams about these guys in black uniforms with guns, the keys, the banging, the smart remarks. ♦

## LET'S TALK ABOUT SEX

Appointments  
& 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
- \* Multicultural information & interpreter services
- \* Needle syringe exchange
- \* Safe sex information

**SYDNEY SEXUAL HEALTH CENTRE**  
Sydney Hospital, Macquarie St

(near Martin Place Station)

No medicare card required

## New HIV/AIDS treatments & party drugs: do they mix?

**Date:** September 19, 1997  
**Cost:** \$45  
**Venue:** Sydney

Having a big night out but worried about possible interactions between party drugs like ecstasy, speed, heroin or alcohol and anti-HIV therapies?

At this one day forum, key information will be shared by HIV workers, researchers and PLWH/A. We will also explore practical strategies people use to reduce harm associated with possible interactions and the implications these have on HIV progression and wellbeing.

Applications close: **Monday September 15**  
For further information and registration contact:

**Rob Wilkins 9818-0467**

Free for PLWH/A

Centre for Education and Information on  
Drugs and Alcohol



# Keeping the love alive

*Sally's partner, Bill, was imprisoned between 1991 and 1994. She told their story to David Barton, Co-ordinator of the Positive Heterosexuals support group.*

***What were your initial concerns about Bill being HIV positive and being sent to prison?***

Although I was upset I was relieved that he had a place where he was safe. He was off the streets, where he had been for a while. At first I didn't have any real concerns because he had been in prison before and I thought he would be able to look after himself. But when I visited him he had put himself under protection. He feared harassment or assault because he was known throughout the prison as being HIV positive.

After that first visit I became anxious. Because he was under protection he was isolated in a very hot cell in the middle of summer. The conditions sounded very primitive and I worried about his health. Although he had a roof over his head he was despairing.

***What problems did Bill have to overcome on a daily basis living with his HIV and mixing with other prisoners?***

When he was sentenced he was in the main prison population. He said he had to check everybody out because many prisoners didn't know him. He felt suspicious and anxious and frightened that he would be abused. In the prison at that time there was a lot of stigma about HIV. Many of the prison officers had a real attitude about it. They can be very abusive verbally and if they can throw something in about AIDS they will. Bill was seen as worse than a prisoner - he was someone with AIDS, likely to infect them and dangerous. Because a prison officer had been stabbed with a syringe there was always that fear. They had on their belts a little bag with gloves in case there was an assault and blood got spilt. Although they had been ed-

ucated about HIV many were paranoid about transmission. Although he wasn't violent, Bill was seen as infectious and dangerous. He was a sensitive man and it was all very distressing for him.

One time he was transferred to Cessnock Prison and placed under protection, unable to mix with other prisoners. I was told, "His life is in danger because of his HIV". There was no evidence of this and Bill wanted to be in the main prison because he liked to mix with other prisoners. The staff must have breached confidentiality about his status. They didn't want an HIV positive person at Cessnock. "You've got AIDS, what are you doing here," the guards said when he first arrived there.

***"You learn very quickly there are so few things you can do for someone in prison."***

***As a partner who would regularly visit him, how were you viewed by prison staff?***

Initially they treated me as they treated most visitors: with a lot of distance, coldly. When I became more known and saw the same prison officers on a regular basis they would acknowledge who I was by a slight flicker in their eyes. There was never any warmth but a sense that you were looked down on. I felt that to prison officers, prisoners are just crims, low life, and because you are associated with them, you're also low life.

In the visitors' room I could wait half an hour for Bill because he would not have been told I had arrived. It depended on their

mood, which prison officers were on, and if they felt like being difficult. When I first started visiting there were toilets in the visitors' room. A visit might last two hours, but one day those toilets were closed for security reasons, which made absolutely no sense. So if you wanted to go to the toilet you had to leave your visitor but you weren't allowed back in.

One winter's day he was transferred to Cessnock. There was no heating in the prison van and Bill was in his pyjamas with no way of keeping warm. Because of other stops on the way the journey took four hours. When I arrived he had been placed under protection, still not wearing enough clothes, on a freezing cold day. He was traumatised and only through a great effort on my part he was returned back to Long Bay in Sydney.

***When he got sick Bill was moved from prison to hospital facilities. How was this different for him and you?***

In the main prison Bill was one of the main population. In the hospital it was a different mix of people. There were psychiatric prisoners and a different feeling, a lot more fear, in the visitors' room. Then when he was moved because he was too ill to remain in the prison hospital, he was under guard at Prince Henry Hospital.

There are two situations for prisoners at Prince Henry. There is the hospital annexe, which is a locked ward with prison officers there all the time, or they can be in a bed with two officers guarding them on special shifts day and night.

I always found these conditions much, much more difficult. The prison officers would be sitting outside his room and some of

them would come in and tell me not to sit on his bed and not to touch him.

He had escaped from custody once on a ward and he was put back into the annexe. Then the officers had it in for him because they were seen to be not doing their job. They would only let me have short visits, say 20 minutes. I felt they were endlessly trying to punish me because I was in a relationship with this person who had to be punished.

*How did you manage to keep yourself well and keep the love between you alive while he remained in prison?*

Keeping the love alive wasn't difficult because Bill was protected from his own chaotic behaviour. He could reflect upon what he wanted from life, wishing he hadn't got himself in prison and that he was with me. I also knew I would be seeing him on a regular basis. When he was living chaotically I didn't know from one day to the next where he would be. At this level keeping the love alive was okay but at another level I would feel abandoned and he would feel guilty for this.

I found the visits tremendously draining. The morning of the visit I would be on adrenaline wondering what it would be like, whether I would be kept waiting, whether they would let me in, whether he would be transferred to another gaol, as they would do those things without telling you. Emotionally it was just terrible.

I felt helpless. You learn very quickly there are so few things you can do for someone in prison. You can put money in their account, give them books and magazines and a few clothes. That's about all. I knew the circumstances in there were bad for his health and that he was sick as well as deprived.

Towards the end of his stay in prison he wasn't being looked after properly. For example he had a very bad sore on his face which got worse and worse. He was in the prison hospital and I asked him several times if he had seen

the doctor. The sore was obviously eating away the side of his nose. Finally two months later he got a visit from the doctor at Prince Henry and it was diagnosed as herpes. They treated it immediately and within a week it was fixed. He had really been in a lot of pain, I thought that was just disgusting. Such a simple thing to treat. If they could do that I wondered what else was happening to him.

Prison hygiene was not great, the food wasn't much, and he clearly wasn't getting the correct medication a lot of the time. I felt powerless, helpless and very de-



spairing about what would happen to him there. As he got sicker he had less ability to survive. He didn't have the physical strength to protect himself. They could put one over him and treat him badly – that worried me.

*Looking back now, after Bill's death, what stands out for you as the positive part of this prison experience and what were the hardest things to bear?*

I had never been exposed before to somebody in prison. It gave me a fantastic education about how prison is misrepresented in the media. Prisoners are really out of

sight and out of mind, a group of people pushed outside society.

It's a terrible experience to watch families coming for visits. Elderly people would arrive saying they had come from the country to find their son had been transferred to another gaol miles away, but they hadn't been informed.

Being in that culture, in that environment, you felt an outsider, wrong and abandoned. I would try to protect myself by imagining I was surrounded with white light and nobody could touch me. But as soon as I got to the prison gates I started despairing. I could feel the cruelty and violence, it was very black and overwhelming and I would try not to take this on board. Yet, when I left the prison these feelings were still with me for the next 24 hours. Even if I went to the movies, whatever I did, only time made a difference.

I struggled a lot with the authorities to get him better treatment. Once I complained to the Ombudsman but after that felt I was known for doing this. I felt quite scared about what they could do to me and how I could be harassed, for example by a strip search. That really scared me as that would have been a terrible physical assault, what with body cavity searches as well. That never happened though, because I suspect they knew I would complain. However, they do have the right to do this to anyone.

At Long Bay there was an atmosphere of male violence, authority and power. That was the worst part for me.

Whenever I went to visit Bill there would be kids bawling, parents shouting at their kids, elderly people looking utterly miserable standing in the cold, being kept waiting, being told roughly by the prison officers, "Come here, do this, do that". No joy, no laughter, no fun there. It's all terrible. That's all there is. ♦





# The Lifestyles Unit: Minimum attitude

*For prison inmates diagnosed with HIV or hepatitis C, the Lifestyles Unit at Long Bay Prison provides a stress free area for access to information about health, treatments, and lifestyle changes, says Gino Vumbaca, Manager, HIV & Health Promotion Unit with the Department of Corrective Services. John Cumming interviewed Gino for Talkabout.*

"AT ONE STAGE THE ATTITUDE OF the previous State Government was to keep positive prisoners locked away, Cuban-style, to stop infection. Our view now is if you treat people as people, they're more likely to accept their responsibility as part of society."

It was refreshing to hear Gino speak so frankly about the changing situation for HIV positive prisoners in NSW. The opening of the Lifestyles Unit at Long Bay Prison in 1992 meant a vast improvement from the draconian treatment they'd received in the past.

For the first four years of its operation the Unit was used exclusively by HIV positive inmates. Currently however, the inmates of the Unit are almost all Hepatitis C positive. "HIV is still a priority", says Gino, "but the problem we're having with the Unit is using scarce resources effectively. There is an obvious need for Hep C, given the large numbers, and the declining numbers of HIV positive prisoners".

The Unit accommodates eight residents in four shared rooms. Each room has a shower, heater and fan. All residents are responsible for their own laundry and the cleaning of the Unit and they pre-

pare and cook meals in the fully equipped kitchen. Entry into the program is voluntary, with each program running for twelve weeks and a total of four intakes per year.

Gino describes the overall prison population as very transient. "The average sentence is only nine months, so people are coming in and out of the Unit all the time. We deal more with injecting drug users, who are the hidden group of the positive population. They don't tap into a lot of the services available. When we get them, we give them a lot of information and advice."

Word seems to have gotten around that the Unit is producing good results. "They're always a bit wary when they arrive, they're not sure if they're just putting their hand up to be segregated for the rest of their sentence," says Gino. "Once they've been to the Unit they don't want to go. We have a waiting list, we don't have to pressure people to go into the Unit. Some of the guys have been back in two or three times - we have more trouble explaining that they have to leave."

The emphasis on nutrition is one reason why there is a waiting list. Being able to prepare their own food, and having access to herbs, garlic and spices gives inmates a welcome change from normal prison food. "Nutrition is quite a big part of the program," says Gino. "The one thing guys who've been through the Unit always miss is the cooking."

## **Confidentiality**

The usual principles of confidentiality do not apply in prison. "That's because there are laws regarding the sharing of cells," says Gino. "When prisoners are being transferred to another prison, the Governor of the new prison needs

to be made aware of a person's HIV status. Prisoners may get locked up for 12 hours a day. Given that we know that there are sexual predators within the prison system, and for a whole range of other reasons, including liability, people who share the cell need to be aware of the person's status, or they (the HIV positive inmate) need to be housed alone."

Although prison staff receive training about HIV, the prison environment amplifies some of the stigma attached to HIV. "With other prisoners and staff there's probably more fear associated with the Unit when the group is HIV positive. Because they're HIV positive prisoners, people look at them and think, boy, they have nothing to lose. There's a fear that they will react in a dangerous way."

## **Access to therapies**

Positive prisoners, Gino says, have access to every therapeutic drug that is approved. Access to drug trials is not so easy. The KM1 herbal trial was not approved by the Department of Corrective Services Ethics Committee, a decision that caused some controversy.

"We're very wary of trialling anything. We weren't rejecting herbal treatments, in fact we are quite supportive of them. But prisoners are a captive audience. They have very few rights. You can talk them into anything. People in that environment are in a vulnerable state and you have to be careful what access you give to people wanting to trial things."

## **Positive women**

The Unit provides information about HIV and Hep C one day a week to the women's prison at Mulawa. Women only represent about 4% of the prison population

and HIV positive female prisoners are rare. Gino theorises that this is because of lower numbers of positive women in the community and the fact that many positive women have children. "It may be that the magistrate takes this into account when passing sentence on HIV positive mothers. Obviously the family is going through a hard enough time as it is without the mother being incarcerated. We've spent long periods without having any HIV positive women. Unfortunately 80% of the women (in prison) are testing Hep C positive, much higher than the men."

### Follow up

During their twelve week stay, inmates become familiar with service providers like ACON and the Kirketon Road Centre, which means they are more likely to access those services when they are released. The situation is different for inmates serving longer terms, or life terms. "They've argued that they should be able to spend their

sentence in the Unit", says Gino, "but if we keep them there the whole time, that stops other people from using it."

Although some inmates keep in touch with the Unit after their release, the Unit has not monitored the progress of inmates who have been released, largely out of respect for their privacy. Gino has plans to maintain contact with them after their release. "We're interested to find out how well prepared they were for getting out. We're also keen to talk to the ones who come back. Unfortunately, after a period in the community some of them re-offend and end up back in prison. We want to talk to them about factors that might have led to them re-offending: lack of housing, lack of support, whatever it may be."

How does Gino see the Lifestyles Unit benefiting the wider community? "It's about the responsibility that we engender in people, the knowledge that they don't have to be fearful of having

HIV. Unfortunately we still get some people who haven't dealt with their HIV infection until they come into prison. If you're using [recreational drugs] on a regular basis, you can avoid having to deal with having HIV. Some people think they have only nine months left - the Grim Reaper thing. People who think like that tend to make erratic and dangerous decisions because they believe there's not much of their life left. That's why it's important to get people from agencies like ACON to talk about their experiences, to hear it from people who have been living with the virus for 13 years.

It's a benefit to the community to have people leaving the prison believing they have a future. Some of them are not aware of the developments, that there's more than just AZT now. That's why we put a lot of energy into people who are leaving. In terms of the treatment available, it can only get better. It makes a huge difference." ♦

**SYDNEY GAY & LESBIAN MARDI GRAS presents**



# Atlantis

**SLEAZE BALL 97**  
**A GAY & LESBIAN COSTUME PARTY**  
**SYDNEY SHOWGROUND**  
**SATURDAY 4 OCTOBER**



**Plunge to the murky depths of your desires in Atlantis.**

With five venues filled with creatures of the deep, fabulous shows and amazing lighting, this year's Sleaze Ball is set to be most sensational ever.

As ever, there will be full medical support and time out space for people with HIV or AIDS. For details contact ACON or the ACON dispensary at the Party.

Tickets are available now for members and their guests at \$70 (\$35 concession) from Sydney Gay & Lesbian Mardi Gras, 21-23 Erskineville Road, Erskineville, The Toolshed 81 Oxford St, Darlinghurst, The Toolshed 196 King Street, Newtown.

For information on membership contact Sydney Gay & Lesbian Mardi Gras on (02) 9557 4332, fax (02) 9516 446, email: [members@mardigras.com.au](mailto:members@mardigras.com.au)

### **COSTUME PAGEANT**

For the first time there will be a Costume Pageant at Sleaze with **\$1000** prize in each category: best male\*, best female\*, best group (\*or identified as such). Report at 12.00 midnight to SS Titanic, the Chill Out Space to strut your stuff.



# Letters from prison



*In Australia very few HIV positive people are likely to be in the prison system at any one time. In the United States, the situation is dramatically different. In 1995, there were 24,226 HIV positive prisoners in the US. Newsline, the monthly magazine of the People With AIDS Coalition of New York, has a regular section devoted to letters and articles from prisoners. This month, we reprint two of these letters which give some insight into the American system.*

## After the tears and fears

I FOUND OUT I WAS POSITIVE IN 1994 while in prison. My T-cell count was low which lead me to believe that this disease has been inside me for a while. Now after the tears and fears, I notified my lover and my mother. After doing that, I decided not to let this destroy me. I am determined to fight this. I have decided not to get stressed out or worried. I also decided not to take any AIDS medications until my inner self tells me different. The only medication I am taking is Bactrim.

Due to the fact that I am in prison, I am trying my hardest to watch my own health. I am 22 years old and I do not trust any of the doctors here! It bothers me that these doctors are so old and lack experience with this disease. Every time I go see these doctors they tell me that I need to take AZT or the new protease inhibitors, instead of talking to me about my condition and explaining what I want to know. I constantly tell them no. This past October I gave blood for a viral load test and it has been more that four months and I have not received the results.

I have to deal with a very racist correctional system that continues to oppress the prisoners. I have to deal with a very uneducated young prison population that continues to put down prisoners with HIV/AIDS. I have to sit in prison wondering if I'll live long enough to see my family and the one I love. I can't help but shed tears. I feel I am too young to die.

Now, I am stronger than ever! I don't let anyone put me down. I keep my head held high all the time and take care of myself. I look after my own health, every six months I get copies of my medical file and study them. I get as much up to date information from outside organisations that I can. When I feel the stress beginning to erupt I do what I love to do, sing. I keep a smile on my face, and I have learned not to worry. I set goals for myself and I pray to my higher power. I strongly believe that I am blessed. I don't think about AIDS most of the time, I think about my health. I think about what's good and what's not good for my body.

I have learned to deal with this disease by the following:

1. Don't be afraid to ask doctor questions and don't be so quick to expect their advice.
2. Ask for copies of your medical files and study them.
3. Write to the many AIDS organisations that exist for information, they will help you.
4. Have faith in yourself and have faith in your belief.
5. Never allow stress or anything to bring you down. Love yourself!

I am writing this in dedication to all my brothers and sisters who are infected with HIV/AIDS. To all the brothers and sister who have departed from this earth and to all the brothers and sisters who are incarcerated.

Your Brother in the Fight!

- anonymous, Great Meadow Correctional, April 1997

## To my sisters

I AM A 25 YEAR OLD WOMAN/mother/educator/counsellor and convicted criminal. When I entered the Department of Correctional Services (DOCS) as an inmate in June of 1988, I knew exactly nothing about the virus and how it would affect me. Since my incarceration I have seen approximately 100-150 women die when they didn't have to. Most of them I would call my friends.

In Bedford Hills Correctional Facility we have a program called ACE which stands for AIDS Counselling and Education. It's a peer program run by the women for the women. I am a member of ACE, I will always consider the women there my sisters. I am a peer counsellor/educator and advocate for the women concerning medical problems. The infirmary was my second home, and burnout is no stranger to me.

I was transferred to Albion Correctional Facility in April of 1993. I fought it as I didn't consider my work to be done there. However, as anyone in the system can testify, you can't choose where you want to be. When I arrived, I managed to get a job at AIDS Resource, which is a program run by the women inmates. It is the only way I can do my life's work.

I soon realised that there is a true epidemic here. We have a population of approximately 1,400 women; of that number 60 - 70% are HIV positive. At first I couldn't believe it. In Bedford there are two full time infectious disease specialists for about 650 women.

There are none in Albion. Women who are HIV positive have to go to the outside hospital for treatment, sometimes after a long wait. I have written to people who could change this and no-one seems to care.

It is sometimes very difficult speaking to the women because with all the information out there many still do not consider themselves to be at risk. I have counselled women who have gone home negative and re-entered the system 12 months later and tested positive. It breaks my heart to see them, knowing that it didn't have to happen. I have dedicated the rest of my life to this work.

I know and consider myself to be lucky because it could have been me. I was an unpaid prostitute; if someone was to dare me to have sex with them I would. I never used protection of any kind and didn't think I needed to. I came from an upper middle class family. I lived in a small rural community and I slept with whomever I wanted to. I figured I was safe. I knew absolutely nothing about IV drug use, crack, cocaine, VD, or anything else. Of the men that I've kept in contact with, ten are HIV positive. I can only imagine how their loved ones must treat them. I know the stigma in my town is very high. We have no programs at all. The closest one is 30 -40 miles away at best.

I plan on doing my best not only to prevent anyone else from getting it but also to help those who are infected. I fight stigma every day and it comes in many forms. I have seen medical personnel refuse to assist a PWA; why, they can never seem to tell me. I have asked for help in teaching various medical issues and so far, little or no help has been given.

Albion Correctional Facility is in typical rural America. The counsellors, civilians and officers all need education. There have been breaks in confidentiality and the women are afraid to say anything about it. The majority of the officers who work here are related to each other, so if a woman has a

"Prisoners are dying of AIDS at a much faster rate than non-prisoners, and it is primarily due to the lack of proper medical and holistic treatments. . . .

Here, in New York, to live with HIV/AIDS in prison is to live with an unlegislated death penalty assigned to you. . . .

Prisoners are systematically deprived of the proper medical care, primarily because the Department of Correctional Services feels it doesn't have to answer to anyone. . . .

. . . it is evident that prisoners are not viewed as humans, since the departments established to enforce humane care do not have jurisdiction over them. The State Department of Health and its AIDS Institute have their hands tied when it comes to ensuring that prisoners receive proper medical . . .

We don't have to look to South Africa, Bosnia, Palestine or elsewhere to be moved to do something about blatant human rights violations when they are strongly banging on our front doors"

- Yusuf A. Shakoor, PWAC NY Newslines, May 1996



problem with one she'll have a problem with the whole family. If I see a woman in crisis and hug her I can be accused of a sexual act. I continue to do so and will accept the consequences if caught. It is sometimes all you can offer — simple comfort and a caring person to listen.

It has been a matter of working the system to my advantage and others'. Every facility is different and no two officers are the same. As a certified pre- and post-test counsellor, I am hurt by the fact that I am prohibited by DOCS rules and regulations from doing that work. I am working on challenging it, but I will, more than likely, be paroled before any decision is made.

I also fight for the women who will follow in my footsteps. There is an old timers' saying which states it very clearly, "Each one, teach one." However, the women coming in now, do not know it or follow it. I have found some of the world's most beautiful women in prison, and I am glad that I have found myself at last.

I see whole generations of women dying and often children with them. Society sees them as dispensable. Until we can change society's feelings, we will never be able to conquer this disease. It is up to us as women to pull ourselves up and get to work. If we

don't help ourselves no one else will.

The Parole Department is also notorious for placing women in drug infested shelters which are doubly dangerous for those with HIV/AIDS, as many of the women are recovering addicts. The shelters are also a perfect habitat for TB - which is very dangerous and deadly when combined with HIV. Ample time and better resources should be made available to the women.

I can only end by saying that it will take all of us to beat this epidemic that is going to destroy our world if we don't stop it now.

This is dedicated to those who are gone but not forgotten. To my beloved Diana Di Gomez, aka Savage, who passed away on November 10, 1992. In addition, to all of the women who are positive or who have cared for someone with the virus.

Keep on fighting, I will.

**Pride and Power,  
Pamela J. Chase, 1994**

**Postscript:** Pamela did get to work as a counsellor after being transferred to another prison. She was due for release in April this year.

*These letters reprinted with permission from PWAC NY Newslines, May 1996 & April 1997.*

# HIV and prisons:



GRAPHIC: PHILLIP McGRATH

*George Selvanera is a member of the NSW Community Working Group on Prisons and Blood Borne Communicable Diseases. At the third Global AIDS Impact Conference in June 1997 the group presented the 2nd edition of "Prisons and Blood Borne Communicable Diseases: The Community View". The paper, which the basis for this article, provides an update on the progress made since June 1995, when "The Community Policy", written by the same group, had made recommendations regarding the conditions for HIV positive prisoners in NSW and strategies to minimise the transmission of HIV within prisons. "The Community View has been adopted by a number of organisations, including ACON, NUAA, Hepatitis C Council of NSW, the Gender Centre, Prisoners' Action Group, Justice Action and CRC Justice Support.*

HIV rates in NSW prisons have been estimated at 0.25% to 0.8% of the population through the 1990s (up to 40 times higher than that of the general community). Among male prisoners in NSW in 1994, 37% tested positive for Hepatitis C (HCV) and 31% tested positive to Hepatitis B (HBV).

The fact that prisoners do not have the same access to safe sex and injecting equipment as the rest of the community, and the way in which prisoners with HIV and other communicable diseases are treated, have increased recognition that "prisons may be far more significant in terms of public health measures to control HIV and other infectious diseases than previously acknowledged."

"The Community View" emphasises that prisoners' are incarcerated *as* punishment, not *for* punishment, and that vigilance in preventing transmission of infectious diseases should dictate public policy.

With a November 1996 study confirming that of 14 HIV positive ex-prisoners, seven had seroconverted in NSW prisons, the need to deal with prisons as a source of infection for the wider community cannot be underestimated. At the same time the

needs of positive people must be respected.

## **IDU transmission**

Injecting drug users (IDU) are over represented in Australian prisons. 50% of Australian male IDU have been to prison. Researchers have found that, on average, 42% of IDU have injected while in prison, with 81% having shared injecting equipment.

"The Community Policy" *Recommendations*: include free and confidential access to new injecting equipment and methadone maintenance for people with a history of heroin injecting.

*In 1997*: there are no plans to make needle and syringe exchange available in NSW prisons, despite the evidence of prevalent and unsafe injecting drug use; and the NSW Government has 500 places available in the NSW prison methadone program to cater for a static population of 6,500 (of whom, at least 3,000 have a history of IDU). This is better than other states and territories, but the Government needs to go further. The Department of Corrective Services is to be commended on introducing bleach dispensing machines in most prisons, with all

# a community policy

prisons expected to be supplied during 1997.

## Sexual transmission

*Recommendation:* all prisoners should have free and confidential access to dental dams, condoms, latex gloves and water based lubricants, as recommended by the 1st National HIV/AIDS Strategy.

1997: Following the success of a condom distribution trial in three NSW prisons during 1996, the Minister for Corrective Services, Bob Debus, announced that the program would be expanded to all prisons during 1997 and that dams would be available to women prisoners. This is ahead of all other States and Territories.

However, to date, women remain unable to access dams and the condoms are still only available in three prisons.

## Testing

*Recommendation:* Voluntary and confidential testing for HIV, HBV and HCV must be put in place offering prisoners testing on entry, during their stay and soon before discharge, in accordance with NHMRC protocols concerning ethics, counselling and confidentiality.

1997: Serious breaches of confidentiality continue to occur in NSW prisons, despite legislative and regulatory provisions regarding confidentiality.

## Positive rights

*Recommendation:* HIV positive prisoners must be accorded the same rights as any other prisoner and care, treatment and support of positive prisoners must be of the same standard as exists for people outside prison.

1997: The Department is to be commended on establishing the Lifestyles Unit at Long Bay Gaol. The Lifestyles Unit provides a residential program and has recently taken on a HCV focus. [See pp. 16

- 17 for more info on the Lifestyles Unit].

The Department is establishing a specialised therapeutic program for women at Mulawa prison, within which an educational module about HIV, HCV and HBV will be incorporated.

The Lifestyles Unit needs to be expanded and prisoners fortunate enough to access the Lifestyles Unit also need to have continued free access to the therapies and treatments at other prisons after leaving the residential program.

## Women prisoners

In 1993 women comprised 5.3% of the NSW prison population. However, evidence suggests a far greater prevalence of communicable diseases in women's prisons than in male prisons. Victorian research found 67% of women tested positive to HCV, compared to 39% of the men.

*Recommendation:* women are entitled to the same level of education, prevention and care as male prisoners. Program development should address women's particular needs and those of their families.

1997: the Department has established a program at Mulawa prison, although it is not as intensive as that available to male prisoners. Further, information and treatment availability for women prisoners must occur at prisons of all classification levels and not only those participating in the Mulawa therapeutic program.

## Education

The department is supported by the parties to "The Community Policy" for widening the scope of education programs and services and the renaming of the Prison AIDS Project as the HIV and Health Promotions Unit.

"The Community View recommends that educational strategies need to be further widened and include as a matter of urgency,

modules related to breaches of confidentiality and discrimination towards positive prisoners, among other issues.

"The Community View" recommends that regular refresher training on communicable diseases issues should be offered to all prison staff, to prevent relapses in attitude. Research shows that newly graduated prison officers are influenced by older, more experienced officers when they go into prisons on active duty, where they become less tolerant than they were during training or immediately after graduation.

## Overall

The Department and the Corrections Health Service have undertaken initiatives that are beneficial, particularly in providing condoms, bleach and methadone, the residential program for some positive male prisoners and formal and peer education programs for prisoners and staff.

"The Community View" acknowledges that implementation of other harm minimisation programs is controversial, and will require foresight and tolerance among all parties. The particular needs of women and transgender prisoners must not be overlooked. The Department has prevaricated on respecting transgender rights issues.

NSW leads the way in prison policies about communicable diseases within Australia. NSW should confirm this role by implementing all the recommendations of "The Community Policy" and in so doing, not be the best of a bad bunch but the world leader in prevention strategies and respect for the rights of positive prisoners.

<sup>1</sup>Dolan K., Wodak A., Hall W., Gaughwin M and Rae F. (1996) "HIV Risk Behaviour of IDUs Before, During and After Imprisonment in New South Wales" Addiction research 1996, Vol.4 No 22

# I live with AIDS, so what?

*Born in Poland during the second World War, Peter lost his parents to the Nazi death camps. Smuggled out to New Zealand and adopted by wealthy parents, he ran away from home at age 15. He spoke to John Cumming about where his life has taken him since then.*

AT 18 I GOT ARRESTED FOR HAVING sex with another man, and they sentenced me to six months of aversion therapy. Every week I was forced to watch porn with electrodes attached to my genitals. Whenever I got aroused by male erotica, I would get an electric shock. It didn't make me straight but it might have given me a taste for S & M!

## **An international career**

I wanted to be an opera singer and to do that I had to leave. In New Zealand people could live very comfortable lives with very little effort, providing they didn't want to do anything individual. They were a whole race of white, Anglo-Saxon bankers, accountants, lawyers, doctors, all those middle class occupations. In my 20s I left for Australia.

Here, my career developed to the stage where I was working internationally and earning reasonably good money, but I was in a rut and not going anywhere. My talent would not have taken me much further and I would never have done anything else. In 1984 I was at a beat and I wanted sex and I thought, I should have a condom: fuck it I haven't got one – doesn't matter. And I made that choice. Whether that's the time I

contracted HIV or not I don't know. I made my choices and I've had to live with them all my life. It's not my fault I got AIDS, but it is my choice to have taken the risk that put me in that situation. OK, I lost the gamble and I have to live with the consequences, but I'm not going to die from them.



*“I've got to the point where I quite value life.”*

## **12 weeks to live**

Five years ago I had meningitis fairly badly and that was the first time they told me I was going to die. They put me on AZT, a fairly high dose. I was going into hospital every two or three weeks and having day-long blood transfusions. After a few months I said to the doctor, I'd rather be dead, forget it I'm not taking AZT

anymore. He then put me on ddI and ddC and within 14 weeks I started developing peripheral neuropathy so I just told them I wasn't taking anything.

Then I did a whole pile of Chinese herbs for months and months. They smelt revolting, they tasted appalling and they were very expensive and you had to boil them up. But they made me feel quite good. Until I had the stroke.

Leading up to the stroke, all kinds of things were happening to me that I couldn't explain and nobody else could either. I've been an opera singer all my life and I was starting to forget words in the middle of an aria and suddenly one day I couldn't sing. I'd get all these headaches which seemed to be nothing to do with HIV and no-one knew what the hell it was. Then I had the stroke and they knew what it was.

They diagnosed it as PML – progressive multifocal leukoencephalopathy – a brain disease that attacks the outer casing of the brain. At the time there was no treatment, there was no cure and they told me I had 12 weeks.\* That was a bit of a shock but I had been told I was going to die once before so I was able to handle it.

Ten days or so after I got the diagnosis, the triple combination therapy came out. I was asked if I wanted to go on it and I thought – well, I've got nothing much to lose. I didn't think about the side effects at the time because I was looking at 12 weeks to live. I just thought “oh well, I can afford to be a guinea pig”. So I went on Saquinavir, AZT and 3TC. Immediately my viral load dropped below detectable, my T-cell count

went way up and I certainly survived the 12 weeks.

Now we don't know whether I've gone into 'spontaneous remission' from the PML or whether it was the combination therapies that put me into remission. But once things started getting a bit better I did start thinking about the long term effects of this unbelievable toxicity I was pouring into myself, and that's when I started doing massive counterbalancing. It may not be having any effect at all but I certainly feel better. I take masses of vitamins and anti-oxidants. I also make a juice of beetroot, celery and carrot every day.

### Handling treatments

Recently my viral load went up a bit so I'm changing the combination therapy to Nevirapine, Indinavir and d4T. My doctor thinks I might have built up resistance to the old one, because I've been on it for over a year. I'll have to take the new combination at 7.30 in the morning, 3.30 in the afternoon and 11.30 at night. The major problem is going to be the afternoon one, because I'll probably get too busy and forget. It'll be 4.30 when I'll think, Oh fuck! But I guess I'll handle it.

I've always led a fairly busy lifestyle and I got really bored with not being able to sing anymore and so I started a business putting on opera in the pub. That keeps me busy and involved in the field that I've always been involved in.

Sure, I'll have days I feel like shit. For a while I used to give in to those, but after a while I decided that you very easily get into a habit of having a bad day every day, and never getting out of bed and never doing anything. So if I wake up feeling bad, I might stay in bed till 10:30, but then I get up and I make myself do things. I can't sit around and do nothing.

I've been through a helluva lot in my life, emotionally, and I've got to the point where I quite value life. I'm not afraid to die, but

I'm certainly not expecting it in the comparative future. I know that PML will never go away and unless they come up with a cure, HIV won't go away, but I don't really expect to die in the next year or two. I expect to be around for another 20 odd years or more. I don't smoke, I don't do drugs, but that is a personal choice I've worked through after so many near death experiences. As a singer I've always been taught that my body is my instrument and has to be looked after.

In 1993 I wrote a song cycle called "The Odyssey" for the Mardi Gras and I performed it at the Lizard Lounge. I put down a lot of my thoughts about my journey, from the day I went for the test till about a year after I'd had meningitis. The last song of the cycle is called "So What". The words went along the lines of, "I'm alive, I live with AIDS, so what?". That's basically been my philosophy: I've got PML, so what, I have to live with it. Ninety per cent of my experience of HIV has been really positive. I've met some superb people, I've had a really good look at my life and have been able to work out what's really important and to let go of what's not important. If I hadn't contracted HIV I would never have done that.

### Facing the facts

I can't help thinking why young guys are being infected with HIV. They must have read the literature, they must have seen the campaigns. Why are they going out and fucking without condoms with total strangers? Young people have to face facts and make some lifestyle decisions. Unfortunately they have to listen to older people, which they don't like doing. Because we've been there and done that.

I think the only thing younger people can do is ask older people and not sit there and try to work it out all by themselves because that's impossible. At 18 or 20 you can't know all the answers. I don't

know all the answers even now, but I've worked out a few and that seems to be working for me.

Life is too beautiful to do nothing. If you are on the therapy and it is working for you then surely you can go out and do something. It doesn't matter what it is. People look at me and say how do you do it? But if I said to them, look, you go out every night of the week, you take speed and party, they think I'm being judgmental, so I don't say those things. I've done most of it on my own, simply because I've had to.

I know a lot of young HIV people who are not about to die. Even if you're only 18 and you haven't got life experience to fall back on, you can at least make yourself learn something or develop some talent where you could do something. I'm not saying give up the pension and go back to a 9 to 5 job, but be motivated to do something and motivate yourself to enjoy your life more.

I'm going to Europe soon which is much more important to me than having HIV or PML. I've got concerts to do when I get back in October. I'm planning to do a Shakespeare festival in Mittagong next year. They're more important things to me than having a couple of diseases. We are planning on doing up the house this year, going to Adelaide and seeing the Ring Cycle and the year after that we're planning to go to Canada, and then we want to go back and see the rest of New Zealand because we've only seen the top half, and the next year we want to go to France. As far as I'm concerned all those plans will come to pass.

\* PML is caused by a viral infection of the nerve cells in the brain and spinal cord. Symptoms vary according to where the damage occurs in the central nervous system. They can include loss of co-ordination, clumsiness, weakness of muscles, aphasia (speech disorder) and visual field defects.



# Sharing *and* problem solving

*Living Well with HIV/AIDS*, by Allen L. Gifford, Kate Lorig, Diana Laurent and Virginia Gonzalez I, \$32.95, Bull Publishing Company.

KATE LORIG, ASSOCIATE PROFESSOR at Stanford University School of Medicine in the USA is one of four co-authors of "Living Well with HIV & AIDS" a book aiming to enable people with HIV to self-manage their illness.

In June this year, Kate Lorig addressed a seminar at the University of New South Wales' Faculty of Medicine on Behaviour Change and Compliance.

She has been researching and designing Self Management and Self Efficacy approaches to chronic illnesses such as arthritis and diabetes. Ms Lorig told the seminar that 80% of all care needed by elderly patients with chronic arthritis is actually provided by themselves. Her aim is to increase the level of self-care to 85%. This leads to a better quality of life for participants and substantial cost savings for healthcare providers.

Kate Lorig's approach to chronic illness encourages a patient and doctor partnership, leading to better problem solving, better decision making, and increased patient confidence. Her self management programs teach communication skills, nutrition,

depression management, and these skills are reinforced at each session.

Chronic disease self-management is based on sharing and problem solving, with a buddy system in order that people help themselves and each other. Kate Lorig has found that participants in her programs,



when followed over a four year period had significantly better outcomes than those who did not participate. Participants' doctor visits were reduced by almost half, pain and discomfort were significantly reduced, and quality of life was improved. By gathering information from physicians, other health professionals, family and friends, participants made better decisions about their health.

As HIV positive people, we found one of the most user-friendly parts of "Living Well with HIV & AIDS" to be the section on evaluating symptoms. Common physical symptoms are listed and an action chart indicates whether you can treat yourself at home or seek medical advice. Emotional symptoms like anger and depression are explained and strategies for management are suggested. The book also deals matter-of-factly with the big issues – sex and death.

To people like us who have been living with the virus for a long time and have developed our own strategies through trial and error, many of the book's strategies will be familiar. For a person who is recently diagnosed with HIV infection the book may be a valuable short cut to setting in place those same strategies for self management of their health.

The book is angled towards US readers but this does not reduce the relevance of content for Australian readers. For any positive person, no matter what health management strategies they use, the book is practical and insightful.

*Living Well with HIV/AIDS is available from The Bookshop, Darlinghurst and from the libraries of ACON and the Albion St Centre.*

– Robert Rogers and John Cumming





# A punt into reality

*Sydney's Positive Living Centre is going through a change of management and location. John Cumming talked to the Centre's President Drew Mollineau and Transition Manager Joe Kelleher about the changes happening at the Centre.*

THE POSITIVE LIVING CENTRE is now a non Government organisation (NGO). What's the benefit of that and what exactly does it mean? "The benefit of being a NGO is that it opens our door to co-operation with other organisations," explained Centre President Drew Mollineau. "Since we've become an NGO we've had government departments wanting to be involved with us. Sarah Yallop, who provides the Positive Employment Service on the North Shore, is trying to expand her service to the eastern suburbs and wants to work from our new premises."

Drew says the transition process that the Centre is going through is like an opera. "To put on an opera, you've got a conductor, a musical director, a stage director, the opera director. They all have their own defined roles but they're also all working in harmony together. Because if they didn't, the opera wouldn't get on the stage. Everyone has to have a defined role and purpose. But they have to work in harmony."

Joe Kelleher has released details of the consultation process that will take place over the next few months. In mid September HIV service providers, groups and individuals will be asked for written input on how to create an effective

and relevant Centre. A series of focus groups will be held with the Centre's members, volunteers, staff and associates to discuss the purpose, values and goals of the Centre in late September.

Throughout October and November other service providers will be consulted further to help to locate the Positive Centre within an integrated and co-ordinated network of services working for people with HIV and AIDS.

Although the transition process seems drawn out and lengthy, Drew regards it as necessary. "There have been a lot of people in the past who have tried to make changes and it's been done at such a pace that they've really tripped over themselves," said Drew. "We are taking a slower pace to make sure that every contingency is looked at so that the end result is something that is viable, not just a vision of one person. The lives of PLWHA have changed dramatically with the advent of protease inhibitors and other drugs. I have noticed that AIDS dementia is becoming more and more prevalent in the positive community. We have to look after those people. We've been talking about where we fit into the community. People do still fall through the safety net. Whether we are the most appropriate service for those people

remains to be seen. The services of the Centre and the doctrine of the Centre have not changed to reflect what's happening in the positive community."

Joe Kelleher has been deeply involved in facilitation processes during the fifteen years he has worked in communities. "I guess I've seen the best and worst of changes," he said. "The worst of it is where people are not provided with a focus of how they can be useful to the process and to what purposes. That can lead to a lot of confusion and unhelpful tactics. I hope to provide opportunities that will give those committed to the Centre's future, a chance to contribute at depth information and feedback. In the end, any process of consultation can only try to involve as many interested people as is possible, come up with shared understandings and take a punt, so that what you come up with is close to people's real needs and expectations."

He describes running community based organisations as "notoriously difficult. A lot more difficult than running organisations that have lots of professional structures and resources. Lack of these supports has affected the history of the Centre and imposed tremendous stresses on volunteers and paid staff. It's remarkable that

the Centre has continued to survive, given these stresses. This is a testament to people's commitment and energy."

Joe says the transition will seek to make the Centre operate more efficiently and effectively. There will be moves to create internal structures and procedures that are

easily followed by users of the Centre. "A lot of work will be done on developing sound operating policies," he said. "But the first thing that needs to happen is for there to be a development of a sense of the Centre's mission and purpose, and some discussion about the unique character of the

Centre. As well, there seems to be an underlying concern, a general consensus, that the Centre can be most effective working as part of other HIV and AIDS groups and organisations in Sydney, interdependent with them."

## **NOT ON HIV TREATMENTS?**

**We are conducting a project to explore the reasons why people may choose not to take HIV/AIDS treatments.**

We are particularly interested in hearing first hand from people with HIV who have decided to defer or not take prophylaxis and treatments.

If you would be interested in coming along to one meeting of a small confidential focus group, consisting entirely of other people who have chosen to delay or decline treatments, please give us a ring.

We don't want to talk you into taking treatments. That choice is yours and we respect your decision. We are simply interested in

exploring the reasons behind your decision. Your confidentiality is assured. You don't need to give us your name to attend the focus group.

The meeting will be held in early October, in the early evening to enable those who are working to attend.

For further details please ring Anne on 9564 1174 or email to amalcolm@ozemail.com.au.

This project is being funded by the NSW Health Department AIDS & Infectious Diseases Branch.

David Lowe Consulting and Anne Malcolm Consulting  
45 Davies St Surry Hills 2010

## **Ugly Toenails?**

Thick and crumbling toenails and fingernails due to a fungus are very common in HIV infection.

Taylor Square Private Clinic is studying the antifungal nail lacquer Loceryl™ as treatment for HIV-related fungal nail infections. Loceryl is very effective in HIV-negative people and is licensed in Australia.

Lacquer is applied weekly for 12 months with clinic visits every three months or so. There is no placebo. Lacquer is provided free of charge (normally about \$70) and payment is made to cover your incidental costs.

For information please contact Margaret Slade RN or Dr Neil Bodsworth at Taylor Square Private Clinic, Darlinghurst on 9331 6151 – email: neilb@clinipath.com.au.

# Look before you Leap

*Are you concerned about being retrenched or considering resigning on health grounds? Make sure you get your Super.*

LEAVING WORK FOR GOOD IS A very important event, particularly in legal terms. The way you approach the end of your employment can have a big impact on your access to benefits which you could be entitled to. This is especially the case if you want to claim a Total and Permanent Disablement (TPD) Benefit. The HIV/AIDS Legal Centre NSW Inc (HALC) has acted for clients in relation to a number of TPD claims and recommends:

### 1 Don't just go

Even if your fund does provide TPD cover, that cover may cease at the moment you resign/are retrenched or soon after at a time specified by the fund, eg 30 days after resignation / termination. Preserving your eligibility is vital – it may even be preferable in the long term to take unpaid sick leave

while you seek legal device on your entitlements.

### 2 Find out if you're covered

Not all funds provide members with TPD cover. Whether or not TPD benefits are available to you is important information, which you need to know before you finish work. You should try to get all information possible about TPD cover in your fund, from pamphlets to your annual members benefit statements. Quite often member's benefit statements go astray if the fund does not have your current address. Information can be obtained by the fund, or from your employer (who makes compulsory contributions under the Commonwealth Superannuation legislation).

### 3 Take legal advice before acting

Because the decision to leave is so important, HALC recommends that you seek legal advice before resigning. Again, it may be preferable to take unpaid sick leave before ending your employment permanently. Taking legal advice before you resign avoids

many of the problems which can arise in pursuing TPD claims, especially the time limit for applications. Even where late applications are allowed, HALC's experience suggests that succeeding in a TPD claim made after the time limit is more difficult.

To prove "total and permanent disablement", fund members have to get certificates from two medical practitioners stating that they are unlikely ever to be able to work again in a job for which they are reasonably qualified by education, training or experience.

Getting this documentation and proving disablement to the satisfaction of the fund is harder the longer after the end of employment it is attempted. With proper legal advice you should be able to access all the benefits which your fund provides. HALC is always willing to assist with HIV related TPD claims and actively helps in preparing evidence and collecting medical reports as required.

**Paul Garde**  
HALC Co-ordinator  
Ph: 9206 2060

## Inner West Sexual Health

Totally free and confidential  
No Medicare card needed

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



Livingstone  
Road Clinic

182 Livingstone Rd Marrickville  
Phone: 9560 3057



Canterbury Sexual Health Centre  
Rear 63 Tudor St  
Campsie  
Phone: 9718 7655

## NorthAIDS

for all positive people

### Des Kilkeary Lodge

#### Dee Why

Supported accommodation and respite care with warmth, dignity, respect.  
phone 9982 2310

### Myrtle Place

#### Crows Nest

Monthly Sunday brunch  
Lunch every Friday and Wednesday. Support and information.  
Newsletter available  
phone 9982 2310

## TAYLOR SQUARE PRIVATE CLINIC

Dr Robert Finlayson ◆ Dr Ross Price  
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8am - 8pm Mon to Fri ◆ 10am - 12 noon Sat  
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# HOME AT LAST

*The recent opening of Bobby Goldsmith House, a housing project for PLWHA run by the Bobby Goldsmith Foundation (BGF), is a major achievement for the charitable organisation and for the positive community. John Cumming spoke to a tenant about how moving into Bobby Goldsmith House has changed her life.*



"SINCE I'VE MOVED IN HERE, I'M starting to get things together. Before, I was starting to live like someone who'd lost control of their lives." Sitting in her comfortable armchair as mid-afternoon sun streamed through her cathedral-style lounge windows, Linda reflected on how her life has changed since she moved into the BGF's housing project in inner Sydney. Next to her chair is the walking frame she has to use for mobility, a legacy of an accident some years ago that damaged one of her hips. The walking frame holds a tray for easy access to handy things, including a copy of *Talkabout Contacts*. Linda, who is in her mid-40s, contracted HIV in the mid 1980s and has been on a disability support pension since 1991. Six years ago she moved to Sydney from Melbourne to access what she regarded as superior medical services for PLWHA. "I moved into a hostel run by a charitable institution that was close to everything I needed, hospital, doctors, transport. As far as location goes, it was fine," she said.

But when she slipped and fell in the hostel, triggering a medical condition called necrosis which permanently damaged her hip, she found the hostel conditions almost life threatening. "They had a disabled toilet, but no disabled

shower", she told me. "To have a shower, I'd have to improvise with a plastic kitchen chair."

Although hostel staff were supposed to monitor the health of residents, when Linda isolated herself in her room because of depression, staff did not check up on her. As a result, she went without food for five days.

The environment became more stressful for Linda as more psychiatric patients moved into the hostel. "Sometimes, the only sane person I could talk to was me," she explained. "I did once see someone having a conversation with a banana, but it was pretty one-sided!" Eventually the stress affected her so much that she spent most of her time in her room. "It was about the size of a small kitchen. It had a single bed, a sink and a wardrobe. And my books were everywhere - I love my books. James Ellroy is my favourite author."

When Linda entered a hospice to receive respite care, her medical practitioner refused to discharge her because re-entering the hostel was considered a health risk. It was then that Linda applied for a place in the BGF Housing Project. "I was told I would only have to wait seven weeks, but it was more like seven months. They kept running into delays and I would keep

getting apologetic phone calls. When she got the news that a flat was ready and went to look at it, "even though it was empty, I knew it was mine," she said. "It felt so right."

Since moving in several weeks ago, Linda has noticed amazing changes in her life. She found herself telephoning her mother for the first time in ten years. "I feel happy - I can't remember the last time I felt like this," she told me. Linda is enjoying things that people in secure accommodation take for granted. "Before I die I decided that I wanted to use a bathroom that no-one else had used," she said. "That was very important to me - and now I have it".

In her previous accommodation at the hostel Linda had been forced to buy extra food because the house meals were substandard. Now, although the rent in her new flat is higher, Linda is able to save money for the first time in years. She thinks this is because she is making better shopping choices and because she is accessing services that she should have been using but didn't. "I know it's a cliché, but me and all the other tenants have bonded with each other really quickly," she told me. "Some nights I lie in bed and think I'm going wake up to find it has all been a dream." ♦

# What is the Luncheon Larder?

THE LUNCHEON CLUB LARDER OFFERS free food and essential products to people living with HIV/AIDS and others struggling to survive on the pension.

The Larder evolved from a previous service run by the Metropolitan Community Church, when it was known as the Manna Pantry. The service was due to close at the end of June but after discussions between Rev Greg Smith of the Metropolitan Community Church and Carole Ann King, President of the Luncheon Club AIDS support Group, the Luncheon Club Larder was recently established at Sydney's PRIDE Centre as a service of The Luncheon Club AIDS Support Group Inc.

Paul Tansley, the manager, understands from personal experience the transition from earning a good wage to being unwell, on the pension and below the poverty line. "Even if you're really together, it can be quite shattering," he says. "Financial hardship can

strike overnight, especially if a person is abandoned by their family or if they are evicted by a landlord or lover."

He is keen to provide advice based on his skills and experience. "When people come in I ask them a bit about how they manage their finances," says Paul. "We keep a record of what people are receiving and requesting to make sure we can accommodate their needs in the future."

The Larder provides: shampoo, soap, razors, toothpaste, toothbrushes, toilet paper, cleaning products, sugar, tinned food, coffee, tea, cereals, sandwich spreads and eggs.

Volunteers at the Larder create a warm and friendly environment, serving tea, coffee and cake to clients on their arrival and they are encouraged to sit and chat while waiting to be individually attended to by Paul.

Paul emphasises the need for people to overcome their embarrassment about asking for help. "If

you don't, you just make things worse for yourself", he says. Paul wants to help people avoid getting into a situation of need. "There has been too much of a Band-Aid approach", he says. "What I aim to do is refer people to other services available to them and empower them to help them beat poverty."

The message he most wants to emphasise is that everyone at the Larder is friendly and understanding and that people should not be too embarrassed to ask for help. "If you don't ask for help", he says, "you may go under."

The Larder is located at the PRIDE Centre, 26 Hutchison St Surry hills. It is open every Wednesday and Friday from noon till 4.00pm. People who want to use the Larder need to provide evidence of eligibility in the form of their pension card. Volunteers are also needed to help - phone Paul on 9389 7477.

# CONTACTS

*No, it's not the new Jodie Foster movie  
but positive lesbians will find useful phone numbers.*

It is **the** resource guide for people living with HIV/AIDS, their friends, carers & service providers

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# Talkabout

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