

No. 101 September 1999

Talkabout

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

◆ Where We Speak for Ourselves ◆

Life or serostatus?

A view on the 'changing needs' debate

Bearing the load

New research on women's viral load

Treat me right

Prisons update

Chasing the Coláo dream

BGF

Celebrating 15 years

The remarkable story of Bobby Goldsmith ... and friends



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The 4th Annual Living Heterosexually with HIV/AIDS Workshop

Practical

Stuff

Saturday 25 September 1999

9.30am - 4.30pm **Surry Hills, Sydney**

S E S S I O N S

Practical stuff What works, what doesn't *A panel's view*

Tricia Collins Albion Street Centre **Bill Robertson** Foley House
Mark Tietjen BGF **Marie Lavis** Pozhetwest

Kick start your life! Sharing ways of beating depression

Angelo Morelli Darlinghurst Community Health Centre

Men's work Maintenance, repairs and smooth running

Greg Millan Australasian College of Sexual Health Physicians

Women's work Wear, tear and self care

Miranda Shaw Women and AIDS Project, Family Planning NSW

Down on the pharm Making the treatments decision

Jo Watson AIDS Treatment Project Australia

What's cooking? Filling your trolley with goodies

Monique Rennie Redfern HIV/AIDS Community Team

Like cures like Using homoeopathy

Francesca Murdoch Homoeopath

Numb and number and the body snatchers

Managing peripheral neuropathy and lipodystrophy

Denise Cummings Clinical Nurse Consultant, Royal Prince Alfred

Sound and healing Express yourself through music

Diane McCombe Voice and sound healer

Your own healing power Guided visualisation

Matra Robertson Circles of Light

Lots to do (choose your own sessions)
fabulous food fun and laughter (as well as the
serious bits) old and new friends childcare
... and heaps more reasons to come along!

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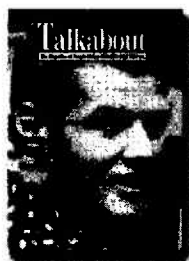
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This month's cover features a memorable image of Bobby Goldsmith.

Editorial

September 1999 marks the 15th year of operation for the Bobby Goldsmith Foundation (BGF). This is a significant milestone. Since 1984, BGF has raised and distributed more than ten million dollars to people living with HIV/AIDS. Today, more clients than ever are accessing the services offered by BGF. Given the financial hardship experienced by so many of us, we wish BGF the very best with their current fundraising campaign – Friends of BGF.

This month we ask a diverse group of PLWHA and service providers for their views on the 'Changing Needs' Service Providers Forum II to be held on 7 September.

We pay tribute to Vincent Dobbin who died on 26 July. Many of you would know Vincent from his work with PLWHA (NSW) and the HIV/AIDS Legal Centre (HALC). Many may never have met Vincent, but have benefited from his achievements and involvement in the community response to HIV/AIDS in NSW.

This month you can read about the added difficulties faced by HIV positive prisoners, the gap left by the Coláo Project, updates on treatments, services and what's happening, a review of the new *Taking Care of Yourself* booklet as well as news from around the world.

Over the last two months there have been changes in the design and contents of *Talkabout*. The changes reflect recommendations from the 1998 review of *Talkabout*. We welcome your feedback. Thank you to those who provide us with compliments and constructive criticism.

We know that our readers find the personal stories published in *Talkabout* very useful. If you want to share your experiences of life with HIV, contact with our editor, feona studdert, who can assist you with writing and publication.

Claude Fabian

Guest Editor

Talkabout Publication Working Group



PLWHA (NSW)
People Living With HIV/AIDS

PositiveAction with Ryan McGlaughlin

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Planning for our future

Goodbye ... and thank you

Once again I begin this column noting more departures from the PLWHA (NSW) team.

Paul Cummins and Janice Forrester have resigned from the management committee.

Paul is leaving for personal reasons and Janice because of study commitments. Both have been good advocates over the last year and particularly through their persistence on the St Vincent's Hospital Consultative Committee. This has often been a frustrating process due the lack of common understanding around the meaning of 'consultation'.

Paul became involved with PLWHA (NSW) when he was passionate about the attempted closure of the gym at the hospital. Through this shared commitment the gym remained open. At the time of his resignation he had just become Treasurer of the organisation and was implementing a more effective structure for financial reporting.

What's cooking?

Gerrard Hodshon who has been a dedicated volunteer and acting as Publication's Assistant over the last few months has also resigned. He has left to take up a full-time position in the catering industry. Once again, it is pleasing to see volunteers gain confidence and skills that assist them re-entering the workforce.

Opening new doors

Michael Riches has recently joined the management committee after completing the second advocacy and campaign course as well as the first writer's course. I encourage other PLWHA to participate in these courses and become more involved in this organisation. Michael brings to the organisation knowledge in the area of mental health.

Strategic planning

The team at PLWHA (NSW) recently held its annual planning day. The major outcomes of the

day are to establish an Advocacy Support Working Group to look at training and peer-based one-to-one advocacy. Another resolution is to commence short-term working groups to look at rural issues; and training strategies for volunteers.

The committee will conduct a strategic planning process later in year that will include consultations with our constituents and other service providers. Watch this column for more information. ■

Vale Vincent

It is with sadness and huge respect we pay a final tribute to Vincent Dobbin who died in late July.

Vincent was a valued ex-committee member of PLWHA (NSW). He was also a fine human being with great integrity, intelligence and a sense of humour. (See our tribute on page 10.)

Local trials target Lipodystrophy

A study of Human Growth Hormone (HGH) for HIV wasting is enrolling at St Vincent's Hospital, Taylor Square Medical Clinic and the Royal Prince Alfred Hospital in Sydney, and at the Prahran Clinic in Melbourne. People with lipodystrophy may be eligible. St Vincent's is conducting a 16-week, placebo-controlled study of gemfibrozil for people on protease inhibitors who have elevated triglycerides. Places are still available.

Promising study of HIV pregnancy

A study in Uganda, sponsored by the United States National Institute of Allergy and Infectious Diseases, found that a single oral dose of nevirapine given to an HIV infected woman in labour, plus a dose to the infant within three days of birth, cut HIV transmission to 13.1%, compared to a similar short course of AZT. The study will follow the infants for 18 months. The new regimen will be used for pregnant woman who do not know they are HIV positive until it is too late to take the standard regimen. (ATN. Issue 323)

Managing symptoms

The University of California, San Francisco, is conducting a web-based survey examining symptom management strategies for PLWHA. The goal is to learn about self-care strategies used to manage symptoms. The survey will target PLWHA, carers, and professional care-givers. See the site at <http://www.hivsymptoms.com>.

Protease study

A retrospective observational study has been published in Archives of Internal Medicine with results showing that more than 50% of PLWHA treated in a clinical setting failed to achieve viral suppression with highly active antiretroviral therapy (HAART) that included a protease inhibitor. Missed clinical visits, more advanced disease, and higher plasma HIV RNA levels may predict treatment failure, and present different results to the clinical trial setting. The findings mirror those of a similar study conducted by Johns Hopkins researchers and reported in July 1999.

Abacavir released

A new anti HIV medication was released in Australia late last month. Abacavir, also known as 1592 and trademark Ziagen™ was welcomed as a positive step forward in the management of the HIV virus. The drug has been available in Australia on the compassionate access scheme since 1997.

Spokesperson for the National Association of People living with HIV/AIDS (NAPWA), Peter Canavan, said that PLWHA would be encouraged that another drug in this class was available for their combination therapy choices.

"The other drugs in this class have been used extensively in the Australian PLWHA population and it will be useful for many to have the use of abacavir, either as a replacement or in addition to these other drugs."

Abacavir is the latest of the nucleoside analogue class of antiretroviral drugs. The other nucleoside drugs are AZT, ddc, ddI, d4T, 3TC.

Canavan told *Talkabout* that the antiretrovirals that are available in Australia have become increasingly important in the long-term management of HIV/AIDS. The release of abacavir will assist PLWHA around issues of long - term compliance to the combination drug regimes.

"In terms of the dosage requirements and rigorous compliance demands for HIV

antiretrovirals PLWHA can find it difficult to manage all our drugs to fit into our individual lifestyles. We are pleased that abacavir is recommended as just the one tablet twice a day, and without any restrictions on food or fluid intake. Hopefully this will maximise the effects of the treatment in the long term," he said.

Combination therapy, combining a number of drugs to treat a disease, has become a standard practice in the management of HIV/AIDS.

The HIV Futures Study prepared by the Australian Research Centre in Sex, Health and Society and released in May this year noted that 85 percent of PLWHA who use antiretroviral drugs use triple combination therapy.

As a new drug in an existing class, abacavir has a significant class sparing benefit (ie doctors can use abacavir as the third drug in a nucleoside reverse transcriptase inhibitor (NRTI) combination, thus reserving other classes, such the protease inhibitors, until later in the treatment regime.

Potential side effects include tiredness, fever, malaise, nausea and vomiting. About three percent of people taking abacavir have a hypersensitivity reaction to the drug which can be life threatening. The symptoms of this reaction are fever, nausea and sometimes rash.

Glaxo Wellcome, manufacturers of the drug strongly recommend that patients experiencing these symptoms stop taking abacavir and

contact their physician immediately. Symptoms of this reaction generally subside following discontinuation of abacavir. Patients who experience this reaction must not take abacavir again.

Abacavir has been shown to be one of the most potent in its class with demonstrated efficacy equal to that of protease inhibitors (PIs). It will be used in convergent therapy - the latest treatment approach where drugs within a class are combined to maximise potency.

Speaking at the launch, Professor David Cooper, Director of the National Centre in HIV Epidemiology and Clinical Research, said the arrival of abacavir was exciting because it provided patients with an opportunity to extend and maximise future treatment options, thus potentially making HIV more like a manageable chronic condition.

According to NAPWA no significant interactions between abacavir and other drugs used in combination therapy are known at this time.

Abacavir has been approved for marketing in Argentina, Brazil, Canada, the European Union, Israel, Mexico, New Zealand, Switzerland, Uruguay and the United States.

For further information contact your doctor or the AIDS Treatment Project of Australia on 9281 0555. ■



Planet Positive held its regular social evening at Annie's Bar in Darlinghurst. The positive evening is an initiative of the AIDS Council of NSW, HIV Living Project.

HIV Service Provider's Forum

Tuesday 7 September, 1999. 1pm - 5pm. Heffron Hall, Palmer Street Darlinghurst.
 All HIV Service Providers and volunteer service providers are invited to attend. Afternoon tea will be provided. For further information call Drew Mollineau on (02) 9699 8756

Health con exposed

Sydney The Australian Competition and Consumer Commission has filed proceedings in the Federal Court, against Colin Ronald Dixon, Vital Earth Company Pty Limited and its director Darryl John Jones and Raylight Pty Ltd and its director Herbert Nathan, alleging breaches of sections 52 and 53 of the *Trade Practices Act 1974*. Raylight has marketed alternative therapy products 'Parasite Zapper' and the 'Colloidal Silver Kit'. Advertisements published in *Nexus New Times*, a health magazine, claimed that the 'Parasite Zapper' passes an electric current through a person's blood effective in treating a number of serious medical conditions including HIV. Vital Earth has marketed a number of products including the 'Vital Silver 3000 Zapper' and the 'Vital Silver 2000' which it represents as being able to create colloidal silver which it is claimed has been used successfully to treat a number of serious medical conditions including AIDS. The ACCC is seeking refunds, injunctions and corrective advertisements. *Reuters*

OPTIONS plan to go national

Sydney OPTIONS, the Employment Service that specialises in assisting PLWHA to return to work, plans to establish offices in Melbourne, Brisbane and Perth. In a statement OPTIONS Manager Peter Garvan said he hoped the Federal Government would provide funding in the next tender for the Job Network.

OPTIONS is one of 200 Job Futures outlets, a national not-for-profit employment agency sponsored by a broad coalition of community, local government, ethnic and religious organisations. The Federal Government is scheduled to announce the successful bids in December.

It is estimated that there were 13340 PLWHA in Australia by the end of 1998. By 2000 the number of PLWHA will have increased to 13830. According to the 1998 HIV Futures Community Report the majority of PLWHA who are not working are considering returning to the workforce.

Doctor jailed

Melbourne A former doctor was jailed last month for at least three years for having sex with his wife despite knowing he was HIV positive. Christopher Dirckze, 43, was sentenced to four years and two months by a Melbourne court for endangering his wife's life by having unprotected sex. Neither the mother nor her child has tested HIV positive. Dirckze was struck off the Victoria state medical register in August 1997. *Reuters*

Housing initiative launched

The Bobby Goldsmith Foundation has launched an initiative in supported accommodation for PLWHA with complex needs.

The Floating Care Housing Project will provide community based accommodation linked to a range of support services coordinated through case management.

The initiative will provide up to 20 units of community based rental accommodation for clients. Project Manager, Bill Paterson said the project affirms the right of PLWHA to live in the community and be consulted and as involved as possible in case management, housing management and support decisions affecting their lives.



PLWHA (NSW) staff and committee members are active in many projects, consultations and meetings that effect the interests of PLWHA. **Antony Nicholas** – our Community Development Project Worker – profiles what's happening in NSW this month.

New social worker at Clinic 16

Nandini Ray has been appointed as the HIV Community Social Worker at Royal North Shore Hospital. Nandini previously worked at the Parramatta Sexual Health Clinic at Westmead Hospital. She takes over from Angelo Morelli who joined the AIDS Dementia Complex and HIV Psychiatry Service.

HOPE begins

A new drop-in group has been trialled at the Tree of Hope Centre in Surry Hills. The group is called HOPE and aims to address issues linked to HIV. HOPE will operate an alcohol and drug-free space and is open to all PLWHA and their carers. For more information contact Ray on 9360 3008 or Kath on 9660 1325.

Meditation, yoga, and herbs

The AIDS Council of NSW (ACON), Northern Rivers Branch will run introductory sessions on meditation during August. Follow up courses in yoga and herbs will run in September and October. Sessions will be once a week for eight weeks. PLWHA and gay men welcome. Contact ACON Northern Rivers on 02 6622 1555.

HACC review

The Review of Home and Community Care services is under-way. Consultants Anne Malcolm Consultancy will run pilot strategies to improve access and equity for PLWHA to existing HACC services. The project will span twelve months. Pilot strategies are expected in the inner city, out west and at a regional service. PLWHA who have comments on HACC services can contact me on 02 9361 6011.

Ready to re-construct

The Reconstruction Project will shortly appoint a project worker to coordinate workshops designed to assist PLWHA with pre-vocational needs. We will keep you informed of impending sessions.

Forum #2

Volunteer service providers and PLWHA are urged to attend the second Changing Needs forum. The forums are an opportunity to discuss and reassess the changing service needs of PLWHA. A questionnaire was distributed in *Talkabout* last month. The questions cover what the HIV sector does well, what it doesn't do well, where the gaps are and what other opportunities are available. If you want to attend the forum or complete a questionnaire please call me at PLWHA (NSW). Copies of the minutes from the first forum are available. The forum will be at the Heffron Hall, 7 September, 1-5pm.

Respite needs out west

The Haven, ACON, PLWHA (NSW), the Bobby Goldsmith Foundation and Central and Western Sydney Area Health Services plan to work together to achieve the best possible services in Sydney's Western Suburbs.

The Haven now operates a drop-in group and respite service from the old Bethany site. Volunteers currently run the service. The Haven can be contacted for details on 9672 3600. ■



Photo Hazz Images

With the support of more than 200 people, NorthAIDS volunteers raised over \$400 last month with a raffle at the annual Southern Cross Outdoors Group Bushdance at the Marrickville Town Hall. The group's next event is the Mardi Gras Bush Dance which is to be held at the Petersham Town Hall in February 2000.

Pregnant women to receive HIV tests

London All pregnant women in England are to be given an HIV test under a Government scheme to reduce the number of babies born with the virus. Tessa Jowell, the Health Minister, announced in mid-August that HIV screening would be made available under the National Health Scheme at every ante-natal clinic in England. The United Kingdom has one of the highest maternal HIV transmission rates in Europe, and one of the lowest identification rates among pregnant women. Of the 265 positive women who give birth every year, up to 50 babies are born with the virus, mainly because their mothers are unaware that they are HIV-positive.

The Independent

Army investigates

Washington Members of the United States Congress and the Service Members Legal Defense Network are questioning Army discharges of at least nine HIV-positive personnel. The *Washington Blade* reports that the current Department of Defense policy on HIV-positive service members "unequivocally allows any HIV-positive person to serve in the military on active duty until his or her T-cell count drops below 200, at which time the person is funnelled into the disability system." All nine of the discharged personnel had T-cell counts above 200. *Washington Blade*

US back down on AGOA

Washington The conflict over South Africa's law aimed at obtaining cheaper HIV/AIDS therapies could soon be resolved. United States negotiators are no longer seeking the repeal of the controversial Africa Growth and Opportunity Act. Instead, they are asking SA to sign a statement promising that the new law won't violate intellectual property rights. In 1997, SA passed a law that allowed importers to buy drugs from the cheapest sources available, with or without manufacturer approval. A second provision, compulsory licensing, allowed the SA Government to license local companies to produce cheaper versions of drugs whose patents are held by multinational firms. Forty drug companies sued in SA courts to overturn the law, and the government has held up implementation until the case is resolved. *Wall Street Journal*

Sistagirls do it for themselves

The need for culturally specific education around HIV and sexually transmitted infections was the overriding message of the First National Indigenous Sistagirl Forum.

Thirty-five Sistagirls, from communities across Australia gathered on the Lands of the Wulgurukaba people (Magnetic Island, Queensland), for the four-day forum in late July.

Michael Costello, who coordinated the event, said that during the course of the forum it became apparent that sexual health is only one aspect of a much broader predicament for the Sistagirl community.

"It was clearly reinforced throughout the forum that the low levels of understanding and awareness of HIV/AIDS and other STIs found in the Sistagirl community, need to be addressed through educational provisions that are word specific and culturally appropriate with a localised focus."

The forum addressed issues of sexual health and treatments, identity, violence, community isolations, the history of Sistagirls and transgenderism in indigenous communities, human rights and anti discrimination and drug and alcohol issues.

The forum passed 25 resolutions relating to government, Australian Federation of AIDS Organisations and its member organisations as well as Aboriginal Medical Services and indigenous health agencies.

The forum built on the vision of Anwernekenhe 1, the first



The smiling faces of some of the thirty five Sistagirls who attended the first National Indigenous Sistagirl forum on Magnetic Island

gathering of Sistagirls held at Hamilton Downs, Northern Territory in 1994, and the AFAO National Indigenous Gay and Sistagirl Steering Committee. ■

The term 'Sistagirl' is used to describe all indigenous people who identify as Sistagirls or who have transgender qualities.

AIDS Trust and Gay Games laugh their way to \$3,500

Sydney's 2002 Gay Games and the AIDS Trust of Australia raised \$3500 in a joint fundraiser billed as the 'international passport to stand-up comedy'.

Hosted by Julie McCrossin and Bruno Bouchet, the night featured the spectacular organising skills of Glen Horder. Pictured (far right) is local comedian Jackie Loeb with representatives from the AIDS Trust and 2002 Gay Games. ■



Photo: Alizz Images

Man wins case to remain in Britain

London An HIV positive Ugandan man may have won the right to remain in Britain. The man who first entered the UK in 1990 with permission to stay for six months, successfully argued that the better treatment he would receive in the UK would extend his life by up to three years. His lawyer said that if his client returned to Uganda the prohibitive costs of treatment in the country would mean that his life expectancy would be reduced. *Daily Mail*

Early AIDS case identified

United States Clinical, immunological and genetic studies performed on tissue taken from the earliest known AIDS patient in the United States suggest that HIV existed there prior to the late 1970s, but in a different form. The findings were presented by Dr. Robert F. Garry, Professor of Microbiology and Immunology at Tulane University Medical Center in New Orleans, at the 11th International Congress of Virology in Sydney. Results of tests conducted on serum and autopsy specimens frozen since 1969 indicated a virus closely related or identical to HIV. Polymerase chain reaction (PCR) analysis of gene sequences from tissues, found a subtype of HIV closely related to a different strain than that known to cause AIDS today. Dr. Garry reported that the "findings suggest that viruses related to the strain may have been more prevalent prior to the current virus strains." Garry believes the discovery challenges the human-chimpanzee HIV link and suggests that HIV mutated slower than previously thought.

Murder case dropped

South Africa Police in Johannesburg, have dropped charges against four youths suspected of killing an AIDS activist after she publicly disclosed she was HIV positive. Gugu Dlamini, a 36-year-old volunteer field worker for the National Association of People Living With HIV and AIDS, was fatally beaten after publicly disclosing her illness on radio and TV at a gathering on World AIDS Day. Police arrested four youths in January and later released them into the custody of their parents. The 1 December beating occurred in a town in KwaZulu-Natal province, where an estimated 20 to 30 percent of the population are living with HIV or AIDS. Over eight percent of the total population is HIV positive. Police deny the case, has been dropped. A police spokesman is reported as saying, "The charges have been provisionally withdrawn pending further investigation by a special unit." *Associated Press*

Positive diversity

The Multicultural HIV/AIDS Service (MHS) has launched a national project that aims to better service PLWHA from culturally diverse backgrounds. The two-year Information Project will implement a number of strategies to enhance access and equity for PLWHA from culturally diverse backgrounds.

A national report commissioned by AFAO in 1998 estimated that up to 30 per cent of PLWHA in Australia are from culturally and linguistically diverse backgrounds.

Coordinator of the MHS, Tadhg McMahon told *Talkabout* that although this figure seemed high the report also points to the invisibility of PLWHA from culturally diverse backgrounds. McMahon argued that many services do not acknowledge the cultural diversity of people from, for example, Eastern and Southern European backgrounds because they speak English with little or no accent.

"Our research tells us that many positive people from culturally diverse backgrounds experience a different epidemic with some not knowing of the difference between HIV and AIDS and many experiencing racism when they access services. They



also highlight that accessing positive information in languages other than English and culturally relevant support is a priority issue.

In *Current Issues for PLWHA - A Community Report*, prepared by Latrobe University in 1997, a positive guy comments: "I would love to talk with another positive person who knows where I am coming from. Not necessarily French, German, Greek, or just European, just not Australian, but I don't know how I would meet them."

McMahon said that while Australia is known as a multicultural society it is difficult to estimate the proportion of PLWHA from multicultural backgrounds because information on ethnicity that would paint an accurate picture is not collected.

"We do collect 'country of birth' with AIDS diagnoses but this is only part of the picture as many

people from culturally diverse backgrounds are Australian-born. A more accurate picture would emerge from also knowing the language spoken at home, but this is only collected here in NSW and is only collected with HIV notifications" McMahon said.

The project, funded by the Commonwealth Department of Health, will conduct a national stakeholder consultation and will then implement strategies. A priority is to work closely with community organisations from the HIV/AIDS and ethnic sectors to develop positive information in languages other than English. ■

The MHS is keen to hear from PLWHA from culturally and linguistically diverse backgrounds. To get in touch with the project call Irena Brozek on (02) 9515 3098. If you want to use a telephone interpreter call 131 450 (free interpreting, just the cost of a local call) and ask the interpreter to call us at the number above.

Reefer madness

A campaign to legalise cannabis for medicinal purposes will be launched this month by the Australian Committee for Medical Cannabis (ACMC).

A proposal prepared by ACMC recommends provision of medical cannabis to people with defined and approved medical conditions.

Convenor Timothy Moore told *Talkabout* that legalising cannabis for identified medical conditions would benefit patients for whom cannabis is the only treatment that is effective.

At present the major scientific evidence for the efficacy of cannabis is in the treatment of AIDS wasting syndrome and in treating the side effects of cancer chemotherapy.

"For some patients cannabis is the only effective treatment for their conditions. Seriously and terminally ill patients would gain the most from these changes" the proposal states.

ACMC argue that if legalised, patients will no longer be engaged in the black market and would be under medical rather than criminal supervision. Ongoing research carried out on patients who are using medical cannabis would ensure efficacy and to monitor any side effects of cannabis.

Moore said the ACMC believe the proposal to allow access to cannabis for medical purposes would require minimal changes to current legislation.

"The ACMC propose that the Federal Government reschedule Cannabis under the drugs act to acknowledge its medicinal value; develop guidelines for the prescription of cannabis and exempt or license production, distribution and supply of cannabis for medical and research purposes" he said.

A variety of cannabis known as hemp is already used in a wide range of industrial applications,

including paper, cloth, and building materials.

Six states in the United States recently approved access to medical cannabis. The recent Hollywood film *Step Mom*, featured Susan Sarandon as an uptight, upright mother who resorts to smoking cannabis to cope with the nausea brought on by chemotherapy for her breast cancer.

In the United Kingdom, a scientific report released by the House of Lords in November 1998 recommended the trialing of cannabis for medical purposes.

The United States Office of National Drug Control Policy recommended this year that trials be carried out to examine the efficacy and applications for medical cannabis. The report stated "Medical marijuana can be helpful and there is not evidence that legalising its medical use will lead to 'reefer madness'". ■



Write to **HotBox** at
PO Box 831 Darlinghurst
NSW 1300



Candles out?

Will this year's candlelight memorial be the last? Would it be better to have a permanent memorial to all those who have died of AIDS? **HotBox** asked a few people what they thought.

It is important to maintain the essence and meaning of the vigil, but I feel a permanent memorial with an annual service would serve the community well.

Michael – positive male

I believe the vigil should continue annually at a permanent memorial.

Ray Hansen

People don't attend the vigil as much anyway so it's probably time to look at a permanent memorial, it would be more fitting for the new millennium.

Negative male

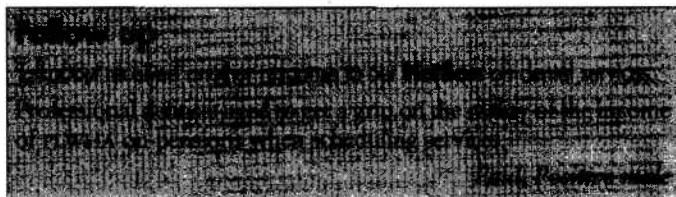
If they won't move it to summer, give me a memorial.

Positive male

A permanent memorial and the vigil should still take place annually.

Lisa Maree Syron

If you have an opinion that you would like to share, call *Talkabout* on 02 9361 6750 or write to **HotBox**. Letters must include your name and address. Please state clearly if you do not want your name published.



Personals

Guy outgoing, HIV and long term survivor. Gay 40ish plus a little dog is seeking to share. Unfurnished room ok. Cost relative to pension. Paddo, Surry Hills, Darlinghurst, Bondi or Inner West areas. **Reply 010999**

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 number in pencil on the outside.
- Place this envelope in a separate envelope and send it to: **Olga's Personals**, PO Box 831, Darlinghurst 2010.

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. However, claims of HIV positivity are welcomed and encouraged.
- It's OK to mention you're straight, bisexual, gay or transgender.
- Any ad that refers to illegal activity or is racist or sexist wording will not be published.
- Send the ad to **Olga**, including your name and address for replies. Personal details strictly confidential.

Events

Listen up in the bush

The Health Care Complaints Commissioner, Ms. Merrilyn Walton is conducting consultations throughout New South Wales to hear the problems of health service consumers at first hand. The Commissioner will be in Wagga on 25 October and in Albury on 29 October. For more information call Maida Talhami on (02) 9219 7428.

Commemorate life: plant a tree

SPAIDS invites you to plant a tree, provided by South Sydney Council, to commemorate someone who has died from HIV/AIDS. Sunday, 5 September, 10.30am to 3.30pm in the dedicated AIDS Memorial Grove at Sydney Park, St Peters. Enter at Old Brickworks chimneys entrance, opposite St Peters Rail Station. Contact Mannie De Saxe: phone: (02)9718 1452 or Email: josken@zip.com.au

Services

Lunch in the park

Positive Outings will hold its first free barbeque lunch on Friday 10 September at midday in Centennial Park. RSVP and transport details call Jane at South Sydney Community Transport 9319 4439 or ACON on 9206 2000.

Free computer courses

An introduction to computers and other courses at TAFE. At Sydney Institute of Technology. Phone Jenny at Outreach (02) 9339 8657.

Shopping spree

The Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt. They'll pick you up from home, give you two hours to shop, then drop you off again. \$4.00. Available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville or Darlington. Call Diana on 9516 4755.

Living with loss

An evening group (six weeks) for people who have had someone close to them die within the last two years. If you are interested phone the Sacred Heart Hospice on (02) 9380 7674.

Help for drug and alcohol dependency

Groups for gay men, lesbians and heterosexual men and women are available. For further information call the Sydney office on (02) 9261 0055. Narcotics Anonymous can be contacted on (02) 9212 3444.

Tax help

The Australian Taxation Office runs a free service to help low income earners and people on Centrelink benefits with their tax returns. The service is only available for a short time. Phone 132861.

Conferences and Forums

Talk Sex

Gay and bisexual men's sexual health national training day. 17 September Euro Rex Hotel Potts Point Sydney. Presented by the Australasian College of Sexual Health Physicians. Contact Greg Millan, Education Officer. Ph 02 9382 7587.

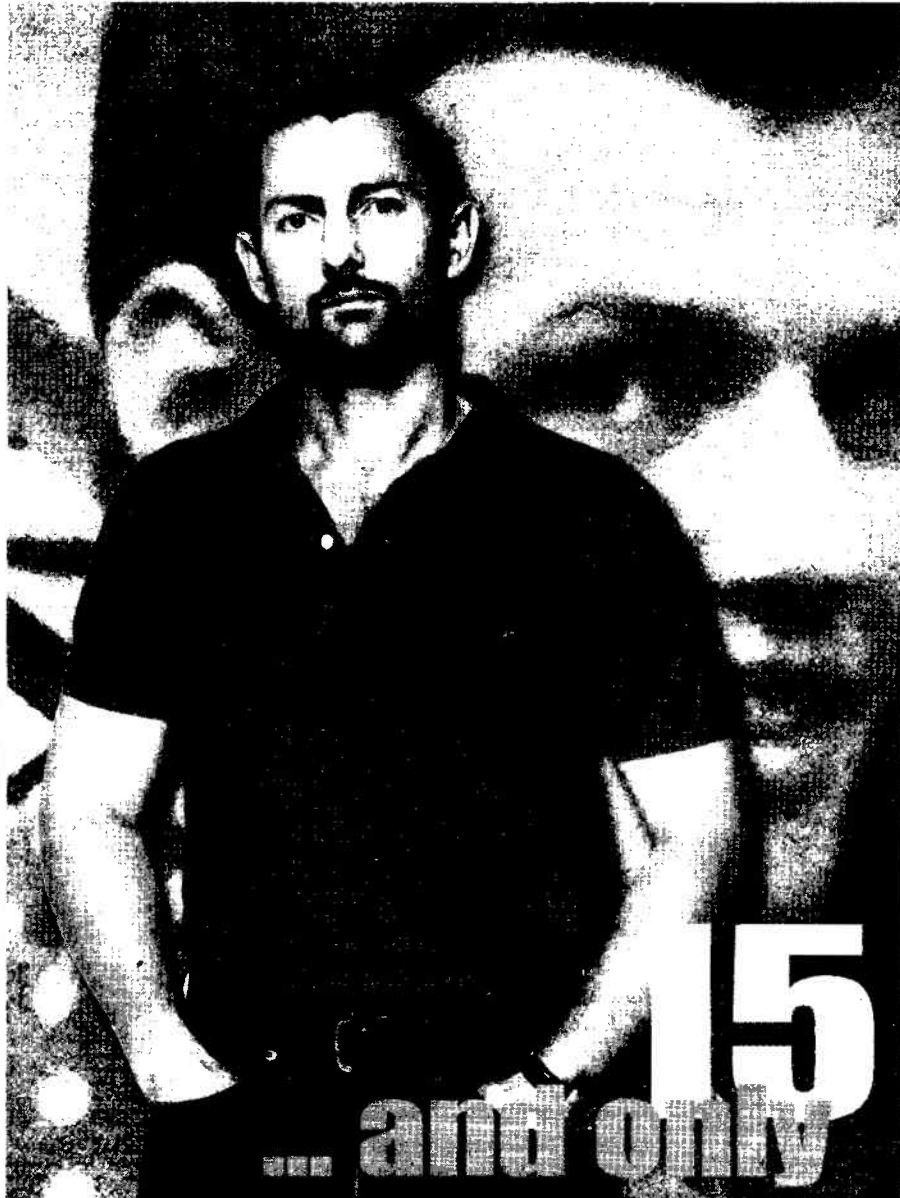
Health in Difference 3

National lesbian, gay, transgender and bi-sexual health conference. The Hyatt Regency, Adelaide 20 – 22 October. Contact Rob 08 8362 1617.

Indigenous Health Conference

National Aboriginal and Torres Strait Islander Health Workers Conference 3. 18–20 October, Cairns Qld. Info. Ruth Simon. Ph 9661 8493 or 9311 2593, fax 9311 2418, email: aihwjournal@indigninet.com.au.

\$10,000,000 Ten million dollars



Digital Image Geoffrey Williams Photo of current BGF client Branco Galca

Fifteen years after Bobby Goldsmith died the Foundation established in his memory has raised over ten million dollars to assist PLWHA with the basic necessities of life. *Talkabout* charts the considerable achievements of BGF over the last fifteen years

Certainty in uncertain times

Is the HIV/AIDS crisis over? Fifteen years on, the demand on BGF services is growing at an alarming rate. The success

of treatments and falling death rates have been accompanied by increasing numbers of PLWHA who are faced with an uncertain future and poverty. For nearly two decades the HIV/AIDS sector and government agencies have facilitated a culture of dependency, welfare and neediness. Today PLWHA are suddenly being encouraged to become more independent.

Already this year BGF staff, Mark Tietjen and Ben Alfred, have written 3,404 cheques totalling \$232,572, our Financial Counsellor, Maree Crosbie, has had 248 appointments with PLWHA

interested in options for change, and 125 people have walked through our doors seeking help from BGF for the first time.

There have been a lot of firsts for BGF recently. All of them fly in the face of the notion that the AIDS crisis is over. If the epidemic was coming to a close, the Foundation wouldn't have created my position, taken on a new Housing Programs Manager, Bill Paterson, launched a new housing project, the Floating Care Initiative, and recruited a second Financial Counsellor. This growth is motivated by necessity alone. If BGF didn't develop we would fail in our mission to alleviate the widespread poverty caused by HIV/AIDS. We would also fail to adequately empower and respond to the needs of people living with HIV/AIDS. We have only been able to do this because BGF is lucky enough to have a loyal and committed supporter base.

We currently assist 873 PLWHA with direct financial assistance and many more PLWHA access our client services. Our clients aren't looking for handouts. Most of our clients come reluctantly to BGF after many years of struggling to maintain life's basic necessities on their own. Through the generosity of our supporters BGF is able to bridge the gap between public funding and private need.

On 11 September BGF volunteers will take to the streets to recruit new Friends to BGF. The commitment of our Friends will assist the organisation to plan ahead and commit with confidence to projects. The commitment of our Friends will also give BGF a more powerful stand to advocate the needs of PLWHA. This is something we can't put a value on. For as long as it is needed, BGF is committed to carry on fighting the poverty trap faced by growing numbers of men, women and children who are living with HIV/AIDS in our community today.

AIDS is everyone's business, it doesn't discriminate and it isn't going away. A huge and heartfelt thanks to everyone who has donated their time, energy or support to BGF in the last fifteen years.

Georgina Harman
Executive Director

bgfmajorevents history

1984
May The first AIDS event in Australia at the Midnight Shift raises \$6,000 to help care for Bobby Goldsmith

June Bobby Goldsmith dies

September BGF officially formed by Trust Deed under the name the AIDS Benefit Fund ● The first information brochure on AIDS and safe sex titled G'Day is published ● Trustee, Peter McCarthy, granted funds to establish the Community Support Network (CSN)

December BGF and the AIDS Action Committee call a meeting to devise a unified and centralised body to tackle AIDS. This body would subsequently be known as the AIDS Council of NSW (ACON)

1985
February 1985 In conjunction with the Gay Counselling Service, BGF provides funds for the 'Rubba Me' safe sex campaign ● BGF helps organise an AIDS public awareness meeting at the Teachers Federation ● The AIDS Benefit Fund renamed the Bobby Goldsmith Foundation Incorporated

1986
February BGF granted status of a Public Benevolent Society and registered charity of NSW



September First Boys Own Bake Off held at the Seymour Centre



February BGF raises funds at Mardi Gras for the first time

April The BGF organisational structure is reviewed and a permanent administration officer appointed ● BGF wins the CAPS Award for community service at the Imperial Hotel

August Aid for AIDS Celebrity Auction at the Wharf Theatre, in memory of John Galletly, founding President of BGF. The event raises over \$20,000

September BGF gives \$10,000 to St Vincent's Hospital AIDS Ward to buy medical equipment

1987
 BGF takes on two more staff members

1988
 BGF has 120 clients

1995
 Of the 1,995 known AIDS cases in NSW, 837 are clients of BGF

June BGF is the first organisation in Australia to sell red ribbons to raise awareness about HIV/AIDS



1993
February Red Ribbon Ride raises over \$43,000 ● First Shop Yourself Stupid raises \$20,000 ● Mardi Gras Cash Collection raises over \$32,000

August Teddy Auction at the Park Lane Hotel raises \$97,000



1994
 Client Services and Housing sub-committees formed ● First BGF Raised Seating at Mardi Gras Parade

1995
 Client expenditure breaks the \$300,000 mark ● Staff increases to four full time, one part time

November First Fantasy Auction at the Imperial Hotel raises over \$32,000



1997
January BGF Supported Housing Project established

July BGF becomes eligible to distribute EAPA vouchers for payment of clients' electricity accounts

August Bobby Goldsmith House opens its doors

November Financial Counselling Service launched ● Client Services promoted for the first time and demand increases by over \$100,000 to \$429,541.

December BGF office moves from Riley Street to the ACON building in Commonwealth Street

1998
September Friends of BGF program launched

December Affair98 at the Green Park Hotel raises \$40,415 ● BGF conducts an organisational review

1999
June Executive Director appointed

July Bobby Goldsmith House celebrates its second Birthday ● BGF launches its second supported housing project - the Floating Care Initiative

September 15th Anniversary of BGF

Bobby Goldsmith was a Sydney gay man who died in June 1984 of medical complications caused by AIDS. He was 30 years old.

Bobby was an active member of the gay community and had a wide circle of friends. He is remembered as Australia's swimming sensation at the world's first gay Olympics in 1982, bringing 17 medals (11 gold!) home from San Francisco.

As Bobby's health deteriorated, a group of his friends got together to find a way to care for him at home, instead of going into hospital. They organised the first major AIDS fundraising event in Australia which took place on Mothers' Day 1984 - a party at the Midnight Shift on Oxford Street. The money raised was used to buy a wheelchair, a commode, a video recorder and a special support mattress. With this assistance Bobby was able to maintain a more comfortable life at home.

Although Bobby died a few months later, an idea had been born. Named in his memory, the Bobby Goldsmith Foundation (BGF) was formed by Trust Deed on 11 September 1984. Fifteen years later, BGF continues to provide services to help improve the quality of life of PLWHA. In 1999, the client services now help a staggering 15 percent of PLWHA in NSW.

The BGF mission

Our mission is to assist people, who are directly disadvantaged by HIV/AIDS, to maintain a reasonable quality of life. To do this BGF provides financial assistance, financial counselling and supported housing.

\$10,000,000 ... and still counting

Over its 15 year history, BGF has raised \$10,892,695 to help PLWHA. Overwhelmingly, this money has come from the pockets of concerned individuals and businesses. In 1998, 63 percent of BGF income came from events, appeals, donations and bequests.

1985/86	\$148,608	1987	\$162,243	1988	\$472,282	1989	\$312,519	1990	\$348,513
1991	\$404,636	1992	\$522,165	1993	\$1,445,288	1994	\$637,196	1995	\$783,700
1996	\$1,379,970	1997	\$1,308,995	1998	\$1,804,477	To June 1999 \$1,162,103			



*Vincent Dobbin died in the company
of family and friends in Ward 17 of
St. Vincent's Hospital, Darlinghurst.
A long-term survivor of HIV, Vincent
died from an acute, undiagnosed
infection after a brief illness.*

*October 28, 1949
July 26, 1999*

The next day, a Mass of Thanksgiving was celebrated in the beautiful Chapel of the Sacred Heart Hospice, Darlinghurst. The large congregation came from many walks of life and reflected the rich and varied life Vincent had led.

Vincent was educated in Ayr and Mittagong. At different times, he completed degrees in both Arts and Law and had studied for the priesthood. His first profession was that of teaching. Later he was admitted to practice as a Barrister of the Supreme Court of New South Wales.

In the course of his eulogy, Tim Ostini-Fitzgerald, close friend and fellow Barrister, spoke of Vincent's great calm and skill as an advocate and of the high regard in which all his colleagues held him. Suffering the effects of the virus, Vincent retired in 1994.

By then his partner, Noel had died and even in 1999, Vincent spoke of the lingering shards of pain he still felt at that loss. Despite that grief and his own less-than-robust health, he threw himself into a life of voluntary work, committed to advancing the interests of others living with the virus.

Vincent joined the HIV/AIDS Legal Centre as a volunteer and went on to be employed as its Coordinator in 1998, a position he held with distinction until his death. The current President of the Centre's Committee, David Low started as a volunteer there around the same time as Vincent. He speaks of Vincent being inspired and highly motivated by the urgency of the needs of the positive community. Committed beyond the duties of his position, Vincent was always patient and welcoming to those with whom he dealt.

HALC was not the only community organisation to benefit from Vincent's selflessness and energies. Joining PLWHA (NSW) Inc., he was appointed its Secretary in the course of 1995-6. The following year was a critical time for the association as it began its devolution from the AIDS Council of New South Wales. An essential part of this process was the successful development of an enterprise agreement.

Luke Smith, the Finance and Administrative Officer of PLWHA at the time, recalls Vincent's skill and devotion to this task, whether it was in research or negotiations, providing the vital lynchpin between staff and management committee. Happily, Vincent's labour was rewarded with the joint receipt of an Attorney General's Award earlier this year.

Vincent worked tirelessly to ensure the voices of positive people were heard during the debate on the Northern Territory's euthanasia legislation. He was one of the early convenors of the organisation's Legal Working Group.

It was in this capacity that I met Vincent Dobbin. I had also retired from a career as a barrister and it is to my great loss that I did not know him in those earlier days. For me, Vincent played an invaluable role, showing me, by example, the way back to a productive life. My memories of his gentle encouragement and other acts of kind support are ones I shall long hold dear.

At about the same time as Vincent was planning to go to this year's Mardi Gras Party, he was unable to attend some committee meeting, he informed me, because he was playing the organ at his local church. All this told me much about the rich quality of Vincent's life.

With many others, I mourn the loss of a good man, one who lived his life with grace and dignity. Many have come to value highly his contribution to professional life and to the positive community. His family spoke of how he died peacefully, and at peace, untroubled by fears of death. If one can speak of 'a good death', Vincent had such an end to his life. No one could doubt it was his just reward.

An innovative approach to peer support has introduced a group of positive women to complementary therapies. Sue* was at the recent Pozhet Women's Clinic and reports that the day was an absolute success.

Absolutely Fabulous

The Absolutely Fabulous Women's Clinic, held on a sunny July afternoon at the Tree of Hope in Surry Hills, was an absolute winner. Fourteen women came from Newcastle, Western Sydney, and the Blue Mountains and across the metropolitan area to be cared for by women practitioners.

Show of strength

The Clinic showed the strength of women caring for each other. The atmosphere was fantastic: busy yet peaceful, deeply nurturing, full of warmth, laughter and wisdom, and a shared understanding of the issues women face living with HIV/AIDS. The Clinic was a women's space of fun, comfort and indulgence.

By the close of the afternoon we were so relaxed we couldn't even talk!

Screens, furniture, massage tables, greenery, oil burners and soft music created small, private consultation spaces. In this intimate and comfortable setting women chose a mix of treatments over two hours. An outdoor café in the Tree of Hope garden was for tea and cakes, chatting and soaking up the glorious winter sun.

A smorgasbord of therapies

Forty appointments were quickly booked out. Monique gave practical advice on nutrition and HIV and brought lots of goodies. Sue and Betty gave relaxing Swedish massages that blissed everyone out. Irene and Alex helped a Pozhet member who came especially for their session with expert advice on HIV and pregnancy. Jo's wisdom and experience in HIV treatments were invaluable and reassuring. Toni brought a friend and together they gave superb Reiki massage. Miranda's appointments were an opportunity for expert advice on better sexual health. Noeline filled the room with aromatherapy fragrance and Marie and Jan unwound tension with Reflexology. Renata gave comforting, sensitive psychic readings to the many women who lined up well into the afternoon to see her. Gina and Deirdre worked hard as the reception staff. Patricia and Margaret kept it all running smoothly.

Enthusiastic response

David Barton, coordinator of Pozhet, was overwhelmed by the response of therapists. "Everyone I approached was happy to donate her services. The clinic provided networking opportunities but many of them also felt that heterosexual positive women were getting little in the way of services. Many of the women who came had never tried complementary therapies so this was a great opportunity for everyone to learn and have fun. It's a new way of thinking about peer support."

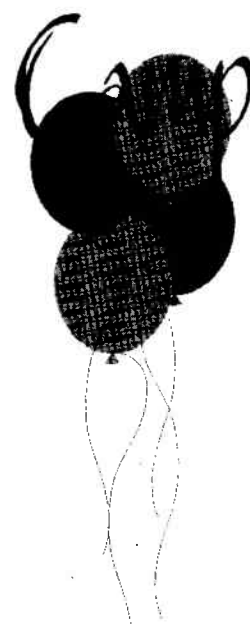
Pozhet plans to run another Absolutely Fabulous Women's Clinic and hopes to run a similar clinic for heterosexual men. Anyone interested in signing up for the next women's clinic can contact the PozHet freecall service on 1800 812 404. ■

**Not her real name*

Congratulations to the winner of the Opera ticket raffle. Enjoy! Absolutely grateful thanks to the Redfern HIV/AIDS Community Team, Sacred Heart Hospice, NSW Midwives Association, Family Planning NSW, AIDS Treatment Project NAPWA, Pozhetwest, Tree of Hope, and St. Vincent's Bereavement Service. And cheers to Opera Australia for supporting the first of many Pozhet Women's Clinics.



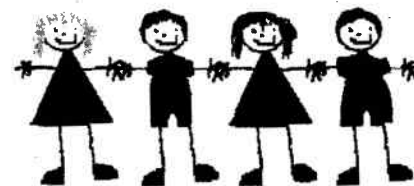
2000
Goodtime
January 21-24



A special place for summer fun, relaxation and respite for children and families living with HIV and AIDS. Camp Goodtime is free to all who attend.

For further information and an application form phone Cassie Romberg 9382 1851 or Michele Goode 9382 1654.

"It's my second time. I like all the fun things. The Best thing is all the people you get to meet and all the memories."
Matilda (aged 8)





The jury is still out on whether or not women experience HIV disease progression at lower viral loads than men.

Megan Nicholson reports.

A National Study about the Lives of HIV Positive People

For a copy of our confidential survey

Phone 1-800-064-398

hivfutures@latrobe.edu.au

www.latrobe.edu.au/hiv-futures

also at AIDS councils and PLWHA groups

earing the lead

Viral load is a key marker in HIV disease progression. The higher a person's viral load, the more chance they have of disease progression. Generally, a viral load above 5000 or 10000 is thought to put a person at considerable risk of disease progression. When disease progression occurs, CD4 count falls and opportunistic illnesses may occur. Most of the data on viral load has been collected from large cohorts of gay men and men with Haemophilia.

Research shakeout

A study published in the *Lancet* by Dr H Farzadegan in November 1998 found a trend towards lower viral loads in women than men, when CD4 counts were matched. Although not all the results were statistically significant, this study found on average that women had 0.25 log lower viral load than men at equivalent CD4 levels. Three previously published studies found no evidence that women have lower viral loads than men. The Farzadegan study analysed the results and found that women were at 60 percent greater risk of developing AIDS than men with similar viral loads and CD4 counts. This finding has caused a flurry of research into women and viral load. Swiss researchers reviewed data from the Swiss HIV Cohort Study and found that female injecting drug users had lower viral loads than men, but that women who had never injected drugs did not.

Women and IDU

So, is injecting drug use (IDU) a factor in viral load? Not necessarily. Another study, also published in the *Lancet*, found the opposite of the Swiss review. Non-injecting (heterosexual) women were found to have a 0.25 log lower viral load than men. In contrast, average viral load for all women in the study (including IDU) was only 0.13 log lower than in for the male cohort. More recent data has lent further weight to the argument that women with HIV have lower viral loads than men with similar CD4 counts. Dr Anne Rompalo and colleagues from the Johns Hopkins University in the United States reviewed data on over 700 women; half of the women had a history of injecting drug use. When controlling for CD4 level, Rompalo found that viral load was substantially lower in this group of women, compared with the viral load of men in the Multicentre AIDS Cohort Study (MACS) and the AIDS-Linked Intravenous Drug user Experience (ALIVE) study.

Inconclusive

However other studies have failed to find any difference in viral load between women and men. A review of the Johns Hopkins database did not find a significant difference in viral load based on gender. Another study looked at the viral load of women from the Women's Interagency HIV Study (HERS) and the viral load of men from the MACS study, finding a very slight difference (about 0.1 log). Furthermore, the difference only occurred among women and men with high CD4 counts.

While some research shows that women have a slightly lower viral load than men at equivalent CD4 counts, other research has found no difference. While women with HIV may keep in mind the possibility of gender differences in viral load and disease progression, further research is needed before there can be any definitive advice specifically directed to women concerning disease progression and response to treatment. ■

This is a very smart virus and can lead you and your doctor on a merry dance as **Tim Alderman** discovered.

games

The moral to this story is never to brag! I'd been telling a work colleague that my weight was over 70 kilograms. This was a record I was damn proud of. My health, including T cells and viral load, had been excellent in the 18 months since I'd returned to work. I may have become complacent about my good health. Within a few days chaos had set in, and I had to fight for my treasured weight.

It started simply. The peripheral neuropathy (PN) in my feet is slowly progressing. When the staggering started, I immediately thought this was just another phase in the PN. I could not walk a straight line, and staggered quite visibly from one side of the footpath to the other. At the time, I mentioned to people that I wasn't feeling 'right'. I was going through some changes to my combination therapy, and thought that may have had something to do with it. Well, it did! But not in the way I expected.

It became an effort not just to get up in the morning, but to get dressed, and to motivate myself to get to work. I lost my appetite, and libido. Then I started to drift off to sleep on the bus and in front of the TV at home. When I nodded off in front of the computer at work I realised something was seriously wrong.

I had iron, folate, B12 and Thyroid tests. They were all normal. I went to Albion St Clinic and tested negative for Addison's disease. I had Gallium and CT scans, and nothing showed up. By this stage, my walking had deteriorated to such an extent that I was relying on a walking stick to get around. I was even prescribed an anti-depressant. My weight dropped to 58 kgs, and I had no appetite at all. Going out anywhere was a long ordeal, the only advantage was that I always got a seat on the bus.

My doctor eventually ran out of possibilities and made an appointment for me to see a neurologist at St. Vincent's

Clinic. His diagnosis wasn't hopeful. He told me it could have been one of several very nasty diseases, including one called PML. I didn't actually know what PML was, but the look on his face said all that had to be said. There was a possibility of undetected Syphilis infection from years ago, but a test soon cancelled that option out. He decided that I should have a magnetic scan. These scans are more thorough than CT scans, and more likely to disclose problems.

As mysteriously as it started, it began to reverse. When I returned to the neurologist a week and a half later he was as surprised as I was to see me walking again.

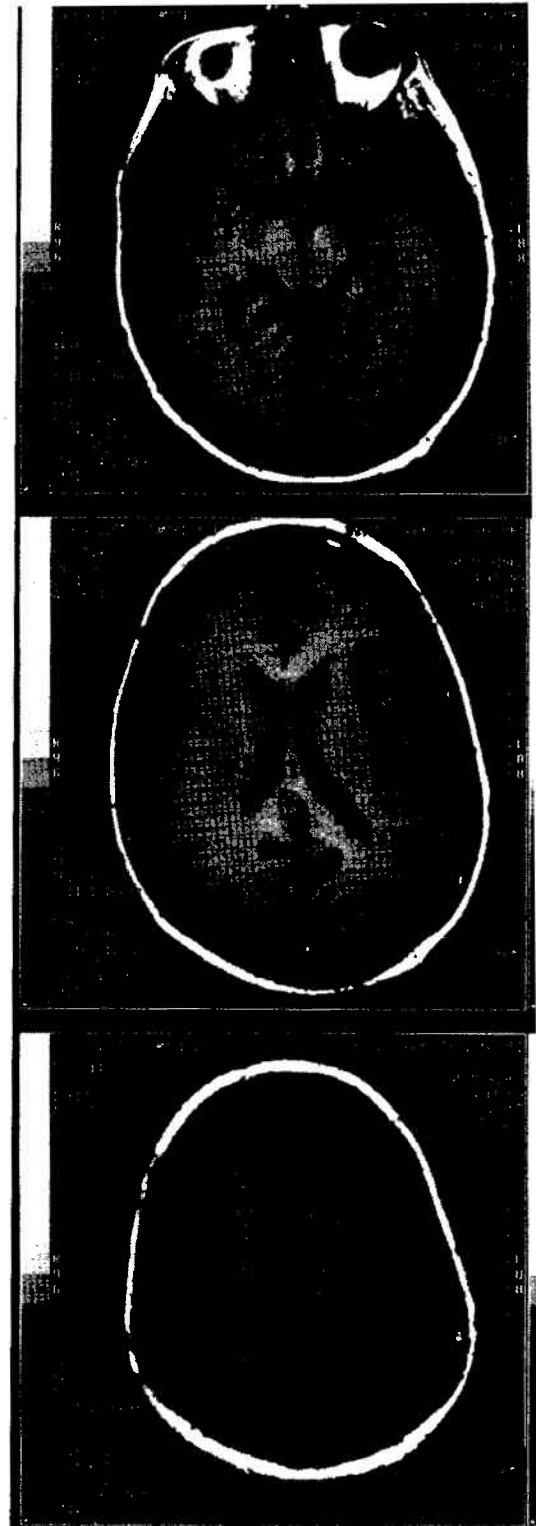
The story was there in the magnetic scans; they showed clearly visible evidence of HIV infection on the brain.

To say this frightened the shit out of me is an understatement. I am very good with my treatments, and consider myself 95% compliant, which is good, considering how many pills – and for how long – I swallow.

Somehow, the virus had used an opportune moment between combinations to cross the blood/brain barrier. Everyone on combinations takes at least one drug to prevent this happening, so it shows you how persistent the virus can be. It doesn't so much hide as sneak around, looking for opportunities to invade various parts of us that are not so well protected. I stared at the magnetic scan images, and admired just how sneaky it can be. The pale grey 'clouds' that drifted over the image of my brain were evidence of its brief visit. It would be some time before I forgot the disorientation and fear it caused.

If I ever thought there was an argument not to take drug holidays, this is it! What damage it could have done to my brain horrifies me, especially the prospect of Dementia. They seem to think that the anti-virals brought it under control, and for my sake I hope they're right.

A month later I am back to normal – appetite, energy levels, libido, the works.



The virus as it appeared, temporarily, "like pale grey clouds" on Tim's brain scan.

I hope to return to work within the next month. The lumbar puncture to check viral load in my spinal fluid came back undetectable. Over the period of the illness my plasma viral load rose for the first time in almost two years. The frightening part is that within one week, it rose from 3000 to 19000. It is now back under control.

Almost all my time as an active gay man has been spent as HIV positive. I have put up with, and survived, a number of HIV related illnesses. I intend to live a lot longer with it. If drugs and hope are the ways and means I have to use, then that is just what I will do. ■

setting new standards

The Lifestyles Unit (LSU) at Long Bay Prison is a health-based education program that targets inmates who are HIV and/or Hep C positive. It is the only unit of its kind in the world. The Unit is the initiative of the HIV and Health Promotion Unit, the health promotion arm of the NSW Department of Corrective Services. The unit is funded by the DCS and the NSW Health Department.

The health based education model used in the Lifestyle Unit has proved so successful that the department has confirmed plans to open a similar unit at Mulawa Women's Prison.

Personally I find it very rewarding to work in the LSU. It's exciting to introduce inmates to the various disciplines available in the unit (usually for the first time) and to see the changes taking place in them. It is rare to see no improvement in people, whether it is to their general wellbeing, emotional growth, an improvement in their blood results, or all of the above. We've had a couple of PLWHA whose viral load has become undetectable without taking combination therapies during their stay in the unit. Having said that I wish to make it clear that inmates are always encouraged to make their own decisions with their treatments and are always fully supported, whatever protocol they choose. One of the benefits of being in the LSU is that it is possible to monitor inmates and offer a very high level of support when they are undergoing a new treatment.

When it opened Lifestyles was designed to cater exclusively to HIV positive inmates as part of a comprehensive effort to address the issue of HIV within the

prison system. The rapid rise of hepatitis C, has meant that the focus of the unit has shifted to address this additional health issue. The unit now holds one three-month HIV course, and six, seven-week Hep C courses a year.

Numbers for each group are limited to eight inmates to allow for intensive case management. Although officers do not take part in the groups, they are encouraged to interact with the inmates, and are often invited to share a meal; this has proven to be a great way of breaking down barriers.

... the Lifestyle Unit has proved so successful that the department has confirmed plans to open a similar unit at Mulawa Women's Prison

Both programs use the Integrated Medical Model, in which inmates are encouraged, through education and counselling, to explore alternative and complementary disciplines and then integrate this knowledge into their treatment protocols. They are encouraged to take responsibility for their own health and to adopt a proactive approach in the management of their individual health issues.

In the assessment stage of the program, inmates are assessed for Alcohol and other drug issues (AO&D) and literacy and numeracy problems. Any problems that show up can then be addressed during their stay in the unit. There is a weekly AO&D session and one to one counselling when possible.

The program is structured and fairly intensive with an emphasis not only on living skills such as cooking, hygiene, and nutrition, but equally on psycho-neuroimmunology which is addressed by groups covering Reiki, meditation, Reflexology, various concepts of spirituality and communication skills. There is also an art class that introduces creative expression and a TAFE accredited fitness leaders course. The exact content of the groups obviously will vary according to the interests and needs of the individuals in the groups.

A vital part of the program is the weekly support group run by a psychotherapist specialising in grief and loss issues. Outside agencies are invited to the unit to present the most up to date information on treatments and other issues.

Individual blood analysis including PCR (test used to measure viral loads) is done. A public health nurse and the professor of hepatology and immunology visit inmates to explain the results, treatment options and the procedures involved.

The naturopath/nutritionist attends the unit for three hours each week to go through each inmate's blood analysis as well as covering nutrition and general health issues. The approach to both the HIV and Hep C virus is two tiered - suppression and immunological support. To facilitate self-empowerment, the immuno-suppressive actions of drugs - both legal and illicit - is covered at some length. Specialists also supervise access to a vitamin and herbal tonic protocol that is provided free to the participants in the program. (Inmates not in the program can access these vitamins at a wholesale price through a distribution scheme run out of the LSU.) ■

Vassilly* is currently in Long Bay Prison and has completed the Lifestyles Unit course. He shares his story.

hardpressed

Being in jail in 1999 would have to be the most traumatic experience that any one could go through. Our jails are at their worst and it's not getting any better! I've spent the last 7 out of 10 years in jail (I'm not proud of this). When I was released last time I thought, "well that wasn't so bad", but let me tell you, this time I will be trying my hardest to never come back.

My advice to you is to think twice about coming to jail: it's hell. There are people out there thinking 'oh, it's just a week, I can handle it'. But once here - I don't care who you are, or how tough you think you are - deep down nobody wants to be here. I could sit and write a whole book on all the bad shit I've seen, but I would be hard pressed to fill one page on the good stuff. If you are HIV positive, gay, different from the majority, or show any sign that you are weaker, it makes it all the harder.

I've been HIV positive for 12 years, and doing well. I am from a European background. I think that makes it hard for

my family to talk to me about HIV. My father left when I was young and I don't see him. I live with my mother and have two sisters. They never ask me questions about being HIV positive. Sure they ask me how I'm going, and how I feel, but if I start to tell them about treatments, they get uncomfortable, so I don't push.

Getting treatment in jail is, to say the least, very poor. The prison medical system is very slack and unsatisfactory. You can wait up to three weeks to see the doctor, and if you are seen seven days after you put your name down then you're doing great! There have been many occasions in the past when I have had to miss my meals (and my treatments) for some reason or another. If it wasn't for the HIV and Health and Promotions Committee (at Long Bay) and John Cummings at ACON, things would still be the same. I made complaint after complaint, and now it is easier to get my pills when I need them. But things should be better for all inmates. I don't want to say much more as I still need to get medical assistance. ■

Not his real name

HIV, Hep C & NSW prisons

- ◆ There are a total of 27 prisons (including one private) in NSW. This includes seven maximum, eight medium and eleven minimum security prisons.
- ◆ Since the Lifestyles Unit opened in 1992 approximately 40 people a year have taken part in the Hep C and HIV programs offered.
- ◆ There are 7300 people in full time custody in NSW - 6850 men and 450 women.
- ◆ Of the total prison population in NSW between 0.2 and 0.5 percent are recorded as HIV positive. The Department of Corrective Services records a slight decrease in the recorded numbers of HIV positive prisoners since the unit opened in 1992.
- ◆ Officially, 40 percent of NSW inmates are recorded as Hep C. In 1997, the NSW Department of Corrective Services HIV and Health Promotion Unit reported that 80 percent of women prisoners were testing Hep C positive.
- ◆ The first comprehensive study of Hep C in the NSW prison system was done in 1997. As yet there are no comparative figures for assessing change in the Hep C prison population.
- ◆ No figures are available regarding the incidence of dual diagnosis.
- ◆ The greatest percentage of inmates (20.4%) are serving terms of between two and five years.
- ◆ Around 10 percent of inmates are serving sentences for drug offences but surveys by the DCS show that 70-80% are in prison for drug related crime. For example, robbery to support a drug habit.

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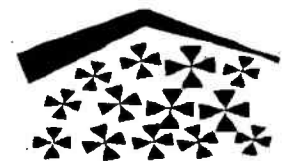
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Important Announcement



POSITIVE LIVING CENTRE

*Due to capital improvements at 703 Bourke Street,
the PLC will temporarily be re-locating to*

**The (un)Common Room
Level 2, RSSCHC, Joynton Avenue, Zetland
from the 3rd of August, 1999**

*Whilst at Zetland, the PLC will open
Tuesday - Friday from 10.00am to 3.00pm*

During the relocation our telephone number will remain the same

9699 8756

For most inmates prison has become a revolving door. For the first time, there are over 7000 prisoners within the 28 prisons in the NSW System. Each year, there are 15,000 receptions into prisons. The average stay is just over seven months. For administrative or security reasons, prisoners are moved about within the system: in 1998 alone there were over 20,000 prisoner movements.

because of the needles. Other than the services available through the Lifestyles Unit at Long Bay Goal there are no subsidised alternative therapies available for inmates in the NSW prison service. Vitamins are available at wholesale prices to the general prison population in Long Bay Goal. Prisoners can apply to receive a visit from an alternative therapist, in much the same way as they apply for a legal visit. The cost of such services is no doubt prohibitive for the majority of prisoners. That's as good as it gets.

given for sharing a cell. In these circumstances, confidentiality about a prisoner's HIV status goes out the window. More than that, each time a positive prisoner is transferred within the system, they have to go through the whole process of being found appropriate accommodation.

When a prisoner finally emerges from those revolving doors, it is essential that adequate medical treatment continues. Either the Corrections Health Service – responsible for the health care of prisoners – or the HIV Lifestyles Unit at Long Bay,

Revolving Doors



Douglas Barry, who sits on the Legal Working Group at PLWHA (NSW), considers the implications for HIV positive prisoners.

I have sometimes thought about my being in prison. Apart from the fantasies of *Prisoner*, and whatever else I have seen on television or in the movies, I find it difficult to imagine how it feels to be locked up, day in and day out.

I have visited people in gaols and been conscious of what it meant for those heavy iron doors to be shut behind me. I could go home at the end of the visit – to my world of making my decisions, for myself, about myself.

Solzhenitsyn, writing from his experience in the Russian gulags, said that "the thoughts of a prisoner [are] not free either. They keep returning to the same things."

I am HIV positive and have maintained an undetectable viral load for three years. If I was in prison, my thoughts would keep returning, I know, to my health: to the virus and my medication; I'd worry about whether I could stick to my drug regime and about what could happen with side effects.

Earlier this year, on behalf of PLWHA (NSW) Inc., I went to a Public Health Association Conference about health in prisons. Later I did some reading to find out about positive prisoners in NSW. That's when I began to think about how positive prisoners in NSW prisons cope with their treatments.

For those who want to use alternative or complementary therapies, the position is simple: access is extremely limited. Only conventional medicines are fully subsidised by the authorities. Acupuncture is out

The problems for positive prisoners considering or attempting to maintain a treatments regime can be many – there has to be a medical file which keeps up with the individual prisoner, each and every time that prisoner is transferred within the system. What happens when the file is delayed and a positive prisoner needs medical attention?

For those who want alternative or complementary therapies ... access is extremely limited.

What happens to an inmate on combination therapy who is to be transferred at short notice and who simply isn't given the time to collect his or her drugs before moving? We are all warned about the dangers involved in not adhering strictly to drug regimes, of the potential for drug resistance to develop. I can only guess at the anxiety of such a prisoner as he or she is bundled off into those revolving doors without their combination therapy.

When the health of an individual is dependent on daily, routine access to medication, there is great potential for abuse in the form of prison authority.

The policy of the NSW Department of Corrective Services is for HIV positive inmates to be housed alone in a cell, unless they request single accommodation or the informed consent of another prisoner is

may have introduced a positive prisoner to proper medical care for the first time, or to a responsibly healthy lifestyle. Those efforts will be wasted unless there is adequate direction and encouragement given to a prisoner on release into the general population.

Positive people, with their freedom, experience enough difficulties in adhering to treatment regimes, whether in the work place or around any social activity. It's not a great leap of the imagination, then, to realise the problems a positive person just released from goal must face with treatments. Yet, one of the principles of imprisonment is, ideally, that the NSW Department of Corrective Services has a duty of care to provide appropriate medical services to inmates. Ideally this would be comparable to that enjoyed by the general population. Is that wishful thinking? Probably.

The basic problem lies in the authoritarian and correctional nature of prisons – prisons function through discipline and restriction on freedom of movement. A positive prisoner must have a compassionate and flexible environment that acknowledges a basic human right to have access to regular and appropriate health care.

As Mr. Justice Michael Kirby of the High Court of Australia has said, people are sent to gaol as punishment, not *for* punishment. To place obstacles to adequate health care in the way of HIV positive prisoners, to let them be swept up and lost in the revolving doors of the prison system, is an extra punishment. ■

Maximum Risk



Photo Geoffrey Williams

For Ruby* coming out as HIV positive in the Victorian prison system is a big no no.

I am HIV positive. I first found out I was HIV positive almost six years ago when I was in prison. They test you for HIV and Hep C every time you go to prison. I had been tested when I went to prison six months before and my results were negative. I had been a few months on the outside before I went to prison again. I think I got HIV sharing needles with a friend of mine. I thought I would be safe because I figured it was safe to share with a friend. I didn't know you could get HIV from a friend.

When I first got HIV they used to put you into B Division at Pentridge Prison†. Pentridge was the men's prison and B Division was one of the oldest most run down sections of the prison. There was only ever ten to twenty women there at a time and they came from all over Victoria. We all knew that we had been separated because of our condition but no one talked about it much. We were all scared that the other prisoners would find out that we had been in B Division or that the screws would lag because if any of the girls found out our lives wouldn't be worth living, inside or out.

Now the prisons have been privatised they don't separate you from other

prisoners if you are HIV positive. You can't tell anyone that you are HIV positive and you can't take HIV medicine because it is too risky that the others may work it out or the screws may dob. I find it all a bit odd, everyone in prison has Hep C and there is not big time harassment or discrimination. It is OK to take Hep C medicine – women won't share drink bottles or use your knife and fork if you have Hep C – but it is really no big deal. I find this strange because I believe you catch HIV and Hep C the same way, but women are so scared of HIV. Well, I think they must be scared because it's not talked about and it is a big no no to talk about it or tell anyone you have it. I remember a couple of years ago I was in prison in Perth and rumours were going around about these two women that everyone thought were positive. The screws locked us in a room and told us no prisoners had AIDS.

I guess the final thing I'd like to say is that I hope more than ever I don't stuff up and end up in prison because my condition has worsened in recent months and I seem to be getting sicker from all the medications I have to take. Soon I won't be able to blame my sickness on Hep C because all the women know what the symptoms are like. ■

* Not her real name

† Pentridge Prison closed in 1997. There are 180 women in Victorian prisons. Women are now sent to either the maximum-security private prison at Deer Park or the low security prison in Tarrenrower. Testing new inmates for HIV and Hep C is not compulsory according to the Victorian Department of Corrections. The community advocacy group for women, Flatout, assists women with lifestyle issues once they are released including funds for medications and alternative therapies. ■

Got a story to tell?

Talkabout welcomes stories and letters from PLWHA.

In October **Talkabout** looks at St Vincent's Hospital, the Ankali Project, AIDS related dementia, employment ... plus a lot more! **For more information please call The Editor, feona studdert, on (02) 9361 6750, or email your story to feonas@plwha.org.au.** **Talkabout** welcomes your feedback on future directions for the magazine – so get involved ... it's your magazine. **Deadline for the October issue is 10 September, 1999.**



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



Dream Realising

Tim Alderman took part in the first workshops of the innovative Coláo Project. He tells *Talkabout* why the project's closure has created a hole that needs filling.

There have been many plans and dreams for PLWHA in Sydney. Many have failed, some have worked okay, and a few have worked well. Amongst those that worked well, the Coláo project stood out.

From the beginning, life-saving drug combinations have been a problem. They demand unbelievably difficult compliancy, and many PLWHA experience awful side effects.

For a long time now, the needs of people on combination therapy have not been met. Doctors and clinicians see the problem from a clinical perspective: Your viral load is suppressed, and that is how you must keep it, regardless of personal cost. Compliance and side effects are a big problem. Many newly diagnosed PLWHA

are not taking up treatments after hearing horror stories from people on combination treatments. Others are touting drug holidays, and yet others are giving up their regimes completely. The answer for many of us lies not in HIV support, but in treatment management.

Eighteen months ago, there came a bright light in treatment management called the Coláo Project funded by drug company money, (Roche Pharmaceuticals) and run by an occupational therapist with many years experience working with PLWHA. Coláo heralded a new dawn for PLWHA struggling with treatment management. Tied in with how to maintain the momentum that you needed to take treatments over a long period of time,

were concepts of self-motivation, and stress management. Being involved in the first Coláo project group, I received many benefits, including the ability to re-establish myself in a work environment, and to begin dream projects that I had never had the motivation to pursue. I was not the only one drawing on Coláo for new impetus. Many plwha went through Coláo's doors in the two years it operated.

Then, without warning, a small notice in the local press to say Coláo had closed its doors. No reasons, and nothing to replace it. The AIDS Council of NSW, (ACON) is one of our major HIV organisations. Surely it can see that Coláo was a successful model for treatment management. Have they considered taking it out of private hands, and placing it in the hands of the community? I know that Roche did not withdraw funding. The closure is through no fault of the drug company but surely by now we are sceptical enough to realise that corporate grants and sponsorships are not guaranteed; any service or project that is dependent on such funding is vulnerable.

The fact that the whole concept of Coláo was left in the lap of this one project shows an incredibly short vision. ACON is currently running a campaign to discourage people who are on combinations taking drug holidays.

This is being done without a treatment management group for PLWHA, which makes the entire campaign difficult if not futile.

The answer for many of us lies not in HIV support, but in treatment management.

Something has to be put in place quickly; how many PLWHA will stop their drugs before this problem is rectified? The answer lies where it should have been found in the first place - with the community sector. ■

Facing the future

Coláo Project was created in November 1997. It aimed to assist people with HIV/AIDS to deal with the diverse issues they face when living with the demands of antiretroviral combination therapies, and changing life issues. The project closed in June 1999.

The project was NSW based and funded through an educational grant from Roche Pharmaceuticals. It was set up as an independent clinical support service, based in the heart of the community scene in Oxford Street, Darlinghurst.

The project provided practical skills training and support, based around a problem solving approach from the perspective of a professional occupational therapy model. Occupational therapy aims to alleviate dysfunction, and enable individuals to develop to their highest potential in all aspects of living, but primarily through the acquisition of practical skills required in achieving everyday tasks.¹

The Project Coordinator – Pene Manolas – played an integral role in the project's conception and development. She was the clinical facilitator of the service from the initial proposal stages through to its conclusion.

A referral system was established between the project and HIV prescribers and other health professionals, many of whom reported a high degree of satisfaction with the service due to the perceived benefits that patients had gained from their involvement. It should also be noted that a number of health professionals reported that they had gained a better understanding of their patient's psychosocial issues around treatments, as well as being prompted to consider others who may benefit from the service.

The project was also operated with many clients self referring, or being introduced by other clients to the service. This is a significant statement of the support many PLWHA had for the Coláo project, but it is also an indication of the need for a service which a large number

of clients have identified as being independent and autonomous from other community based organisations, or hospital clinical services. Due to the structure of the workshop outlines, and the follow up for prescribers with feedback reports, Coláo was also acknowledged as a service which could quickly address support needs for PLWHA dealing with complex therapy regimes, and their ramifications.

Clients were offered a holistic assessment at their first interview that took into account all aspects of a client's life, both psychologically and physically. The assessments would consider everyday coping mechanisms, and psychological adjustment to the changes that are experienced when experiencing the positive and/or negative effects of antiretroviral therapies. These assessments formed the basis for placing appropriate participants in the workshops being offered in the program.

The three initial workshops developed were:

- Maintaining the Motivation: pushing on with treatments,
- Stress Management: a skills development workshop; and
- Goal Setting: re-establishing control and Facing the Future.

Workshops usually ran for six weeks, with two hourly sessions, and an average of eight participants in each group. They were run by the Coordinator as closed groups, and offered as either evening or day schedules.

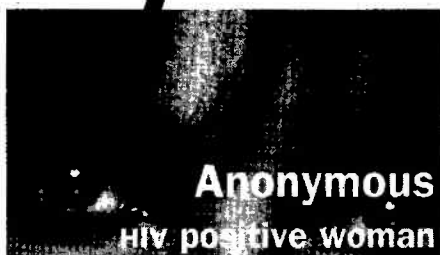
In short, this was an innovative and professional project that offered initial clinical assessment and developed within a facilitated peer workshop format. It appealed to PLWHA who wished to explore a range of issues in a more anonymous and structured format. It also appealed to those prescribers and health professionals who saw the service as a complement to their own client/patient services, and who gained professional support through having another referral option for their patients. ■

¹ 1999; Manolas, P – Coláo Project Report.

The Coláo project was a great success for many Sydney PLWHA. **Jo Watson**, Coordinator of AIDS Treatment Project Australia, was a member of the Coláo Project Advisory Group. She looks at some of the reasons for the project's success.

The question of how service providers can best adapt to the changing needs of PLWHA is one of the major debates of 1999. **Michael Riches** asked six people what the HIV/AIDS sector does well, does badly, where the gaps are and what are the opportunities for improvement.

better



What do you think the HIV/AIDS sector does well?

The Positive Heterosexual group is good, but only two or three people are doing all the effort. The Positive Women's groups are good too, so I suppose group support is being well provided.

What things do you think the sector does not do well?

Referral to community organisations from doctors, especially for things like emotional support or psychosocial issues. There is not anywhere specific for people that are newly diagnosed, there is lots of information, but not for meeting other people, or to examine what issues being newly diagnosed brings.

Gay groups feel exclusive. I am a straight woman, and I think they think I am just a worker when I go to their events.

I would like to see a wider range of support for women, like night groups, retreats, structured groups with a training or educational aspect.

What do you think the gaps are across the sector?

There is nothing for heterosexual men. Even across multicultural or indigenous cultures, the focus is on gay men, or women. Communication between doctors and complementary therapists; they have no idea about working together.

What are the opportunities for the sector?

Courses or training on re-entering the workforce, relationships, and psychosocial aspects of being positive. What about the people who are not on treatments? How do they manage their health, work, and sex (lives).

What do you think the HIV/AIDS sector does well?

Access and research into treatments. Care and support. However the lack of numbers prohibits comprehensive access. Gay and lesbian education around issues of safe sex.

What things do you think the sector does not do well?

- More research and development into treatments for those whom (combination) therapies have failed to help
- Need to have more (treatment) options and not just rely on the United States. Not enough research is being done in Australia
- Education for non-gay identifying people
- Not enough use of local media (mainstream) in rural/regional areas

That many city people in the sector have little or no knowledge of the issues faced in rural/regional NSW

What do you think the gaps are across the sector?

- There is very little communication between the HIV/AIDS sector and natural health
- That many city people in the sector have little or no knowledge of the issues faced in rural/regional NSW

What are the opportunities for the sector?

- Opportunities to increase the level of communication between services

What do you think the HIV/AIDS sector does well?

- Addressing medication and related issues
- Addressing HIV and cognitive impairment
- Community nursing

What things do you think the sector does not do well?

- Funding transparency
- Collaboration and partnerships between health service and non-government organisations
- Creating forums to enable more 'voices' to be heard for example, plan for community discussion around issues that may make PLWHA feel demoralised

Gay groups feel exclusive. I am a straight woman, and I think they think I am just a worker when I go to their events.

Anonymous HIV positive woman

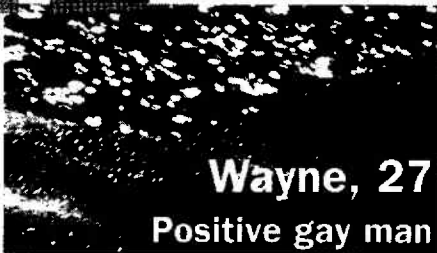
What do you think the gaps are across the sector?

- Advocacy for long term survivors
- Community health resources for 'difficult' clients
- Relationships between HIV GPs and other agencies

What are the opportunities for the sector?

- More partnerships arrangements between agencies
- Consultation with rural clients and services providers

Rw/Orse



Wayne, 27
Positive gay man

What do you think the HIV/AIDS sector does well?

- Creation of the structures (services) within the sector eg, Darlinghurst Community Health Centre, Ankali, CSN, and St. Vincent's Hospital
- ACON identifying the needs of plwha eg, the support groups, MAGs, Fun and Esteem, Long Term Survivors, HIV Living Project
- Community Education, use of posters as an education medium

What things do you think the sector does not do well?

- Clear and open communication within organisations eg, ACON
- That ACON seems to want to be seen as representing the gay and lesbian communities, where as I feel that their primary objectives should be to the HIV/AIDS communities
- Encouraging a continuous strong and committed volunteer base
- Organisations are sometimes too politically focused and therefore miss out on the grass roots necessities of the positive communities

Organisations are sometimes too politically focused

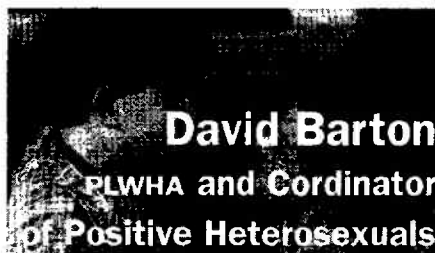
What do you think the gaps are across the sector?

- Doctors have such varying methods of practice and belief, therefore coercing consumers into things that they may not really want, or not giving them enough guidance

- Hospital outpatients and pharmacies not realistic in their opening times for the positive working person
- There needs to be an easier access to treatments and drugs

What are the opportunities for the sector?

- Greater sponsorship with mainstream companies to validate the PLWHA community
- Broaden our fundraising, make it fun, and use our environment
- Raise the profile of our service providers



What do you think the HIV/AIDS sector does well?

- The range of publications
- The treatment information and advocacy culture
- Sexual Health Centre services, counsellors and social workers are popular and heavily used by heterosexual positive people

What things do you think the sector does not do well?

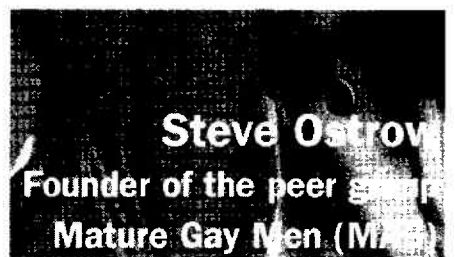
Services like Sexual Health Centres, counsellors and social workers are working hard, but in general we do very little face-to-face care and support for affected persons. Do we need forums addressing issues such as 'changing needs' when we know there isn't a homogenous HIV/AIDS community, or a unique positive experience of life, sex and treatments? We need tailored, on-the-ground peer support initiatives. It seems HIV/AIDS dollars are playing to a dominant set of concerns related more to the needs of service deliverers than to those of service receivers.

What do you think the gaps are across the sector?

Short, point-in-time, care and support interventions are not up and running. We need resources for counsellors and social workers who are our major face-to-face support. Our biggest gap now is planned support for positive people in renegotiating their broken relationships with the work, financial and training sectors of the wider community.

What are the opportunities for the sector?

We need to explain to the workplace, the money people and the educators what the 'Lazarus Syndrome' means. Get positive people's skills recognised with advanced standing in accredited training. Our troops of positive volunteers in HIV/AIDS organisations need formal skill recognition to give them currency in the job market. Accredited training under the Australian Qualifications Framework, within courses run by registered training providers, is the way to go.



What do you think the HIV/AIDS sector does well?

- Blowing the distinction between the positive and negative communities. The issues of positive people are as important as education for negative people
- Providing information to the positive community
- The information available on alternate and complementary therapies, and emotional support
- Lobbying is better than ever before, with good quality education in all of ACON's projects

What do you think is not being done well?

Getting the message across to the gay – but especially the non-gay population – that the present combination therapies are not the total answer.

There is still not a lot of support for older gay men. The support seems to centre on middle age and younger positive people. Many guys access MAG because they feel ostracised.

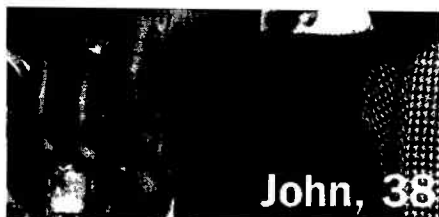
What do you think the gaps are across the sector?

There should be more support for those affected by HIV/AIDS, not only those who necessarily have it.

There is still not a lot of support for older gay men. The support seems to centre on middle age and younger positive people

What are the opportunities for the sector?

The gay community should organise itself towards more public relations humanitarian gestures aimed outside the community. The gay and lesbian and straight communities in so many ways have helped us; it would be good to give something back to third world countries, and positive heterosexuals.



John, 38

What do you think the HIV/AIDS sector does well?

Despite the fact that governments continue to retreat from their commitments to marginalised groups, (including the HIV/AIDS community), services have been retained and there is a level of support for PLWHA and those affected by the pandemic. The support exists because ordinary people remain committed and active and manage to safeguard the sector.

What things do you think the sector does not do well?

Contact with younger people and hearing how they understand what this dis-ease (sic) means.

More work needs to be done on making the sector inclusive for all PLWHA. Great efforts have been made to understand what is happening with Aboriginal communities or people from different cultural backgrounds. Some good women have spoken out and, with a lot of effort, stated their needs. But this inclusiveness remains elusive.

I know it is a contentious issue but HIV/AIDS needs, I think, to be seen as part of a wider health framework. Sure the crisis continues but I think we would be

listened to more if we were able to place our needs within a broader framework for healthy communities.

What do you think the gaps are across the sector?

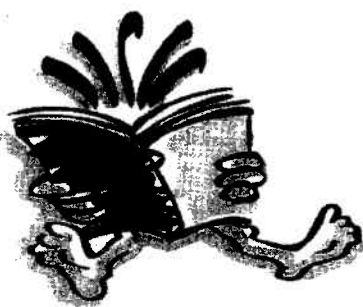
The positive/negative divide is still huge. We need to understand that medico-technological processes create this divide. We need to understand the health industrial complex as one that inevitably creates divisions. This is still the biggest gap – to find a space to talk about these things – I think the forums are a good initiative in this sense.

What are the opportunities for the sector?

Well I'm really going to go to town here. The opportunity, as always, is to understand how power operates in our society. Having understood what that means as people living with HIV/AIDS, people affected by HIV/AIDS or service providers trying to work to meet the needs of those groups we can then continue to articulate what is we are learning. Then others external to the sector can understand what we have been experiencing and perhaps learn from us about these experiences or join with us in continuing to battle those structures that seem to control us. I remain hopeful about this process.

These questions were devised by the Working Group for the 2nd Services Providers 'Changing Needs' Forum. The forum is on Tuesday 7 September at Heffron Hall between 1pm and 5pm.

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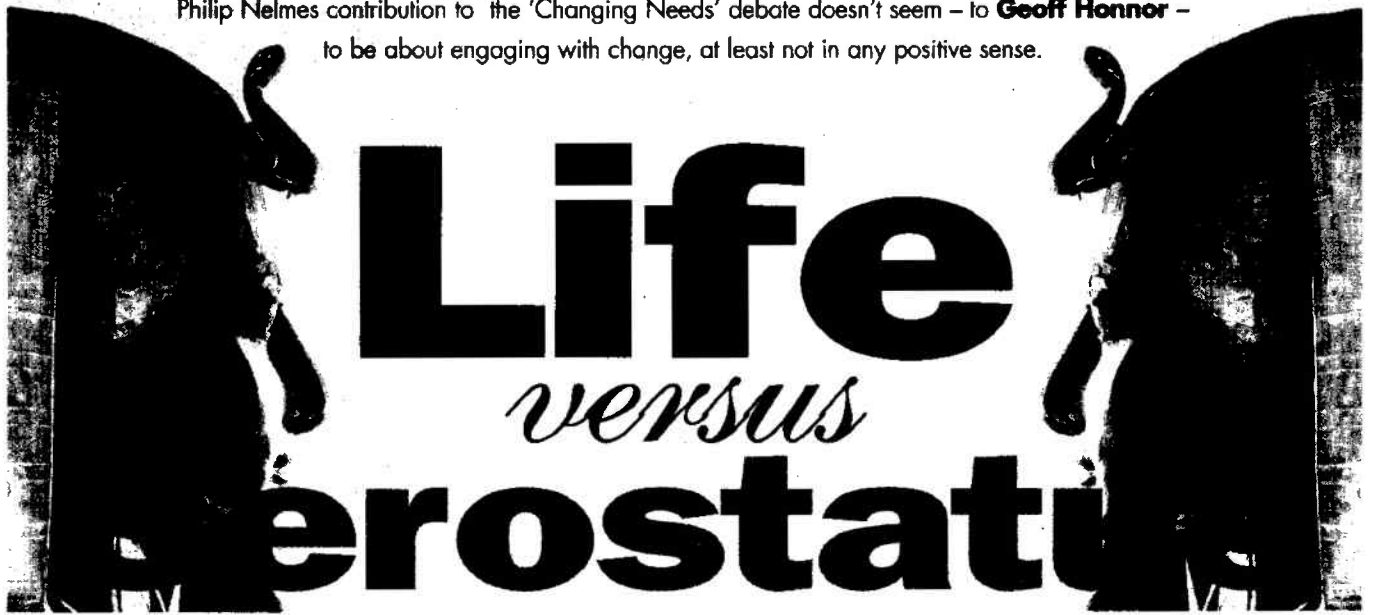
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Life *versus* serostatus

The needs Philip wrote about were very much personal. They're no less valid for being personal but our universal tendency to interpret the whole range of positive life experience through our own frames of reference is often a one-way trip to Judgment City.

I sort of liked the Clint Eastwood movie subtitling – “Forgiven, Unforgiven” etc, but ultimately found the categorisations unhelpful. Bits of all of us were in all of them, given different times, places and circumstance and, anyway, shoving people into boxes usually only results in cardboard claustrophobia.

Positive life experience is messy, bitsy, up, down, can be all over the place and everywhere at once; ‘king of the world’ one minute, ‘helpless victim’ the next. Positive life is much more about life ultimately, with all its vagaries, (but more so) than it is about being HIV positive which is, after all, pretty much unalterable. Yes Virginia, you still have a life in which you will have many problems and tribulations, joys and celebrations that have nothing whatsoever to do with your serostatus. I well remember hearing a positive person at the Bobby Goldsmith Foundation Community Forum telling the gathering that some mornings getting up was almost too difficult. “Me too,” said the negative person next to me.

If you have to divide positive life up – and resisting the tendency to do so is probably best – then I'm of the view that the only meaningful division is the very broad and shifting one that's about an ability to decentralise the disease in order to manage it. If HIV is the sum total of who we are, of our existence, so central that all other aspects of our lives have to fit into it, then we seem generally not to do as well – in whatever sense – as people for whom the reverse is roughly true.

Decentralisation or denial

Decentralisation isn't about denial. You can't decentralise HIV till you've owned and dealt with the fact that you and it are a couple. No matter how much you look forward to the divorce. Decentralisation isn't necessarily about treatments either, be they ‘working’ or not though, clearly, in many cases treatment has made a considerable difference. We shouldn't forget that positive life experience was spread across a huge spectrum – engaged/disengaged, decentralised/centralised whatever –

You can't decentralise HIV till you've owned and dealt with the fact that you and it are a couple.

long before combination therapy. Its arrival certainly broadened the options for many of us though it's perhaps, (in terms of our own epidemic realities) been less about turning HIV/AIDS into a ‘manageable disease’ than the cessation of the once overwhelming tide of opportunistic infections: the once ever-threatening MAC, PCP, KS etc. Treatments have also brought new HIV issues like long-term toxicity uncertainties, compliance, lipodystrophy and that eternal question when should you start treatment? “Preferably, before you die” as one black-humoured queen recently observed.

Decentralisation is easier when these things are ‘issues’ rather than ‘problems’. If something is offered to you as a problem before you engage with it, you tend to treat it as a problem rather than an issue.

Disease decentralisation is possible in the face of viral rebound and low CD4 but certainly isn't if you're too weak and sick to drag your self out of bed.

Decentralisation isn't linked to paid remuneration necessarily but grinding poverty makes getting there very hard. Grinding poverty makes getting anywhere very hard. Decentralisation doesn't mean forgetting where you've been or who was there with you but it does mean being able to quantify a future be it next month or next year, (which is long enough for me!). Love seems inextricably linked too; in whatever way you want to interpret it. Sex is for many of us a powerful part of the love equation though the restorative qualities of sex without specific love linkage can be equally powerful, particularly for positive gay men. Philip spoke of the spiritual journey in preference to the sexual – which obviously works for him – but disease seems to me, in itself, a less than optimal way to spiritual enlightenment. There are surely better ways to get there.

Hooked on grief

I'm also incredibly wary of ‘accepting’ HIV or being ‘at peace’ with it, (as opposed to owning the reality – and limitations – of its presence), and deeply suspicious of health professionals who advocate it. Particularly when they're not positive themselves. There are people hooked on grief and suffering, yours to be precise, and a deeply empowering decentralisation technique is the one where you tell them that you're not currently available to fulfil their disease dis-empowerment requirements.

There is no ‘correct’ way to be positive, no goodies and baddies, no experience that is any more ‘valid’ than the one you're currently having. Don't postpone joy! Unless you really have to ... ■

Geoff Honnor is a positive person. Philip Nelmes' Insider Outsider? first appeared in the July issue of Talkabout.

New link to Lipodystrophy

Megan Nicholson reports on long-term use of nucleoside analogues and their links to the body fat and metabolic disorder known as lipodystrophy.

Treatment strategies

A recent community forum, held at St Vincent's Hospital on 29 July, has heard that the long-term use of nucleoside analogues has now been linked to the body fat and metabolic disorder known as lipodystrophy.

Many people attending the forum had visible signs of the syndrome such as wasting of the face, arms and legs and increased abdominal fat and breast size. Metabolic features of lipodystrophy include high blood fats such as cholesterol and triglycerides, insulin resistance and diabetes. Lipodystrophy had originally been linked to protease inhibitors.

Not just d4T

Reports from the recent workshop held in San Diego suggested that d4T is the nucleoside analogue most likely to cause the fat wasting. Physician, Professor David Cooper, argued that long-term exposure to AZT is also associated with lipodystrophy. Professor Cooper cited 'AZT bum' as evidence that AZT also causes wasting. Both d4T and AZT belong to a sub-class of nucleoside analogues called thymidine analogues, which may damage the mitochondrial DNA of human cells leading to a range of side-effects including wasting and peripheral neuropathy.

Despite available evidence, Professor Cooper is not planning to investigate the impact of switching people from d4T or AZT to other anti-HIV drugs. "I don't think the data is good enough," he said. In addition, dropping potent drugs such as AZT or d4T may lead to viral rebound.

A man with lipodystrophy on the combination nevirapine/d4T/3TC asked Professor Cooper if he could simply drop d4T from his regimen. "You've got to substitute another drug and you don't know that that (new drug) is not going to be worse," Professor Cooper responded. He said only one mutation is needed for HIV to develop high level resistance to nevirapine, so it is essential to maintain undetectable viral load while taking that drug. Nevirapine and delavirdine are the only drugs that have not been linked to lipodystrophy to date.

Professor David Cooper, dietician Ms Danae Brown and researcher Mr John Miller discussed current strategies to address lipodystrophy at the recent community forum.

Dietary changes and exercise may benefit people experiencing body fat and metabolic changes, although the syndrome will not reverse. A diet high in protein and carbohydrates, with moderate fat intake, plus resistance exercise, may reduce the appearance of lipodystrophy as muscle size increases. Reducing food intake may exacerbate facial and peripheral wasting. Consulting a dietician is advised before making dietary changes.

Steroids may disguise the appearance of body fat changes but they will not change fat distribution or metabolic disorders. Steroids are a risk factor for high blood fats and heart attack.

Human Growth Hormone (HGH) is a synthetic hormone that promotes protein production in muscle cells and energy release from fat cells. It may temporarily reduce abdominal and peripheral fat (see *Treatments Briefs* on page 3).

Metformin is a diabetes drug that reduces central abdominal fat. It is broken down in the liver in the same way as the protease inhibitors, so it is rarely prescribed to people on antiretroviral therapy. People on metformin should have their liver function and drug levels carefully monitored. The drug may cause nausea and subsequent weight loss.

Triglitazones are a new class of drugs for the treatment of adult-onset diabetes, which are unavailable in Australia at the present time. Australian researchers are hoping to set up a placebo-controlled, six-month, clinical trial of an experimental triglitazone called rosiglitazone, to investigate its effect on body fat changes due to anti-HIV therapy. Liver toxicity may be a problem for people taking protease inhibitors. Researchers hope rosiglitazone,

recently licensed as a diabetes treatment in the US, will reverse insulin resistance and lead to subcutaneous fat gain among people with highly active antiretroviral therapy (HAART)-related lipodystrophy.

Cosmetic surgery is not the solution to lipodystrophy, according to Professor Cooper, because the abnormal fat deposits quickly return while people remain on treatment.

Gemfibrozil is a drug that lowers triglycerides (see *Treatments Briefs* on page 3).

If wasting is due to mitochondrial toxicity, vitamin and mineral supplements may reduce side effects. Trials may be designed to test the impact of supplements on lipodystrophy.

Professor Cooper told the forum that experts do not yet know whether switching from particular drugs, such as protease inhibitors, will reverse the syndrome. A number of studies are underway worldwide to investigate the impact of switching drugs. Professor Cooper said that Australian researchers are now analysing data on 80 people who either continued PI therapy or switched to an NNRTI. Anecdotal reports from study participants indicates that some people report feeling "less bloated", although whether this means there is a reduction in abdominal fat is not known.

St Vincent's has seen a number of cases of premature coronary artery disease among people taking HAART therapy. High levels of fat in the blood increase a person's risk of blood clots, which can cause heart attack if clots occur in the brain. People on HAART with other risk factors for cardiovascular disease (such as family history, smoking, high cholesterol, lack of exercise, and cocaine and steroid use) may consider dietary and life-style changes to reduce the risk of heart attack and blood clots. ■

Megan Nicholson is a freelance medical writer

Complementary Therapies



Astragalus 8*, or Huang Qi, is a formula developed from traditional Chinese medicine practises (TCM) and modern scientific research. **Paul Keogh** reports.

Astragalus is a major tonic that can lower blood pressure, dilate peripheral blood vessels, nourish the body, reinforce the stomach, increase urinary flow, reduce pain and stimulate the central nerves.

It has been traditionally successful when used as a qi and blood tonic, alleviating such symptoms as lack of appetite, fatigue, diarrhoea, prolapse syndromes, uterine bleeding, frequent colds, shortness of breath, excessive sweating, edema, chronic ulcerations and sores, post-partum fever and wasting and thirsting syndromes.

Since 1983 Astragalus 8 has emerged in Australia as one of the most powerful and effective treatments for weakened and depressed immune states, from any cause.

Over the intervening years this remedy has brought relief for thousands of immune compromised people in Australia.

Potential causes of a disturbed immune system vary from simple recurrent infections like cold and flu, through to

more serious things like glandular fever, Ross River fever, Barmah's Forest Virus, even hepatitis, HIV and cancer.

Immune dysfunction can also be triggered by physical trauma, certain drugs, chemotherapy, psychological stress, or develop gradually, without an obvious trigger event.

Chronic immune dysfunction is believed to result from the body's failure to overcome or adapt to the trigger event. The immune system, which ordinarily gears down after an infection remains in high gear.

Over time unwarranted and persistently high concentrations of immune-activating factors in the bloodstream can damage crucial body systems, especially the immune, hormonal, nervous and circulatory systems.

Eventually, 'immune system reserves' become depleted. This, together with the damage to sensitive body systems, causes a generalised breakdown in health with a profound loss of vitality.

In this situation it is very important not to merely stimulate or support the immune system, as symptoms might dictate.

In the works of Dr Peter Cheney, MD, PhD, (Chronic Fatigue Syndrome specialist) "immune system imbalance is complex and not generally susceptible to specifically directed immune therapy, for example, gamma globulin, steroids and anti-inflammatory agents. A more satisfactory modulation of the immune

system can occur if one makes use of the natural complexity of the immune system to modulate itself."

A review of the chemistry and pharmacology of Astragalus 8, even from a Western perspective, confirms its ability to restore and support the immune system's ability to regulate itself.

Astragalus 8 enhances "the natural complexity of the immune system to modulate itself" and therefore always tends to normalise the immune response. This balancing influence is capable of both regulating weakened or depressed immunity to fight infection or cancer and also regulating allergic responses.

Overall, this ensures greater stability and readiness for any future immunological challenge.

Dr Pi-Kwnag Tsung PhD, in his book *Immune System and Chinese Herbs*, discusses the link between ageing, immunity and Chinese Herbs. He cites research to show that ageing is directly related to the body's state of immunity. Many diseases prevalent in the elderly today are being shown to have an immunological base to them. ■

Paul Keogh holds a Dip Med Herb, ND. He can be contacted at PO Box 98, Alstonville NSW 2477.

This article first appeared in Rainbow News.

For a copy of Astragalus 8 Chinese Herb Formula contact ACON

**Astragalus 8 can be found in the broad spectrum tonic, GM5 Resist Formula (Ling Zhi Qi Tang) manufactured by the Sydney based Green Medicine Company.*

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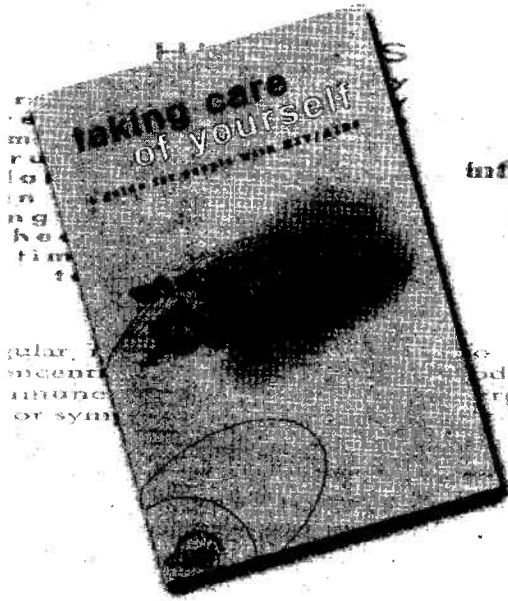
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Active component

- Flavonoids
- 19 amino acids
- saponins
- soyasaponins
- polysaccharides
- androgen
- sitosterol
- triterpenoids
- folic acid
- aminobutyric acid
- trace minerals

Major actions

- Antitumoral
- Interferon inducement
- Immuno stimulant
- Antinfective
- Leukocytogenic
- Phagocyte stimulant
- Increases reticuloendothelial
- Phagocytic activity and Lymphocytic rosette formation
- Renal restorative
- Anhydrotic
- Liver protective
- Hemostatic
- Antibacterial



...aware
informed choice
...to decide

In the mid-1980s there was an A4 brochure titled something like 'Everything You Need To Know About AIDS'. As I recall, the front page was bright red and only carried the title, the back page contained the limited number of referral points available at that time. What space was left told you everything you needed to know. The apparent belittling of their predicament understandably upset many people. Clearly the number of questions people had, following a positive diagnosis, could not be answered in this scant document.

The resource – its not quite a book, but far more than a booklet – assumes that the reader is just that, a reader. It does not assume any preexisting knowledge about HIV, medical terminology or science. In this regard it is excellent at presenting often-complex information in a plain English format. It is not repetitive or condescending. It would probably also be rejected by the non-reader. I make this comment as an observation, not a criticism. No resource will be appropriate to everyone.

Taking Care Of Yourself

Published by
The Education Team
Australian Federation of AIDS Organisations

Reviewed by
Levinia Crooks, Coordinator of the HIV Prescribers Project

Taking Care Of Yourself demonstrates just how far we have come in responding to the information needs of people living with HIV. The past 15 years has seen the development of a plethora of resources aimed at meeting these many and varied needs. I think *Taking Care Of Yourself* will hit the spot for many people with HIV. Sixty-six pages of text and eight pages of directory make it a substantial volume. It is current and contemporary, reflecting developments in treatments, and recognises that we are still learning about the long-term use of antiretrovirals. It also covers issues that we have recognised as perennial for people living with HIV/AIDS.

My one major criticism of the resource is that it has no introduction or preamble. This is an oversight, which I hope will be rectified in any subsequent publication. The title is descriptive: *A Guide For People With HIV/AIDS*. A short introduction explaining that the resource aims to be inclusive of all people would reinforce this message. It contains information for someone newly diagnosed seeking support, while at the same time addresses the issues of a long-term survivor or person needing hospital care. Equally it would be very useful to any person wanting to get a greater insight into HIV and HIV management. I strongly recommend that all PLWHA get hold of this book. ■

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Glossary

Adherence Often shorthand for 'strict adherence to therapy', meaning pills are taken exactly as prescribed - on time, every time, and observing any specific dietary requirements. Also referred to as 'compliance'; less frequently, as 'concordance'.

B12 Vitamin occurring in meat and animal products. Necessary for the growth and replication of body cells and the functioning of the nervous system.

Blood-brain barrier A barrier between the blood vessels and the tissue of the brain, which is part of the brain's specific defence system. Many drugs can't pass through this barrier.

Cannabis The dried flowering tops of a type of hemp plant which contain unique chemical substances, some of which are capable of producing psychoactive effects.

CD4 cells (also called T cells or T helper cells) A type of blood cell involved in protecting the body against viral, fungal and protozoan infections. CD4 cells are part of the human immune response. The CD4+ test is a measure of how your immune system is coping.

Cholesterol A pearly, fat-like substance produced by the body through the liver. Also found in external dietary sources like animal fats. High levels of cholesterol are associated with hardening of the arteries and heart disease.

Combination therapy Treating HIV with a combination of two or more antiviral drugs at once to suppress viral replication and minimise the opportunities for the virus to become drug resistant.

Compliance See adherence

CT Scan (CAT) Technique using Computerised Axial Tomography to x-ray a x-section of the brain.

Dementia Chronic intellectual impairment (loss of mental capacity) with organic origins that affects a person's ability to function in a social or occupational setting.

Diabetes A chronic condition in which the body is unable to effectively metabolise fat, protein and carbohydrates. Related to insufficient production of a body chemical known as insulin.

DNA (deoxyribonucleic acid) Genetic material located in the nucleus of cells. The DNA molecule can make exact copies of itself through the process of replication. Controls hereditary characteristics of nearly all living things.

Drugs that directly treat HIV (antiviral drugs)
There are three different classes of drugs currently in use, which block HIV replication at different points in the life cycle of the virus.

- Nucleoside reverse transcriptase inhibitors**
Abacavir (Ziagen) also known as 1592
AZT (Retrovir) - full chemical name zidovudine
ddI (Videx) - full name didanosine
ddC (HIVID) - full name zalcitabine
3TC (Epivir) - full name lamivudine
d4T (Zerit) - full name stavudine

- Non-nucleoside reverse transcriptase inhibitors**
nevirapine (Viramune)
delavirdine (Rescriptor)
Protease Inhibitors
Nelfinavir (Viracept)
Indinavir (Crixivan)
Ritonavir (Norvir)
Saquinavir (Invirase)

Folate Form of folic acid. Vitamin of B Complex found in liver, green vegetables and yeast.

Haemophilia Blood disorder caused by impaired blood coagulation.

HAART Highly active antiretroviral therapy. Usually means a combination of at least three HIV antiviral from at least two of the three classes of anti-HIV drugs available.

Hepatitis C Viral disease caused by the hepatitis c virus. Can cause liver disease in the long term. Principally transmitted by exchange of blood via transfusion or intravenous drug use.

KS (Kaposi's Sarcoma) A tumour of the wall of blood vessels. Usually appears as pink to purple, painless spots on the skin, but may also occur internally in addition to or independent to lesions.

Lipodystrophy A clinical condition involving body fat redistribution and high levels of glucose, cholesterol and triglyceride levels. Men commonly experience increased fat around the stomach and upper back and women experience a narrowing of the hips and breast enlargement. Thought by many to be associated with the use of protease inhibitors.

Log Short for 'logarithm, a log acts as a mathematical shorthand for recording large numbers.

Lymphoma A cancer of the lymph cells that are responsible for normal immune function. Symptoms may include lymph node swelling, weight loss, and fever.

Metabolism Sum of all the physical and chemical processes occurring in body tissue. Includes those reactions that convert small molecules into large (anabolism) and those reactions that convert large molecules into small (catabolism)

Mycobacterium Avium Complex (MAC) (see opportunistic infections) A disease caused by an organism found in soil and dust particles. In people with HIV, it can spread through the bloodstream to infect many parts of the body. Symptoms of MAC include prolonged wasting, fever, fatigue and enlarged spleen. It is usually found only in people who have cd4+ counts less than 100.

NNRTIs (see Non-nucleoside Reverse Transcriptase Inhibitors)

Opportunistic infections (OI) HIV damages parts of the immune system. Once the damage reaches a certain level (roughly indicated by your CD4 count), some of the infections your body could normally deal with may establish themselves.

PCP (see opportunistic infection) Pneumocystis carinii pneumonia. Life-threatening inflammation of the lungs caused by a protozoa (parasite-like particle). Common in immune suppressed people unless preventative measures are taken, and the disease is fatal in 15 to 30 percent of people. Bactrim is the commonly used and effective prevention measure.

Peripheral Neuropathy (PN) Nerve damage, usually involving the hands, arms, fingers, legs and feet.

drug /drag/ n, v. **drugged, drugging.** -n 1. a chemical substance given with the intention of preventing or curing disease or otherwise enhancing the physical or mental faculties of a person. 2. a habit of using drugs. 3. a habit of using drugs. 4. a habit of using drugs. 5. a habit of using drugs. 6. a habit of using drugs. 7. a habit of using drugs. 8. a habit of using drugs. 9. a habit of using drugs. 10. a habit of using drugs. 11. a habit of using drugs. 12. a habit of using drugs. 13. a habit of using drugs. 14. a habit of using drugs. 15. a habit of using drugs. 16. a habit of using drugs. 17. a habit of using drugs. 18. a habit of using drugs. 19. a habit of using drugs. 20. a habit of using drugs. 21. a habit of using drugs. 22. a habit of using drugs. 23. a habit of using drugs. 24. a habit of using drugs. 25. a habit of using drugs. 26. a habit of using drugs. 27. a habit of using drugs. 28. a habit of using drugs. 29. a habit of using drugs. 30. a habit of using drugs. 31. a habit of using drugs. 32. a habit of using drugs. 33. a habit of using drugs. 34. a habit of using drugs. 35. a habit of using drugs. 36. a habit of using drugs. 37. a habit of using drugs. 38. a habit of using drugs. 39. a habit of using drugs. 40. a habit of using drugs. 41. a habit of using drugs. 42. a habit of using drugs. 43. a habit of using drugs. 44. a habit of using drugs. 45. a habit of using drugs. 46. a habit of using drugs. 47. a habit of using drugs. 48. a habit of using drugs. 49. a habit of using drugs. 50. a habit of using drugs. 51. a habit of using drugs. 52. a habit of using drugs. 53. a habit of using drugs. 54. a habit of using drugs. 55. a habit of using drugs. 56. a habit of using drugs. 57. a habit of using drugs. 58. a habit of using drugs. 59. a habit of using drugs. 60. a habit of using drugs. 61. a habit of using drugs. 62. a habit of using drugs. 63. a habit of using drugs. 64. a habit of using drugs. 65. a habit of using drugs. 66. a habit of using drugs. 67. a habit of using drugs. 68. a habit of using drugs. 69. a habit of using drugs. 70. a habit of using drugs. 71. a habit of using drugs. 72. a habit of using drugs. 73. a habit of using drugs. 74. a habit of using drugs. 75. a habit of using drugs. 76. a habit of using drugs. 77. a habit of using drugs. 78. a habit of using drugs. 79. a habit of using drugs. 80. a habit of using drugs. 81. a habit of using drugs. 82. a habit of using drugs. 83. a habit of using drugs. 84. a habit of using drugs. 85. a habit of using drugs. 86. a habit of using drugs. 87. a habit of using drugs. 88. a habit of using drugs. 89. a habit of using drugs. 90. a habit of using drugs. 91. a habit of using drugs. 92. a habit of using drugs. 93. a habit of using drugs. 94. a habit of using drugs. 95. a habit of using drugs. 96. a habit of using drugs. 97. a habit of using drugs. 98. a habit of using drugs. 99. a habit of using drugs. 100. a habit of using drugs.

drug abuse -abus/ n: the improper use of one or more drugs, especially narcotic and hallucinogenic drugs.

drug lord /-lad/ n: someone whose wealth and power can cause from abuse, tripping or blurring sensation, pain and muscle weakness. It is a side effect associated with some HIV antiviral, particularly Zidovudine. 1. (often lower case) one of an order of ministers or ministers of religion among the ancient Celts.

PML (Progressive multifocal leukoencephalopathy) Rare, subacute and progressive demyelinating disease of the central nervous system that appears in immunosuppressed adults.

post-partum fever fever occurring after childbirth or after delivery.

drum /drum/ n, v. **drummed, drumming.** -n 1. a hollow body covered with a tightly stretched membrane, or head, which is struck with the hand, a stick, or a pair of sticks. 2. any hollow or similar object that can be struck to produce a sound. 3. either of these. 4. any noise suggestive of it. 5. someone who plays the drum. 6. a natural drum by which the body via the act of breathing and facilitated by correct diet.

Qi (pronounced chi) Flow of energy through the body.

Special Access Scheme A scheme that allows persistent access to experimental drugs prior to being licensed in Australia.

Steroids (anabolic) Any of a group of synthetic derivatives of testosterone, which are clinically prescribed to promote growth and repair of body tissues in senility, debilitatory illness and convalescence. Also used by body builders to build muscle.

Syphilis Transmitted through sexual contact. Generally primary syphilis is characterised by sores on the vagina, cervix, cock, genital area, throat or arse.

T cells White blood cells that play an important part in regulating the immune system. All cells are derived from the bone marrow, and where they mature will determine their function. T cells mature in the thymus, whereas B cells mature in the bone marrow. There are two major types of T cells, CD4+ (T4) and CD8+ (T8). Each type of cell has subsets that perform different functions. CD4+ cells can be TH1, TH2, or TH0 cells, each of which supports different types of immune responses. CD8+ cells are often cytotoxic cells, which seek out and destroy infected cells.

Thyroid One of the endocrine glands. Found in the lower part of the front of the neck. Secretes, stores and liberates thyroid hormones which play a major role in regulating the metabolic rate.

Toxicity The capacity to cause a poisonous or unwanted reaction.

Triglyceride A compound of fat molecules that can release fatty acids into the blood.

Viral load The quantity of virus measurable in blood serum or other fluid or tissue. This test is used to show how active the virus is at any particular time. The test is also used to show whether the treatments you are on are having any effect.

Sources
Terms taken from, but not exclusive to, the following:
Dorland's Medical Dictionary, 28th edition, 1994
Taking Care of Yourself, AFAO NAPWA, July 1999
HIV Drug Book, AFAO, 1998
Living With HIV/AIDS, Peter de Ruyter, Allen & Unwin, 1996
Positive Living, various, AFAO 1999

Hyper.Active



Under construction

... with our regular internet cyber-surfer **Tim Alderman**

Avert

<http://www.avert.org/>

Rating Very comprehensive up-to-date site. Had been updated the day I visited.

When the home page loaded, I thought this was going to be another basic HIV/AIDS site (nothing wrong with basic, it's just that they don't stand out), but I reassessed that assumption when I got involved. There is plenty of the general information, including items for 'young people'; UK AIDS and HIV News; History and Origins of AIDS and HIV; HIV/AIDS for Women and Children; Information for Healthcare Workers; a FAQ section (Frequently Asked Questions); HIV/AIDS and Sex; AIDS and HIV Statistics. I found the Resource Section particularly interesting and useful, with a selection of well produced booklets that are available to download. You can play the AIDS Quiz in a separate window, with 10 questions on each of general, statistics, and harder categories. There is also an online survey.

Hint The site is best viewed if you have a soundcard. Acrobat Reader (download directly from site) is required if you download booklets.

Positively Working

<http://www.positivelyworking.org>

Rating Not finished, and probably never will be. What's available is good.

A difficult site for me to be unbiased about. Return-to-work issues for PLWHA are important to me personally. I worked for the Positively Working Project for eight months, until funding ran out. This unfinished site (a dream, really) is an example of what happens under these circumstances. 'Returning to Work' and 'Your Benefits' are the only pages up and



running, with a good selection of fact sheets on the work issue. The other pages are marked 'Under Construction', and I fear will remain so. There is, however, a good selection of links, including ones to AID Atlanta, and National AIDS Fund (*see reviews last issue*).

Gay Mens Health Crisis

<http://www.gmhc.org/>

Rating Not impressive.

Despite all the coverage this organisation gets, and despite being linked to nearly every HIV site, I was singularly unmoved by their home page. It appears to be a site with more relevance to the United States than anyone else. The information is very basic. The library has only a small selection

of articles, mainly their own publications. The press release section was up-to-date, and included a press release on their own restructure and renewal. Here's hoping!

Hint Request a copy, by email, of the results of the *The 1998 Beyond 2000 Sexual Health* survey.

HIV/AIDS

<http://www.hivoids.webcentral.com.au/>

Rating Despite reviewing this site as a favour to the Editor (I have a friend ...), I found the site interesting.

This site has been created as a resource to share experiences, and stories, of life with HIV/AIDS. The 'Stories' link leads to a selection of stories from women, men, carers, and IDU users. They welcome unsolicited stories. The 'Positive Women' link is the site of Positive Women Victoria Inc., with an index linking to general information, a newsletter, stories, links, and a run down on their 10th Anniversary. 'Images' unveils several photographs from the Melbourne and Brisbane Candlelight Rally. Again, there is a request to add to the photo collection. 'Notice board' gives a listing of HIV/AIDS and PLWHA organisations Australia wide, and the 'Links' section includes both Australian and International sites.

Hint Sites like this rely on support to keep them active. If possible, provide a story or photograph to help it expand. ■

Cyber-whoops

We made a boo-boo in our review of the AFAO site last month. 'What Now!' and 'What's Up' are found in the site's general menu and both *HIV Herald* and *Positive Living* are now on line. Sorry.

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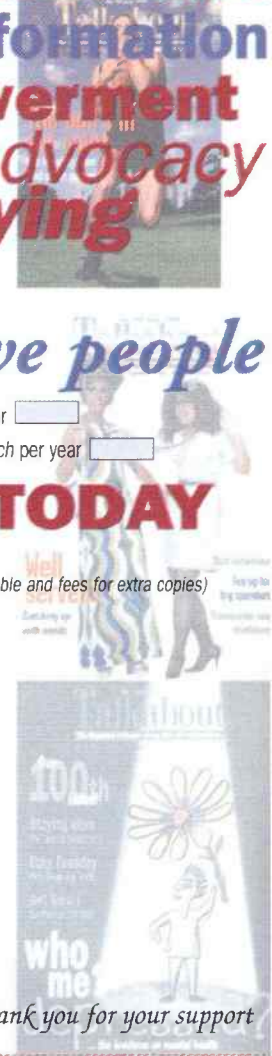
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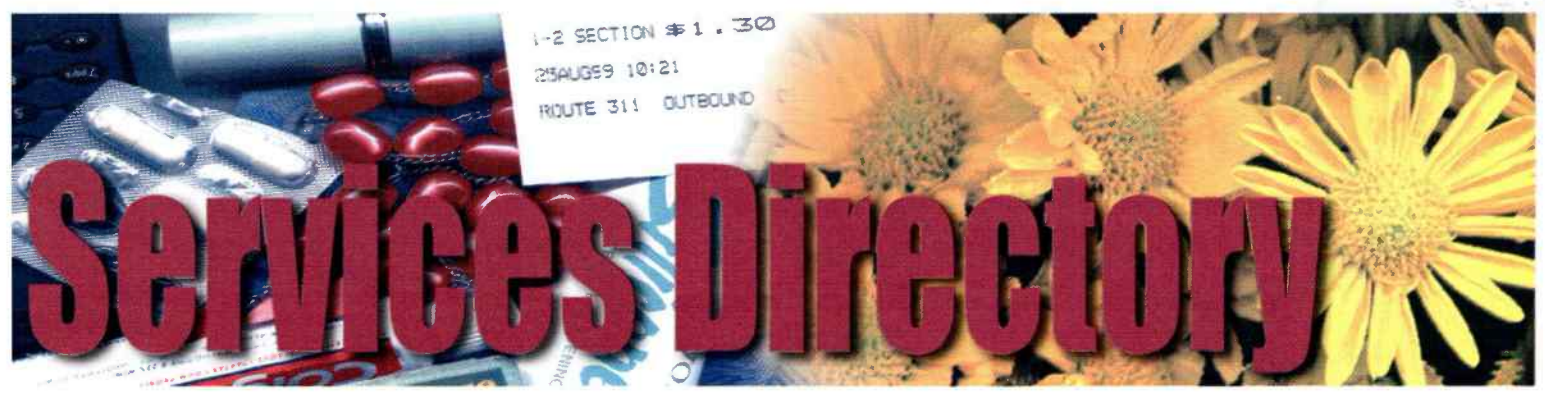
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