

No. 58 September 1995

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆

Demented?

PLWH/A News



THE FUTURE OF POSITIVE LIVING Centres, access to new HIV treatment, our response to ACON's draft Voluntary Euthanasia Bill and a rise in HIV infection rates are some of the main issues that PLWH/A has been focusing on.

We have also appointed a new Co-ordinator. Ryan McLaughlin will be joining our staff team from September 4. Ryan has extensive involvement in the community based AIDS response, both in Australia and overseas. He is currently working for the National Association of People with HIV/AIDS (NAPWA) as Acting Communications Officer. We very much look forward to Ryan joining PLWH/A.

PLWH/A attended a conference on August 17/18 which looked at the future of Positive Living Centres for People with HIV/AIDS. The conference was organised by NAPWA. A report on the conference will be given in the next *Talkabout*. The NAPWA conference was a timely event, especially in light of the review of Sydney services for people living with HIV/AIDS which is now underway. PLWH/A will be following this review closely.

We have been finalising our response to the ACON draft Voluntary Euthanasia Bill. Our comments on the Bill will be covered in the next issue of *Talkabout*. We would like to thank those people with HIV who took the time to give us their views on euthanasia and the draft Bill. We will be lobbying State politicians and community groups like ACON with the aim of having the best possible Bill on voluntary euthanasia become law in NSW.

Treatments continues to occupy a major part of our time — which is as it should be. We were involved in a meeting with Glaxo about the new antiviral 3TC. While Glaxo have eased their restrictions on compassionate access to 3TC, there are still some major problems to be resolved (see report in this issue). And in case Abbott Pharmaceuticals think we have forgotten them — don't worry, we haven't! We are continuing to work with AFAO and other community groups to make Abbott provide their protease inhibitor to those people with AIDS who desperately need it. We also had a productive meeting with Professor David Cooper of St Vin-

cent's Hospital to discuss community consultation about upcoming trials and treatments issues.

There has been a rise in HIV notifications and new HIV infections in NSW over the past six months. Most of these infections were among gay men but there was also an increase in heterosexual transmission rates. As a result of the rise in infections, the NSW Department of Health is looking at ways of improving and expanding HIV preventive education. PLWH/A has been invited to participate in this process.

Finally, very special congratulations to Claude Fabian. Claude was presented with an award recognising his outstanding service to the gay and lesbian community and the fight against HIV/AIDS at the annual Diva Awards held on July 31. Well done and thoroughly deserved.

— Bill Whittaker, PLWH/A
Convenor

هل أنت بحاجة إلى معلومات عن فيروس HIV ومرض AIDS في جنوب سيدني؟

معلومات سرية مسجلة.
هاتف رقم: 391 9971
عيادات صحة جنسية مجانية وسرية.
هاتف رقم: 350 2742
خدمات مستشفى مجانية وسرية.
هاتف رقم: 350 2955

مراكز لتبديل الابز والحقن بدون
مقابل وبصورة سرية:
في منطقة كنتربري، هاتف رقم: 016 288504
في منطقة سان جورج، هاتف رقم: 018 479201
في منطقة سذرلند، هاتف رقم: 018 277717



People Living With HIV/AIDS (NSW) Inc.

Current committee

Bill Whittaker: Convenor

Vivienne Munro: Deputy Convenor

Eric Sleight: Treasurer

Alan Brotherton, Mark Cochrane, Chris

Horden, Peter Hornby, Rolf Petherbridge,

Bill Rigney, Larry Wellings

Claude Fabian: A/Coordinator

Paul Roberts: A/Admin Asst

Shane Parkinson: A/Positive Speakers

Bureau Coordinator

Jill Sergeant: *Talkabout* Editorial

Coordinator

Paul Canning *Talkabout* DTP/Advertising

Phone: 361 6011

Talkabout: 361 6750

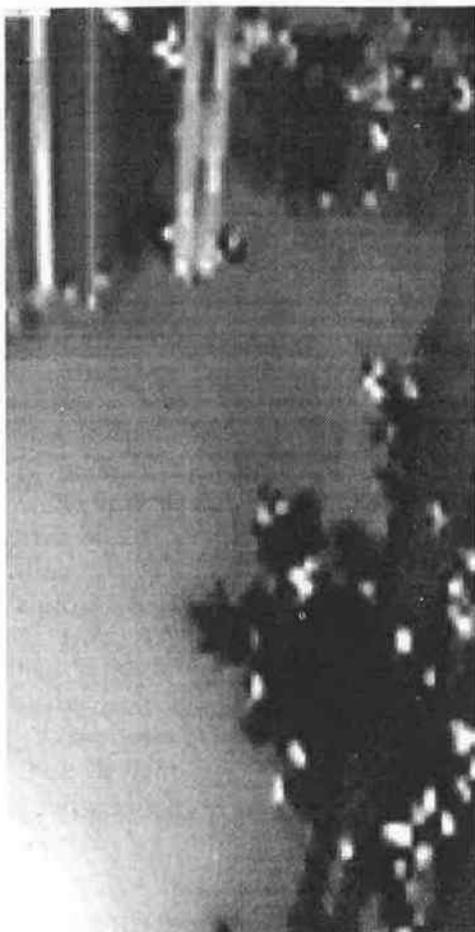
Fax: 360 3504

Post: Box 831, Darlinghurst NSW 2010

Office: Suite 5, Level 1, 94 Oxford St,

Darlinghurst

Contents



Tributes: Brenton Heath-Kerr	10
Mark Cashman, David Martin	11
Montreal HIV	95
Dementia care unit	19
Dementia: some hope	20
Mental as Anything	22
Superannuation: Leaving on a Jet Plane	25

Regulars

PLWH/A News	2
News	4
Olga's Personals	9
Contacts	15
Gloria's Food: soups	27
Fair Treatment: Rehydration formula	29
Beyond Prognosis	30
Subscriptions	31

This month's cover

By Paul Canning. Feeling demented? Well, perhaps not — but you might be feeling worried. Dementia is one of the illnesses that arouses most fear among people with HIV. That's why it's important to keep well informed about both Dementia and other HIV related mental illness. Our special feature on Dementia and HIV Mania is a good place to start — turn to page 20.

Talkabout

Talkabout welcomes unsolicited contributions. However, we cannot accept responsibility for manuscripts and photographs or for material lost or damaged in the post.

Letters submitted to *Talkabout* or its editorial coordinator are assumed to be for publication in whole or in part unless specified otherwise.

For further information contact Jill Sergeant (Tuesday, Wednesday or Friday).

For advertising contact Sandra. Send contributions to: PO Box 831 Darlinghurst, NSW 2010.

Deadline for the next issue: August 16

If your venue/organisation is interested in distributing *Talkabout*, contact the editorial coordinator. Call the editorial coordinator on 361 6750 for the date and time of the next Newsletter Working Group meeting.

Talkabout is published every month by People Living With HIV/AIDS Inc. (NSW). All views expressed are the opinions of the respective authors and not necessarily those of PLWHA, its management or members.

Talkabout is produced by the Newsletter Working Group of PLWHA Inc. (NSW) and printed by Breakout Printing ph: 281 5100. Copyright for all material in *Talkabout* — text, graphics and photos — resides with the respective contributor. Contact the editorial coordinator for information on reproducing articles or illustrations.

Talkabout is made possible by subscriptions, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* is also grateful for the assistance of the AIDS Council of NSW and thanks the many volunteers without whom its publication would not be possible.

ISSN 1034 0866

Briefs



● Despite laws that bar them from entering the country, China will permit people with HIV/AIDS to attend September's World Conference on Women in Beijing. China will establish special quarantine and sanitary requirements for conference participants. By the end of 1994 there were officially 1,774 HIV infected Chinese, of whom 65 had developed AIDS and 45 had died. (Reuters)

● A woman with AIDS facing twenty years in prison for having sex with her boss has been freed by a North Dakota Court. The Judge dismissed a charge that makes it illegal for PLWHA to have sex without revealing their HIV status. The woman says she was raped. (Brisbane Courier Mail)

● Northern Irish WBO welterweight champion Eamonn Loughran threatened to pull out of a title fight against Luvuyo Kakaza of South Africa unless Kakaza was tested for HIV. Loughran said he was worried about recent reports that 34 professional boxers in South Africa had tested HIV positive. (Reuters)

● For her new telemovie *A Mother's Prayer*, *Terminator* star Linda Hamilton lost 12 pounds to play a widowed mother with AIDS who tries to find a family for her son before she dies. Hamilton urged viewers to watch the movie because "it's something people need to see so that AIDS isn't an indictment of a lifestyle. It shows the other side of AIDS, through the eyes of a heterosexual woman." (USA Today)

● Documents filed at a Canadian Commission of Inquiry into the events which left more than 1,000 people infected with HIV has found that the Canadian Red Cross was offered a heat-treated blood product for haemophiliacs in late 1983, but refused it because it cost more per unit. The agency rejected the product again in early 1984, 18 months before it was made available. Red Cross officials played down the benefits of the safer concentrate. One senior official even ordered a supplier not to include a warning that the concentrate that was not heat-treated could be infected with HIV. (Toronto Globe and Mail)

● Most women in the US who die of cervical cancer probably die with undiagnosed HIV according to Mitchell Maiman of New York State University. Maiman based his contention on a large study's findings that 19% of women under 50 with cervical cancer were HIV+. (Journal of IAPAC)

● Germany's parliament has approved the creation of a \$180 million pension fund for nearly 2,000 people (and their dependents) who became infected with HIV when, beginning in the early 1980s, in order to save money, firms failed to screen blood donors properly and check blood supplies for HIV for nearly ten years. (Reuters)

Positive relief

HIV/AIDS ORGANISATIONS HAVE been called on to hold an urgent summit meeting to find solutions to HIV related poverty. This resolution was passed by 40 people who attended a public meeting to discuss an interim report produced by Positive Relief.

The group was founded earlier this year by AIDS activist and long-term survivor Michael Glynn to bring attention to financial hardship experienced by people living with HIV/AIDS.

Positive Relief's report concluded that services addressing issues associated with poverty and HIV/AIDS do exist but that there are gaps which people fall through.

Michael Glynn told the meeting that "a hell of a lot of people are not accessing services because of pride or dignity." Suggestions had been made to the group that PLWHA use services such as Sydney City Mission or the Salvation Army, however they say that PLWHA "clearly see these places as inappropriate".

In its survey of community organisations, the report slams the Gay & Lesbian Rights Lobby and Sydney Gay & Lesbian Mardi Gras for: "contributing to an 'us and them' mentality" through the recent "debacle" over fundraising during the annual parade.

Among the other organisations coping serves is the AIDS Council of NSW (ACON). The report says that perceptions exist that ACON "is a bureaucracy with uncontrolled growth and little contact or knowledge of what is happening out in the trenches".

ACON Executive Director Don Baxter responded to the criticism, saying that "what Michael [Glynn] has done is defined what the problems are." He argued that the long term solution involved changes to Federal Government social security policy and said that ACON had been working on the issue for some

time — without success.

"I'm frustrated that we've been unable to do anything. [But] maybe we need to stop doing some things and reorganise priorities within ACON."

Baxter also said that ACON would undertake research on poverty and inadequate nutrition and will investigate with PLWH/A (NSW) the publication of a comprehensive information booklet.

Greg Smith, Pastor of the Metropolitan Community Church (MCC), said that he regularly sees hungry PLWHA asking for food parcels. The Church is setting up a 'Food Bank' in addition to its Sunday lunches which attract between 50 and 70 people.

They plan permanent food collection bins similar to one set up in Oxford St store Aussie Boys during a successful Food Collection Day in early June. However, Smith said that the MCC suffered from a volunteer and resource shortage and fears that the new service "will be swamped". Organisations wishing to help the MCC can do so by providing food or money, he said.

— Paul Canning

3TC 4 U

MORE AUSTRALIANS WILL HAVE ACCESS to 3TC both in the clinical trial, and through the compassionate access scheme, due to changes announced by Glaxo Wellcome Ltd on August 2. The company is expanding access to the clinical trial by 64 places (bringing total Australian participation in the worldwide trial to 370). As well, the Australian criteria for compassionate access to 3TC will be brought in line with the international protocol.

PLWH/A Inc. (NSW) welcomed the changes as a step in the right direction, but was critical of earlier inadequacies in community consultation by Glaxo, which reduced levels of access to the drug.

PLWH/A Convenor Bill

Whittaker also said the new protocol does not go far enough. "Some people with low immune function who are failing on approved antiviral therapies will be able to gain access to 3TC, but the criteria for failure is too narrowly defined", he said. "For example, a drop of more than 50% in CD4 count over the previous six months is required. We consider this far too restrictive. A situation could arise where someone with 300 CD4 cells is required to drop to 150 before being granted access to 3TC. Requiring such a dramatic progression in HIV disease is unacceptable."

PLWH/A will be taking up the matter with Glaxo. The company has agreed to regular consultation with the community.

PLWH/A is pleased that the 3TC supply situation has improved, with a small waiting time (one week) for compassionate access.

Trial consultation

FORMAL COMMUNITY CONSULTATION is to be a key part of the planning of HIV related clinical trials operating out of St Vincent's Hospital. This agreement was the main outcome of a meeting on July 31 of David Cooper (Director, St Vincent's AIDS Unit), Don Baxter (ACON, AFAO) and Bill Whittaker (PLWH/A, NAPWA).

The meeting was held following recent criticisms by PLWH/A, ACON and AFAO of the lack of consultation on the trial of the Abbott protease inhibitor ritonavir.

The position of these groups is that there must be full consultation with community based AIDS organisations before any major HIV related clinical trial goes ahead in Australia.

Under the agreement, representatives of the major AIDS and PLWHA community organisations will meet Professor Cooper every six weeks to discuss proposed clinical trials and treatment issues.

"This agreement is a sensible



Polly, Cindy, Fanny & friends do Diva for The Luncheon Club.

resolution of what was potentially a serious breakdown in co-operation", Whittaker said.

AFAO is currently organising a meeting between community organisations and Abbott Pharmaceuticals to discuss compassionate access to the Abbott protease inhibitor, ritonavir.

Illawarra views

SUPPORT, CONFIDENTIALITY AND A lack of sensitive, appropriately trained doctors are key issues for PLWHA in the Illawarra and Shoalhaven region, according to a needs assessment conducted by the HIV Community Development Project, (funded by Illawarra Area Health Service (IAHS) and based at ACON Illawarra). The needs assessment, which concluded in July, aimed to improve services and support for the local HIV/AIDS community.

Respondents to the survey identified the need for support not only for HIV positive people but also for their carers, family and friends. A shortage of counsellors and isolation were mentioned as factors that needed to be addressed. Many PLWHA seek treatment in Sydney because of concerns about confidentiality and perceptions about

the quality of care provided locally.

In general, respondents felt that the Illawarra and Shoalhaven communities were less accepting of PLWHA and that health care workers were less knowledgeable than in Sydney. The need for culturally appropriate education and services for Aboriginal people and people of non English speaking backgrounds was also perceived as important.

The needs assessment also identified that various basic needs such as financial and legal assistance, domestic support and child care, were not as readily available as they should be.

Jackie Braw, ACON Illawarra Manager, is pleased at the progress already made on implementing the needs assessment recommendations. "One of the most exciting aspects about this project is the activity that has already been generated within and outside the HIV positive community", she said. "Whilst the needs assessment process has highlighted areas of concern for service providers, there is a very real sense of commitment in the Illawarra and Shoalhaven communities to work together to resolve the problems that exist and to make services more accessible

Briefs



● A residential workshop for PLWHA addressing anger, loss, grief, death, shame, guilt, separation and the pain associated with living with HIV will take place at Vaughan College, Marsfield on the weekend of September 16 & 17. Organised by the HIV Social Work Team at St Vincent's, it costs \$50/\$20. Call Helen Golding, 361 2213, to book.

● Bondi Youth Accommodation offers supported accommodation for young HIV+ people. If you would like to consider this housing option and be considered for it, call 389 7453.

● Welcome to Bernard Pearce, new counsellor with the HIV/AIDS team of the Mid North Coast Health Service. The team provides education, counselling, clinical nursing service and needle exchange. If you live in the Coffs Harbour, Nambucca and Bellingen areas, call Bernard for an appointment on (066) 59 1424. The service is private and confidential.

● Michael Bartos of the National Centre in HIV Social research will speak on "the Queer Excess of Public Health Policy" at an HIV/AIDS Forum organised by the National Centre, Tuesday, September 12, 5.30 — 7.30pm, Save Sight Theatre, Cnr. Albion & Crown Sts. Surry Hills.

● The future of HIV/AIDS services in Victoria is under threat as the centre of many services, Fairfield Hospital, is likely to be closed or relocated. This could result in a reduction of services. The Victorian AIDS Council and PLWHA are fighting for the Hospital to stay at its current site.

● An Honours student at ANU is seeking HIV+ people to participate in focus group sessions. Iain Anderson is examining and comparing PLWHA's estimates of their risk of contracting HIV (prior to diagnosis) and TB. Discussion topics will include knowledge of risk factors, availability of information and opinions on appropriate public health responses to the diseases. A copy of the resulting thesis will be available to participating individuals and interested organisations. Call Iain on (06) 249 0740.

● If you live in the Illawarra, you can now tune in to HIV Radio Diary, Regional ABC, 97.3FM. Averaging three minutes per segment, HIV radio diary is in the format of a Positive person's diary. It airs once a week just after the 9.00am news in Vanessa Morris' timeslot.

● The fourth HIV/AIDS memorial tree planting at Sydney Park will take place on Saturday, September 2.

● HIV+ people may be outlawed from serving in the Australian Defence Force. Minister for Defence, Robert Ray, is pushing for legislation on the grounds that all service personnel should be "potential soldiers". This follows last month's ruling by the Human Rights Commission that the ADF broke the law by dismissing a soldier who was HIV+. (*Capital Q*)

and user friendly. The title of the needs assessment report conveys this sentiment well: 'United Views. Building a Stronger Community'."

The most significant recommendation was for the establishment of a Positive Space, to be run by and for Positive people and their significant others. Fundraising activity and networking for a Positive Space has already begun.

As well, initial planning is underway to set up a carers' support group, with involvement from ACON, Community Support Network (CSN) and the Port Kembla Sexual Health Clinic and several carers.

PLWHA are also represented on a Transport Working Group with IAHS which will look at the issues people face when leaving hospital or travelling from one hospital to another. This is an outcome of the IAHS Health Consumer Workshop held in April.

The Sexual Health Education for GPs Project, funded by IAHS, will also address some of the concerns expressed in the needs assessment. ACON and members of the HIV positive community are represented on a working group for this project.

Copies of 'United Views. Building a Stronger Community', are available from ACON for \$10. All proceeds go towards setting up the Positive Space.

PI resistance can be overcome?

NEW CLINICAL DATA PRESENTED AT the Fourth HIV Drug Resistance Workshop held in Sardinia, Italy in July, showed that therapy with Hoffman-LaRoche protease inhibitor (PI) saquinavir does not cause cross resistance with other PIs.

The results were described in a Roche press release as significant because previous trial experience had suggested that once resistance (decreased sensitivity) to one PI had developed, treatment with another PI would not be possible because

of insurmountable cross-resistance. These worries have raised concerns about the future of this drug class, according to the company.

GMHC Treatment Issues speculated in June that taking one drug as a monotherapy may mean losing the opportunity to use that drug in the future in a potentially more effective combination strategy.

It must be the right combination of drugs since an inferior mix may have little effect or could be toxic. The right combination may significantly delay the development of resistance, but it may take an almost complete suppression of the virus to achieve this.

Combination drug therapy, tailored better through viral load testing and careful dosage, between PIs (as well as with other antivirals) may now be possible that can overcome HIV's resistance.

A combination of saquinavir and AZT may delay the emergence of resistance to either drug, according to researchers.

Additional studies have suggested that resistance to saquinavir (which will go by the trade name Invirase) is the slowest and least substantial to develop amongst the PIs.

A 'New Drug Application' for saquinavir will be filed globally by Roche this month.

— Paul Canning

Changes

YOU MAY HAVE NOTICED THAT ACON's HIV Support Project hasn't been running its Wednesday Information Nights recently. This is because we're about to embark on a new information strategy: weekend workshops.

Why weekends? In the last ten months we have been getting requests for a one stop shop for information instead of having to wait weeks in between the Information Forums of particular interest. The other issue that has been raised is confidentiality.

These weekends will only be

open to Positive people and their nominated partner, friend or carer.

We are also asking participants to drop in for a chat before the workshops so that we can tailor the information to people's specific requests.

The workshops will run from 10am to 6pm on both days with lunch provided. Interested? Give us a call on 206 2014.

— Stephen Gallagher

HOME base

POSITIVE PEOPLE ARE IN CHARGE OF the day to day operation of the HIV+ Open Minded Environment (HOME) that opened in Lismore on August 15. This centre, funded by ACON Lismore and community donations, is the result of an informal workshop at the Positive Men's Retreat at Lennox Head earlier this year.

The HOME Team want to create a safe space for PLWHA, not just with warm fuzzy feelings, but with bricks and mortar! They'll be running a series of workshops in home renovation and gardening and at the same time transform their new house into a beautiful environment for Positive people on the North Coast.

HOME will be a resource and drop-in centre, chill out space and venue for information workshops, cooking classes and complementary therapies — to name just a few of the planned activities. Movie nights and games nights are also on the calendar.

"This is an adventure in working together and community building", say the organisers, "we'd like *you* to be involved."

However, a shortfall in the available funding for ACON's Northern Rivers branch is causing concern as services may be reduced at a time of growing client demand. Services in Lismore and Byron Bay are a particular problem according to the branch.

The region has the largest



(Centre) Mark Douglas (previously ACON Illawarra Committee member) toasts the launch of the HIV Community Development Project on June 29 at the ACON office. About 40 people celebrated the culmination of the Project's needs assessment, and the future of the HIV community. A new HIV community Development Officer, Frank Vellozzi, has recently been appointed. Frank can be contacted Mondays, Wednesdays or Fridays on (042) 26 1163.

number of PLWHA outside of Sydney. According to ACON Northern Rivers manager Di Furniss, many people are registered in Sydney — not in the region. This affects Government funding which is based on the number of notifications registered with the NSW Health Department within each region.

Furniss believes that a large number of people in the region don't access ACON services because they are living well, but stresses that they may need them at some point in the future.

A Needs Assessment survey has been launched by the branch in order to determine the extent of present and future needs. To take part in the survey contact ACON Northern Rivers on (066) 22 1555.

(Shortfall info: *Queensland Pride*)

BGF Update

AT THIS TIME OF YEAR DEMAND FOR BGF assistance increases significantly as the electricity and gas accounts roll in. As well, there are

never ending requests for appliances and, understandably, heaters and dryers are hot items. All BGF owned appliances are now listed on a computer data base and even we are surprised at how much equipment we have in circulation out there.

However, we unfortunately still have to maintain waiting lists for just about everything. When items are donated, returned or purchased our policy is to allocate them first to those clients who are known to be most in need, and then to the next name on the list.

As at July 26, in the Sydney Metropolitan area, we have been donated 23 fridges, 5 washing machines, 5 TVs, 5 VCRs, 5 microwaves and about 20 heaters. Including these donations plus a few necessary purchases, in the same period we have allocated to clients: 56 fridges, 19 washing machines, 8 dryers, 30 TVs, 8 VCRs, 17 microwaves, and 40 heaters. And still we are unable to clear some quite long waiting lists. These figures do not include appliances

Briefs



At the Ninth Annual Congress of Immunology, held in San Francisco late July, the growing consensus among researchers of the need for early treatment of HIV infection was confirmed. Also at the conference, Dr Robert Gallo announced that he will start gene therapy in HIV positive people at his new Institute (see *Talkabout* August) within a year. (*San Francisco Examiner*)

Cleaning the birth canal with a common antiseptic might be a safe and effective way to prevent the transmission of HIV-1 from mother to infant according to a study of 160 Malawi women. The wash with 0.25 percent chlorhexidine was found to be practical and non-toxic. (*AIDS Patient Care*)

French studies of passive immunotherapy using HIV+ plasma from asymptomatic individuals reduced the incidence of AIDS defining events by threefold in people with advanced AIDS. However researchers warn that the approach may be difficult due to problems in obtaining large quantities of HIV+ plasma. (*Proceedings of the National Academy of Sciences*)

(Investigation of this therapy is on the agenda of the Immune Based Therapies Working Group of the NCHER).

At a recent conference on KS, the causal role of a newly discovered herpes virus (KSHV) in Kaposi's Sarcoma was disputed by a number of researchers. Although the original research has been duplicated by some researchers, others, including Dr Robert Gallo, say that they have been unable to find the virus in KS cell lines. Researcher Robert Biggar also questioned the virus' causal role, suggesting that it may be involved in all sorts of proliferative lesions. (*Treatment Issues*)

Clarithromycin produced a psychotic reaction in two patients, reports the journal *Clinical Infectious Diseases*. The two, on a high dose of the drug to fight MAC, suffered symptoms including anxiety and delusions of grandeur, which resolved after the drug was discontinued but recurred when the drug was restarted. One patient was taking fluconazole, so drug interactions could not be excluded. Marketing approval for Clarithromycin has been granted in the US.

US biotechnology company Infected has been granted a patent for a new MAI test. The MAI Identikit allows for simple, early detection of MAI. The company says that the test could be combined with gene amplification methods for rapid treatment results.

A report by the US Treatments Action Group has recommended that PLWHA and health care givers be made more aware of AIDS-related lymphoma symptoms (such as fevers, chills and night sweats) because of the importance of early detection and treatment.

(*Treatment briefs/Paul Canning*)

purchased for clients living elsewhere in the state. BGF always accepts donations of appliances in good condition and in good working order.

BGF has a number of exciting fundraising events coming up so we urge you to keep an eye out for the advertisements, join in, have some fun and provide support if you can. The next major event will be a huge fantasy auction at the Imperial Hotel in Erskineville on November 19.

On August 21, BGF launched this year's greeting card, featuring the exceptional painting *Jabirus* by Patrick Hockey. It's available from BGF (360 9755), David Jones and various Oxford St and King St businesses.

— Mark Tietjen

CLASH Update

PROJECT CLASH, WHICH PROVIDES peer support to heterosexuals with HIV, is now into its third year of operation. Project CLASH runs a Freecall phone line, staffed by Positive volunteers and a support group twice a month.

Project CLASH recently released their Annual Report, which records an overall increase in the use of both the Freecall line and the Support Group. There has been a 35% increase of women attending the CLASH Support Group, although attendance has been down for men. This is partly due to the loss of two members.

Project CLASH also organised social activities for members, partners and families during the year.

Partners of HIV positive heterosexuals have had several meetings at a partners' support group.

Project CLASH thanks the following organisations for their support and assistance over the past year: Project CLASH Steering Group, Albion Street Centre and staff of the AIDS information Line, Ankali Project, *Talkabout*, NUAA and Positive Women.

The CLASH Support Group meets on the second and fourth Fridays of the month at Ankali House in Crown Street.

Call (Freecall) 1 800 812 404.

Sydney needs

RECENTLY A MEETING WAS HELD BY the AIDS Infectious Diseases Branch of NSW Health Department to address issues regarding day services for people living with HIV/AIDS in the Sydney metropolitan area. The outcome of the meeting was the establishment of a community development project.

Two consultants, Anne Malcolm and Lesley Goulburn, were contracted to conduct a needs assessment through a community consultative process and then to make recommendations regarding the most appropriate service delivery model of day services for people living with HIV/AIDS.

Both consultants, who have extensive knowledge of HIV/AIDS services, will be involved in the community consultative process, which will include a large number and cross section of PLWHA. The consultants will conduct a series of focus groups, public meetings and distribute a survey through major treatment centres in an attempt to reach as many PLWHA as possible.

Organisations involved in the provision of HIV/AIDS services will also be consulted. It is envisaged that the project will be completed within three months with a final report being submitted to the steering committee.

Have your say by calling Anne (564 1174) or Lesley (327 8128).

Notice

Matthew Cook, "Bundjalung warrior", HIV/AIDS worker and Positive Aboriginal spokesperson, died last month. We hope to publish a Tribute to Matt in the October *Talkabout*.

Talkback



Share your story

I wish to get in contact with PLWHA who would be interested in being interviewed on camera for a proposed documentary focusing on the issues of poverty and HIV/AIDS.

Confidentiality can be assured if so desired. It would be preferable that you be open and honest about your sexuality and positivity. We have already begun filming.

This is a group effort and is being carried out on the tightest of G-string budgets that a pension will allow. Any community groups or organisations interested who are willing to support this project should also contact me. This is not a get rich quick scheme, all we want is to air the stories of how the HIV/AIDS community is suffering, mostly in silence.

Please respond to Mark Ireland, c/o PO Box 831 Darlinghurst 2010.

— Mark J. Ireland

Applause I

I noted with interest in your July edition of *Talkabout* "Stand up and be Counted" carrying editorial from Jonathan Vincent which I enjoyed and empathised with.

I applaud every effort on your part in highlighting the growing

number of people still living ten plus years. In 'my day' (1984) there was no such hope, no such possibility. I saw so many of my dear friends give up under the weight of gloom and bad news. I hope today people can see examples of what is possible and your magazine goes a long way to that end.

Thank you for providing such a solid platform of support to the HIV+ community — God knows we need it.

— Phillip

Applause II

I thought the August issue of *Talkabout* was one of the most interesting and helpful publications to date. It is always good to read other people's personal stories of living or working with HIV. Although some of your readers complain about the facilities for PLWHA in Sydney they should try coping in a place where there is practically no help.

Keep up the good work, don't get disillusioned.

— Michael R. Jones

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



**Talkabout, PO Box 831
Darlinghurst 2010**

Olga's Personals

Guy 52 HIV+. Honest, sincere, still healthy & employed. Non scene, non smoker or drugs. Enjoys movies, theatre, dining out, quiet times at home, etc. Would like to meet HIV+ guy honest & sincere, similar interests who is interested in forming a loving mutually respecting relationship.
#950905

If at first you don't succeed, try try again. 33yo HIV gay male has always wanted to be a father. Any HIV+ lesbians or women (or other men) out there in a similar predicament that want to Talkabout things? I'm a nonsmoker, nonscene.
#950910

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 # in pencil on the outside.
- ★ Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on.

How to place your advertisement

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

If you're a positive woman and you're interested in receiving occasional information, social news, invites and medical updates — especially for women — then call VIVIENNE MUNRO or JACQUELINE FRAJER, at ACON on 206 2012 or 206 2058 to join the mailing list

Tribute



Brenton Heath-Kerr

1962 — 1995

This above all — to thine own
self be true;
must follow, as the night the
day,

Thou canst not then be false to
any man.

— *The Upanishads* (chosen by
Brenton for his memorial
service)

When I first met Brenton I didn't like him at all — we 'rubbed' each other up the wrong way. But, as I've seen happen with others, Brenton changed (and maybe I changed as well).

Working with him, listening to him, getting to know him, I grew to appreciate his grounded attitude to life. Writing up his life for *Black and White*, I discovered a side to the guy that was almost the exact opposite of the in-your-face didn't givva fuck costumier most would perceive him to be.

Heath-Kerr was born in Brisbane in 1962 and grew up on the Gold Coast, a "concrete void with no centre", as he called it.

According to his mother Irene, as a child he was a perfectionist: "His school projects always had to be the best. At twelve he'd be up till three o'clock in the morning doing them. I was worried!"

After a spell as 'an outcast' at college he got in his car — like many a Queensland gay before him — to make the pilgrimage to Sydney and the gay ghetto.

The first (recollected) costume was one he created for a graffiti party — Brenton interpreted graffiti as hieroglyphics and went as a

just-discovered Egyptian tomb, complete with lights. Interest in 'full looks' and anonymity was kick-started when one of his robot-like flashing outfits attracted abuse. "Someone yelled 'oh that fuckwit's got such a big ego'", he said. "It was so horrifying, I was just doing it for fun. So that's why I did masks."

First as a fly. Totally black, its invisibility in a dark dance party fascinated him.

At the 1992 'Jungle' theme Sleaze Ball he produced the finale with Sydney drag identity Maudie. A gigantic King Kong rose out of a stage placed in the middle of the enormous dancefloor then chased Fay Ray around, eventually scooping her up into its massive paw. Inside Kong was Brenton: "That was the biggest mask I've ever worn!"

Heath-Kerr applied the same description to being "trapped inside of this thing" that Warhol Superstar Edie Sedgwick did in *Ciao Manhattan* to being high on drugs: "That absolute high. That

sense of total freedom."

"I'm not a designer — I'm an artist," he argued, "or a visual artist, that's as far as you can categorise it."

"With my art the whole idea is to create this singular entity and you don't know if I'm black or white. It could be anyone inside it and that's the whole thing — that it is what's inside that counts."

Miss Gingham: the first character to draw an overwhelming rapturous response — its origins were actually a humble David Jones Houndstooth plastic bag.

The Nevada parties: one with the room turned upside down based on the seventies disaster movie *The Poseidon Adventure*. As a tribute to the Shelly Winters drowning scene (made infamously camp by Bette Midler) guests had to worm and squirm their way past obstacles just to get in. Another with a country theme had chickens and pigs running about.

Tom: A sexual character represented as a flat and one dimensional



Brenton Heath-Kerr photo: Mazz Images

thing. "And that's what it is," he said, "the whole argument. Yet it was embraced by the very people I was trying to make comment on, which was good because they saw the funny side."

écorché: The one that made him really famous. One of his most confronting and personal experiments, boldly and wonderfully commissioned by ACON for *Don't Leave Me This Way: Art In The Age Of AIDS*. (It did its job, shit stirred).

He said of the disease: "To fight off problems I personally look at the lighter side of things, it's in my nature to be an optimist. I think things are funny. Life is funny. Muscle men are funny."

"The disease has changed me for the better. I've mellowed into the person I would like to have become. I'm calm and non-judgemental. I see everyone as the same, perhaps that sounds strange or egotistical. Everyone is on the same basic search and you find that through simplicity rather than through conquering the world. You can conquer it on the inside."

All these words, from our various interviews, were carefully chosen but much the same as he chose for everyday life. And, unlike others, he never regretted, or

wanted to change, a single word.

Three of Heath-Kerr's most familiar costumes will form the centrepiece of a major Mardi Gras costume retrospective at the Pow-erhouse Museum next year.

The Brenton that I grew to like so much has gone but his particular contribution to Sydney's queer soul will live on.

— Paul Canning

Mark Cashman

Action Cashman is the preferred nickname by many who knew Mark. Active in every sense — Mark lived every single second of his life with an energy, a wit and an understanding that few could match.

In his working life as a social worker, Mark worked tirelessly at fighting for, maintaining and improving services for those with HIV and AIDS. Before his five years with ACON, Mark worked on the HIV/AIDS ward at Royal Prince Alfred Hospital. At ACON he worked on numerous projects including HIV Support, Counseling, and most recently as the Staff and Volunteer Support Officer. Mark was also involved in many groups such as Social Workers in AIDS, The National AIDS Counsellors Association, and AIDS

Dementia working groups.

An outstanding and engaging speaker, Mark was often invited to give papers or workshops on HIV/AIDS related issues or to sit on discussion panels. He was always out there doing something to make people think, listen and act.

On a personal level too, Mark's energy and capacity for whipping all those around him into a frothing frenzy of excitement and enthusiasm made him the most wonderful person to be around, even if exhausting at times.

Mark had an incredible and enviable relationship with his family, as well as with his numerous friends. Mark was one of the best friends I ever had. He was also a mentor, giving me direction and drive and always willing to share and give of his amazing understanding and talent. Mark gave so much to everybody around him and his death will always be a heart-felt loss.

— Alex Sosnov

David Martin

David Martin was a small, quirky person (his nickname was 'gnome'), who was drinking buddies with a tall, lanky person: Robert van Maanen. Robert, who brought David on board PLWH/A, would have been the best person to write a tribute to him.

David was a PLWH/A Committee member from 1993 —1994. Unfortunately, ill health often limited the amount of time he could give to the organisation. But when he did give it, he was unstinting. David's main achievement with PLWH/A — apart from quite a few of the invisible volunteer tasks around the office — was co-ordinating, with Vaughan Edwards, the 1994 PLWH/A Mardi Gras float.

David was a friendly, warm and enthusiastic person whose presence in the organisation (and the Flinders) will be missed.



🍁 **Montreal HIV '95** 🍁

2nd International Conference on Home & Community Care for Persons living with HIV/AIDS



A community HIV/AIDS memorial in the gay quarter of Montreal. Photo: Stephen Gallagher

By Stephen Gallagher

RED RIBBONS WERE UBIQUITOUS IN Montreal, but, interestingly, were being sold by high school students in shopping malls and near metro stations. The awareness that the ribbons were originally intended to evoke was actually happening in suburban Montreal — so unlike Sydney.

So, unlike Sydney, the publicity surrounding the conference was handled well by the press and TV. Commercial TV in this country

could certainly learn from the Canadian media, especially given the focus of the conference was on care for PLWHA rather than prevention.

About 1,100 delegates from over 60 countries attended the Conference: doctors, health care professionals, activists and PLWHA from community based AIDS organisations around the world. Unfortunately, given the smooth running and organisation of the conference, there was a serious hiccup when Stefan Collins, the Canadian board member of GNP+

(Global Network of Positive People) was denied entry to the conference because he couldn't pay the \$580Can registration fee and the organisers were not prepared to accept his offer to pay the advertised PLWHA reduced rate. (The cut off for this rate was three months before the conference. Surely the organisers realise that sometimes for PWA it is impossible to plan long distance trips so far in advance.) The organisers did eventually allow Stefan to attend with a press pass as he was writing a report on the conference. (Press

allowed in free, but hardworking, committed PLWHA volunteers have to pay, strange logic indeed!) But overall the thought and planning that had gone into the conference was impressive.

HIV 95 was interesting in many ways but as there were up to ten sessions running simultaneously it was impossible to attend everything I wanted to. None of the sessions presented any earth shattering news but listening to the experiences from people around the world and observing the subtle differences in addressing various issues were very enlightening.

Speaking at the opening of the Conference, Mr Jean-Pierre Belisle (Committee of People with HIV Quebec) was scathing in his criticism of Canada's Provincial (State) response to the epidemic. Canadian Provinces seem to have more autonomy than Australian States, so those government responses and programs differ markedly in different parts of Canada.

The next speaker, Ms Diane Marleau (Minister of National Health & Welfare, Canada) proceeded to self-congratulate the Canadian Government (politicians are the same world-wide). During her diatribe there was a sense of discomfort and as I turned around to face the huge audience, it was moving to see that a number of PLWHA from all over Canada had stood up and turned their backs on the Health Minister while she spoke. A silent protest criticising the federal government's cut-back of specific AIDS health care services.

The range of symposia and workshops at the conference was comprehensive, covering topics and issues such as: "Issues in dying at home", "Does living with HIV mean living with injustice", "Empowerment of PLWHAs" and "Complementary approaches", along with updates on antivirals, prophylaxis against opportunistic illnesses (OIs), oral hygiene, nutrition and pets as therapy.

One of the most valuable sessions I attended was titled "Oral and dermatological manifestations of HIV Infection". Dr Susan Fletcher (Montreal General Hospital) presented a paper on preventative oral care and HIV/AIDS related mouth infections. The emphasis was on regular visits to the dentist. Nothing new, we all know that we should visit the dentist at least twice a year, but what I found most interesting was the correlation between the dreaded dry mouth (xerostomia), and oral candida, mouth ulcers and gingivitis (chronic gum disease). PLWHA who visit their dentists regularly and gargle with solutions of chlorhexidine are less prone to oral candida and gingivitis. Fletcher went on to say that anecdotally people who did not succumb to mouth and gum disease are less likely to succumb to other bacterial infections such as oesophageal thrush. Good news indeed, I've been gargling constantly since then. Dr Fletcher also mentioned the importance of gargling with water after the mouthwash as chlorhexidine has a strong taste which masks the flavours of anything eaten for a few hours after gargling.

In the session titled "Issues in dying at home", Ms Robin Cumming (Vancouver Health Department) noted the decline in the number of people choosing to die at home. A number of people in Vancouver with late stage AIDS were asked their preference as to where they would prefer to die. Sixty percent nominated a hospice as they felt that they would not 'cope' with dying at home. Twenty seven percent lived alone and felt it would place a 'burden' on their loved ones. This is a great shift in attitude compared to five years ago when many more people chose to die at home.

Several references were made (by certain politicians and Health Department bureaucrats) to the

importance of fostering community based volunteer involvement purely on the basis of 'cost effectiveness' in times of health cost rationalisation, (relinquishing responsibility in the provision of health care?). In some parts of the world volunteer carers are taught medical procedures. It is a necessary measure in nations where universal health care is non-existent, but a frightening concept when grabbed onto by bean-counters in developed countries.

Some interesting news on treating CMV Retinitis was presented by Dr Kathleen Squires (University of Alabama, Birmingham). Oral ganciclovir has been approved in the US as an alternative maintenance therapy of CMV Retinitis. (After presentation of active disease people require life-long treatment). It has also been approved as prophylaxis. The approval criteria for use as prophylaxis is 100 CD4s with a history of previous active OIs or at 50 CD4s with no previous OIs.

The results drawn from drug trials 1653, 1174 and 034 are:

1) Oral ganciclovir is an effective alternative to IV maintenance therapy.

2) It may significantly reduce the incidence of active CMV disease.

None of this information is new, treatment activists have been lobbying for oral ganciclovir to be made available in Australia for the last nine months. What is promising however, from Dr Squires' presentation is that on oral maintenance therapy there are fewer presentations of neutropenia (depletion of neutrophils which fight off bacterial infections) or anaemia and fewer episodes of sepsis (infection associated with long term intravenous administration of drugs).

A golden opportunity to present new information about complementary therapies was missed at this conference. How often have we heard that there isn't any informa-

tion about the efficacy of complementary therapies? The presenters of this session presented no documented clinical data and constantly referred to anecdotal evidence such as 'people like complementary therapies,' or 'people feel better.' People who had attended the session to learn something walked out — I was one of them. If acceptance of complementary therapies is to be achieved by public health officials, doctors etc, some hard and fast evidence needs to be documented. 'People feel better,' doesn't cut the mustard. Presentations such as this only support the cynics who continue writing off any evidence to date.

International conferences are interesting phenomena. Much of the treatment information is nothing new to those of us fortunate to be living in Australia, however the opportunity to meet PLWHA and community workers from around the world is invaluable. The experiences of care and support programs around the world are a constant source of inspiration. Financial and staffing resources in all community organisations are severely stretched, so to learn about various services and programs which work (and about those that do not) enables us to share what limited resources there are available, and to be able to second guess any potential shortcomings about services which are in the planning stages.

In Australia we are fortunate, we have a free health care system, we have social security benefits and limited access to public housing programs. But we still don't have a dementia/palliative/respite care facility in Sydney — the epicentre of the Australasian epidemic. They have had one in Toronto, Canada, now for nine years. They too had hurdles to overcome with various bureaucracies and funding difficulties — greater than ours. They overcame their hurdles nine years ago! It's a shame that the Sydney

people given the task of setting up such a facility can't just get in touch with Casey House in Toronto to learn from their experience. Canada has health care and funding arrangements not dissimilar to ours, they set this service in place proactively.

It's a shame more people working in support and care in Australia don't see the value in attending international forums and conferences of this scale. There were three Australian delegates out of 1,100 in

total. Perhaps if more Australian workers saw the value in learning from international colleagues (there is more to conference attendance than sitting in sessions) we might not still be waiting for our version of Casey House, ten years into the epidemic.

Stephen met workers from PLWHA organisations and attended some of their workshops and forums while he was in North America. He'll talk about it in a future issue.

TIME OUT!

It's Sleaze Ball time again and although PLWH/A will not be co-ordinating a sponsored ticket scheme, we will be staffing a Time Out Room for people living with HIV/AIDS.

The Time Out Room is a safe, quiet space where we can be a part of the party without being part of the dance floor. A space where batteries can be recharged or assistance sought.

The room will be located upstairs in the Hordern Pavilion. If you can't find it, ask a Mardi Gras security officer or marshal for directions.

If you want to help out, that would be appreciated. We need assistance with setting up and particularly with packing up!

For more information and to offer help call 361 6011.



Contacts



Pull Out

AIDS Council of NSW (ACON)

9 Commonwealth St, Surry Hills
(near Museum Train Station).
Switchboard: 206 2000.

 **COMMUNITY SUPPORT NETWORK (CSN)** Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.

COUNSELLING Professional counsellors available for anyone living with or affected by HIV/AIDS. Free and confidential service, including: One-to-one counselling; home or hospital visits; telephone counselling. Call 206 2000 for appointment
CSN WESTERN SYDNEY Pat Kennedy 204 2404.

FUN AND ESTEEM WORKSHOPS For gay and bisexual men under the age of 26. Groups in Parramatta, Campbelltown and city. 206 2077.

 **GAY & LESBIAN INJECTING DRUG USE PROJECT (GLID UP).** Outreach, information & referral. We are sensitive to the issues faced by lesbians & gay men who inject drugs. 206 2096.

HIV/AIDS LEGAL CENTRE Legal advice/advocacy on HIV/AIDS related problems. 206 2060.

HIV living

SUPPORT GROUPS give you the chance to meet others with HIV, exchange ideas and make friends. If you'd like to join a group, become a facilitator, or just find out more about them, give us a call on 206 2014.



ACON HOUSING PROJECT We offer help & advice about public housing, in particular: accessing priority housing; transfer; and the special rental subsidy as well as housing discrimination, harassment and homelessness

The Housing Project also has a number of houses and units available to clients who are waiting for public housing. You must be eligible for priority housing and in the process of applying

Call Arnel or Fred on 206 2043 for an appointment



POSITIVE ASIAN MEN'S PROJECT Looks at the needs of all HIV+ Asian men. Michael Camit. 206 2036 or 206 2090.

 **POSITIVE WOMEN** Individual or group support for and by HIV/AIDS positive woman. Non-judgemental and completely confidential. Women and AIDS Project Officer or Women's HIV Support Officer, 206 2000; TTY for the Deaf 283 2088.

ACON WESTERN SYDNEY 9 Charles St, Parramatta. 204 2400.

ACON ILLAWARRA 129 Kembla St, Wallongong. (042) 26 1163.

ACON MID-NORTH COAST 93 High St, Coffs Harbour. (066) 51 4056.

ACON NORTHERN RIVERS 147 Laurel Ave, Lismore. (066) 22 1555.

ACON HUNTER 13-15 Watt St, Newcastle. (049) 29 3464.

GENERAL

AIDS TRUST OF AUSTRALIA 221 2955.
ALBION STREET CENTRE INFORMATION LINE 332 4000.

ASIANS & FRIENDS SYDNEY A social, cultural and support group for gay Asians and their friends, meets every Friday from 7.30-10pm. Gus or Jim (02) 558 0061 a/h.

AUSTRALIAN FEDERATION OF AIDS ORGANISATIONS (AFAO) 231 2111.

AUSTRALIAN NURSES IN AIDS Special interest group for nurses. John Miller 339 1111 or Maggie Tomkins 332 1090.

CIVIL REHABILITATION COMMITTEE Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Joanne Wing 289 2670.

KIDS WITH AIDS (KWAIDS) and parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772.

HANDS ON PROJECT Community based

HIV/AIDS training program for youth workers. 267 6387.

INNERSKILL Needle & syringe exchange, information & referral, also a range of free services for unemployed people. 810 1122.

METROPOLITAN COMMUNITY CHURCH (MCC) 638 3298. MCC Sydney 332 2457.

 **MULTICULTURAL HIV/AIDS EDUCATION AND SUPPORT PROJECT** Workers in 15 languages who provide HIV/AIDS information. Also provides cultural information, training & consultancy. Peter Todaro 515 3098.

NATIONAL AIDS/HIV COUNSELLORS ASSOCIATION 206 2000.

NATIONAL AUDIO VISUAL ARCHIVE OF PLWA Royce 319 1887 (after 1 pm).

NATIONAL CENTRE IN HIV EPIDEMIOLOGY & CLINICAL RESEARCH 332 4648.

NATIONAL CENTRE FOR HIV SOCIAL RESEARCH (Macquarie Unit). 805 8046.

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH AIDS (NAPWA).

NSW ANTI-DISCRIMINATION BOARD Takes complaints of AIDS related discrimination. 318 5400.

NSW USERS AND AIDS ASSOCIATION (NUAA) Community/peer based organisation providing support, referral and advocacy for injecting drug users and their friends. Needle exchange services. 369 3455.

QUILT PROJECT Memorial project for those who have died of AIDS. 360 9422.

SEX WORKERS' OUTREACH PROJECT (SWOP) 319 4866.

SILK ROAD Social and support group for Asian gay and bisexual men. Meets every Friday. Workshops, discussions, social activities. Arnel 206 2000.

SOCIAL WORKERS IN AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Also acts as a lobby group for people affected by HIV/AIDS. Anthony Shembri or Pina Commarano on 661 0111.

Tiffany's Transport 206 2040

Tiffany's provides transport for PLWHA to hospital or clinic appointments. The service operates early morning to early evening, Monday to Friday. For more info, or to make a booking, please call 206 2040. Ask for Monica. (Office open 8am — 3pm)



**Are you an HIV
Positive Woman?**



**Screamline
1800 630
075 (Toll Free)**

**You don't have to
be alone
Talk to another
Positive Woman**



ACON MID NORTH COAST

We offer support for PLWHA's alternative therapy subsidies; vitamin co-op; home based care & support; short-term accomodation; links to other PLWHA's; various health information

The branch also runs HIV prevention and safer sex education

93 High St, Coffs Harbour
PH: (066) 514 056



Sydney Sexual Health Centre

Sydney Hospital
Macquarie St (near
Marlin Place Station)

for an appointment
or information

223 7066

*no medicare card required
for recorded information

11646

Services provided:
➤STD test, treatment and
information
➤HIV/AIDS tests and care
➤Hepatitis B tests and
vaccinations
➤Counselling
➤Safe sex information
➤Free condoms, dams and tube
➤Multicultural information and
interpreter services
➤Needle syringe exchange

TAYLOR SQUARE PRIVATE CLINIC

Dr Robert Finlayson • Dr Ross Price • Dr Mark Robertson
Dr Anna McNulty • Dr Neil Bodsworth • Dr Debbie Coudwell
Fellows of the Australian College of Venerologists
and Dr John Byrne

8am to 8pm Monday to Friday • 10am to 12 noon Saturday

302 Bourke St Darlinghurst

331 6151

Call for appointment • Health Care Card Holders Bulk Billed



Livingstone Road Clinic

We provide HIV/STD
testing, treatment,
counselling and

education in a friendly cottage
enviroment. We provide total confidential-
ality (medicare cards are not required)
and there is easy off street parking.

182 Livingston Rd, Marrickville
560 3057

SUPPORTING POSITIVE ASIANS
Volunteer group for Asians (men and women) who are positive. Do you need support, info? 206 2036.



SYDNEY PLWHA DAY CENTRE A safe space to relax among peers. Services include: delicious lunches Tue-Fri; massage; acupuncture; reiki; feldenkrais; international healing; shiatsu; yoga & meditation; child care facilities; library; sewing facilities; pool table. We also have access to a retreat throughout the year. All our services are free of charge. 20 William Lane Woolloomooloo. 357 3011.

SYDNEY SOUTH WEST NEEDLE EXCHANGE
For access and locations 827 2222, 828 4844 or Mobile 018 25 1920.

TREE PLANTING PROJECT AIDS Memorial Groves. Sydney park, St Peters, in conjunction with South Sydney City Council. Mannie De Saxe 718 1452.

VOLUNTARY EUTHANASIA SOCIETY OF NSW INC. 212 4782.

WORLD AIDS DAY NSW 350 2611

CLINICS & HOSPITALS

ALBION STREET AIDS CENTRE Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. No Medicare card required. 332 1090.

CALVARY HOSPITAL Rocky Point Rd, Kogarah. Inpatient, respite and pain/symptom control (care by Victoria Furner). Full community support team. Stuart Pullen 587 8333.

EVERSLEIGH HOSPITAL A palliative care inpatient facility and community service. 560 3866.

GREENWICH HOSPITAL Palliative care inpatient unit, day hospital and community outreach. 439 7588.

HAEMOPHILIA UNIT Royal Prince Alfred Hospital. 516 7013.

KIRKTON ROAD CENTRE Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am-8pm, Mon-Fri. Social welfare service, needle & syringe exchange 2-6pm, Sat-Sun. Outreach bus 8pm-midnight, 7 days. Darlinghurst Fire Station, Victoria Rd, Kings Cross. 360 2766.

LIVERPOOL SEXUAL HEALTH CLINIC/HIV OUTPATIENT CLINIC Elizabeth/Bigge Sts., Liverpool. Free, confidential HIV/STD services, counselling, HIV support groups, practical support. 827 8022.

LIVINGSTONE ROAD SEXUAL HEALTH CLINIC 182 Livingstone Rd Marrickville. Open Mon, Wed, Thur 1-5pm. For appointment, 560 3057. No medicare card required.

NERINGAH HOSPITAL A palliative care inpatient facility, domiciliary and community service. 4-12 Neringah Ave. South, Wahroongah. 487 1000.

PRINCE HENRY (Special Care Unit) Anzac Parade, Little Bay. 694 5237 or 661 0111.

PRINCE OF WALES Children's Hospital (Paediatric AIDS Unit) High St Randwick. 399 2772/4. Dental Clinic, Acoca St, 399 2369.

ROYAL NORTH SHORE HIV outpatient, day treatment, medical consultations, inpatient services, counselling, support groups, sexual health clinic, testing. 438 7414/7415. Needle & syringe exchange 906 7083. Pacific Highway, St Leonards (by railway station).

ROYAL PRINCE ALFRED (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

SACRED HEART HOSPICE A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

ST GEORGE HOSPITAL HIV/AIDS Services Inpatient, Outpatient and Day Treatment Centre: South St, Kogarah. 350 2960
Sexual Health Clinic: Belgrave St, Kogarah. 350 2742.

ST VINCENTS HOSPITAL HIV MEDICINE UNIT Victoria St, Darlinghurst. Multidisciplinary HIV specialist care including medical, nursing, counselling, physiotherapy, occupational therapy, nutritional advice and community liaison. Switch 339 1111. Inpatient care: Ward Cahill 17, 361 2337/2285. Outpatient care: Immunology B clinics, Tu, Thur and Fri AM by referral, 361 7111. Ambulatory care/Urgent triage nurse practitioner on call, 339 1111. Clinical Trials, 361 2435. Dental Department, 361 7129.

SYDNEY SEXUAL HEALTH CENTRE Sydney Hospital, Macquarie St. 223 7066.

TRANSFUSION RELATED AIDS (TRAIDS) UNIT. Crisis/long term counselling, welfare support. Pam 843 3143. Red Cross BTS: Jenny 262 1764

UNITED DENTAL HOSPITAL Chalmers St, Surry Hills. HIV/AIDS service, Sue Mathieson 282 0246.

WESTMEAD CENTRE (Westmead and Parramatta Hospitals). Westmead 633 6333. Parramatta 843 3111.

EMOTIONAL SUPPORT

ACON COUNSELLING SERVICE Call 206 2000 for appointment

ANKALI Emotional support to PLWAs, their partners, family and friends. Trained volunteers provide one-to-one non-judgemental and confidential support. 332 1090.

CARERS SUPPORT GROUP South West Sydney. Runs Wednesday Evening in Liverpool, 6pm. Janelle or Julie on 827 8022

CLASH Confidential group of HIV+ heterosexuals who support each other by taking away some of the hardship of being alone. (Free call) 1-800 812 404.

FAMILY SUPPORT City: A support group for

family members of people with AIDS. Regular short term groups. Helen Golding on 361 2213. Outer Western suburbs: Meets evenings on a regular basis. Claire Black or Kevin Goode at Wentworth Sexual Health and HIV Services on (047) 24 2598. **FRIDAY DROP-IN** for PLWHA at ACON Western Sydney. 204 2402 for confidential information.

HIV+ SUPPORT GROUP South Western Sydney. Meets in Liverpool Wed 6.30pm. Julie 827 8022. Transport can be arranged.

PARENT'S FLAG Parents and friends of lesbians and gays. Meets 2nd Mon of the month. Heather, 899 1101, or Mollie 630 5681.

POR LA VIDA Un servicio de informacion y apoyo para personas afectadas por el VIH y El Sida. 206 2016.

QUEST FOR LIFE FOUNDATION Emotional support and education for people with life threatening illnesses, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.

SUPPORT GROUP FOR PARENTS OF HIV+ ADULTS Every 3rd Fri in the month 7-9pm at Ankali House 335 Crown St. Confidentiality assured. Grahame Colditz/Bern McPhee 332 1090.

SUPPORT OF POSITIVE YOUTH 360 2945.

SYDNEY WEST GROUP A Parramatta based support group. Pip Bowden 635 4595.

YOUTH HIV SUPPORT WORKER Counselling, advice, information to positive youth and their peers in the Central Sydney area. 690 1222.



YOUNG & POSITIVE A confidential service for young HIV+ gay guys. Support, information, groups, workshops, social events. Call Aldo or Jaimie 206 2076.

PRACTICAL HELP

BADLANDS Residential harm reduction service providing safe, non-coercive space for people who are at high risk of HIV transmission or acquiring HIV. Residents are mainly injecting drug users and/or sex workers. 211 0544.

BARNADOS FAMILY SERVICES Support for families affected by HIV/AIDS. Respite care, short/long term foster care and assistance with permanency planning for children whose parents have HIV/AIDS. 387 3311.



BOBBY GOLDSMITH FOUNDATION A community based, registered charity providing some financial assistance to approved clients. 360 9755.

DES KILKEARY LODGE Respite and Step-down support for PLWHA and their carers. Small day centre. Located on the Northern Beaches. Paul, 982 2310.

FUNERAL CELEBRANT General funerals, free in cases of financial hardship. Patrick Foley

on (018) 61 1255.

FOOD DISTRIBUTION NETWORK Cooperative distributing cheap boxes of fruit & vegetables. 9am - 4pm M-F, 699 1614.

HANDS ON MASSAGE AND REIKI for PLWHAs. Training of volunteer masseurs. Richard 660 6392.

PETS The Inner West Veterinary Hospital will never refuse urgent treatment for a pet because of lack of money. Please call 516 1466 for more information.

THE SANCTUARY Centre for complementary Therapies focussing on relation therapies. Tu-Fri 1.30-5.30pm. Gebe Neighbourhood Centre. Transport can be arranged. Bookings essential. Phone Lindy on 516 7830.

SHOPPING SERVICE FOR PLWHAS Fortnightly on Fridays, inner-city only. Bookings/& further information 360 2043.

YOGA Posture, breathing, meditation with Miren. Sydney PLWHA Day Centre Tuesdays 2-4pm. 357 3011 for more info.

OUTSIDE SYDNEY HAWKESBURY & BLUE MOUNTAINS

BLUE MOUNTAINS HIV/AIDS CLINIC Services include testing, treatment, monitoring and counselling/support. (047) 82 0360. 9.30am-1pm, M&F.

BLUE MOUNTAINS PLWA SUPPORT CENTRE Wed 11am-3pm (lunch). Fri 6.30-10.30pm (dinner).

(047) 82 2119 or Dennis (047) 88 1110. **CSN BLUE MOUNTAINS** Hands on practical help for people with HIV/AIDS. Pat Kennedy, (02)204 2404.

HAWKESBURY SEXUAL HEALTH/HIV CLINIC 8 Ross, Windsor Tues 4-7. Appointments (045) 78 1622.

KARUNA BLUE MOUNTAINS Emotional support for PLWHA, their partners, family and friends. Ann (047)82 2120.

NEPEAN HIV CLINIC Nepean Hospital Mon 3-8, Thurs 9-5. (047) 24 2507 for all appointments. Counselling & Support (047) 24 2598.

SOUTHERN HIGHLANDS HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional and practical support for PLWHAs, their family and friends, living in the Bowral district. Marion Flood (048) 61 2744 or David Willis (018)48 3345.

WENTWORTH HIV/AIDS CLINICAL NURSE CONSULTANT (018) 47 9321

CENTRAL COAST & HUNTER

CENTRAL COAST SEXUAL HEALTH SERVICE Offering HIV clinic for testing, monitoring, treatments, support. Patrick (043) 20 2114.

CSN NEWCASTLE Rosemary Bristow, ACON Hunter, 13-15 Watt St, Newcastle. (049) 29 3464.

NSW HIV/AIDS Information line
Mon-Fri 9am-8pm, Sat 10am-6pm
Advice and referral information for HIV/AIDS

008	451	600
Rural	Project,	ACON
Mon-Fri 10am-6pm		
General advice and referrals on HIV/AIDS in country areas		
008	802	612
Take	Control	Line
Mon-Fri 10am-6pm		
Confidential and frank information on treatments for HIV/AIDS		
008	816	518
C	L	A S H
Confidential group of HIV Positive heterosexuals		
1	800	812 404

People Living With HIV/AIDS (NSW) Inc.

361 6011 Fax 360 3504

Post: PO Box 831, Darlinghurst NSW 2010
Office: Suite 5, Level 1, 94 Oxford St, Darlinghurst

ACCESS

PositHIV Radio

2SER FM 107.3 Tuesday 9.30pm
PO Box 473 Broadway NSW 2007
ph: 516 4772 fx: 330 3099
2SER FM 330 3000

COASTAL CONNECTIONS Gay & lesbian social group. (043) 65 3461. PO Box 259, Toukley 2263.

HUNTER AREA HIV SUPPORT/ACTION GROUP 6.30pm, 4th Wed every month at ACON. Inquiries (049)29 3464.

JOHN HUNTER HOSPITAL (Clinical Immunology Ward). Lookout Rd, New Lambton, Newcastle. (049) 21 4766.

KARUMAH DAY CENTRE. First floor, 101 Scott St, opposite Newcastle Railway Station. Open Tues 6-9pm (games night), Wed 6-9pm (games night & masseur when available), Thur 11am -3pm (lunch & activities). (049) 29 6367.

KONNEXIONS DAY CENTRE 11am-3.30pm Mon for lunch & social. Lesley. (043) 23 2095.

NSW ANTI-DISCRIMINATION BOARD Newcastle. (049) 26 4300.

NEWCASTLE GAY FRIENDSHIP NETWORK Peer support, workshops and activities for gay men under 26. ACON (049) 29 3464.

POSITIVE SUPPORT NETWORK Emotional/hands on support for PLWHAs on the Central Coast. Lesley Digram (043) 23

2905. Suite 3, No6 Burns Cres, Gosford
2250, PO Box 2429 Gosford.

THE LAKES CLINIC (Tuncurry) A sexual
Health Service. Bridgepoint Building 2nd
flr. Manning St. Thu 10 -2pm. Free and
confidential.(065) 55 6822.

**WOMEN'S HIV/AIDS & SEXUAL HEALTH
SUPPORT NETWORK** For positive women,
their partners and friends. Awareness
raising. Helen (049) 524362.

NEW ENGLAND & NORTH COAST

ARMIDALE HIV EDUCATOR Melinda Spinks
(067) 73 4 712.

BLIGH STREET SEXUAL HEALTH CLINIC.
(Tamworth) Free & confidential STD/HIV
testing & management. (067) 66 3095.

CHAPS OUT BACK (Coffs Harbour)
Confidential support, advice & social
activities. Hydrotherapy & gym classes
Tues/Thurs. John (066) 51 2664 or Victor
(066) 51 6869 or Chris (066) 52 1658.

CLARENCE VALLEY PLWHA Support Group.
Peter (066) 46 2395.

CLINICAL NURSE CONSULTANT Karin Fisher
Providing service to barwon, Lower North
Coast, New England & North West (067)
66 9870, page 016 020 x 61 1476.

CLUB 2430 (Taree) Manning Area Gay and
Lesbian Support Group. Social functions,
newsletter, monthly meetings. Lloyd (065)
52 7154 or Liz (065) 51 1409.

COASTAL LYNX Mid north coast gay &
lesbian support group. (065) 62 7091.

GAY/MSM WORKER Bernie Green. Bligh
St Clinic Tamworth. (067) 66 2226.

GRAFTON HIV/NESB WORKER Sharyn
Dilossa. (066) 42 3333x229.

**GUNNEDAH & DISTRICTS HIV/AIDS
SUPPORT EDUCATION GROUP** Elaine (067)
44 1212 or Val (067) 69 7522.

HASTE (Hastings AIDS Support Team &
Network). Craig Gallon (065) 62 6155.

KEMPSEY AIDS NETWORK Madelaine
Mainey (065) 62 6155, HIV Program
officer Craig Gallon 018 66 4186.

LISMORE SEXUAL HEALTH/AIDS SERVICE A
free, confidential service for all STD and
HIV testing and treatment. (066) 20 2980.

**NEW ENGLAND NEEDLE EXCHANGE
PROGRAM** (067) 662 626 or 018 66 8382.

NORTH COAST POSITIVE TIME GROUP A
support and social group for PLWHAs in
the North Coast region. (066) 22 1555.

TAGLS (The Armidale Lesbian & Gay
Society) Norman (067) 71 1890.

**TAMWORTH & DISTRICTS HIV SUPPORT
NETWORK** A confidential meeting space for
PLWHA to get together for emotional &
practical support & share experiences. Karin
(067) 66 9870, page 016 020 x 61 1476.

TAREE SEXUAL HEALTH SERVICE 93 High St
Taree, Tue 2-6pm, Thurs by appointment.
(065) 51 1315.

TBAGS (Tamworth Boys & Girls Society)

Bernie (067) 85 2147.

TROPICAL FRUITS Gay & lesbian social
group. Regular events. (066) 22 4353.

WOLLUMBIN CARES (North Coast)
Community AIDS Resources, Education and
Support. Gerry or Keven (066) 79 5191.

ILLAWARRA

CSN WOLLONGONG (042) 26 1163.

NSW ANTI-DISCRIMINATION BOARD
Wollongong. (042) 26 8190.

PORT KEMBLA SEXUAL HEALTH CLINIC
Confidential and free support for PLWHAs.
Fairfax Rd, Warrawong. (042) 76 2399.

POSITIVE SPACE ILLAWARRA A confidential
meeting place to chat, listen and share with
other positive people. Don't hesitate to call
(042) 26 1238 to chat with or meet others.
Wednesdays and Fridays 12pm-5pm.

THE CLUB Social & Support group. Contact
Frank Velozzi (042) 26 1163.

SOUTH WEST/EAST

ALBURY AIDS SERVICES Community Health
Centre 665 Dean St (060) 23 0206.
Needle & Syringe Exchange, Judy Davis.

**ALBURY/WODONGA HIV/AIDS BORDER
SUPPORT GROUP** (060) 23 0340.

**BEGA & EUROBODALLA SHIRES-HIV/AIDS
WORKER** Jenni Somers, 018 604 180 for
free, confidential info, counselling & support
from Bateman's Bay to the Vic. border.

BEGAY Bega area gay & lesbian social
group 018 60 4180.

**COOMA/SNOWY MOUNTAINS HIV/AIDS
VOLUNTEER SUPPORTER GROUP** Emotional
support for PLWHA, their family and friends
living in this area. Lorraine on (018) 48
4834 or (064) 52 1324.

GRIFFITH HIV EDUCATOR/SUPPORT WORKER
Laurane Pierce. (069) 62 3900.

NOWRA SEXUAL HEALTH CLINIC
Confidential and free support for PLWHAs.
Nowra Hospital, (044) 23 9353.

QUEANBEYAN HIV/AIDS/STD WORKER
Yantene Heyligers (06) 29 89236.

**SOUTHERN HIGHLANDS HIV/AIDS/STD
WORKER** David Williams 018 48 3345.

SOUTHERN TABLELANDS HIV/AIDS WORKER
Paul Davies, Goulburn Community Health
Centre (048) 27 3113/018 48 2671.

**WAGGA WAGGA HIV & SEXUAL HEALTH
SERVICES** Paula Denham (069) 38 6411. AIDS
Task Force (069) 25 3055 or (069) 38 6411.

**YOUNG HIV/AIDS VOLUNTEER SUPPORTER
GROUP** Valerie, (063) 82 1522.

W E S T

BROKEN HILL HIV/STD WORKER Darriea
Turley. Community Health Centre. (080)
88 5800.

**DUBBO/MUDGEES SEXUAL HEALTH/HIV
SERVICE** Robert Baldwin. HIV/STD Worker.
Community Health Centres Dubbo (068)

Regional Health Service

HIV/AIDS Coordinators

CENTRAL COAST

Karen Naim

Ph: (043) 20 3399 (018) 43 6044

CENTRAL SYDNEY

Lesley Painter

Ph: 550 5366

CENTRAL WEST

Dr. Dan Russell

Ph: (063) 32 8576/8538/8571

EASTERN SYDNEY

Marlene Velecky

Ph: 399 4832

HUNTER

Tony Butler

Ph: (049) 29 1292

ILLAWARRA

Vivienne Cunningham Smith

Ph: (042) 75 5823/76 2399

NEW ENGLAND

Christine Robertson

Ph: (067) 66 2288

NORTH COAST

Wendi Evans

Ph: (066) 20 2145

NORTHERN SYDNEY

Graham Stone

Ph: 438 8237

SOUTH EAST

Greg Ussher

Ph: (048) 27 3148

SOUTHERN SYDNEY

Colin Clews

Ph: 350 2959

SOUTH WEST REGION

Dalton Dupuy

Ph: (060) 23 0350

SOUTH WEST SYDNEY

Mark McPherson

Ph: 827 8033

WENTWORTH

Elizabeth O'Neil

Ph: (047) 22 2255

WESTERN SYDNEY

Chris O'Reilly

Ph: 843 3118

WESTERN NSW

Dr Michael Douglas

Ph: (068) 81 2222/2242

85 8937 & Mudgee (063) 72 6555.

OUT WEST A social & support group for
gays & lesbians in western NSW. Grant
(068) 82 5033 or Paul (063) 72 4477.

ORANGE COMMUNITY AIDS TASK FORCE
Shirley-Ann Bailey. Central West HIV
Support worker, Luke Austin. Community
Health Centre. (063) 62 6422.

**Please let us know if you want to
update your listing or add a new one!**

Dementia Care: *Beyond The Bin*

A meeting of the HIV/AIDS Related Dementia Care Working Party (DCWP) on August 18 has taken people with Dementia and their loved ones a step closer to resolving the longstanding problem of appropriate accommodation for people with AIDS related Dementia, reports Jill Sergeant.

PEOPLE WITH DEMENTIA OFTEN SLIP through the net of HIV/AIDS services because they need a specific kind of care that's not readily available. They may need acute care nursing because of other AIDS related conditions, but also, particularly in severe cases, need 24hr care so that they do not place themselves or others at risk. Currently, people with Dementia are admitted either to hospital, a hospice, psychiatric wards, or are cared for at home, which can place carers and loved ones under considerable stress.

It's a far from ideal situation, and the need for a dedicated Dementia residential care facility has been identified for a number of years. Unfortunately, there has been very slow progress on doing anything about it. In 1994 \$1 million one-off funding became available from the Mark Fitzpatrick Trust to address the needs of people with Dementia. A working group of representatives of various health care, government and community organisations was set up to identify the best way of spending this money (the DCWP), which was bolstered by an additional \$1 million from the Health Department.

Two proposals were submitted to the Health Department late last year. One, from Central Sydney Area Health Service (CSAHS), specifically focused on a residential care unit. The other, from Eastern Sydney Area Health Service (now South Eastern Sydney AHS), was a broader proposal which incorporated a specialist dementia



care team to provide statewide outreach, backed up with additional beds in existing facilities and a program of Dementia education for health care workers.

The process of deciding between the two options has been held up by the Health Department's need to find recurrent funding for whatever options they choose, as well as various delays due to the change in State Government this year. The Department has been making some money available on a case by case basis to people with Dementia in acute need of housing, but this has been a costly and not always satisfactory way of handling the problem.

Vivienne Munro, Deputy Convenor of PLWH/A, is critical of the delay in resolving the issue and the lack of feedback to the community on what proposals had been put forward.

"People with Dementia have been dying without access to this

money or specialised care", she said.

The meeting on August 18 decided that the combined approach of a Dementia residential care facility (developed by CSAHS) with statewide outreach team and the back up of extra beds and a psychiatric team (developed by SESAHS) was the best way to go. Both Area Health Services are to resubmit their proposals with revised budgets. In the meantime, the Health Department has said it will provide recurrent funding of \$1 million annually.

"It's envisaged that all the services will be integrated in some way and that the two Area Health Services will work well together", says Marlene Velecky, HIV/AIDS Co-ordinator with the Eastern Sydney sector of SESAHS. "I would hope there would be an allocation of funding very soon. Obviously, we'd like to get on with it", she said.

How long the process of approving the new proposals will take is unclear, and once funding is approved it could still be some time before a Dementia care unit opens its doors. Negotiation for a suitable building is underway, however renovation and processes such as getting Council zoning approval and employing staff may be time consuming.

"Both Area Health Services are committed to working as quickly as we can on this issue", says Lesley Painter, HIV/AIDS Co-ordinator with CSAHS.

Munro is pleased to see action on the issue. "The combined approach covers all aspects of care and the prospect of supported accommodation looks exciting. Let's hope we're not left waiting", she said.

Dementia: There's Hope

Dr. Bruce Brew is optimistic about the early diagnosis and treatment of AIDS Dementia Complex (ADC).

FOR TOO LONG ADC HAS BEEN DISMISSED as untreatable, too infrequent to worry about or occurring too late in the course of HIV infection to do anything about. Each of these opinions is wrong, as I will explain.

Faults can be found in several areas: medical bureaucracies sometimes see the recognition of ADC as a potential threat to their funding; pharmaceutical companies, with few exceptions, have chosen to develop antiretroviral drugs without any consideration as to whether the drugs would enter the brain; carers and patients find the prospect of ADC terrifying and prefer to ignore it, hoping that it will just disappear.

With the possibility now of early detection of ADC, the identification of risk factors for ADC and the advent of several antiretroviral medications that are active against HIV in the brain, the case for consideration for early diagnosis and treatment of ADC has become stronger.

What is AIDS Dementia Complex?

AIDS Dementia Complex, otherwise known as AIDS dementia or HIV dementia, is a complication that occurs in some HIV infected patients as their immune system becomes more compromised. While the term "dementia" carries a lot of emotional baggage it still accurately describes the disorder in keeping with the definition of dementia: loss of intellectual power as

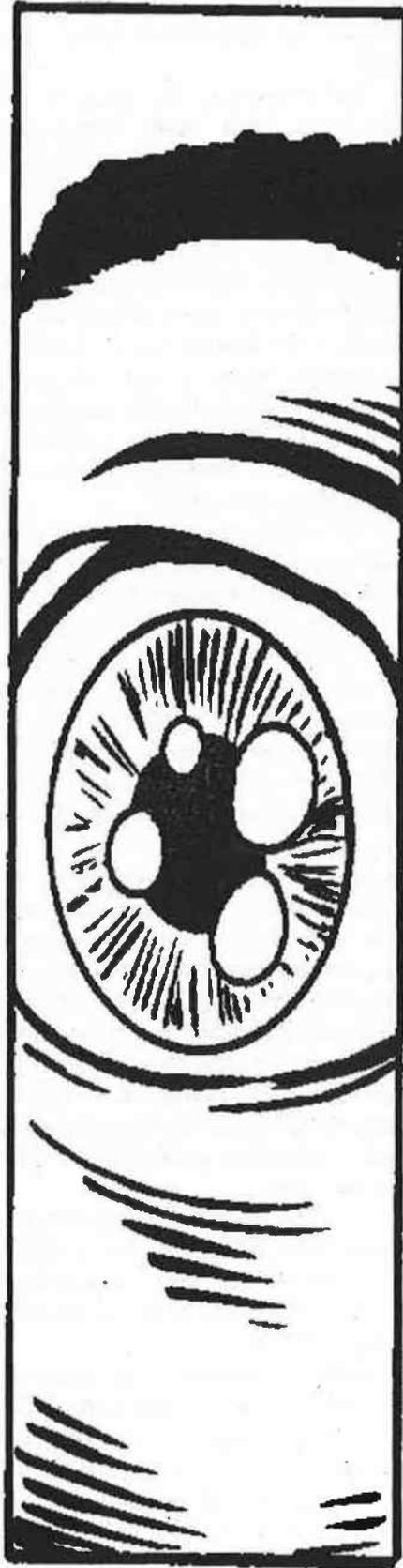
the result of brain disease.

It is certainly true that "dementia" has a whole host of connotations such as insanity, loss of control and loss of judgement, none of which is necessarily the case in an individual patient — people may have mild to moderate ADC and still be in control of their affairs and able to make judgements. Unfortunately there is no acceptable alternative term at present.

In some ways ADC is similar to Alzheimer's disease in that it is a disease that affects the brain, eventually leading to compromise in the person's ability to think clearly and make decisions. However, there are some important differences. ADC is mainly a disorder where thinking is slowed and concentration is poor but the content is only mildly abnormal, whereas Alzheimer's disease is the opposite; indeed the main problem in Alzheimer's disease is poor memory.

Apart from slowed thinking and poor concentration, people often find that their dexterity and balance are impaired so that they drop things more easily, bump into walls and so on. Often they complain that their handwriting has become sloppy and sometimes that their signature is no longer recognisable. Additionally, people become emotionally 'flat' and find that they are no longer interested in keeping up with friends.

No one person has all these complaints but most people with ADC



have some. The disorder often begins slowly and insidiously over several weeks and more often, several months. Frequently, patients dismiss their complaints as being related to stress or depression.

How common is ADC?

Figures vary according to the population being assessed and the definition of ADC that is used. In people with T-cells under 200, approximately 30% will have mild ADC and about 12% will have more significant ADC. These figures may increase over the next few years in the light of the widespread development and use of antiretroviral drugs that do not enter the brain.

What are the risk factors for the later development of ADC?

In patients who do not have AIDS, there are several factors that indicate a higher chance of developing ADC. These include more constitutional symptoms such as unexplained diarrhoea, weight loss and most importantly low haemoglobin. In people who have fewer than 200 T cells, there are certain proteins in the spinal fluid, the higher concentrations of which indicate a higher risk of developing ADC. A T-cell count below 50 is also a risk factor but curiously, haemoglobin is no longer important when patients have low T-cells.

Are there any 'signals' that ADC might be present in an individual?

Apart from the previously mentioned complaints, there are other features that may alert both you and your doctor: the prominence of constitutional symptoms of HIV disease such as fatigue, weight loss and diarrhoea, particular abnormalities of walking and significantly elevated levels of neopterin (a marker of how the immune system is functioning) in the blood.

How is the diagnosis made?

Your doctor will have a very good idea in most cases but sometimes it can be difficult to sort out the importance of other conditions

that might mimic ADC. Indeed, some people have been mistakenly thought to have ADC when in fact they have had an easily treatable condition such as toxoplasmosis. It is usual therefore, to have a brain scan to exclude these possibilities. Sometimes a lumbar puncture is also recommended to rule out cytomegalovirus (causing brain impairment) and to confirm the diagnosis of ADC by checking the levels of certain proteins in the spinal fluid. Neuropsychological testing will also often be performed to confirm the diagnosis.

What treatment is there?

Currently, Zidovudine (AZT) in as high a dose as can be tolerated is the only recognised treatment for ADC. This is because Zidovudine is the only freely available antiretroviral drug that can enter the brain — other drugs cannot enter because they cannot cross a barrier in the brain known as the blood brain barrier. However, there has been one promising pilot study of a new antiretroviral drug for ADC and another is currently being conducted. Moreover, beginning next year there will be at least one other trial of a potentially effective drug.

How much improvement can be expected with treatment?

This varies with the individual; some return to normal while others improve to a lesser extent and still others do not improve at all. Response to treatment is partly related to how severely affected the person is — the more severe the less likely a favourable outcome will be. Presently, zidovudine has a 50% chance of leading to significant benefit but there are no figures for the other, newer therapies. It is important to realise that treatment does not have to be aggressive. According to the patient's/power of attorney's wishes treatment can be tailored to individual needs, for example to lessen distressing confusional episodes or to improve balance and coordination so as to

restore some degree of independent mobility.

What are the advantages of early diagnosis and treatment of ADC?

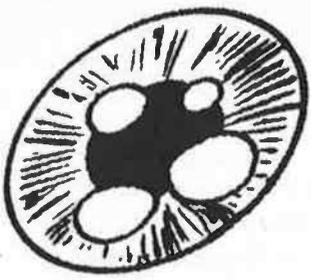
The main advantage is that the patient will have the best chance of having a favourable response to treatment. Also of importance when the diagnosis of ADC is made early is that you will be able to take control of the situation and prepare for the best as well as the worst outcomes by deciding exactly what you want: you can decide if you want treatment and for how long. Also, you will be able to put your affairs in order by choosing a power of attorney, sorting out your will and preparing to farewell loved ones. On too many occasions I have been involved with people who have developed ADC to the point where they cannot make decisions for themselves and a power of attorney has not been appointed so that medical staff do not know what the patient really wants done or not done.

What are the disadvantages of early diagnosis and treatment of ADC?

The major disadvantage is that you have to confront the reality of an illness that may rob you of your intellect, control and identity. This can be a terribly daunting experience. Additionally, there will be the disadvantage of having further tests performed and being further 'locked into' the medical system.

In conclusion then, the option of early diagnosis and treatment of ADC is now a reality. The decision to confront the possibility of ADC is clearly a personal one, transcending purely medical criteria. Nonetheless, the hardship in dealing with ADC has perhaps been made somewhat easier with advances in assessment and more especially, treatment so that early diagnosis and treatment can tangibly and substantially help people.

Dr Bruce Brew is Senior Staff Specialist, St Vincent's Hospital and Senior Lecturer in Medicine, University of NSW.



Mental

At a forum on dementia and psychological problems in June, Dale spoke about having had HIV mania. Dale described his experience to Peter Hornby.

Had you ever heard of HIV Mania before?

No. I'd heard of Dementia of course, but not HIV Mania. Now that it's happened I'd be more aware of the signs, as they come along.

About six months before I moved here from WA, I was very hyperactive and all these spooky things were happening for about a week.. Even my dog would keep away from me. I think that was my first experience of it.

With the more recent onset of HIV Mania, how do you remember it starting?

I don't know what the turning point was, but I became very hyperactive for about a month. You couldn't shut me up, I was running around here, there and everywhere. My partner picked up that something was wrong.

Eventually, I was in this warehouse down in Woolloomooloo. Being an artist, it was an artist's delight, there was junk everywhere. I wasn't even aware of the time, it was night. There was this old camper van and I had these visions of driving it. I just kept beeping the horn. Eventually the neighbours rang the police. They were really good, they took me off to the police station. Apparently I rang my boyfriend, Geoff. He explained to them what was happening. They were going to charge me, but he said there was a bed waiting for me at Prince of Wales, and they took me over there.

I was there in the psych ward for about a month. I had my own

room, which was really good. For the first couple of weeks I still had the Mania. It was like I could talk to the television, the people on the TV shows were talking to me and vice versa. I would read whatever was in my mind in the newspaper.

I had to take pills, I don't know what they were, Geoff knew. When I came out of hospital I was still taking them. My partner shouted me a trip to see my family, because they were really worried. I only stayed a week because I had very low energy levels. When I came back I was still very depressed, that was around Christmas time. We went up to Queensland to stay with friends, and I really kept to myself. I stayed in the room we were sharing and read. It was out in the country so I could look out into the bush. I was depressed until about end of February, early March.

How are things now?

Great! Really good. I haven't been depressed for a long time. I haven't been on the medication for

months, except for my Bactrim and things like that.

How would you describe the experience of HIV Mania?

You think the world is a wonderful place (and it is partly), you're just not really with it, you're in

your own little society. It was enjoyable, I had a great time, but afterwards, coming down off it, you want to go back up there.

What would you say to anyone who was concerned about mental problems?

Go and see your GP or go to the Albion St clinic or St Vincent's and talk about it. Tell the medical professional about your concerns. They're there to help you.

Do you think it's difficult for other people when they see people acting a bit unusually to know what to do? It's a big decision for the other party to say: I'm going to take him off to Albion St because I think he's weird.

It's a difficult one because everyone has their own rights and their own ways of dealing with things. I think if you can try and reason with them, that's all you can do. You can't force anyone to have any treatment unless they're wanting to. The worst part is, if they get into trouble with the police then you can get treatment for them.

How important was your personal support?

I'm very lucky that I have good friends and family who haven't disowned me. It helps a lot. When I started getting better, my parents

"I became very hyperactive for about a month. You couldn't shut me up, I was running around here, there and everywhere."

would be ringing up every couple of days to see how I was. My partner and other friends would come and see me, or take me out for the afternoon. That was really good. A lot of people don't have that sort of support.

as anything

You should be so lucky! Geoff, Dale's partner, was able to recognise that Dale had a mental illness and do something about it quickly because he worked at the Inner City Mental Health Service (ICMHS). He gave his side of the story to Peter Hornby.

Were you aware of any changes in Dale's behaviour before the incident where the police came?

Only in the two weeks before. He had a friend from Perth who was over here for a conference. He was very excited the whole time she was here. He couldn't keep still. They were awake fairly late hours, talking to each other. She was excited too, so I gave him the benefit of the doubt, but after she left the excitement never died down. He kept getting more excited, and sleeping poorly.

Things got worse the last few days prior to the police getting involved, and I actually called the Crisis Team at the Inner City Mental Health Services. I got one of our doctors to go down and see him with the crisis team. I went down with them, to let them in, but he wasn't there, the doors were open and he was out somewhere.

I went down several times over the next two or three days to try and catch him, but he was out and about having a good time, (in his words), and eventually we raised a Schedule Two, which is a commitment to treatment form written by the doctor here, based on my information and that of friends who know Dale. He'd run into everybody over a period of a week or two and they'd all noticed this escalation in mood and behaviour.

When you arranged that commitment notice, did you find any difficulty between your professional role and your personal role?

No, it had happened to me

before. Some of the first clients I'd met in this job were people with HIV and mental illness. They seemed to be a difficult group that nobody wanted to know very much about. I just happened to get involved in it and I've liked it ever since. Several HIV positive friends of mine have had Dementia

with the medication. You tend to use drugs that are not as strong, but it's much the same routine. Dale was on a mood stabilising drug and an anti-psychotic drug which was to slow him down a little bit. People with Mania tend not to sleep. There's too much happening, they're extremely active, they rush around all day and all night, they quite often forget to eat and drink, so you have to slow people down. Life's very grand, life's fantastic. He probably told you he thought it was fantastic, one of the best feel-



Geoff (left) and Dale photo: Mazz Images

“Life's very grand, life's fantastic. Usually treatment is against their will, because they don't see anything wrong.”

or mental illness.

Dale said that you knew what treatment he'd had at Prince of Wales.

When people get Mania the treatment is standard, whether they have HIV or not, except with HIV you have to be much more sensitive

ings he'd ever had. People with Mania feel like that. Usually treatment is against their will, because they don't see that anything is wrong.

And the problem is that they're not relating to other people, they may

risk hurting themselves?

It's Mania, things escalate. There's a big danger they may go and spend all their money in one hit. People's personal financial affairs may well be in disarray. Usually their affairs are in a mess and their lives are in a mess.

But the medication works, it just takes a little bit longer for people with HIV, because you have to consider their immune system. You've got to balance the combination between the mental health drugs and any drugs the person's receiving for HIV or AIDS. Usually the HIV drugs don't change, it's the mental

“It's like being on amphetamines. But unlike with recreational drugs there's no coming down from it”

health drugs that change. With Mania, a non-HIV positive person might settle down with medication in a couple of weeks, and a HIV positive person may take longer. *Is there a risk of recurrence?*

There is. With non-HIV Mania there's probably a higher risk. Dale's not having any medication at all for Mania now, he stopped that at Christmas, and the idea was for him to be fairly well educated about the signs and symptoms, so he could recognise if it was starting again. Once people have that in their grasp you usually can stop medication. There is a chance, if he doesn't keep an eye on it, that it might come back, but usually we find with people with HIV, it's only once or twice. It also seems to happen towards the later stages of HIV/AIDS.

Do you think that's to do with HIV in the brain?

It seems to be. Usually with people with HIV and Mania or any mental illness, there isn't any family history and they've never had it before. There are other factors, of course, such as stress, that you take into account as well.

Are recreational drugs a trigger?

They can be. But that alone

wouldn't be enough.

Briefly, what's the difference between Mania and Dementia?

Mania is considered a mental illness, whereas Dementia is considered a physical change in the brain. The Inner City Mental Health Service does not look after people with HIV/AIDS.

Although people with HIV/AIDS dementia may show improvement, the condition is a deteriorating one.

People with HIV/AIDS and mania usually recover with medication and a well organised management plan. I have cared for many people

with this condition over the last eight or nine years and just about all have recovered from the mania as displayed in Dale's case.

Are there any signs partners, friends and HIV positive people themselves, can look for?

It's difficult to pick up Mania in people who take recreational drugs, because it's like being on amphetamines. But unlike with recreational drugs there's no coming down from it.

People with Mania get very hyperactive, they have an inflated sense of how wonderful they are. It's a general speeding up of every-

thing. They often become very irritable and intolerant.

It's worth getting someone to assess the person, but it's easier said than done. People are more than welcome to come to the ICMHS. We offer assessment and a 24 hour service. If you're unsure then it's worth calling someone in for an assessment.

People may have some concerns about being committed, about going to a psychiatric institution?

Most of our assessments are done in people's homes. We talk to whoever has made the referral, then to the person who's thought to be ill and any other significant person. The Mental Health Act states that anyone with a major mental illness has to be looked after in the least restrictive form of care, so hospital is, by far, the last choice.

If the person agrees to it then you probably do all the treatment at home. The mental health team may need to go two or three times a day to make sure the person is alright. They'd also be the person's advocate for, for example, financial troubles. Hospital is the last choice, but sometimes it's the only one.

The Inner City Mental Health Service can be contacted on 360 3133. If you need to talk to someone about HIV and mental health, you are also welcome to contact Dale, ICMHS Coordinator, or Geoff through the same number.

**Cần giúp đỡ hay hướng dẫn
về siêu vi khuẩn HIV/Bệnh AIDS
trong vùng Nam Sydney?**

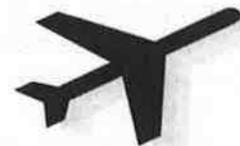
Máy ghi âm giải thích kín đáo. Điện thoại : 391 9987

Những Trung Tâm Bài Trữ Hoa Liễu Miễn phí và bảo mật. Điện thoại : 350 2742

Những dịch vụ Nhà Thương Miễn phí và bảo mật Điện thoại : 350 2955

Dịch vụ Trao đổi Ông và Kim Chính Miễn phí và bảo mật :
Xung quanh vùng Canterbury. Điện thoại : 016 288 504
Xung quanh vùng St George. Điện thoại : 018 479 201
Xung quanh vùng Sutherland. Điện thoại : 018 277 717

Leaving on a jet plane



Thinking about early retirement? Well think very carefully, especially about financial matters, says Mark Tietjen, or you might get some unpleasant surprises.

THE MANAGEMENT AND TREATMENT of HIV and AIDS is improving at a rapid pace. In the past we might have witnessed a steady decline following a person's AIDS diagnosis, but now a lot of people bounce back and experience longer periods of relatively good health. Regular monitoring means that situations where people experience sudden severe illness should be reduced.

In my job I think one of the biggest problems I see is boredom, lack of occupation, and people spending a lot of time focusing on relatively minor problems and events until they are virtually climbing the walls, or spending too much time worrying about how ill they are or are going to be.

I'm not about to say "if you're well, go out and get a job!" However what I would like to say is that before you consider retiring, think it through. Use the system when you need it, not because you are eligible. Do you really want to rely on a very low income, are you able to keep yourself occupied every day when there is no money to spend? Could you manage by taking some sick leave or similar?

I think it is time to change attitudes as to how we manage our lives once the disease process starts to move towards the danger zone. In the past many doctors and referring persons have 'felt sorry' for their patients having to cope with this 'terminal disease' and have freely provided appropriate medical documentation and letters of support. Many people have since discovered that they didn't die within a couple of years, that not being occupied is certainly not a life of relaxation and no worries — in fact many years may have passed

and many of these people are now suffering poverty, boredom and depression. Some try to find work but discover that having been out of the workforce for a number of years is a distinct disadvantage. Many are very focused on what their life has become.

There is no easy solution. The pension is survival income only. For many of us there can be huge personal barriers to break through before asking for help and/or tapping in to the system. This process can devastate self esteem. The system provides for a basic standard of living only. Having to rely on the system can be frustrating, unfulfilling and unpleasant.

THINKING ABOUT SUPER

What is Superannuation?

Simply, superannuation is a savings plan where payments are made by your employer and/or yourself to a superannuation fund on the understanding that when you retire, you will receive this money back, plus interest, to allow you to have a better standard of living than if you had to rely only on the Department of Social Security pension.

Superannuation is usually paid back to a superannuant in one of two ways;

1. as a lump sum which you can then spend or invest to provide for future income
2. as a regular income similar to a salary.

For people with HIV and AIDS superannuation is increasingly important as many superannuation funds have provision for a disability pay out which is usually in the

form of a lump sum. Advanced HIV and AIDS these days is recognised as a disability. Your superannuation fund may have provision for a disability pay out. In essence this means that the fund recognises the disabled superannuant is unlikely to be able to work again so should receive the benefits of retirement early.

What is Superannuation for?

Many people see their superannuation pay out as a chance to be able to do all the things they have never been able to do before, such as travel the world, buy that snazzy sports car, even buy their own home. A bit like winning the lottery!

For people living with HIV and AIDS who are disadvantaged as a result of ill health there is a well developed government and community based safety net. Admittedly it provides only a very basic standard of living but in many countries people are not so fortunate. When an Australian is unable to work any longer as a result of illness, they are then able to receive a basic income in the form of the Department of Social Security Disability Support Pension, they can be housed by the Department of Housing either in public housing or in the private market with generous subsidies, and they receive free medical care and hospitalisation and heavily subsidised pharmaceuticals and treatments. From within our own community we have additional specific community based charities and services such as the Bobby Goldsmith Foundation, the Metropolitan Community Church, People Living With HIV/AIDS Inc., the Community Support Network,

Ankali and the AIDS Council of NSW with its range of services and projects.

A superannuation pay out allows a superannuant to not have to rely entirely on Government and community organisations. The Australian Government introduced compulsory superannuation to reduce the demand on government expenditure in the form of social security pensions and to allow individuals to be able to take more responsibility for their retirement and to be able to provide for themselves.

To receive financial support from the government or charities there are income and assets limits. You may discover that once you receive your superannuation pay out, your pension is reduced or stopped, and you are no longer eligible for assistance from the Department of Housing, BGF and others. This is because it is considered that you are now able to support yourself and therefore no longer need to rely on

the "safety net" system. This is what your pay out is for — to allow you to support yourself and make your own choices and to do so with dignity.

How a superannuant spends their pay out and what others might think is the responsible way to spend it can be very contentious and lead to considerable diversity of opinion.

One school of thought is along the lines of: "I have always had to pay taxes and therefore anything I can get back from government is my entitlement." At the other end of the scale is the line of thinking that: "I am a responsible citizen and should only rely on government support when I have exhausted my own resources and am unable to support myself."

Social Security spending is one of the biggest budget items for the Australian government. Government reaction to this can currently be seen with their advertising drive aiming to have every working

Australian contributing to a superannuation scheme. When governments, especially conservative ones, are looking for ways to reduce Government spending, Social Security is often the first to experience spending cuts — this happened in New Zealand!

With more and more people with HIV and AIDS needing support and assistance and those already receiving it needing that support and assistance for much longer periods of time, there is a constant increasing strain on many organisations with limited resources and on the people and volunteers working for those organisations. When my health fails as a result of this ghastly virus, I hope that I will be able to have access to the same level of support we are providing today.

Mark Tietjen is an employee of the Bobby Goldsmith Foundation. The views expressed here are his personal opinions and do not necessarily reflect those of BGF.

Have your say about day services for people living with HIV/AIDS

What do you think these should be?

What kind of activities should be offered?

How would you like these provided?

Where would you like these provided?

We are conducting a needs assessment to find out the best way of providing a range of day services for people living with HIV/AIDS in the Sydney area.

If you would like to comment or participate in community discussions please contact Anne on (02) 564 1174 or Lesley on (02) 327 8128 before the end of September 1995.

JUST AROUND THE CORNER JUST DOWN THE STREET

We Offer:

- Hospital Inpatient Services and Outpatient Clinics (morning & evening clinics - pph 515 6111 page 6849)
- Community Nursing Care
Contact your local community health centre or phone 550 6700
- Dietary Advice & Consultations
Phone 515 6111 page 6737
- Emotional Support & Counselling
Phone 515 8131
- Equipment Lending i.e. Wheelchairs, walking aids, spence mattresses & other home comfort aids
Ph HIV OT 690 1222
- Gym/Exercise & Hydrotherapy Classes
Ph 515 6111 page 6861
- Injecting Drug Users Counselling
Ph 660 5455
- Mental Health Counselling
Ph 560 4500
- Multicultural Support & Education
Ph 515 3098
- Newtown Needle Exchange
Ph 515 3138
- Pain Management/Palliative Care & the On Call Nursing Service
Ph 515 7744
- Relaxation, Stress management & methods for maintaining your energy levels
Ph 515 6111 page 2550
- Sexual Health Advice & Screening
ph 560 3057



At Royal Prince Alfred, Concord & Eversleigh Hospitals and Community Health Centres near you.

HIV CARE IN YOUR COMMUNITY

CENTRAL SYDNEY AREA HEALTH SERVICE
PROVIDING QUALITY CARE IN THE INNER WEST
For further information please phone David on 560 3057

Gloria's Food



SOUPING IT UP

SERVE SOUPS WITH HOT CRUSTY BREAD rolls. You can buy day old bread from most bakeries (cheaper), freeze it and warm it in the oven before serving.

Viv's Vichyssoise (Potato and leek soup)

3 large potatoes
2 leeks
salt, pepper
sour cream or grated cheese

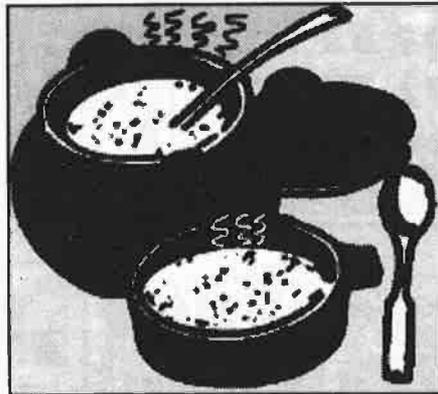
Peel potatoes if desired and thinly slice sideways. Wash and bring to boil in medium saucepan, with salt. Simmer gently for 5 minutes. Add sliced leek, cover and simmer for a further 10-15 minutes. Serve with sour cream or grated cheese and pepper. Serves four.

Gloria's good old vegie soup

1 kg beef bones
3 litres water
1 & 1/2 cups soup mix
3 cups chopped vegetables
e.g. carrots, potatoes, parsnips
salt, pepper

Put bones, water, and soup mix in a large saucepan. Bring to the boil and simmer for 2-3 hours until meat is falling off the bones. Remove bones, fat and gristle from the soup.

Winter's over (at last!) but the spring winds can still be pretty chilly. One way to stay warm and keep up your fluid intake at the same time (see p29) is to get stuck into soup. The other advantage of soups is that they're cheap and very easy to make. Thanks to Pip and Viv for sharing their recipes.



Add the vegetables and cook for further 40 minutes. Season with salt and pepper to taste.

Atomic onion soup

30g butter
2 large onions
pinch of sugar
2 teaspoons plain flour
6 cups beef or chicken stock
salt, pepper

Peel onions, cut into thick slices. Heat butter in pan (you may need a little extra butter) add onions and

sugar and cook, stirring, until golden and transparent. They should not be dark in colour. Sift in flour, slowly stir in stock. Season to taste with salt and pepper. Cover and cook gently for a further 20 minutes.

Serves about six, not suitable to freeze.

Pip's pumpkin soup

750g pumpkin
1 large potato, chopped
1 onion, chopped
4 cups chicken stock.
Salt, black pepper
nutmeg

Put pumpkin, potato and onion into a large saucepan. Add stock, cover, bring to the boil and cook until vegetables are soft. Puree in a blender or push through a sieve. Season with salt, pepper and nutmeg. For extra flavour add some bacon bones while cooking.

Serves about four people or use what you want and freeze the rest.

VOLUNTEER

Positions Vacant: Pedants required for proof reading; Speed typists with lots of patience) for transcribing interviews. Your chance to preview TALKABOUT before it goes to press! If you have the time, skills and inclination to assist the production of TALKABOUT in these ways, call Jill on 361 6750, or drop by the office Tuesdays, Wednesdays or Fridays.

**IF YOU LIKE A NIGHT ON THE WILD SIDE
YOU MIGHT NEED A SERVICE ON THE NORTH SIDE
CALL US, WE'LL CONNECT YOU WITH THE SERVICE YOU NEED**



SCM NS 01 Q1DP

- testing
- counselling
- treatment
- in/out patient
- homecare
- hospice
- respite



**NORTHSIDE
NETWORK
(02) 926 7788**

FOR TOTAL SEXUAL HEALTH CARE - INCLUDING HIV/AIDS

mon-fri 9-5: after hours appointments available totally confidential & free

NSW SOCIAL WORKERS IN AIDS

A special interest group of The Australian
Association of Social Workers Ltd.

1995 ANNUAL CONFERENCE REFLECTIONS INSPIRATIONS ACTIONS

Breaking out of the mould

**THURSDAY NOVEMBER
30TH, 1995**

**HYATT KINGSGATE HOTEL,
SYDNEY**

**FOR MORE INFORMATION, PLEASE CONTACT
ANDREW HARVEY ON (02) 515 8131**

1995 NSW HIV/AIDS HEALTH PROMOTION CONFERENCE

FIRST NOTICE For workers in education, other health promotion activity, care & support, training, managing, policy & research. Examines key issues & the practise of health promotion in HIV/AIDS. Papers, workshops & posters will be featured. Call for registrations will follow shortly.

conference dates & venue

8 / 10 November, Landmark Hotel, Potts Point

**Pre-conference Workshop Date & Venue < for workers new to HIV/AIDS area > 7 November,
Tusculum House, Potts Point**

Abstracts, workshop & poster entry forms available from Mark Davis < 02 > 391 9247

Funded by the AIDS/Infectious Diseases Branch

NSW HEALTH
DEPARTMENT

Fair Treatment



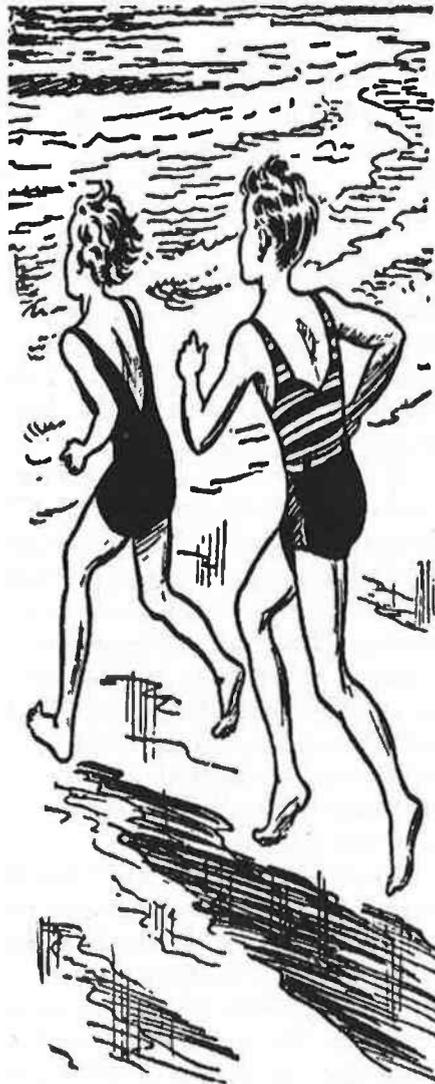
One for the road

Dehydration may be contributing to your symptoms and making other problems worse!

THE COMMON SYMPTOMS OF DEHYDRATION may include: dry mouth in the morning, passing urine at night, dry skin, loss of appetite, fatigue, loss of weight, cramps and headaches, nausea and vomiting, loss of interest and slowness of thought. Thirst may not be a major feature, though the mouth may feel dry. They may not all occur together. Dizziness on standing will occur if the dehydration is extreme.

Fortunately, treating dehydration is cheap and easy: just mix up a batch of the World Health Organisation Oral Rehydration Formula. How much of the solution you will need is not easily established, but if you are having enough, the symptoms mentioned above will be relieved.

Try to drink two litres in the first 24 hours, then a litre a day until you are reviewed by your doctor within the next week. As well as the solution, you should drink about 750 mls of other fluids a day — tea, water, juice, soft drink etc.



Oral rehydration solution

You will need a 2 litre container (a plastic juice or milk container or jug) and a 25 ml medicine cup from the chemist.

In a small amount of hot water, dissolve:

5 mls of salt

5 mls of baking soda and

40 mls of sugar or 20 mls of glucose or 60 g rice flour•

Add cold water (boiled and cooled, distilled, or mineral) and 3 Chlorvescent tablets (potassium)•• to make up the 2 litres. Add the tablets when the container is half full as they fizz up.

• Drink it straight or flavoured with cordial or juice.

•If using the rice flour you need to boil it in water for a few minutes to release the active ingredients before adding the salt, baking soda and Chlorvescent.

••Available from chemists.

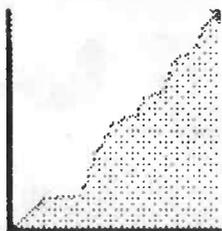
This information comes from the Taylor Square Private Clinic. Watch this space for an interview with Dr. Mark Robertson, who has been researching the significance of sodium imbalance and dehydration in people with HIV/AIDS.

Coming Soon

The October Issue of TALKABOUT will focus on children living with HIV/AIDS.

Your contributions are invited. Deadline: September 15. The November issue of TALKABOUT will have a special feature on Positive pregnancy. Recently there have been a lot of changes in scientific knowledge about HIV and pregnancy — and just as many controversies. Have your say on this topic. Deadline: October 16. Send your articles, poems or images to TALKABOUT PO Box 831, Darlinghurst 2010 or call Jill Sergeant on 361 6750, Tuesdays, Wednesdays and Fridays.

Beyond Prognosis



ANECDOTAL EVIDENCE

In the July issue we started an occasional series of personal stories from long term survivors of HIV. This month, Glen continues the series with his story. Readers are welcome to contribute to this section of Talkabout.

FROM AS EARLY AS '81/'82 I HAD heard of the AIDS virus, which was then called GRID (Gay Related Immune Deficiency). At the time I was as promiscuous as most other people on the 'scene', but, I didn't think that it might happen to me. It was more the case of: I'll worry about it when it appears in Australia. I even asked a doctor if I should be worried. He said I wouldn't have to worry for at least two or three years.

With this in mind I quite determinedly kept 'donating' my services to the Sydney scene. As it turned out, I only had to wait another year. The stories of "Gay Plague", GRID and AIDS had started to emerge in Australia after all.

During the late half of '83 I heard there were one or two lifestyle surveys going around. After some hesitation I decided to participate. The blood test didn't really worry

me. Even when the results came back I was not in the least pessimistic. I just didn't really pay attention to what the doctor told me — I thought I was in the clear. Boy, was I wrong!

It was not until I went for another visit to the surgery that I found out I was infected. I went home and rang up a friend. We had spoken about this disease, we were curious about the consequences of coming down with it. He came around that night, we opened some red wine and I told him about my diagnosis. We talked for a while and in many ways it helped me to accept the situation.

During that first year I heard varied stories of people getting on with their lives, after the fact and those who just vanished, as well as those people who were dying from the virus. My friend, Michael, became the one person I could talk with about it. He was from that

time onwards, my confidante. We would check around to see what could and couldn't be done. I talked with my doctor(s) where I could, and realised that I didn't want this f...ing thing killing me. So I vowed to myself and Michael that I'd live as best I could for as long as was physically possible.

What is strange is that I didn't really change my life style or my habits, although I always kept an eye on my weight. As long as that was up, I realised I was still okay and not suffering anything. As I had picked up a dose of herpes the year prior to my 'Status', I did what I could to avoid stress and depression.

As the months and years started to roll, I noticed that even though my T4 cells were slowly diminishing I didn't feel ill or unfit. I would go for regular blood tests and keep an optimistic view of my health. At the same time I was not trying to reinstate my virginity. I did my best to be careful about the level of sex I had.

I do not hold anyone 'responsible' for my HIV status. What has happened is no one's fault. I don't

Bobby Goldsmith Foundation

BGF provides assistance to people with advanced HIV/AIDS to enable them to maintain a reasonable standard of living by helping to alleviate some of the financial stresses during an extremely difficult time in their lives. For more information about BGF guidelines for assistance, or to make an application for assistance, please contact the BGF Office.

BGF, L4, 376 Victoria St PO Box 97 Darlinghurst NSW 2010
Tel 360 9755 Fax 360 9334



even hate myself for being the 'Slut' that I was (and in some ways, still am). It has made me appreciate life more than I may have.

I had a series of brief flings with guys, but they never lasted. I always told them my status, at least there was always that understanding on their part. Michael was never my lover, he still remains my longest known friend.

I avoided letting my family know for as long as I could, yet there was a nagging guilt about it. I just wasn't ready to do anything about it until there was no way around it. I was afraid of my family discriminating, as I'd heard stories of this.

By 1990, I'd had enough of the 'guilt'. I wrote to my mother. Her reaction was quite surprising — I had to come home "straight away" as it was something that was not to be suffered in silence. Because she knew very little, apart from media reports, she assumed the worst possible scenario, i.e. that I was on my death-bed. It was my sister who asked me if I was HIV or 'full-blown'. I went and stayed with them for six weeks to reassure them that I was okay. In hindsight I should not have kept it from them, it might have prevented the grey hairs emerging too soon.

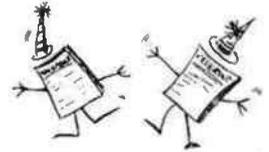
It is now 1995, and I have just started my 12th year with HIV. At the end of each year I go so far as to celebrate it with Michael and my family and why the hell shouldn't I? It is my life and health. I am a Long Term Survivor and I'm proud that I am still here to prove that the diagnosis back in '83 was not my death notice.

At the same time I 'bleed' a bit every time a friend falls to the finality of the virus. I hate the fact that they are no longer here while I am still running around. I'm sorry whenever someone loses the ability to fight the virus any longer. It makes me more determined not to give up my attitude to my life and health.

Talkabout

WHERE WE SPEAK FOR OURSELVES

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



Phillip McGraff

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

PLWH/A membership

Yes! I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year (Membership is only available to NSW residents)

Talkabout annual subscription rates

Please note that *Talkabout* subscribers also receive the quarterly *With Complements* Newsletter for no extra charge!

Individuals

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

Organisations

- Full (business, government, universities, hospitals, schools etc.) \$80 per year (Extra copies \$30 each per year)
- Concession (PLWHA organisations, non-funded community based groups etc.) \$40 per year (Extra copies \$15 each per year)
- Overseas A\$120 per year (Extra Copies A\$40 each per year)

(Please specify number of extra copies _____)

Donations

Yes! I want to make a donation to *Talkabout*:

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

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

Method of payment: Cash Cheque Credit card

Mastercard Visa Bankcard Card # _____

Expiry date _____ Signature _____ Date _____

Make all cheques payable to PLWHA Inc. (NSW), we'll send you a receipt (donations \$2 and over are tax deductible). Please note that the *Talkabout* database is totally confidential. Choose which rate applies to you. ☺ All rates are negotiable — talk to us → Special note for overseas subscribers: talk to us about exchanges with your publications.

First name _____

Last name _____

Postal Address _____

Postcode _____

Phone (w) _____ (h) _____

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



F E E D

there are people in our community who are starving. After rent, utilities and medication, many PLVAs have little or nothing left for food. You can help feed our brothers and sisters by supporting

MCC's Manna Pantry.

Metropolitan Community Church Sydney

Heffron Hall

cnr. Burton & Palmer Sts.

P. O. Box 1237

Darlinghurst 2010

Non-perishable food items and cash donations welcome.

phone **(02) 332 2457** for more information and to find your closest food drop-off site.

T H Y



If you are living with hiv/aids and find it difficult to make ends meet from time to time, please do not go without food.

For emergency assistance in a friendly, non-judgemental atmosphere, please contact Reverend Greg Smith, Metropolitan Community Church Sydney on the number above.

Metropolitan Community Church Sydney also provides many other support services to the hiv/aids community, including a regular free Sunday lunch for PLVAs, their carers and friends.

MCC proudly affirms the goodness of Gay and Lesbian sexuality.

P E O P L E