

talkabout

Where we speak for ourselves

121 | June - July 2002 | The Magazine of People Living With HIV/AIDS NSW Inc.



ภูเขาระตุกผู้ป่วยเอดส์
AIDS PATIENT BONED HILL

Hello! Can I speak with someone who understands my culture and what it is like to live with HIV/AIDS.



HIV & AIDS
VIH/SIDA
الايدز
AIDS

HIV i

ជំនួយនិងការដឹងចិត្តចុះ

ΑΡΧΟ Υ ΔΟΜΠΡΗΝΣΗ HIV AIDS Assistenza e Comprensione

ХИВ/СИДА YARDIM VE ANLAYIS PODRŠKA i RAZUMIJEVANJE

ΣΥΜΠΑΡΑΣΤΑΣΗ ΚΑΙ ΚΑΤΑΝΟΗΣΗ HIV-AIDS الايدز

ช่วยเหลือและเข้าใจ Trợ Giúp Thông Cảm VIH/SIDA

المسانده والتفهيم... HIV & AIDS 支持與理解 ऐष.ओ.वी/ऐदस

ПОДРШКА И РАЗУМЕВАЊЕ ПОМОС I ZROZUMIENIE

HIV/AIDS 愛滋病病毒/愛滋病 APOIO E COMPREENSÃO

나는 몰랐었다고 말하지 마십시오. ជំនួយនិងការដឹងចិត្តចុះ

AIDS는 예방될 수 있습니다.

អាចមែនស្តីនិងជម្លីមែនស្តី الايدز ខ្ញុំមិនចង់និយាយទៅ

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Support and Understanding HIV & AIDS i AIDS

YARDIM VE ANLAYIS

التفهيم... والمسانده

ΣΥΜΠΑΡΑΣΤΑΣΗ ΚΑΙ ΚΑΤΑΝΟΗΣΗ

ជំនួយនិងការដឹងចិត្តចុះ

愛滋病病毒/愛滋病

ऐष-ओ-वी / ऐदस

Trợ Giúp Thông Cảm

ПОМОС I ZROZUMIENIE

HIV i AIDS 支持與理解 VIH/SIDA

Dukungan dan pengertian

ВИРУСОТ HIV И СИДА-ТА

Assistenza e Comprensione الايدز

ПОДРШКА И РАЗБИРАЊЕ

나는 몰랐었다고 말하지 마십시오.

AIDS는 예방될 수 있습니다.

I am so happy my support worker is someone I can trust who does not talk to other people about my situation.



Use Illustration by Annie Knapton

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talkabout

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Photo: Ray Hansen

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do not indicate HIV status either positive

or negative.

from the publications working group



Last month's cover image, and some of the artworks in *Talkabout's* colour section, offended some readers. *Talkabout* respects the views of all readers and feedback is always appreciated. I believe that Positive Footprints, the exhibition featured in the April/May issue, was an important retrospective and I was very pleased to achieve a permanent record of this collection of images and campaigns.

Some readers were concerned that the explicitness of some of the artworks made the issue unsuitable for children. *Talkabout* is not intended to be suitable for children. It is unlikely that it will be in the future. This is a dilemma I face that affects not only the children of positive people, but young people aged 14-17 living in refuges or accessing other crisis youth services. The content of *Talkabout* is often unsuitable for young people in this age group and, as much as I would like to make the magazine available for positive young people in this age bracket, I do not want to change the content or curtail the freedom of expression extended to *Talkabout* contributors by demanding that the content be accessible and suitable for minors.

The previous editorial policy divided content for the magazine into 'themes' to be published in discrete issues. This policy no longer exists. Each issue of *Talkabout* aims to provide up-to-date information about news and events for all positive people, regardless of gender, race or sexuality. In keeping with this new editorial policy to provide timely information, the April/May issue included news that I hope was useful and relevant for positive women. The inclusion of the Positive Footprints images in the same issue was coincidental – the news was there and so was the exhibition. *Talkabout* didn't exclude Positive Footprints to guarantee women readers a 'shock-free' zone, and the space dedicated to news for positive women wasn't – and won't be – measured by the 'numbers'.

The Rural Forum at Nelson Bay was a great opportunity for me to meet face-to-face with some of the people I email and phone. I hope people who attended the forum, particularly the workshop about writing for *Talkabout*, will deluge me with contributions from regional and rural NSW. I can't get out there in any meaningful way. I don't have the time or the budget and it's the people on the ground who know whether promised services are being delivered and policies are being implemented.

Susan Hawkeswood, Editor

in this issue

Fundraising is on the agenda, with a new AIDS Trust campaign and the launch of BGF's winter appeal. In 'No more pictures without context', PLWH/A (NSW) Research & Policy Officer Kathy Triffit reviews the 'images of aids' over the past 20 years on **pages 14-16**. Susan Hawkeswood spoke to BGF's Georgina Harman and Mark Tietjen about 'Tugging heart-strings' on **page 17**.

Return to work could be a post-Budget imperative for some plwha. 'Options that work' on **page 18** and 'PES – employment support for positive people' on **pages 20-21** describe two of the services available for plwha who want to return to work. *Talkabout* contributor Jimbo writes about his own return to work experience on **pages 19-20**.



pos action

with **Antony Nicholas**, Executive Officer PLWH/A (NSW)

So where did all the advocates go? Or did the grassroots get weeded out? During the last two decades, plwha have been key members of the partnership built between government and affected communities. Plwha were instrumental in the formation of many organisations, worked within these and contributed to the development of a strong and innovative hiv sector.

Developing community participation models of engagement, collaboration and input into planning were innovative processes that early aids activists brought to health planning and broader social justice considerations. You would have to be very confident to give that away. However we are seeing less and less opportunity for infected communities to participate in consultation and participation, or have positive communities allowed the level of consultation and participation to lapse?

Over the late 90s and the first few years of the new millennium, we have seen hiv advocates become complacent to the point they are eventually teetering towards invisibility – so where did all the positive voices go? Whatever happened to the passion, the

defiance, the ‘talk with us, not about us’ motto; the ‘thriving and surviving’ tours of the late 80s and early 90s, and the challenge that infected communities placed on organisations and government. Was Gary Dowsett’s phrasing of ‘post AIDS’ at the 1995 NSW HIV/AIDS Health Promotion Conference really a death knell for activism. It certainly was premature in the context of the disease but very accurately indicated a decline of political activism and positive visibility.

How can we change this? In an era of mainstreaming, complacency and increased positive invisibility we have no choice but to take action. But by action I am not talking about frocking up in a nun’s habit and storming the streets. That time may have passed. It was needed in the 80s and 90s but would achieve little now. In fact it probably would be mistaken for some bizarre street theatre, not as political action.

I am talking about individual action, individual responsibility that propels organisations into action. Many organisations claim to represent plwha. Their objectives have lovely motherhood statements about empowerment and action. Ours is one of those organisations but like many plwha and aids organisations our options

If you are not willing to have your voice heard, how can anything change.

are limited. We need to hear your voice, especially in rural areas.

What I am trying to get across here is that complacency and invisibility are very dangerous. It is not ok to sit on your hands and think someone else is going to do it for you. Empowerment through and engagement with aids and plwha organisations is far too important a foundation stone to be eroded. The partnership with government is based with infected and affected communities but you have to commit to that partnership too. If you are not willing to have your voice heard, how can anything change. This is about personal action, honesty and it’s about empowerment. And most importantly it is about plwha being heard and being visible.

Talkabout’s housing feature continues. *Talkabout* regular Tim Alderman gives some advice for the financially challenged – that’s poor in the real world – in ‘The pensioner guide to chic homes’ on **pages 22–23**. The transition from SASS to public housing and back again is described by one plwha in ‘Appropriate public housing for some – a nightmare for others’ on **pages 24–25**.

Supported accommodation service Des Kilkeary Lodge reopened in May. In ‘Take a break at the beach’, DKL Coordinator Rhonda Bancroft and NorthAIDS Manager Adrian Eisler speak about respite care and other services provided by NorthAIDS, and the impact housing issues have on some residents. See **pages 26–27**.

A new regular column from the Positive Speakers Bureau – ‘speak positive’ – is included in this issue of *Talkabout*. *Talkabout’s* regular features include ‘Treatment update’, about New-Fill – a treatment for lipodystrophy – on **page 32**. This issue’s Agony Aunt – BGF’s Mark Tietjen – gives readers a few tips on surviving the DSP to work transition on **page 4**. ‘Treatment Briefs’ is on **page 5**.

agony aunt

Mark Tietjen

Q: I have been receiving the Disability Support Pension (DSP) for a few years but was offered a part-time job that will pay \$400 per week. I live alone in a one-bedroom unit and the rent is \$250 per week. The Department of Housing (DOH) gives me a subsidy and I pay \$87.50 per week. I have spoken to DOH and they told me that I will not get the rental subsidy. If I take the job, I can't afford to live on \$150 per week and I can't afford to move.

A: The Special Assistance Subsidy Special (SASS) from DOH means that a lot of people are living in situations that would not be affordable if there were no subsidies and they had to pay all the rent. If you really want to go back to work and take this job, you will need to move to affordable housing. To make it more difficult, many people have no resources to pay for a bond or moving costs. The bond for the place they are living in may have been paid by DOH, with assistance from DOH or BGF for moving costs. Our advice to people considering re-entering the workforce is to think first about housing and the cost of living before you start work. Before you lose all your benefits, such as assistance from DOH, BGF and similar, try to move somewhere that will be affordable when you are working. For many, this will mean a significant change in their living situation – they will maybe have to consider a share house, a smaller place or moving to the cheaper outer suburbs. The DOH income limit is \$395 per week gross. Anyone earning more than that is not eligible for DOH assistance. There are huge benefits to returning to work if you are able to do so, including improved self esteem, having a routine, mixing with people at work and during the day, and the ability to not rely on benefits. Getting out of the low income trap and poverty is another huge benefit, however to achieve that requires planning and some life style changes.

If you have any questions for Agony Aunt, email Maree Crosbie, Financial Counsellor at BGF: maree.crosbie@bgf.org.au

talkshop

PLWH/A (NSW) Community Development Project Officer
Will Klaasen profiles what's happening in NSW

HIV Rural Forum: 1-3 May

Nelson Bay was the place to be, with hiv/aids service providers and rural and regional plwha gathering together to listen, participate, meet each other, and discuss the state of affairs for regional and rural plwha and the services they receive. This year's forum allowed a more comprehensive level of partnership development between all who were involved. I want to say thanks to those who attended the workshop on HIV-Related Mental Health & AIDS Dementia service delivery in regional and rural NSW. Everyone who participated contributed their views with great honesty and contributed greatly to the overall research the organisation is conducting about this subject. If you live in regional or rural NSW and were unable to attend but would like to express views about any services gaps or overlaps in your area, we would like to hear from you. Go to our website and, under Community Development, print out a copy of the questionnaire, fill it in and return it to our office. All the details you need are included.

Blue Mountains PLWH/A Centre Inc

Blue Mountains PLWH/A Centre is holding a major 'Cowboys and Indians' fundraising night on Friday 7 June. It's a long weekend, so why not get away and have a great time meeting the gang in the Blue Mountains. Call the centre for more information on 02 4782 2119.

Illawarra Region

Our Pathways Inc and a number of ACON services moved into a new jointly leased office space in May. Both organisations will be able to deliver client services of the highest quality. You can call each organisation on their

existing numbers. I look forward to hearing positive things about the new arrangement, and that both organisations now will have an opportunity to meet people's needs and benefit plwha in the Illawarra/Shoalhaven area.

Planet Positive – Plum puddings & white xmas in June

The joint partners – PLWH/A (NSW), Positive Living Centre and ACON – invite you, your family and friends to join in the Yuletide in June at the Positive Living Centre from 6-10pm 28 June, 703 Bourke Street, Surry Hills. Food, drinks and lots of entertainment will be on hand to ensure a great night, so come and meet lots of new people. Contact the Positive Living Centre 02 9699 8756 for more information.

Final thoughts

I learnt at Nelson Bay that regional and rural plwha are having communication problems with their service providers. No matter what the area is, part of your overall health and wellbeing is to know you are receiving the best of quality care. If this is not happening, then remind that provider their job is to do so. It is always important to have a strong open dialogue with your provider. Yes, we hear that all the time and some of us may not be able to stand up for ourself at certain times. Take someone along with you who you trust to be a mediator, or to help you ask the questions you are not sure about. PLWH/A (NSW) Inc does not advocate on an individual basis but we need to know what is going on out there. It's important that you let us know if service providers are not meeting best practice. Also, plwha need to clearly identify what is best practice and quality care, so the organisation would like to hear from you about this. You can forward your views by email to: willk@plwha.org.au.

Speak Positive

Positive Speakers Bureau Coordinator **Paul Maudlin** describes the project, its history and current aims

This is the first of a regular column about the Positive Speakers Bureau (PSB), featuring news and info from me, speakers and project clients. This issue's column focuses on the project's role in the community.

PSB is a project of PLWH/A (NSW) that recognised community demand for public talks by people who are living with hiv/aids. The project was officially launched on World AIDS Day, 1 December 1994 at Paddington Town Hall. I can't tell you anything about the launch proceedings because I was doing my very first speaking engagement at Tullamore, in central western NSW. PSB enables positive people to speak to groups of people in the community, tell their stories and give their own perspectives on what it is like to be living with hiv/aids. The project's role is to reduce discrimination, ignorance and fear that surround hiv/aids, increase the awareness of the issues faced daily by plwha and empower each speaker with the knowledge that they are playing an important role in this process.

Speakers come from all walks of life. What they all have in common is that they are all living with hiv/aids and are willing to talk honestly and frankly about themselves. In the process, speakers directly answer questions their audiences ask.

Speakers have addressed a wide range of groups since PSB's inception. These include high school and university students, youth groups and refuges, Rotarians, Police Academy members, Department of Defence personnel, healthcare workers, volunteer telephone counsellors, government departments, and professional and private organisations and companies.

The project has a large input and representation in education, health and medical courses for hiv health-care professionals around NSW. The project is currently recruiting positive people under 30 of all sexual persuasions who would like to share their stories and experiences. For more details, don't hesitate to contact me on 02 9361 6011 or email psb@plwha.org.au.

'I was satisfied and even emotionally high due to their response. It's funny, to me my story is only average, but to them it was amazing.'

Luke Chipperfield

'I walk away from talks knowing that I have made a difference in addressing community attitudes to hiv, and feeling valued as a positive man.'

Kim Gotlieb

'A real eye opener for some of our students. An excellent talk given. Some were surprised at the speaker being a person having hiv.'

Teacher, Fort Street High School

treatment briefs

Tenofovir and mitochondrial toxicity

A recent study has shown that tenofovir, a member of a new class of drugs called nucleoside reverse transcriptase inhibitors, is less toxic to mitochondria than most NRTIs. Antiviral drugs belonging to the nucleoside (NRTI) class such as AZT, d4T and ddi are known to cause damage to the DNA within mitochondria, which are small bodies within cells responsible for transforming glucose into energy. This damage, called mitochondrial toxicity, can lead to peripheral neuropathy, lactic acidosis and muscle wasting. The study measured the effects of tenofovir and several NRTIs on the mitochondrial DNA within different types of cells of human origin. Tenofovir and the NRTI drugs 3TC and abacavir were found to have the least effect on mitochondrial DNA followed, in increasing order, by AZT, d4T, ddi and ddC. Furthermore, in contrast to AZT and ddC, tenofovir did not cause a significant increase in the production of lactic acid, even at higher dosages. Tenofovir has been licensed in the USA for use in combination with other antiviral drugs by all people with hiv. In the UK and Europe, it was recently licensed for use by people with hiv who are experiencing virologic failure as part of a second line, or salvage, therapy. Currently, tenofovir is available in Australia as part of a Special Access Scheme for people with limited treatment options and has been submitted for approval to the Therapeutic Goods Administration for use by all hiv positive people. www.medscape.com

Once-daily 3TC

The nucleoside drug 3TC is now licensed by the Therapeutic Goods Administration (TGA) for once-daily dosing. Until recently, 3TC was licensed in Australia as a twice-daily medication. Data presented at the 1st IAS Conference of HIV Pathogenesis and Treatment in Buenos Aires showed that 3TC could be safely and effectively used once-daily as a component of combination therapy. Once-daily dosing has been shown to be associated with improved adherence compared to more frequent dosing. *GlaxoSmithKline*

Treatment Briefs are written by ACON's Treatment Information Officers. Phone 02 9206 2036/2013, tollfree 1800 816 518, email treatinfo@acon.org.au

Compiled by *Talkabout* Editor, **Susan Hawkeswood**

Federal Budget targets plwha

The Federal Opposition may join the Democrats and Greens in opposing Budget changes to the Pharmaceutical Benefits Scheme (PBS) and Disability Support Pension (DSP). With the Australian Democrats and the Greens strongly opposed to the changes, Labor opposition in the Senate would be a blow to Budget savings. The PBS savings alone are estimated at about \$1.1 billion over four years.

The expected rises to PBS prescription drugs were announced in the Federal Budget on 14 May. For people who have a health care card, prescription costs will rise by \$1 to \$4.60 per script. For those who do not get a concession, the cost of a prescription will rise by \$6.20 to \$28.60. Changes to eligibility requirements for the Disability Support Pension (DSP) were also announced.

Vice President of the National Association of People Living With HIV/AIDS (NAPWA) David Menadue said the Government thinks this move will encourage people with disabilities to consider the possibility of part-time work, when, for chronic illnesses such as hiv/aids, the reverse is more likely to be the case.

'Moreover, people may be unlikely to take up opportunities for part-time work because they will fear being assessed as ineligible for DSP support,' he said.

ACON warned PBS price rises were likely to discourage people from continuing hiv treatments leading to higher rates of illness and hospitalisation. 'The 27% rise in the cost of prescription drugs will be compounded for people living with hiv/aids who take combination therapies and fill at least three prescriptions at a time, and the increase in the safety net does little to offset this,' said ACON President Adrian Lovney.

'Those with or without a health care card will be hit with a substantial price hike in

their prescription drugs and many people living with hiv/aids are also taking medications to overcome hiv treatment related side effects and the costs of those medications will rise as well.

'Almost a third of people with hiv/aids were living below the poverty line according to HIV Futures II – the 2000 report of the Australian Research Centre in Sex, Health & Society. People in poverty make choices in the face of available resources and if people living with hiv/aids make a choice to discontinue treatment because of cost then this will impact on their health.'

PLWH/A NSW President Mr Robinson said, 'There is no doubt in my mind that this increase will ultimately result in more hospital admissions and health problems down the track'.

From 1 July 2003, new applicants for DSP will have to demonstrate that they are unable to work 15 or more hours a week. The current criteria allows people to work up to 30 hours a week.

'In recent years we have witnessed an encouraging number of positive people returning to the workforce and this has had an enormous impact on their general wellbeing and self esteem. Cutting the number of hours people are able to work, from 30 to 15 a week, before they lose their disability pension will have a devastating effect on the many people living with hiv/aids who have part-time work.'

Disability groups slammed last night's announcement to move people with disabilities who were able to work 15 hours or more a week from DSP to Newstart Allowance. On Newstart Allowance, people with disabilities will be competing with able-bodied job seekers. The Government said 73,000 new training and work program places would be created for those currently on DSP.

Physical Disability Council of Australia President Maurice Corcoran said training programs did little to tempt employers to take a disabled person ahead of an able-bodied applicant.

'There's been a number of people that we represent who have been in vocational education and training for years but they still haven't been able to find meaningful employment,' he said.

Speaking about the proposed block in the Senate, Opposition Leader Simon Crean told ABC radio, 'We still have to consider this internally, but my very strong view is that we have to oppose them.'

'I want to consider the full details, I want to look at the extent of the other savings measures, but my very strong view is that this is a cruel Budget.'

'It's hurting families, it's hurting the disabled, and my very strong view is that we should oppose those measures.'

Treasurer Peter Costello told ABC radio, 'If the Labor party and the Democrats decide to join up against the Budget it would be a great difficulty.'

'They would be doing damage to the longterm prospects of Australia and, at the end of the day, people will suffer because of opportunist politics.' Meanwhile the Australian Democrats called on Labor to 'have some guts' and use the Senate to block the Government's Budget cuts to the sick and disabled. The Budget was mean and nasty and Mr Costello was isolating himself from most Australians, the party argued.

'In the cold, harsh light of day this Budget is mean and nasty still,' Democrat leader Natasha Stott Despoja said this morning.

'It is a national test of how we treat the most vulnerable in our community and if we pass the legislation that cuts PBS or DSP we will fail that test.'

Australians should be embarrassed if the legislation got through the Parliament, she said. 'But we need the Labor Party to get some guts and support us. I've heard nothing but wishy washy statements from the Opposition.'

Senator Bob Brown said the Greens would oppose the Government's Budget cuts to the Pharmaceutical Benefits Scheme (PBS) and welfare outright in the Senate. The

Government's Budget was hard-hearted and its cuts to the PBS and welfare were outrageous, Senator Brown said. 'We'll be opposing those in the Senate outright,' he said.

15/04/02, news.com.au

Myrtle Place looking for new premises

Funding limitations have forced NorthAIDS to look for cheaper premises for Myrtle Place. The service needs premises close to public transport, with disability access, and adequate kitchen and bathroom facilities. Any readers, particularly those with connections to church or charitable organisations that have space to rent, are asked to help with the search. Any information about rental properties that might be suitable can be passed on to Myrtle Place on 02 9929 4288.

ACON West

After more than a year of operating an outreach service from Surry Hills, ACON has leased a property at 6 Darcy Rd, Wentworthville. Located on a main bus route within 10 minutes walk of Westmead Hospital, and Wentworthville and Westmead train stations, the Darcy Road premises also have off-street parking.

With an official opening in May, ACON West's Manager Sonny Williams will be on site, together with some CSN staff, Education and Community Development staff and volunteers.

After a fire destroyed ACON West's Parramatta office, ACON relocated programs and services to other locations. Feedback to ACON indicated that the local community wanted service provision to stay largely as it is, with the addition of a community centre.

Acon Update, April 2002

injecting room trial extended

AUSTRALIA'S first heroin injecting room trial will be extended by one year, the NSW government has said. The 18-month Sydney trial, which officially began on May 1 last

year, will now end in October, 2003.

Special Minister of State John Della Bosca said an agreement had been struck with the centre's licence operators, the Board of Uniting Care Australia, to extend the trial in view of its success. He said there had been 200 overdoses in the Kings Cross clinic, but no deaths. He denied the move was being made to avoid any decision on the trial's future being made near the March 2003 state election.

'The Board of Uniting Care Australia has indicated they are prepared to be the licensee for an additional 12 months.'

Mr Della Bosca said the NSW government would have to legislate for the extension. The move is expected to trigger a fresh debate on the issue in parliament. But Mr Della Bosca said it was 'commonsense' the trial continue at least until the release of an independent evaluation of the clinic was completed in April next year.

19/04/02, news.com.au

needle exchange shut after radio blast

The Minister for Health, Craig Knowles, closed an 11-year-old needle exchange and drug facility in the marginal ALP seat of Ryde after the government was attacked on the issue by radio talkback host Alan Jones. The Sydney Morning Herald confirmed that the order was made from Mr Knowles's office directly to the Education Minister and Ryde MP, John Watkins, and implemented without any formal paperwork or investigation. There was no consultation with the Chief Executive Officer of the Northern Area Health Service, Dr Stephen Christley, or other drug health specialists. No formal complaint about the facility was made in writing. The needle exchange and drug counselling service had operated discreetly for more than a decade without incident.

The founder and CEO of Family Drug Support, Tony Trimmingham, said intravenous drug users between Hornsby and Parramatta were now without a primary needle exchange facility. 'It is disappointing that a service that has been operating in this community in a very understated way for over 10 years without incident becomes a political football,' Mr Trimmingham said.

The issue emerged publicly on 6 March after a local parent of an eight-year-old boy alleged that the child had been searching for spiders underneath a building on the school

grounds and had found a syringe pack and had put it in his pocket. The incident was reported on the front page of the local newspaper, the *Northern District Times*. The following day, 7 March, at 7.48am, Alan Jones told 2GB listeners that the needle exchange facility was nextdoor to the school and that 'apparently there's a hole in the fence where, presumably, addicts had managed to somehow access the school to use drugs.' According to senior sources, there are doubts about the origin and the age of the syringe pack, which appeared to be an old container that was not from the Ryde facility but a local pharmacy.

It is believed Mr Knowles initially ordered that the needle exchange service be moved from the health facility to a mobile van parked in Ryde Hospital. But a press release from Mr Watkins's electorate office stated, 'I am pleased to report to the local community that the van will close ... this is a good result that recognises the wishes and concerns of the local community.' Mr Watkins holds the seat of Ryde for the ALP by just 6.6%, making it one of the most marginal NSW seats.

Late yesterday, a spokesman for Mr Watkins and a spokesman for Mr Knowles conceded that there was no documentation relating to the decision and the closure was ordered at ministerial level after complaints to 'Mr Watkins's electorate office'. Mr Knowles's spokesman said, 'That is a valid process, not everything is documented ... the government has responded to community concerns which seemed reasonable.'

Paola Totaro, 24/04/02, www.smh.com.au

Housing: a serious concern

BGF, ACON and PLWH/A (NSW) are calling on the NSW Department of Housing to address concerns about proposed changes to the Special Assistance Subsidy Special (SASS) and how these will impact on plwha. This alliance of community organisations is working together to seek assurances from the department before the proposed changes are due to be implemented in July. The department has been asked to give a clear definition of 'appropriate' housing when securing properties for plwha close to relevant services and for a commitment to meet rental costs during the new four-week waiting period for SASS clients.

'We are disappointed that we have not been given concrete assurances that our major concerns will be addressed and that

these concerns, initially raised at the HIV Interagency Accommodation Crisis Group last year, appear to have been glossed over,' said ACON President Adrian Lovney. 'We have been given no indication that the department will take into consideration real or perceived threats to safety in assessing appropriateness of housing or proximity to existing social networks. Properties 'close to services' can apparently mean a 40 minute bus ride and, on this basis, Maroubra is considered close to St Vincents Hospital,' he said.

BGF Executive Director Georgina Harman said the proposed changes will impact on the financial and social circumstances of plwha and their quality of life. 'Clients who have rental housing may be forced to go into debt or seek financial assistance to cover the four-week waiting period and this will place an additional burden on agencies such as ours and on the small stock of emergency or crisis accommodation in Sydney,' Ms Harman said.

PLWH/A (NSW) Executive Officer Antony Nicholas said many hiv service providers had already received anecdotal reports of new priority housing clients being coerced into accepting accommodation which they viewed as inappropriate. 'If appropriate housing is not found within the four-week period, SASS clients will have to re-enter the private rental market with the additional disadvantage of being identifiable as a department client. Due to the large existing waiting list we are interested in knowing where all this available housing stock is,' Mr Nicholas said.

pap smear alert

Doubts were raised in April about the pap smear test results of 20,000 women after new concerns about a Melbourne laboratory. The concerns relate to tests undertaken by General Diagnostic Laboratories (GDL) over the past two years. The same lab was at the centre of a major scandal in March over the accuracy of its tests in 1998 and 1999.

Victorian Health Minister John Thwaites said a new report by the National Association of Testing Authorities had raised new concerns about the company's more recent test results. He said letters would be sent to an estimated 20,000 women who would be advised to be retested. 'Women who have

had pap smears processed at GDL in the past two years and who have not since had a pap smear conducted elsewhere are being advised to undertake a fresh pap smear,' he said.

In March, more than 14,000 women were advised to be retested due to suspect results from 1998 and 1999. Mr Thwaites said letters were being sent out as a precaution because the results of the women's pap smears were not necessarily accurate. He said while GDL was free to respond to the accreditation agency's concerns in the proper forum, it was vital that women were advised about such an important health issue.

GDL stopped carrying out pap smear tests at the end of March. It now refers pap smear results to accredited laboratories.

Victoria's Acting Chief Health Officer, Dr John Carnie, said pap smears were an effective way of preventing cervical cancer.

10/04/02, news.com.au

Rural GPs address shortage

Rural doctors held emergency talks in Tamworth in April to discuss solutions to growing shortages of GPs and specialists in country areas. Rural Doctors Association president Ken Mackey said the meeting was sparked by a lack of specialists in the NSW city but the association also recognised the shortage of GPs in smaller towns.

He said the future lay in attracting greater numbers of new medical students but the industry also had to recognise two-thirds of new doctors were women, who tended to have shorter working lives because of family commitments. Australia had to compete with other countries including Singapore, the United Kingdom, Canada and Ireland not only to keep its own graduates, but attract overseas doctors, Dr Mackey said.

Research by Access Economics showed one in five Australians lived in an area where there was a severe shortage of general practice services, rising to one in two people in some rural and remote areas. Access estimated the national doctor shortage at 1,200 to 2,000 GPs, with chronic shortages in inland Australia and parts of coastal NSW and Queensland. It warned the shortfall could rise to 10,500 GPs by 2020 if current trends continued.

18/04/02, news.com.au

cancer deaths higher in bush

Cancer survival rates are 30% lower in remote areas than in more populated areas, a new report has revealed. Poor access to cancer treatment and support services are partly to blame for the figures, according to a report released today by the NSW Cancer Council and Southern Cross Institute for Health Research.

Cancer Council Chief Executive Dr Penman said a lack of access to cancer screening diagnosis and treatment services meant diagnosis was delayed or people found it more difficult to present with symptoms. It also meant people took longer to seek advice about symptoms, the diagnosis might be less certain, or the referral for definitive treatment might be more delayed.

Survival for bowel, cervical, prostate and lung cancer is particularly bad in remote areas, where there is also a higher incidence of cancers related to smoking and alcohol consumption, he said.

The report also found women in remote NSW were 2.4 times less likely to survive cervical cancer than women in cities and regional centres.

'It reflects - in the case of cervical cancer where we know that there's a lower survival - probably lower participation in organised cancer screening programs,' Dr Penman said.

'But it also reflects different patterns of cancer, so that in these remote areas the tobacco and alcohol-related cancers - which are inherently more aggressive and have lower survival - have a higher rate of incidence.'

The report looked at all cases of cancer across NSW from 1992 to 1996, classifying them by an index of remoteness. 'Remote' meant places that were a significant distance and time away from major centres. 'A major problem is that health services in remote areas are stretched to the limit,' he said.

While only 1% of the NSW population lived in areas rated as remote, this included 48% of the state's Aboriginal population.

The report showed there was an urgent need for changes to services in rural and remote NSW to help improve survival rates, he said. 'We're talking here about quite a small proportion of the population but obviously a group that has some fairly distinctive health outcomes,' Dr Penman said.

09/04/02, news.com.au

pos man's sperm used in AI

A Japanese woman who conceived by artificial insemination has given birth. The donor sperm came from her hiv positive husband. Mother and child were confirmed infection-free, doctors said. It was the first successful birth using hiv-infected sperm in Japan, according to Tasuku Harada, a gynecologist and lecturer at the medical department of Tottori University in Tottori. Harada, who led a team of doctors in the case, said he was aware of 250 babies born in Italy and several more in Spain through the same method.

Doctors placed the hiv positive sperm into a centrifuge to separate the sperm from the virus. The sperm was then subjected to a 'swim-up' method in which doctors remove only active sperm to further filter out the hiv virus. 'According to one study, all but one of 4,000 copies of the virus may be removed through this method,' Harada said. The sperm-rinsing procedure is widely available in Japan but there are few places to check if the rinsed sperm is virus-free. As of 24 June 2001, the Japanese health ministry had reports of 7,680 cases of aids or hiv positive patients. This figure includes 1,432 people infected through contaminated blood products. At least 1,225 people have died of aids.

02/10/01, Agence France Presse. CDC HIV/STD/TB Prevention News Update 03/10/01

pos kids often free of severe symptoms 10 years

Most children who are vertically infected with hiv seem to be in relatively good health, according to a European study. As reported in the 1 April issue of the *Journal of Acquired Immune Deficiency Syndromes*, Dr Marie-Louise Newell, from the Institute of Child Health in London, and colleagues characterised the status of 34 positive children who were enrolled in the European Collaborative Study and survived 10 years or more. The median age of the study group was 11.4 years.

The researchers used the US Centers for Disease Control and Prevention system to

categorise the children according to clinical manifestations - N (asymptomatic), A (mildly symptomatic), B (moderately severe symptoms) and C (severe symptoms). Three children remained in class N, six were in class A, 17 in class B, and eight in class C. At 73% of scheduled clinic visits, no symptoms of hiv were present.

At last followup, of the 32 children with CD4+ cell count data, 18 were classified as CDC immune category 1, 11 as category 2, and three as category 3. Most children were treated with three or more antiretroviral agents, although three children had never received any antiretroviral agents, the authors note.

'With the increased use of potent antiretroviral therapies, survival into adolescence and young adulthood is likely to become increasingly common,' the researchers note. After birth, 30 children lived with at least one parent. At latest followup, this number had decreased to 19, the investigators state. The mothers of 13 children had died.

Twenty-six children had been told about their hiv-positive status. 'As they enter adolescence, additional services are needed including support with disclosure to others, therapy, and sexual health,' Dr Newell and colleagues point out.

J Acquir Immune Defic Syndr 2002;29:396-401. Last Updated: 2002-04-15 15:57:19 EDT (Reuters Health)

side fx project

The National Centre in HIV Social Research, at the University of New South Wales, is conducting a research project 'living with hiv treatment side effects and body shape change'. Confidential and anonymous 2 hour indepth research interviews will be held with hiv positive men and women experiencing side effects and/or body shape. The National Centre would like to find out what life is like for people living with hiv treatment side effects and body shape changes, such as lipodystrophy. The information collected will help develop effective health promotion, health care and support strategies for people living with hiv. Interested? Contact Asha on 02 9385 6414, email: a.persson@unsw.edu.au.

pos kids: Saquinavir study

Saquinavir alone does not maintain consistently efficacious plasma levels in children with hiv. Combination therapy with other protease inhibitors (PIs) that inhibit saquinavir metabolism is necessary, researchers report.

Dr Sibylle Grub from F Hoffmann-La Roche Ltd, Basel, Switzerland, and colleagues examined the pharmacokinetics of saquinavir 50 mg/kg given alone three times a day in 14 children and saquinavir 33 mg/kg plus nelfinavir given three times a day in 13 children. The researchers assessed the results after single dose administration and after short and longterm use. They also examined the pharmacokinetics of saquinavir given as a fixed single dose of 1200 mg compared with unrestricted weight-adjusted dosing of 50 mg/kg, according to the report in the March issue of *Clinical Pharmacology and Therapeutics*.

When saquinavir was used alone it resulted in a lower exposure in children and in adolescents compared with adults who were treated with saquinavir 1200 mg three times daily. This appeared to result from increased systemic clearance and lower oral bioavailability, the researchers note.

Saquinavir combined with nelfinavir reduced the clearance of saquinavir and increased the drugs' exposure in the children to levels that were similar to the levels found in adults, Dr Grub's team reports.

The investigators found that among the children there was a significant correlation between the average trough concentration of saquinavir and sustained suppression of viral load. 'The apparent threshold for maintaining viral load suppression was a mean trough saquinavir concentration of above 200 mg/mL,' they add.

Clin Pharmacol Ther 2002;71:122-130. Last Updated: 2002-04-19 17:15:56 EDT (Reuters Health)

ACON Illawarra services continue in two new centres

Two temporary homes in the Illawarra region will provide services for plwha and the gay and lesbian community while

ACON Illawarra looks for new premises.

'We are committed to maintaining a presence in the Illawarra region and over the next six months we will continue to provide ACON services before new premises are opened in September,' said ACON CEO Stevie Clayton. 'This will be an opportunity for us to look at how we can improve our services and better meet the needs of our communities. We have been working closely with clients, communities and service providers in an extensive consultation process to ensure a smooth transition.'

'ACON's plwha services will work alongside Our Pathways Incorporated at a new shared space open five days a week during business hours. All our services for people living with hiv/aids will continue and services provided from this office will include:

- ACON Counselling
- ACON Massage
- Bobby Goldsmith Foundation (BGF)
- Community Support Network (CSN)
- PLWHA Drop-in
- Computer/internet access

PLWHA Services: 1/6 Kenny Street Wollongong. Ph 02 4226 1163 Fx 02 4226 9838

'All our gay and lesbian services will continue in a new Resource Centre and will be supported by the appointment of a new Gay and Lesbian Community Development Officer. Services provided will include:

- ACON Counselling
- ACON Education Workshops
- Legal Service
- Gay Men's Drop In Support Group
- Resources for Lesbian Groups
- Gay and Lesbian Line Illawarra
- TYPE
- Lesbian & Gay Social Network Group

Resource Centre: 26 Belmore Street, Wollongong. Ph 02 4226 1238 Fx 02 4226 9838

These ACON services will continue in satellite offices:

- ACON's Lesbian Health Project will continue as a joint project with Illawarra Women's Health Centre
- Young and Proud will continue operating at CHAIN
- Sex Workers Outreach Project (SWOP) will be located at Port Kembla Hospital
- GP Sexual Health Clinic will be located at FPA Health
- For info on needle and syringe exchange, call First Step on 02 4275 1529

'Port Kembla Hospital will continue to provide condom and lube sales and we are working with Illawarra Area Health Service to ensure continuity in the provision of a Needle and Syringe Program in the Wollongong area,' Ms Clayton said.

new look NAPWA

The National Association of People with HIV/AIDS (NAPWA) held its Special General Meeting in April and voted to endorse changes to the Rules of the Association and a new model of governance. The Executive Committee stepped down to allow an election by the plwha organisation member delegates of nominations for a six-member Board of Directors, and convenors for six national portfolios, covering key issues for people with hiv. It is envisaged that the new structure will allow an enhancement to the NAPWA representation of the diversity of hiv positive lives and issues that exist within the Australian hiv epidemic. It is also hoped that the SGM resolutions will support the objective of realising an increased involvement of individual plwha in the work and representation of the national body.

Newly elected President Phillip Medcalf said, 'With the current reviews of the HIV National Research Centres, and the Review of the 4th National Strategy, NAPWA is keen to utilise the momentum of a very productive SGM and offer the best representation of plwha issues at the national level.'

'I thank the previous President - Peter Canavan - and other outgoing Executive members, who have led the organisation through significant strategic planning and organisational changes, and I feel very confident in the energy and support of all the members to adopting these changes and supporting the future of NAPWA.'

'The new board and portfolio convenors will be quickly settling down to steer the ongoing response to issues such as welfare reform, treatments access and subsidies, and the continuing threat to hiv-specific funding and research that will affect the lives of positive people across Australia.'

NAPWA now consists of: Board of Directors (6), National Portfolio Convenors (6), Member organisations (8), Associate member organisations (3), NAPWA/AIDS Treatment Project Australia Secretariat staff members (5).

President: Phillip Medcalf, Vice President: David Menadue, Secretary/Treasurer: John Robinson, Director: Gabe McCarthy, Director: Jon Willis, Director: Brent Allan.

The new National Portfolio Convenors are: Treatments: Peter Canavan, Care & Support: Vacant, Education: Brent Allen, Indigenous Co-convenors: Tony Creighton and Bev Greet, Women: Amelia McLoughlin, Legal: Vacant.

International research ethics framework proposed

The Nuffield Council for Bioethics, a UK-based think tank, has launched a 205-page report on *The ethics of research related to healthcare in developing countries*. This identifies key ethical issues raised by international sponsorship of research by organisations based in wealthier countries among communities in poorer countries, and proposes a range of action to address them.

The report was produced over a 21-month period by a working group of distinguished researchers and public health experts from a number of countries, chaired by Professor Sir Kenneth Calman, former Chief Medical Officer for the UK Department of Health. The report is available on the Nuffield Council for Bioethics' website. It will be issued on CD-ROM and translations of key sections into French and Spanish are promised.

Julian Meldrum, 25/04/02, <http://www.aidsmap.com/news/newsdisplay2.asp?newsid=1447>

HIV rate in China

New statistics published in China in April estimated that 850,000 people had been infected with hiv by the end of 2001. This is 30% higher than previous government estimates. The estimates, published by the New China News Agency and attributed to health officials, said that 200,000 people might already have progressed to aids. The numbers were the highest yet put out by the Chinese government. The epidemic in china centres on intravenous drug users and people infected through unsanitary practices while either selling or receiving blood. But they still fall far short of estimates made by foreign experts working in China and some Chinese researchers.

According to United Nations figures late last year, an estimated 1.5 million Chinese have hiv. United Nations officials have said the number could rise to 20 million if China does not take prompt and aggressive action. China has never undertaken a comprehensive national

survey so the total number of cases is uncertain.

The reliability of statistics varies by province. In Yunnan, the statistics are relatively reliable. In others, like Henan, there is almost no public information because local officials have often blocked scientific work on what is regarded as a sensitive and embarrassing problem.

In China's report, the Health Ministry said that 68% of China's hiv cases were caused by sharing needles among intravenous drug users and 7.2% by unprotected sex. Blood collecting and transfusion through unclean methods accounted for 9.7% of cases. China has been far more open about confronting the epidemic among drug users than the one among poor farmers. Also, there has been little government effort to define the scope of hiv in China's growing gay community, although researchers acknowledge that the disease has taken hold there.

'China Raises H.I.V. Count in New Report', By Elisabeth Rosenthal, 12/04/02, New York Times

First Female Condom Machine

At the launch of France's first female condom machine, women protesters complained that the female condom's cost – two euros (\$1.76US) – was three times the price of a male condom. The aids awareness group ACT UP denounced the event in a statement as a publicity stunt and said the conservative Chirac was 'using the vagina as an electoral ploy'. French President Jacques Chirac's campaign spokesperson Roselyne Bachelot marked International Women's Day by inaugurating the machine. Bachelot unveiled the new condom machines – blue for men, pink for women – in one of five central Paris metro stations now equipped with them. The female condom has been available in some countries for several years. But amid criticisms that its plastic crackles and that it reduces sensation for both partners, it has not won wide acceptance.

'First Female Condom Machine Is Launched', Reuters 12/03/02. [CDC News] CDC HIV/STD/TB Prevention News Update 14/03/02

Get physical

Exercise for plwha is the focus of a research project by ACON Illawarra and the University of Wollongong.

'This is the first time an exercise project has been run for hiv positive people in regional NSW and the results of the project will interest a wide range of service providers and researchers across the state,' said ACON Illawarra's Acting Manager Scott Berry.

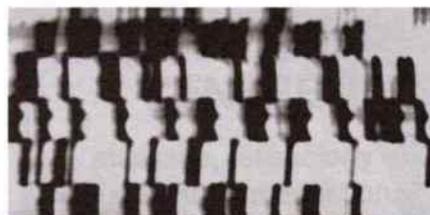
'The Illawarra Positive Exercise Project has been funded by a grant from the NSW Department of Sport and Recreation and we are working in partnership with the University of Wollongong and the Illawarra Area Health Service on the program,' he said.

'This is an innovative project encouraging people living with hiv to become more active and improve their general health and wellbeing. It is also an important research project that will show just how important physical exercise can be for hiv positive people.

'Exercise Science and Rehabilitation students from the University of Wollongong are working with 12 clients on the project and four weeks into the program we are already seeing remarkable improvement in the wellbeing and confidence of people involved.

'The students have designed exercise programs that are tailored to each individual client and working with them in much the same way as a personal trainer. Each client has undergone a fitness assessment at the start of the project and their flexibility, muscular strength and endurance will be re-assessed at the end of the 12 week exercise program. The research component of the program will look at how this exercise has affected CD4 counts, viral load and lipodystrophy.

'The Illawarra Positive Exercise Project is one of a number of projects that ACON Illawarra has developed to help improve the health and wellbeing of people living with hiv/aids,' Mr Berry said.



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diary

Sydney

StraightTalk Daytime support program by Pozhet. Straight Talk's objective is about getting people out where they can make new contacts, socialise and share information or insights. Barmuda Coffee Bar, opposite Newtown Railway station. More info, tollfree 1800 812 404.

Positive Living Centre, 703 Bourke Street, Surry Hills. The centre is a one-stop access point for a range of hiv and community based services. Programs for pos people to help develop new skills, interests and work opportunities. Lunch Mondays, Thursdays & Fridays.

Luncheon Club Mondays, noon, at Positive Living Centre, 703 Bourke St, Surry Hills for plwha.

The Larder, Pride Centre, 26 Hutchinson St, Surry Hills provides free food and essential items to plwha on DSP. Clothing, linen etc Wednesday & Friday, noon - 4pm. Free BBQ every 2nd Wednesday (off pension week).

Fit X Gym At the Community Pride Centre, Hutchinson St, Surry Hills. Positive Access Program (PAP) offers qualified instructors, free assessments, free nutritional advice, free individual programs and a free session to try out the gym. \$2.50 a session, or \$20 for a 10 visit pass. Contact Fit X Gym, 4-7pm Mon-Fri or PAP, 9.30 am-12 noon, Mon, Wed & Fri on 02 9361 3311.

Yoga for plwha Special weekly classes at Acharya's Yoga Centre Mon-Fri 12.30pm-1.30pm. Call 02 9264 3765 for more information.

The Sanctuary offers free massage, acupuncture, therapy information, social work and shiatsu services. Call Robert for details and bookings 12-6pm, Mon, Tues, Thurs & Fri on 02 9519 6142. Also holds cooking programs. To find out more contact Sidney Leung (dietician) on 02 9395 0444.

Community Garden Learn how to grow your own vegies. Great opportunities at Newtown and Waterloo. Call Street Jungle on 02 9206 2000.

Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt. They'll pick you up from home, give you two hours to shop, then drop you off again. Price is \$4 and available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville and Darlington. Call Diana on 02 9516 4755.

Newtown Neighbourhood Centre has a number of groups. Call Charlotte on 02 9516 4755 for details, including cost.

'Outings' from South Sydney Community Transport is always offering day trips and excursions. More information or bookings, call Jane or Robbie on 02 9319 4439.

Southern Cross Outdoor Group's website is full of details of their many up and coming social get togethers, including walks, dances and trips away. See the website www.scog.asn.au or call John on 02 9907 9144.

Dementia Support for Family, Partners and Friends. Telephone/group support for significant others of people with hiv associated dementia, cognitive impairment and/or mental illness. Meets last Wednesday of every month at the Tree of Hope, cnr Riley and Devonshire Sts, Surry Hills at 6.30pm. Contact Angela 02 9829 4242, Margaret 02 9698 3161 or ADAHPT 02 9339 2078.

Poets Anonymous A poetry email group. Communicate on the net with poetry. Covers all poetry forms, with a slant towards free-form and expressionist. Subscribe at http://au.groups.yahoo.com/group/free_former

Myrtle Place at Crows Nest offers

massage services for plwha on M and Th at 1.30pm and 2.30pm, W and F at 10.30am and 11.30am. Meditation and tai-chi on M, 11am-12noon. For appointments and info about other services, call Dennis or Mark on 02 9929 4288.

NorthAIDS service users can get free entry to the latest movies at Greater Union Cinema at Mosman. Join in for lunch at Myrtle Place on M/W/F and take in a movie in the afternoon. Bookings, call Dennis or Mark on 02 9929 4288.

Des Kilkeary Lodge on the north side is back in business and volunteer gardeners are needed. If you can help, call Rhonda on 02 9982 2310.

Southern Sydney

Friends of Waratah is a support group in Southern Sydney for plwha which meets on the first Monday each month in Kogarah. It offers emotional support, information and social activities. For more details, call Amanda on 02 9350 2955.

Western Sydney

Pozhetwest offers peer support and education for men and women living heterosexually with hiv/aids in Western Sydney. Contact 02 9671 4100.

Blue Mountains

Drop in to the **Blue Mountains PLWHA Centre** at 2 Station St, Katoomba for informal peer support. Open Wed and Fri 11am-3.30pm. Lunch Wed 1pm, \$3conc/\$5waged. Ph/fax 02 4782 2119 email: bmplwha@bigpond.com

Hunter

Karumah A meeting place for positive people and their friends in Newcastle and the Hunter. Activities held each week. Pos-only space and open groups. Contact Karumah Inc, 47 Hudson St, Hamilton. Ph: 02 4940 8393. Email: karumah@kooee.com.au

Bambi hiv+ women's social group. Meets 3rd Friday each month, 10.30am-2pm, Hamilton, Newcastle. A diverse group of women who come together to chat, relax, do arts & crafts and more in a safe environment. All women welcome. Confidentiality assured. Contact Karumah 02 4940 8393, Women's Rep 0402 329 986, email poswomen@hotmail.com

Northern Rivers

Support Group for partners, family, friends, carers of people living with hiv/aids. Contact Sue on 02 6622 1555 or 1800 633 637.

HIV Peer Support Group Lismore for all plwha. Fortnightly meetings. **HIV Peer Support Group Murwillumbah** for hiv positive gay men. Contact Ron on 02 6622 1555.

Volunteers Northern Rivers ACON is currently updating availability info of volunteers who are interested in providing direct care and support to plwha. Duties could include assisting with home duties, shopping, or providing support through a chat. Contact Sue on 02 6622 1555.

Pos women's retreat at a resort near Murwillumbah. Motel style accommodation, all meals provided. Workshops, archery, horseriding, discussion groups for women, partners support groups and more. \$35 unwaged, \$50 waged. Held by ACON Northern Rivers. Priority given to women from northern NSW. Contact 02 6622 1555.

Treatments Information Service, Northern Rivers. Confidential, quality service for plwha. Information and support face-to-face, by phone or email about drug side effects and interactions, treatments and pregnancy, starting, changing or stopping treatments, post exposure prophylaxis and more. Talk to Barrie Harrison, Treatments Officer, T, 9am-2pm and W, 9am-5pm, 02 6622 1555 or 1800 633 637, email bharrison@acon.org.au

Vitamins and nutritional supplements at reduced prices for plwha. More info, call ACON Northern Rivers on 02 6622 1555 or 1800 633 637.

Massage Clinic for plwha. Lismore - every second Wednesday, 9am-3pm. \$15. Tweed Heads - Last Monday of the month, 10am - 1pm. \$5. Bookings essential, ph 02 6622 1555 or 1800 633 637.

NSW

Fill out an online survey about use of complementary and alternative medicine by plwha at <http://turing.une.edu.au/~smijajlo/cam-aids/second.html>

Talkabout Diary promotes projects and activities that benefit plwha. Preference is given to free and low cost entries. We especially encourage items from rural and regional NSW. Send items of 30 words or less to Susan Hawkeswood, Editor, *Talkabout* Diary PO Box 831 Darlinghurst 1300. Fax 02 9360 3504. Email editor@plwha.org.au. Ph 02 9361 6750.

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Acknowledgments

In the Feb/Mar issue of *Talkabout*, an article reporting on Art Project 2001 was written describing the various stages of the year-long project, culminating in a World AIDS Exhibition in November. The Art Project was a joint venture between the Community HIV/AIDS Service, Central Sydney Area Health Service and the Ankali Project, South Eastern Sydney Area Health Service.

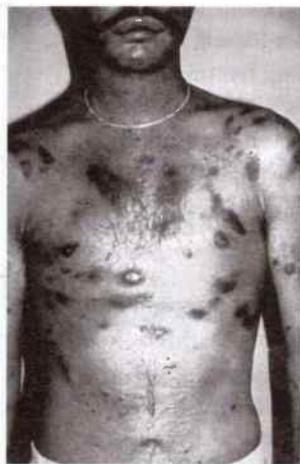
Photographs of works exhibited in the 'Positive Footprints' exhibition published in the April/May issue of *Talkabout* were taken by Jamie Dunbar.

no more pictures without context - the spectacle of aids revisited

PLWH/A (NSW) Research and Policy Officer **Kathy Triffi** recollects two decades of hiv/aids images and compares the latest on the way from the AIDS Trust of Australia



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In *Policing Desire, Pornography, AIDS and the Media* 1987, Simon Watney discussed the way media and medical representations of plwha are framed by moral imperatives, and how the 'struggle' against aids requires a re-thinking of language, media and representation. He exposed the misconceptions that fed homophobic attitudes circulating in mainstream media at that time and the cultural/political and representational regulations on hiv and aids including 'hysterical' media images, discrimination, drug policies and community attitudes. Why?

Images of plwha impact enormously on perceptions of the aids epidemic and on impressions of the identities of plwha. Representations of plwha not only reflect perceptions of the epidemic, they also impact on responses to it – the impressions

they create help to form social conceptions of risk (who is at risk, what is risky) which in turn influence research, policy and preventive education campaigns. Moreover, they impact on the wellbeing of plwha and the way in which they, and their friends and families, live their lives.

Because of the capacity to impart meaning and the consequential tangible social impact, representations of plwha have come into sharp focus as a highly contested political site over the past two decades. A large role in aids activism has been afforded to the critical analysis of the underlying assumptions, meanings and implications of negative, derogatory and stereotypical imagery of people with aids, for example the innocent victim, the dying or dead. Such images, which became intransigent manifestations of the popular understanding of aids during the 1980s, have been the subject of intense criticism for their recuperation of signs that denote moribund, hopeless and passive 'aids victims' contained within 'risk

groups' or, conversely, threatening and contagious 'aids carriers' (image 1).

Aids activist groups have responded to negative and stereotyped images of plwha circulated in mainstream media and biomedical discourse and countered this representation with 'positive' imagery designed to give aids a face – to humanise an epidemic universally represented as a mask of death. Out of this 'counter-representational' work, plwha were reconstructing the public image of aids. Demands for the visibility of plwha 'who are vibrant, angry, loving, sexy, beautiful, acting up and fighting back' were made by ACT UP, New York (AIDS Coalition to Unleash Power) within a larger manifesto – 'No More Pictures Without Context'. In its declaration of 1989, and in more recent times in its objectives, PLWH/A (NSW) calls for the promotion of 'a positive image of people living with and affected by hiv/aids, with the aim of eliminating prejudice, isolation, stigmatisation and

Instead of the shamed silhouetted 'aids victim' we are introduced to the pixilated faces of actors 'to protect their identities'

'AIDS CAR' SHOCKS REPAIR MAN NEV

BY GUY CARROLL

NEV NEVIN'S 'AIDS CAR' IS THE ONLY CAR IN AUSTRALIA WITH A SHEDDING AIDS VICTIM'S NAME ON IT. NEVIN, A 45-YEAR-OLD MAN FROM MELBOURNE, HAS BEEN DRIVING THE CAR SINCE HE WAS GIVEN IT BY THE AIDS TRUST CAMPAIGN. NEVIN HAS BEEN DRIVING THE CAR SINCE HE WAS GIVEN IT BY THE AIDS TRUST CAMPAIGN. NEVIN HAS BEEN DRIVING THE CAR SINCE HE WAS GIVEN IT BY THE AIDS TRUST CAMPAIGN.



7



"That's what living with HIV has taught me - to accept how wonderful life can be."

HIV doesn't discriminate...people do.

For information on HIV/AIDS call 000 01 11 44 ANCA

8



"Isolation and fear is what makes living with HIV so difficult"

HIV doesn't discriminate...people do.

For information on HIV/AIDS call 000 01 11 44 ANCA

9

Instead of the shamed silhouetted 'aids victim' we are introduced to the pixilated faces of actors 'to protect their identities' (image 6) and the 'innocent victim' of aids in the image of Eve Van Grafhorst, who acquired hiv after a blood transfusion and was forced to leave Australia with her family when her antibody status became 'public property'. The discrimination she experienced was influenced by the irrational fear of contagion reported by mainstream media at the time (image 7). While acknowledging the prejudice that accompanied Australian public perceptions of aids in the early days of the epidemic, Eve's story, among others, was used to construct a hierarchy of blame with 'innocent and appropriate victims' of what was represented as a 'gay plague'.

The selected scenarios of the AIDS Trust campaign can never account for the personal, political and everyday details that can be found in the lived experiences of hiv/aids made visible in the National Anti-Discrimination Campaign of 1992-3 (image 8). In presenting personal testimonials and a public face of the realities and diversities of living with hiv, plwha were provided with a cultural space in which to re-construct the public image of aids and simultaneously re-

construct themselves and their relations with the general public, their friends, partners and families. These representations question the involvement of various historical and contemporary institutions in the construction of the image and lives of plwha and offer this as an alternative to the endless circuit of guilt, fear and pity enlisted by charity publicity. The audience is positioned in an ethical relation to these images. A seemingly 'ordinary and everyday' image as represented in image 9 places the viewer in a position where she or he, having found none of the determining signs of hiv and aids, is asked to regard the individual in the ethical sense. It asks us to take responsibility and care, to regard each person represented as we would regard ourselves. These representations of plwha invite the viewer to recognise themselves as a member of the community and, as such, acknowledge their part in the social conditions that constitute the experience of living with hiv and aids. It may be useful to revisit this significant historical precedent in any proposed amendments to the AIDS Trust Campaign.

Finally, Douglas Crimp (1988), in an edition of the art journal OCTOBER - 'AIDS: Cultural Analysis, Cultural Activism'

- comments on the representational strategies of biomedicine and of mainstream media. He argues that:

'AIDS does not exist apart from the practices that conceptualize it, represent it, and respond to it. If we recognize that AIDS exists only in and through these constructions, then hopefully we can also recognize the imperative to know them, analyze them, and wrest control of them.' (p7)

In other words, a full understanding of the representation of hiv/aids requires a comprehensive analysis of the institutional practices that generate and distribute them as well as the audience that receives them.

References

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Front cover of *TIME Australia*, November 3, 1986 *Headline VIRUSES* (image 5).

Tugging heartstrings

fundraising

The Bobby Goldsmith Foundation doesn't want to put plwaha off with its winter appeal. **Susan Hawkeswood** spoke to BGF's **Georgina Harman** and **Mark Tietjen** about this year's campaign.

The Bobby Goldsmith Foundation plans to launch its current fundraising campaign mid-May. The focus of this year's campaign, according to BGF's Executive Director Georgina Harman, is return to work and improved, or changing, health, and the implications for that on individual lives.

'It's an appeal for money to support the Positive Employment Support Service, which is a service that's been running out of BGF now for two and a half years. Funding is ending at the end of June this year, so we're seeking alternative sources of funding to keep the services and its clients going.'

'We're continuing to lobby government to renew that funding at State and local area health service level but also ... to keep the service going in the meantime, we're making it the focus of our winter appeal.'

Client Services Manager Mark Tietjen, is concerned that fundraising campaigns, which sell 'a worst case' scenario, causes potential clients to self select because they think other people are worse off than they are. 'Those people should really be coming and asking for help. ... It's often a very fine balance to get the fundraising message across but also to sell the service to make it accessible to clients.'

Georgina Harman describes BGF's approach as two-pronged, with fundraising forming a major part of the Foundation's activities. 'Without us being successful at fundraising, a lot of client services wouldn't happen. ... What clients need to bear in mind is that we need to send these messages out in order to get money in the door so that we can then provide to people in need. ... We still want them to come to us and seek help from BGF ... The other important role that fundraising plays, and I think clients - plwaha - might be interested in hearing a bit more about, is its advocacy role, its educational

role. A lot of the scenarios that we present in fundraising materials are quite dire and desparate and extreme but they're actually true stories. They're based on the experiences that we see here and it's really important that people understand that a lot of positive people, not all, but many, are living in increasingly difficult situations. It's a really important vehicle for us, getting those messages across to the wider public, to our supporter base and also to people who might not necessarily know or understand what positive people are living through. It's also a

It's an appeal for money to support the Positive Employment Support Service.

way of informing clients, and the general public and our supporter base about the range of services that BGF can provide for positive people.'

Mark Tietjen adds that it's easier to help somebody before their circumstances are really dire. 'The things that tug at the heartstrings and make people dig into their pockets to donate are the extreme circumstances, usually. But it's far easier to

provide a client with very useful support before their circumstances do get extreme. The worse their circumstances are, the harder it is to help.'

About 5% of BGF's funds are currently raised through Friends of BGF, which is an ongoing fundraising campaign launched in 1998 - Australia's first 'friends' campaign for aids fundraising. The Friends program is BGF's most cost-effective program. For each dollar BGF receives from a Friends donation, 92 cents goes directly to help positive people.

'We had an annual turnover last year of \$2.4million and the Friends campaign brings in about \$145,000 a year,' said Georgina Harman. 'We've currently got about 308 Friends.'

The Friends campaign is, according to Mark Tietjen, 'something that you can actually budget on. It's a low risk activity ... if you go out and hold an event, you're never sure how the ticket sales are going to go, how much money is actually going to come in, whereas once you've got so many Friends signed up, you know that you're getting that income every year. The drop-off rate's relatively low and it makes for much more security within the income stream.'

One of BGF's aims, each year, is to attract donors who then become Friends of BGF.

'There's a thing called the donor pyramid, which is a very simple concept. ... The first lower level of that pyramid is what we call one-off donors, people who occasionally make a financial contribution to help the work at BGF. ... What we aim to do is to pull people up through the pyramid so the peak of the pyramid are people who actually leave substantial bequests to BGF to help our work over the longer term after they've passed away. So the next tier, and possibly the most valuable one, and the one that's often the hardest to make people step up to is the Friends of BGF,' said Georgina Harman.

Options that work

employment

Susan Hawkewood spoke to **David Wallace** of Options Employment Service about getting back to work

With a number of positive people on a Newstart Allowance rather than a disability support pension, Options Employment Service provides intensive one-to-one assistance to get a job, study or re-train. A part of the Job Network since 1998, people who want to use Options have to be on a disability pension (DSP) or a Newstart Allowance.

'Over the last two or three years, there's been a bit of a tightening, or resistance, on the part of doctors to support somebody's application for disability support pension. They're hiv positive and yet they're well enough to consider work,' said Options Coordinator, David Wallace.

'The service that we offer is a natural adjunct to the Positive Employment Support Service that Sarah's part of. ... If someone went to them and it was identified that maybe work or study was an option that they would like to consider, then they could refer themselves or be referred into our service. And equally, we can suggest and work with clients to say, ok, you're not quite clear about the sort of work you want to do ... Go back to PES and have perhaps some vocational guidance from them and nut out some of those other issues ... we're not trained to do that.'

Options staff guide clients about the work they might want to do but 'we don't have a bag of jobs over here. ... But, once someone comes into this service, we can sit down with them and find out the sort of work they do want to do, and over what period of time, and then we can ... encourage them to approach potential employers, or actually do that on their behalf.'

Options staff spend at least a year working with someone eligible for intensive assistance after an assessment process

conducted by Centrelink that identifies barriers to getting employment. This could include being unemployed for more than 4 years, living alone, poor access to transport, and education background. These barriers give a score that makes jobseekers eligible for intensive assistance.

'Someone with hiv or hepatitis would usually be immediately eligible for intensive assistance if they want it. ... with someone who's on disability support pension, we can work with them from a minimum of a year up to a maximum of about 18 months,' said David Wallace. 'We get funding to provide ongoing support when someone's in a job. ... We work with them for at least six months after they've gotten into that job and even beyond that if they request it. ... Do they have to talk to their employer about getting time off for doctors' appointments? Is that a real problem for them? Are they going to be in a position of having to disclose? ... If it did occur and a client wanted us to go and talk to their manager or their employer about stuff that was going on for them, then that would be part of our role as well. We could advocate or mediate ... but only obviously with them having asked us.'

During the jobseeking period, Options identifies any re-training needs, helps people put together a resume, and then supports people who move from unemployment to part-time work and then perhaps a fulltime job.

'The spectrum of people who are dipping their toes back in the water' includes people who want part-time work within the DSP income guidelines. 'More people would be looking to go back to work with a view to maintaining the DSP as a support, like as a safety net.'

'We don't as an organisation push people ... Sometimes it's the reverse ...

sometimes it is about setting realistic expectations for someone,' said David.

People are often motivated to return to work for social reasons. 'It will help them with their social interactions and even getting into relationships, or maintaining relationships ... The financial incentive for people to go back to work is quite clear and it's often the one that's put right at the top of their agenda ... for some people it is just about getting an extra \$50 a week, which will keep them below the threshold. They can retain their entire pension payment ... But it's also a step towards them putting their feet back in the water and saying, 'I can do this. I could maybe move into more part-time work and then take the next step.'

Other people want to get off the pension altogether but, apart from this financial incentive, social isolation, 'once you scratch below the surface' plays a big role. 'Part of that is about ... knowledge of their peers, who are on the internet, who are using computers every day. They don't know how to use a computer and they'd like to learn.'

David Wallace has not had to support any clients who have needed to go back on DSP after finding that their health could not sustain a return to work, but Options can give assistance during that transition if needed. In his experience, people's 'health has supported them, either back to part-time work or fulltime work.'

Options has funding available to subsidise the cost of formal training, buy work clothes and cover transport costs to interviews. The service also provides a 'mini office' to jobseekers, who get access to computers, photocopiers, fax machines, paper, pens and an administrative support for typing.

Getting back to it

The next step

employment

Jimbo went to PES in March after a recommendation from 'one of the boys at NorthAids'

'You don't know what to say about being off work for a long time. ... Why would they take someone who they might have doubts about their ability to perform the job. I've been an employer and you'd be mad. ... You would go for someone who looks like they're going to be there for six months, or a year, or two years.'

After Jimbo talked to Sarah at PES about the sort of work he wanted, the two tracked job ads for a while. Jimbo

'I work as a subcontractor. I can control how much I want to do, or how little I want to do.'

describes his expectations as 'always on the optimistic side of the scale. ... I knew that I couldn't go back to what I'd done before.' Apart from peripheral neuropathy, which makes it difficult for him to stay on his feet too long, 'burnout' has kept Jimbo away from his previous occupation as a nurse.

'Sometimes it's such an all involving disease to have ... I haven't anything left to give. When people tell you how sick they are, I know that I've been sicker. 'What are you complaining about?' This is not a great attitude for a nurse to have.'

Because nursing involves interacting with people, Jimbo wanted work that involved interacting with other people. 'I was lucky enough to get a little bit of work as a painter's labourer and I spent all day washing ceilings down ... and it was so boring not having people to talk to, you go crazy.'

'I work as a subcontractor. I can control how much I want to do, or how little I want to do.'

The best thing about going to PES, for Jimbo, was discussing his concerns about going back to work, and breaking what had to be done into achievable steps. 'It was particularly handy to run through things that would happen in the interview and all the issues around disclosure and what one could say, or should say, or might say if asked this or that.'

PES helped Jimbo write a resume: 'another thing that was really handy.'

Jimbo has spoken to PES twice, the first time over a year ago. The work done 'the first time around ... encouraged me to give volunteering a go and, having had some sales experience, doing the volunteer work got me experience in marketing. Jimbo thinks he wouldn't have got his new position without the experience gained from doing volunteer work. 'When I started doing volunteer work ... it was terribly hard. I was at committee meetings and it'd suddenly occur to me ... I should be concentrating on what this chappy's saying and nod my head quickly to look like I haven't fallen asleep or something.' As his health improved, so did his ability to concentrate. 'It's just not advisable to jump in the deep end. ... You build up to things.'

Jimbo's return to work started with volunteer work

I remember thinking: I'm sick of this. I need more money. I want a job. Luckily, my health has given me a second chance. I want to do this right. It seems a longer road than expected. So many challenges. Moving out of comfort zones. Though every step that brings me closer to my goal has proven to be life enhancing, ultimately. There have been a couple of bumps in the road, where my health has let me down. So sometimes it has been according to my ability. All the motivation and positive thinking won't help, if you're not feeling well enough.

Probably the first step in this journey happened more by accident than design. For a number of reasons I started going to Fit X Gym's Positive Access Program at the Community Pride Centre. Going to gym improved my health. It also increased my self esteem (all those positive endorphins, no doubt). I even felt happier with my body! Eventually building up to three times a week gave my week a nice rhythm. I also learned that to achieve something substantial I had to stick with it.

Then my first stop was the Positive Employment Service (PES). This led me to think differently about work. Unfortunately, my health let me down then. Though, when a call went out for volunteers, I thought why not, if it didn't involve much extra walking.

Doing volunteer work has been a real growth. As I became more involved I realised that I couldn't just snap my fingers and reinvent myself. I really needed to improve my computing skills. Luckily, PLC came to the rescue.

I was pretty stressed about it. I have tried to avoid computers but now I was motivated because I could see how much it would

help me with the volunteer work. And hallelujah the class was tiny! It's as good as having a personal trainer. Simon has the ability to see when I'm not getting something, and can re-explain it differently (or repeatedly) to me. That wouldn't happen in a large class. So I feel pretty lucky there, though it isn't without its challenges. Some days I feel like Rumpelstiltsken in the 21st century: everything is so complicated.

Trying to do the volunteer work with the same standards that I would apply to paid work paid off. I was encouraged to apply for a paid position with one of the community groups I had regular contact with. This led to a part-time job. Although I was aware that my health wasn't 100% this would be a great opportunity to test how much I could handle. It turned out to be do-able with a little creative thinking or planning. And I really loved doing something different. It was good to have to use my brain. I also enjoy travelling around, looking at the shops, and the guys in suits and ties. I find that when I work I forget about my problems, at least temporarily.

I decided to re-evaluate my goals, which I think anybody with hiv is probably very practiced at. I would have to aim for something more realistic, say part-time work. PES came back on board. I now needed to update my resume. It had holes one could drive a truck through. I did think of saying that I had been overseas but it's been years since I have been. I just know with my luck I'll get caught out. Also, confessing everything should be kept for church. If I told too much in an interview, I wouldn't even hire me. So many worries.

Working with Sarah from PES has been really useful. We have solved most of my worries and explored some solutions that I never dreamt of. So I feel more confident to face interviews now.

PES aren't like an employment agency, you don't feel under pressure to quickly get any job (regardless of how inappropriate). I have had a miserable experience with that situation. Heard the one about the door-to-door salesman who had peripheral neuropathy? Ha, ha, it wasn't. At least it's diagnosed and receiving treatment now, which is an improvement.

If I needed any reassurances that this was all worth it, BGF and the Ratten Fund provided it. They enabled me to get some new clothes, which as any queen knows is the best boost to the self-esteem. Dress yourself to success! It's important to reward yourself when you have obtained a goal, otherwise it all becomes a bit of a grind.

Well, I don't know which part of this muddled formula was that essential element. But I must have done something right, I got a job! Luckily I didn't get too many knockbacks. If anything it happened very quickly. Sometimes ya get lucky. So while other people my age have a sea change and go down the coast, I as per usual walk to the beat of a different drummer, and return to work, in a new industry, with a whole new set of challenges to conquer.

PES - employment support for positive people

Sarah Yallop is the Coordinator of PES – Northern Sydney, a service for plwha who want to change direction – and that doesn't necessarily mean getting a job. Sarah spoke to **Susan Hawkeswood**.

PES has three services – Northern Sydney, South East Sydney and Western Sydney. The Bobby Goldsmith Foundation provides the service covering southeast Sydney. Western Sydney's service is provided by ACON West. Sarah Yallop, PES Coordinator in Northern Sydney since the service's inception in 1997, describes the service's clients as 'people with hiv who are looking for some sort of change in their work direction.'

The change isn't necessarily paid work but it could be that. 'When we talk about work, we're talking about a broader perspective of work, including volunteer work, developing skills and interests,' said Sarah. 'We provide a one-to-one individualised service for people and we meet with that person over a number of weeks or a number of months, whatever suits them.'

PES staff assess clients during that period to find out what sort of change they're looking for, and to set short-term and longterm goals to work for. Sourcing suitable training courses and providing practical jobseeking

assistance, like resumes and interview skills, are also available.

Career counselling, involves looking at 'people's values and interests and personality and how that relates to what type of work suits them,' Sarah said. 'We basically assist people to make decisions, and a lot of that's about listening and ... assisting them in that process of making decisions about where they want to go.'

Major issues PES deals with are confidence and self esteem. People who have been out of the workforce usually want to find a job for a financial reason, or because they're bored. Although interested in social interaction, many people are isolated and this motivates a return to work.

Apart from difficulties around confidence and self esteem, PES helps people who have been out of the routine of working and interacting with people they don't necessarily choose to interact with negotiate with the boss. Plwha returning to work after an absence also face dealing with confidence about their health. Disclosure of hiv status in the workplace is another major issue for PES clients. 'They're taking medications. They need to do that during work time. What does that mean? Do they have

to disclose to their employer? If they need time off for appointments, if they are ill, how do they negotiate that with their employer?

The impact on finances is something PES discusses before people return to the workforce. 'That's another thing we look at with people,' said Sarah. 'If they're on a disability pension, weighing up ... the financial benefits of returning but ... the things you're going to lose. We work quite closely with the financial counsellors at BGF.'

'I think a lot of people think it's going to be easier than it is. ... when you actually break it down and look at what's required to get to some paid work, it's quite a long process.'

Sarah tells people wanting to return to paid work, 'It's not an easy process and you have to be really committed and motivated just to make that change but that's what PES is about, exploring that.'

'If someone comes in saying, 'I really want to go back to paid work' and they leave saying, 'look, I think it's not right for me to do that at the moment' then that's really a great outcome as well. We're not about pushing people back into the workforce. We're about trying to assist people to find a greater quality of life by being more engaged in community.'

Some clients go through the process of making a decision to return to work and finding a job, then realise that the extra commitment has been too much for them.

Some longterm clients of the service have returned to work when they are well and cut back their hours and do some training when their health fluctuates. 'They find they can cope with more or less, and that's quite a challenge too because the workplace is not always flexible enough to cope with that. ... It's very hard for people to predict how their health is going to be in six months time.' In Sarah's experience, people need to take opportunities as they arise but also be realistic about what could change.

PES usually doesn't negotiate with people's workplaces. 'Most of the people who are returning to paid work are deciding not to disclose to their employer, and so for us to go in as Positive Employment Support would not be appropriate. ... but there have been occasions where a couple of clients I've had who have been open with their employer and in that case, yes I have,

that has been a role that I've taken. ... it's very difficult for an employee to negotiate with their employer so that's certainly something we can do but ... a lot of people don't disclose so that's why we stayed away from that area.'

PES works out the sort of work people are qualified for and makes referrals to training.

'We would look with people at what ... they value in a work environment and what things are really necessary for them to be happy as a person in a work environment.'

'Sometimes that's kind of like dreaming but it's a good place to start and then we look at the realities. Have you got the skills for that? Have you got the training? Have you got work experience? What's the job market like in that area? How realistic is it?'

'We certainly assess what sort of training is required for that particular type of work. I usually recommend that people try and find someone who's working in that industry and talk to them about how they got into it. ... One of the issues there is the funding for training. ... People on DSP can do a TAFE course for free once a year and there's also ... the Rattan Fund through BGF, which can also assist people with training costs.'

PES doesn't have any funds available to pay for training, or the costs associated with finding work, for example transport and clothes.

'That's where we link quite closely with BGF in negotiating those sorts of costs and we've always found them fantastic in providing that sort of assistance.'

'The three of us working at PES are all occupational therapists, so we're very focused on occupation rather than just paid employment. ... I think that's what makes the service different.'

'When I first set up the service that was a real issue for people who were approaching Centrelink. It wasn't Centrelink then but it was all about returning to paid work and for a lot of people that's not really realistic.'

'It's not really what they want and there's a process that needs to happen before they're ready anyway to get into paid work. That's what we're about: increasing people's readiness and having that focus on occupation rather than paid work.'

It is against the law in NSW to discriminate against you because you have hiv or aids, in most types of employment.

This includes:

- when you apply for a job
- at any time during your employment
- when you leave a job

If you can do the job safely and effectively, then you must not be discriminated against. Employers have a legal duty to provide any special facilities or services you need to help you do the job, as long as it won't cause them 'unjustifiable hardship'.

It is also against the law in NSW to discriminate against you if you get into, or are studying in, any state educational institution, such as a university, college, TAFE, or government school.

One example

A manager of a country club was dismissed after his employer discovered that he was gay and hiv positive. The manager was healthy and symptom-free. The manager complained to the NSW Anti-Discrimination Board about the way he was treated. After conciliation, which is confidential, he received a compensation payment equivalent to his annual salary for being dismissed.

If you think you are being discriminated against, contact the Anti-Discrimination Board of NSW

Sydney

(02) 9268 5555 TTY (02) 9268 5522
tollfree 1800 670 812 (only within NSW)
Level 17, 201 Elizabeth Street, Sydney NSW 2000

Wollongong

(02) 4224 9960 TTY (02) 4229 4143
tollfree 1800 670 812 (NSW)
84 Crown Street, Wollongong 2500

Newcastle

(02) 4926 4300 TTY (02) 4929 1489 tollfree 1800
670 812 (only within NSW)
Level 1, 414 Hunter Street, Newcastle West 2302

General Enquiry Service & Employers Advisory Service

Sydney

(02) 9268 5544 or
tollfree 1800 670 812

Newcastle

(02) 4926 4300

Wollongong

(02) 4226 8190

Website: www.lawlink.nsw.gov.au/adb

the pensioner guide to chic homes

Tim Alderman gives the economically challenged – that's broke – a list of must visit locations on the bargain circuit

Regular readers of *Talkabout* might remember my article 'Cheap Chic', published in 2000. I got some very good feedback on that article and many people followed my advice on how to dress well without breaking the bank.

As a follow-up, this article tells you how to make your home a showcase without spending a small fortune. Every idea and suggestion in this article isn't necessarily something you can rush out and buy, or do, with your next pension cheque. Hopefully, you'll either get some ideas, or inform you of something you can save up for over several cheques. I wrote the article on clothing because I believe that if you look like nobody loves you, that is probably just how you feel. That situation can be remedied, to some extent, with something as cheap as a \$5 T-shirt. Looking good=feeling good, at least some of the time. The same applies to the environment we live in.

Most people on pensions don't have enough income to go out doing things seven days a week, so we spend quite a bit of time in our homes. If this is a dingy, depressing environment, then that is going to affect how you feel and relate to others. A lot of us have little say about where we live, or the condition of the places we live in, but that doesn't mean we have to live in dirty, depressing surroundings. This problem can be rectified with minimum outlay.

I am not saying that cheap is good or economical in all circumstances. Some things in one's home require a reasonable outlay to get efficiency and value. I am not backward at being forward when it comes to dropping hints to partners, friends and family for items that I cannot afford to purchase myself, and these are birthday, anniversary and Christmas gifts that are very much appreciated. It is useless buying a \$2 can opener if it falls apart the third time you

use it, or that toaster that doesn't have a decent toasting regulator on it and burns every slice of toast unless you stand over it to pop the bread up at the right time. Kettles that burn out after a small amount of use, beaters that don't beat and knives that don't cut are items we have all encountered along the way. So, for that special occasion, drop HEAVY hints for electrical appliances, saucepans, kitchen utensils, and kitchen knives. Quality items in these areas will ensure years of untroubled use, which makes the outlay on them worth it.

However, our general surroundings can be changed quite cheaply out of our own pockets. Perhaps the worst thing we have done as far as some stores go is make the word 'reject' fashionable. All of a sudden, reject stores in places like Paddington put a \$6 price tag on a \$2 item, just to maintain the 'image' of the area. I'm sorry to say it, but Paddington's ideas of reject are not mine.

However, cheap purchases are still to be had, and you don't have to look very far to get a good buy. I recently did a foray out to the Grace Bros Clearance Centre at Maroubra called, appropriately, Good Buys. This is an entire mall of seconds clearance stores, and weren't there some great items to be had!

In Good Buys, towels were going for under \$12, there were tables of plastic wares for \$5-\$8, goblets and tumblers \$2-\$5 ea, dinner sets for \$15 (even little-old-lady florals, if that is your taste), coloured contemporary vases \$7-\$12. Never underestimate the impact of a strategically placed vase on a table, sideboard or mantle. Out in the mall, a store called Table Top was full of little home designer pieces at really cheap prices. What I noted from there were dinnerware separates from \$1 a piece. This means you could put together a dinner set for four people over a few cheques without breaking the bank, or outlay about \$20 in total. They also had

some really colourful little balcony chairs for \$5 each. The same chairs from The Reject Store in Eastgate at Bondi Junction were \$17, which made them great value. Despite dearer chairs than Maroubra, this store in the Junction has just been revamped, and is a regular treasure trove for the budget buyer, even for furniture.

Reject Store Bargains

- frypan/saucepan set (2 pieces) for \$8
- dinner sets \$15
- 32-piece plastic container set \$10
- ornamental vases and lamps \$6-\$8
- tealight holders \$1
- collapsible ironing boards \$34
- quality kitchen accessories \$2
- glasses \$2
- glass spaghetti jars (great for floor displays) \$10
- glass tea makers \$6
- platters \$8-\$13
- crockery \$1 piece
- meditation water fountains \$26
- framed beachside collages (much nicer than they sound) \$10, and a matching beach shed CD holder \$17
- single pieces of plastic ware from 88 cents
- queen size quilt covers \$15
- queen-size sheet sets \$30

Furniture

- contemporary open-cube 150cm x 150cm units \$99
- bedside tables \$35 ea
- a bookcase and cupboard unit 59 x 29 x 176cm \$70
- wooden bathmats \$10
- 5 drawer chest \$89
- very smart cast-iron outdoor balcony lamps \$25
- various sized wooden shelves \$7-\$13
- a 90 x 180 cm bamboo blind for \$12

Other suggestions for budget buys are to visit places like Birkenhead Point, which has homewares stores selling items very

A lot of us have little say about where we live, or the condition of the places we live in, but that doesn't mean we have to live in dirty, depressing surroundings.

cheaply, Ikea has sales a couple of times a year, and the items are often dirt cheap. I challenge anyone to walk into Ikea with \$20 and not come out with 2-3 items, plus some change. Their homewares are not only cheap, but reasonable quality, and they often have very unusual decorator items for well under \$10. Unfortunately, their competitors, Freedom, who used to be budget oriented, are now very expensive, even for basic items.

If you need curtains, for God's sake ignore all the people who tell you that calico looks great. It doesn't! However, small areas of muslin trimmed with braid can look great. Buy some cheap coloured cotton fabric and use your imagination. Drape it over rods, or combine several colours together for effect. Places like Priceline and Home Yardage always have sales on fabrics, bed linen, cushions, rugs and home accessories. Indian sari fabric can often be bought cheaply from places like Spotlight, and is great for curtains, cushions, table runners and serviettes. Take advantage of parents, family and friends who sew. It takes very little time to sew a set of curtains (unless you are anal) and it is now fashionable to have them draping over the floor.

Sofa covers can often be bought very cheaply at above mentioned places, and also at K-Mart. Best and Less often have towels and bathmats on special, as well as sheet sets.

Ikea is great for light fittings (and long-life globes). They currently have a cosmic-looking range of rice paper shades (and I'm not talking your basic rice paper ball) from \$7 to \$25. The ones in the upper price range reach almost from ceiling to floor. Ikea often has cheap mosquito nets, clocks, picture frames, shower curtains, tab curtains, rag and Wilton rugs (I bought a very trendy 120 x 170cm Wilton rug from there recently for \$35), bedside lamps (as little as \$15 ea).

Do shout yourself a day at Ikea. It's a great place for cruising and buying.

For the shabby chic brigade, we always have St Vincent de Paul, and a whole world of secondhand furniture stalls. We also have friends and relatives who have garages full of half-empty paint tins, so use this readily available resource. Your grandmother is always good for plants, and you can buy cheap pots to house them from The Reject Shop for about \$5 (glazed ceramic). Don't buy No-Name potting mix from anywhere. It is really low quality and your plants will hate you for it.

So, the end result is that you don't need to spend a fortune to jazz up your home and balcony. I am the first to say that \$2 shops are full of crap and tack but they also have the occasional great find. They tend to just throw everything together, so nice pieces are often lost among the junk. If you want to see a piece, take it off the shelf and look at it as an individual piece, get it away from all the junk and evaluate it as an entity. You may be surprised at what you find.

And, above all else, use your imagination! A budget doesn't automatically rob you of that asset. Always remember: shopping is therapy. Go for it!

- Good Buys
Anzac Parade, Maroubra
- The Reject Shop, K-Mart, Best and Less,
Eastgate Shopping Centre,
Spring Street, Bondi Junction
- Hot Potato
Oxford Street Mall, Bondi Junction
- Spotlight
Ebley Street, Bondi Junction
- Victoria's Basement
Basement, QVB Building, City
- Home Yardage
York Street, City (near Market Street)
- Ikea
Moore Park Supa-Centa, Moore Park

I recently did a foray out to the Grace Bros Clearance Centre at Maroubra called, appropriately, Good Buys. This is an entire mall of seconds clearance stores, and weren't there some great items to be had!

'Appropriate' public housing for some - a nightmare for others

housing

For one plwha, the move from private to public rental housing wasn't the answer

I am an hiv+ private tenant, currently claiming Special Assistance Subsidy Special (SASS) from the Department of Housing (DOH) and wish to remain anonymous to protect my identity and prevent reprisals.

Where and how we live remains a deeply personal issue. Public housing does not suit everyone, and many of the 'unsuitable' aspects of DOH properties do not become apparent until one is already living in such a place. Hiv+ pensioners have varied and constantly changing needs and are therefore not always able to adapt and fall into line with the standardisation aspects of most public housing. To pressure hiv+ private (SASS) tenants, who have built and maintained a basic sense of self-respect, into public housing – where they may be miserable – using the argument that public housing is more stable is an inhumane, pennypinching, bureaucratic trap.

Public housing for some is a degrading, depressing, demoralising experience. Having to cut ties with the private rental market is, symbolically, the last straw in the losing of one's sense of independence and dignity. It is common knowledge that many attempts to escape this trap to get back into private rental later will inevitably result in prejudice and rejection from most real estate agents when they know someone has been in public housing. Such a life change is therefore a potential cause of deep and lasting emotional grief, adversely affecting the person's sense of identity. Recently, I had a disheartening, transitory taste of public housing and dread the thought of going back into it now that DOH have stopped SASS being a longterm housing option for hiv+ pensioners.

I had been comfortable in private rental, with SASS to pay most of my rent, for several years. I had a good, stable tenancy record, having never lapsed in my rent, and changed address only twice by choice in

14 years, and then the owner of the unit I lived in decided to sell her investment. To cut a long story short, in that time of change I voluntarily opted to try living in a DOH property – a so called 'stable housing' option for my uncertain future as an hiv+ pensioner. This made perfect sense in theory.

It was explained to me that there would be a considerable wait, even on the priority list – I had 'locational needs' and DOH properties in my nominated area seldom become available. Several months passed and then I received a call from a DOH letting officer who informed me that a suitable place had become available. The officer strongly urged me to view it, insisting that this was one of their better places, and reminded me that 'the first place you are offered is usually the most suitable there is and if you turn it down you only get one more offer!' I would have to occupy the premises by the end of that week if I accepted, and they needed a more or less on-the-spot decision. I hurriedly collected the keys and went to see the flat. It seemed to be in a reasonable condition and was in walking distance of my community and healthcare facilities. The only obvious drawback, at that time, was that there was no bath, only a shower. That on its own seemed like a weak argument for refusing the offer, even though I had been experiencing intermittent bouts of peripheral neuropathy. In haste, I accepted and moved my whole life in just several chaotic days.

After recovering from this unexpectedly sudden house move, I began to feel prematurely institutionalised. Small details, barely noticeable at my initial viewing of the premises now became clear. An emergency alarm-isolating button featured halfway up my bedroom wall, just the right height for someone in a wheelchair (an automatic assumption by someone that I would become wheelchair bound). Same story with all the power points – wheel-

chair height. A clinical plastic invalid seat folded down in the shower recess. A standard-issue metal handrail was attached to the bathroom wall, presumably ready for when I became incapable of standing unaided. Standard-issue bars across the lounge room windows served, presumably, to prevent me from falling out of it. Added to all of this, the flat overlooked a main, inner-city street, the traffic noise being unbearable day and night. The density of the street pollution aggravated allergies I had almost forgotten I had at intermittent times of particularly fragile health. A toxic layer of grime settled around the flat whenever a window was opened for more than a few minutes. It was mid-summer and I was prevented from opening a window.

I also became aware that I was suffering by not having regular baths, as my peripheral neuropathy comes and goes and hot baths had proven to be one of the best remedies for it. Only when I came to live without a bath did I realise just how integral having one was becoming to my basic wellbeing as symptoms slowly worsened. As I already pointed out, minor details such as these cannot always be clearly foreseen and may seem, on their own, weak arguments against living somewhere. However, minor details add up and our needs are ever changing, just as our health often is.

Once you are allocated one DOH place, getting transferred to somewhere more suitable as one becomes more aware of one's individual needs or as those needs change, can be a gruelling and complicated process – a process which someone who is unwell would most likely avoid as being the worse of two evils. So then you find yourself stuck there, miserable and unheard. It is a far simpler process to move to more suitable privately rented accommodation as one's health needs change over periods of time.

Public housing does not suit everyone, and many of the 'unsuitable' aspects of DOH properties do not become apparent until one is already living in such a place.

Still, at least I was amongst people like myself there, right? Wrong! Some may be lucky to find one or two fellow hiv+ people but we are still only a small minority in the public housing system. Hiv status aside, hoping for good neighbours in some public housing blocks is often unrealistic. Many public housing tenants have very limited life experience outside of the government welfare system and can be worlds apart from many hiv+ people, especially from those of us who have led productive mainstream lives and understand basic self-respect and common courtesy. Many of these public housing tenants have serious social problems and can be extremely difficult to live amongst.

I started finding evidence of other 'presences' in the corridors and other common areas.

Human waste (solid and fluid), empty cans and bottles, cigarette ends, pizza boxes, used toilet paper and other garbage seemed to multiply each day. After about a month there I found a cleaner in the hallway and I asked him how often he came in to clean. Unfortunately he spoke no English. I did spot him again briefly, about six weeks later. He was also blind to much of the mess I had to wade through each day whilst coming in and out of the building and he left much of it uncleaned – as if he knew from experience that nobody would ever notice or complain. My best friend came over one day with rubber gloves and detergents, and between the two of us we scrubbed, mopped and cleaned the lift, garbage room, entrance foyer and firestairs. The very next day the same problem had returned – urine, saliva, fast food containers, cigarette ends, cans and bottles. It was disheartening, degrading and seemed almost malicious after all the effort we had made. Nobody in the block appeared to do anything about this. People had apparently given up caring and become accustomed to living in these conditions.

So I contacted an officer at DOH to discuss the situation. Our conversation was brief – I was one reference number among thousands on a government computer database – and disappointingly inconclusive. The general attitude from that staff member was one of 'we are very busy' and 'think yourself lucky to have a home at all'. There are all kinds of other accumulative bureaucratic restrictions that come into effect too, such as not being allowed spare front door swipe cards in case you get locked out and not being allowed one for a carer who does not live with you in case you are too unwell to let them in.

Disempowerment is one word to describe how it can feel living in the shadows of such a bureaucracy as DOH. It is alarming to feel that so much business concerning such a personal aspect of one's life as one's home can be so influenced by some public servant who doesn't know you and who mightn't seem to want to, either. Especially when you stop to consider the power of discretion some public servants can exercise either in or against your favour in various instances. You may or may not be allocated with a particularly helpful staff member. Yes, there are measures to take if you have problematic neighbours or aren't satisfied with your treatment. You can even apply to be relocated. But if you were already in bed unwell or busy with medical appointments, would you really have the time, energy and inclination to face all of that red tape anyway?

As for getting to know one's neighbours, apart from the fact that many seemed incapable of stringing a sentence together, there was a heavy atmosphere of 'don't look at me, don't speak to me', as if getting to know fellow tenants represented major complications best avoided. Most people I encountered were either drunk or drug wasted, mentally disabled, non-

English speaking or just downright hostile (the word homophobia sprang to mind frequently). The longterm effects of public housing had clearly had a dehumanising effect on many longer term tenants, impacting on their self-esteem and social outlooks. This was distressing for a 'newcomer' to witness firsthand.

After several months in that situation I was clinically depressed. I was also sleepless because of the traffic noise. I had to discuss all of this with a psychologist and also had to be prescribed antidepressants and sleeping pills.

It became imperative to restore my basic sense of grace and human dignity by moving out of public housing and back into the private sector on SASS. I was unusually fortunate to find a real estate agent interested in me now that I had acquired a public housing history. However, people like myself will no longer have this choice when DOH changes its policy and makes SASS only a temporary measure and public housing the only longterm choice available to hiv+ pensioners.

I am appalled that these DOH policy changes, which make SASS only a temporary measure, are being allowed to go through. I am shocked at hiv community organisations for not actively preventing these changes, which allow the very people they are employed to represent to risk being degraded, demoralised and institutionalised in this way.

I fully expect poverty rates to worsen as hiv+ private tenants struggle to resist compulsory public housing, and depression and suicide rates within the hiv community to rise as a direct result of these deplorable reductions in lifestyle choice. I, for one, will be seeking the further support of a psychologist at Albion St Centre in order to try to come to terms with this horrendous news.

Take a break at the beach

accommodation

Des Kilkeary Lodge re-opened – officially – in May. Coordinator **Rhonda Bancroft** and NorthAIDS Manager **Adrian Eisler** spoke to **Susan Hawkeswood** at the opening.

Funded by Northern Sydney Area Health Service, DKL is part of NorthAIDS. A Wellness Project at Crows Nest is the other arm of the service NorthAIDS provides, as well as a new community outreach project based at Dee Why. Closed by fire two years ago, DKL provides short-term respite care on Sydney's northern beaches. Coordinator Rhonda Bancroft, who began working at DKL as a volunteer six years ago, describes the refurbishment that took place after the fire as 'major', including a fire escape.

Four bedrooms, each with king or queen size beds, provide accommodation. 'People can come and bring a partner or a carer, or mother and child, anything like that,' said Rhonda Bancroft. Most guests are from the inner city but DKL has provided care to people from interstate, Wollongong and even had one guest from overseas.

Although the maximum stay is officially four weeks, 'we're finding lately that we have a lot of people with housing issues, and if they can show that they're looking for places and they've got people helping them to look, we don't just say, 'well, you have to leave'. As long as they're making an effort and they're doing the best that they can, we will, at times, extend their stay.'

Guests at DKL with housing problems stay an average of eight weeks. 'Sometimes longer, depending on where they want to live,' said Rhonda. 'We're very lucky. Department of Housing down here at Dee Why is very good.'

Most people looking for housing are approved for SASS and look for accommodation on the northern beaches. 'There's a

fellow staying here at the moment. He's looking for a one-bedroom unit. In Dee Why, he can spend \$220 a week, in Manly he can spend \$300. I think that's pretty fair,' said Rhonda, who provides a housing support role while guests are trying to find somewhere to live. 'But all that takes time: to find the unit, put your application form in, that one falls through, ok onto the next one. And it's just keeping them optimistic.'

'We help out with the moving. We help out with trying to find the furniture with Mark at BGF and take them to Out of the Closet ... We collect stuff here as well. ... We collect jugs and linen ... and then once they're out in the community, we make phone calls ... make sure they're doing ok, help them with shopping, pick them up and take them over to Crows Nest for lunch, things like that. It's an ongoing support for them because once they've moved over this side and they're in this area, they're really on their own. They're away from the inner city, maybe they're trying to get away from that. But they're really starting, not just living in a new unit, they're starting a whole new life and we find they do need that encouragement and the volunteers here will help out with that as well.'

Said NorthAIDS Manager Adrian Eisler, 'As treatments become effective and people can live longer ... that kind of situation's going to develop too. ... The frustration that I feel at times is in the funding environment where, in spite of all the great ... techniques and treatments ... the needs of all positive people have not gone away and are likely not to go away in the near future, and yet somehow our political masters, in some ways, feel that the problem's sorted and they move on to other things. We're trying to battle for increased

People can come and bring a partner or a carer, or mother and child, anything like that.

funding to do what we need to do, whereas the pressure is on us to decrease our funding and I find that intensely frustrating because we're aware every day that the needs are going unmet.'

The two people housed at DKL since November who have had housing issues also had, said Rhonda, 'mental health issues, drugs issues, and one had domestic violence issues. So it's not just the housing.' It is this combination of issues that make it difficult for people to stay motivated, according to Rhonda. 'They've got all these other things going on, and some days it's like, 'I just want to stay in bed and do nothing' but they know that they've got to keep going,' she said.

Adrian believes that 'the strictly hiv component' of some plwha's needs is less of a problem than other aspects. 'Having a

We're trying to battle for increased funding to do what we need to do, whereas the pressure is on us to decrease our funding.

multiplicity of factors ... makes it that much more challenging to meet that person's needs. ... In metropolitan Sydney, there really are only two similar kinds of agencies ... ourselves and Stanford House,' he said.

There is currently no waiting list for respite care but that can change very quickly. The criteria for accessing services at DKL is very strict. Plwha cannot self-refer to the service. A referral from a social worker or case manager is necessary. The physical limitations of the house need to be taken into account, according to Adrian Eisler, when assessing whether DKL is the best place to meet people's needs. 'Rhonda's job is to make those kind of assessments and see whether in fact those needs fit with what our ability is to deliver,' he said.

The 'mix of people' is, according to Rhonda, something the service needs to be careful about. 'I might put someone off for two weeks if I think they might be a problem with a guest that's already here.'

'I wouldn't take any more than, say, two housing issues. There are a lot of clients who come back year after year and if I know that they have, say, a drug problem but I've already got someone else that has a drug problem or is trying to get off drugs, I wouldn't put the two of those together,' she said.

Adrian said, '... as the epidemic changes, as treatments change ... some people do have ... a complex set of needs and some of those behaviours can be quite challenging. We are a four-bedroom house. We aren't funded to provide 24-hour staffing, so necessarily that limits our ability to cater for some people's needs. But we do have other support struc-

tures we can work with. ... It's not a question of making it easy for us, or having a quiet life. It's very much the needs of the clients. We have had a number of clients that we've worked with who've wanted to make changes in their behaviour, whether it be drug or alcohol or another issue ... who have found the stay in the house has been a turning point for them.'

DKL's coordinator is fulltime. An assistant coordinator works five hours a day, five days a week. The rest of DKL's staffing needs are met by volunteers but even with that support, the service is unable to provide 24-hour supervision. Volunteers work until about 9 or 10 pm but not every night of the week. DKL is currently recruiting for a care and support worker to fill the nights volunteers can't cover.

Although DKL cannot provide services for plwha who need 24-hour supervision, 'there might be provision', said Adrian, 'to bring in a package of care that's specifically designed for a certain client.'

'We work together in partnership. It's not a question of us doing it all on our own. It wouldn't be the right thing or in the best interest of the client, he said.

Rhonda said, 'We did have ... a young girl who did become very sick very quickly. She had her carer with her but we also had to get home nursing in during the day, a physiotherapist, to look after her and until we could get her into hospital, we really had to sort of battle through each day because there was nowhere for her to go. There was no beds. She had no home. ... It did get to the point, after much discussion with her and hospitals, that I had to say, 'I can't look after you anymore', and she died two days after she left.'

There is currently no waiting list for respite care but that can change very quickly.

We really had to sort of battle through each day because there was nowhere for her to go. There was no beds. She had no home.

Hiv/aids leader appointed to major global role

The Bangkok-based Manager of Australian Red Cross HIV/AIDS Programs in the Asia Pacific Region **Bernard Gardiner** has been appointed to a key global role in Geneva. **Susan Hawkeswood** compiled this report.

Mr Gardiner, a former General Manager of the Victorian AIDS Council, has accepted the newly created position of Manager – AIDS Global Program with the 178 member International Federation of Red Cross and Red Crescent Societies (Federation). Reporting to Dr Alvaro Bermejo, the Federation's Health Department Head, Mr Gardiner's main task will be to organise the scaling up of the Federation's hiv/aids work in line with the commitments made at the United Nations General Assembly Special Session (UNGASS) on hiv/aids last year.

Mr Gardiner said, 'It really is an honour to be offered this key role. We are at a critical period in the global response to hiv/aids, with our biggest immediate battle to overcome the stigma associated with the virus.'

'What we must do is to correct the misconceptions, provide the facts and in doing so ensure that knowledge is spreading faster than the disease – only then can we hope to beat it,' he said.

Mr Nathan Rabe, International Operations Manager for Australian Red Cross, says Bernard's appointment is recognition for the key role he has played in directing the response of the organisation in the Asia Pacific region, and the role he played last year in developing the Federation's partnership with the Global Network of People Living with HIV/AIDS (GNP+). 'Bernard will be an excellent ambassador for Australia and a powerful advocate for partnership with People Living With HIV/AIDS (PLWHA) and the fight against hiv/aids globally,' said Mr Rabe.

In a report released in Manila last year, the World Health Organization (WHO) called on Asian countries to 'aggressively implement' hiv prevention programs for

drug users, including the controversial approach of providing clean needles to ensure safe injection practices. The WHO said the aids epidemic in virtually all of Asia is concentrated on sex workers and injecting drug users, making the region 'comparatively unique'.

The WHO report said that in the next few years aids will weigh even heavier on Asian countries, with more people stricken and dying of the disease. In areas most affected – Cambodia, Myanmar, Thailand and a few states in India – the death rates of adults will rise 40%, the WHO warned. India alone could see a third of a million deaths due to aids in 2005, the WHO

'In areas most affected - Cambodia, Myanmar, Thailand and a few states in India - the death rates of adults will rise 40%, the WHO warned.'

forecast. For most moderately affected Asian countries, annual deaths among adults will increase by 5% in the coming decade due to aids, the report said.

Despite the aids threat, the WHO said few countries were equipped to deal with the problem with only Hong Kong, Japan, South Korea and Singapore having 'adequate resources to provide for both prevention and care'. The report said 'most countries are targeting efforts at the general public' but warned that 'the only responsible public health action to take' is to focus attention on the groups who are most at risk.

Condoms appear to be reducing the number of new aids cases, but no government can afford to ignore the epidemic,

delegates to the 6th International Congress on AIDS in Asia and the Pacific in Melbourne were told. Thailand and Cambodia have seen the numbers of hiv infected people drop, mainly because of the wider use of condoms. But the biggest concern there, as in other Asian countries, is the spread of the disease via men who have sex with sex workers and then pass on the infection to their female partners.

'It's estimated that 12–13% of all males in Cambodia have sex with more than one type of sex partner', said Dr Hor Bun Leng, of the Cambodian National Center for hiv/aids. In Asia, about 6.4 million people are living with the disease, second only to the sub-Saharan Africa region. Among sex workers, 31% of sex workers are hiv positive, compared with 16% of occasional sex workers such as women who work in bars, karaoke clubs and massage parlors. In 1998, the hiv infection rate among sex workers peaked at 42.6%.

Cambodia has the highest national rate of hiv/aids infection in Asia, but the number of new infections each year has dropped as prevention strategies take effect. Infection levels in Cambodia now are about 2.7%, or about 170,000 adults. Fifteen percent of married men and 21% of unmarried men went to sex workers in 2000, compared with a total of 11% in Japan and 10% in Thailand, surveys have found. So far, the spread of aids across Asia has been relatively contained to high-risk groups including sex workers, intravenous drug users and homosexual men.

'AIDS Battle Must Not Be Ignored, Say Experts', CNN.com 06/10/01. [CDC News] CDC HIV/STD/TB Prevention News Update 09/10/01. 'Adult Death Rates in Asia to Climb 40 Percent Due to AIDS: WHO' Agence France Presse (24/08/01). [CDC News] CDC HIV/STD/TB Prevention News Update 29/08/01

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Contact Danny on 02 9361 6750.

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The Board of PLWH/A (NSW) Inc would like to thank the listed companies for their generous support

by donating various gifts and products for our Annual Volunteer Thank You Party which was recently held at the Taxi Club.

The organisation values the contribution that all of our volunteers give and without their support the organisation would be unable to achieve many of its objectives and outcomes.

If you wish to be a part of PLWH/A's (NSW) team of volunteers contact Will Klaasen on 02 9361 6011 or email willk@plwha.org.au

We are always grateful for your assistance.



Membership costs nothing!

Yes, I want to be a member of PLWH/A (NSW) Inc.

Please tick

- Full member (I am a NSW resident with hiv/aids)
- Associate member (I am a NSW resident)

Disclosure of positive hiv status entitles you to full membership of PLWH/A (NSW) with voting rights. Members' details are confidential.

Membership entitles you to *Contacts*, the Annual Report and a biannual newsletter.

New membership/subscription arrangements start 1 July 2002

Subscriptions

Yes I want to subscribe to *Talkabout* (annual subscription July 1 to June 30). Please select (tick the circle) the rate that applies to you or your organisation.

Subscriptions only

- I am a New South Wales resident receiving benefits - \$5 (Please enclose a copy of your current health care card)
- I am an individual and live in Australia - \$33
- I am an individual and live overseas - \$77

Organisations:

- Full** \$88 (includes all business, government, university, hospital, and schools either for-profit or government-funded)
- Concession** \$44 (includes plwha groups and self-funded community owned organisations)
- Overseas** \$132

Name

Address

Phone or email

I enclose a donation of \$

I enclose a cheque/money order (payable to PLWH/A [NSW]) Inc. of \$ being for my donation

Please charge my Bankcard VISA MasterCard AMEX Diners (C/C Min. \$10)

Expiry Date _____ Signature _____

Name on card _____

Name

Address

Phone or email

I enclose a copy of my current Health Care Card

I enclose a donation of \$

I enclose a cheque/money order (payable to PLWH/A [NSW]) Inc. of \$ being for my annual subscription to *Talkabout* (donation)

Please charge my Bankcard VISA MasterCard AMEX Diners (C/C Min. \$10)

Expiry Date _____ Signature _____

Name on card _____

To save you postage we suggest you put the completed slip in an envelope and address to:

PLWH/A (NSW), Reply Paid 831, Darlinghurst, NSW 1300

DO NOT PUT A STAMP ON THE ENVELOPE

Tax invoice ABN 42 907 908 942. GST inclusive

thank you for your support

Services Directory

If you would like to advertise in
Talkabout's Services Directory, please
contact Danny on 02 9361 6750.


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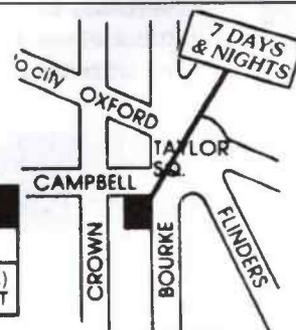
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olga's personals

Hiv+ gay male 42, GSOH, caring, romantic, in good health, enjoys travel, dining in/out, bushwalking. Looking for an intelligent, passionate, genuine active guy to 46 with a view to LTR. Not into drugs or the scene. Genuine replies only. **Reply: 010202**

Homebody hiv+ gay guy early 40s, appreciates the quiet simple things in life, and the occasional affection. Looking for someone similar for LTR. **Reply: 021201**

GM, 50, 22 yrs w/hiv, still good looking, albeit a bit creased. Defined, muscular little body. Seeks someone to share life - Everything from 10 Pin Bowling to discussing books + life's ironies: walking the dog to making love. You smart, kind-hearted and humanoid. **Reply: 011201**

L/North Shore 32yo hiv+ (1 yr) tall dark haired handsome Aussie gay guy into health & healing of body, mind and spirit. Go to gym, yoga, meditation & massage, enjoy music and travel etc. Finding balance & happiness within myself, passionate & sensual. Seeking masculine unaffected mates or friends for friendship & more if compatible. Not into the superficial Sydney scene. **Reply: 031001**

Black gay guy late 30s, versatile hiv+ & romantic. WLTM other positive gay guys for friendship leading to LTR. Please include your phone number. Open to all nationalities & please genuine replies only. **Reply: 021001**

Hiv+ Latino gent, slim, hot, athletic body, intelligent and discreet. Seeking a LTR or friendship with a lady of similar interests, for me to give you all of my love. I'm sensual straight man resident of Sydney and lonely. Would like to meet you. I'm in good health, no drugs, GWM. **Reply: 011001**

Funny, romantic, sincere hardworking 41yo hiv+, divorcee seeks friendship with hiv+ 42yo gent. Must possess a wicked sense of humour and have good intentions. All replies answered include telephone numbers/recent photo. **Reply: 050801**

36yo romantic Greek gay guy, hiv+, seeking 30-40yo newly diagnosed positive male for relationship. I enjoy bushwalking, going for long drives and computers. **Reply: 040801**

Nth Shore, Funky yuppie would like to hear from guys, transgenders & women, any age, looking for friendship & fun times. Background hiv+, like to talk about it. Treatments, still interested gay lifestyle. Future goals! Confidentiality assured, all mail answered. **Reply: 030801**

Attractive hiv+ guy. 40 looks younger and musician, is caring, affectionate and a romantic. I live a 'normal life' and in excellent health. Enjoys a healthy lifestyle and appreciates the finer things in life. Lives in Sydney would like to meet a hiv+ female to share my life with. Let me serenade you. GSOH, and discretion a must. My first advert. **Reply: 020801**

Hiv+ 34yo male, very good looking & humorous. I have many wonderful hobbies & friends, and I am completely together. Looking for someone to share life with and to hopefully love and spoil. NO LOONS PLEASE. **Reply: 010801**

How to respond to an advertisement Write your response letter and seal it in an envelope with a 45c stamp on it • Write the reply number in pencil on the outside • Place this envelope in a separate envelope and send it to

Olga's Personals, PO Box 831, Darlinghurst 1300.

How to place your advertisement Write an ad of up to 40 words • Claims of HIV negativity cannot be made. However, claims of HIV positivity are welcomed and encouraged • Any letter that refers to illegal activity or is racist or sexist will not be published • Send the ad to Olga, including your name and address for replies. Personal details strictly confidential.

A positive voice in an hiv wilderness

Ashok Pillai, the 34-year-old president of the Indian Network of People Living with HIV/AIDS, INP+, passed away in Chennai in April.

Ashok was a symbol of positivism for the hundreds and thousands of people infected with hiv in India. He was the first to start spreading the message that hiv was not just about dying: it was about making the best use of one's limited years. He not only built up a positive people's movement in India but also brought together diverse groups to present a united voice on the issues of positive people.

Even for Ashok it took several years before he could come to terms with his mortality. Ashok was diagnosed positive in 1990, when he was a radio operator in the Navy. He battled the stigma and discrimination that accompanies the infection, for many years. In 1991, discharged by the Navy, he came back to his home, and waited for death to come. He had been given a maximum period of survival of three years by the doctors. He would wake up in the morning thinking he would be dead by the evening and go off to sleep thinking that he would be dead by the morning. This pattern continued for months when he finally realised how wrong the doctors were. There was, after all, life after hiv.

And that is when he joined a group of other young men like him to form the first positive peoples' network. Quite courageously, he announced his status publicly, so that others could learn from him. A poster brought out by him, showing a confident and cheerful Ashok, saying, 'I have a successful career. I enjoy music. I like to workout at the gym,' changed the mindset around hiv/aids. Before that posters on hiv showed horrific images of emaciated bodies and dying people.

In the 12 years that Ashok survived after detection of his infection, he not only built

up a movement of positive people, but also brought together different smaller groups under an umbrella network.

'A positive attitude makes the biggest difference,' he would say, 'If I am living under stress, I will not eat properly, perhaps stop going to work as well, my immune system is bound to suffer.'

He wanted to work until his last day. And he did. Though he had been taken ill by a rare infection of late, indicating that his immunity levels were dangerously low and that he had entered the final stages of aids, he did not give up. He was a soldier; he died like one; just the way he had wanted it.

KALPANA JAIN, NEW DELHI. TIMES NEWS NETWORK | SATURDAY, APRIL 20/04/02

Frank Moore II, Painter

Prominent painter Frank C Moore II, 48, died in April of complications from aids at St Luke's-Roosevelt Hospital Center in Manhattan. Moore, a Manhattan native, created works that are part of the collections of the Museum of Modern Art, the Whitney, and the Albright-Knox Art Gallery in Buffalo. As one of the leaders of Visual AIDS, which raises money to help artists with aids and preserve their work, Moore was instrumental in conceiving the overlapping red ribbon as a symbol of aids awareness. A book of his work, 'Between Life & Death', is scheduled to be published next month by Twin Palms Press.

Newsday (New York City) (23/04/02), Erik Holm. [CDC News] CDC HIV/STD/TB Prevention News Update 23/04/02

treatment update: a treatment for facial fat loss

New-Fill, a treatment for facial fat loss, has the potential to improve many people's self esteem and quality of life but is expensive and difficult to access. Treatment Information Officer **John Cumming** explains why.

One of the longterm side effects of some hiv medication is facial fat loss, one of a group of symptoms known as lipodystrophy. Facial fat loss is particularly distressing because it causes sunken cheeks and other changes in appearance. New-Fill, a new treatment for the cosmetic correction of this condition, first attracted attention at an international conference on lipodystrophy in 2000.

New-Fill has previously been used in cosmetic surgery to treat fine lines, wrinkles and furrows. When injected into the wasted regions of the cheeks it works by plumping out the tissues. It may also stimulate the growth of collagen to promote the development of a thicker layer of skin. New-Fill does not provoke an immune response by the body, instead it is broken down and absorbed. There is no risk of post-operative sagging or moving because there is no implant to sag or move. Recent data on New-Fill appears to confirm it is both safe and cosmetically effective in people with hiv-associated facial fat loss. So why is it so hard to access?

New-Fill was only recently licensed for marketing in Australia. Before that, several Australian plastic surgeons were importing it from France for use on their patients. Dr Brett Archer, a Melbourne-based surgeon, is one of the few Australian surgeons who has travelled to France to undergo the specialised training necessary to administer New-Fill. In the previous nine months, he has used New-Fill on a number of Australian hiv positive people. One treatment with New-Fill involves the injection of 3 mls into each cheek. Dr Archer says that most people need three treatments and severe cases can need up to six.

The Therapeutic Goods Administration has licensed New-Fill for marketing in Australia by a South Australian distributor

called Vexinsouth. New-Fill comes in a box of two vials which, according to Vexinsouth, is generally enough for one treatment. The cost of this box to the surgeon is \$530 (plus GST). Dr Archer hopes to start visiting Sydney regularly in June 2002 to see patients who want New-Fill and says that because of his travel costs he will have to charge about \$750 per treatment. Other surgeons charge considerably more.

Medicare cover is only available for plastic surgery that has a functional as well as cosmetic aspect, such as reconstructive surgery following breast cancer.

Plastic surgeons can claim a rebate from Medicare when they see patients interested in New-Fill who have been referred to them by a GP. However, surgeons get no Medicare rebate for the administration of New-Fill, meaning they can either waive the cost or add it to the fee they charge the patient. Medicare does offer a rebate for restoration of facial contour following disease or trauma but this specifically excludes injection of liquid or semi-solid material. Dr Warwick Nettle, a Sydney plastic surgeon who has been using New-Fill thinks it is very unfair that people with hiv are in effect denied treatment with New-Fill. He said, 'The current arrangements place us (plastic surgeons) in a difficult situation. Because there is no Medicare item number to protect ourselves, we must include a GST in the treatment costs for New-Fill.' Dr Gwynne Morgan, a plastic surgeon in Adelaide, has been lobbying Medicare to cover the cost of liposuction for fat accumulation at the back of the neck (another symptom of lipodystrophy) and for the use of New-Fill. He thinks that if Medicare covered New-Fill treatment, private health insurers would be more likely to offer coverage for it.

ACON is now working with NAPWA to advocate for a national multicentred clinical trial for New-Fill. It is hoped that the results of the trial will strengthen the argument that

Medicare should cover New-Fill. However, finding the necessary funding for the trial is a major challenge.

Questions to ask your surgeon about New-Fill

- How is the procedure done and how painful is it?
- Is it beneficial for fat loss from the temples as well as cheeks?
- Has the surgeon been trained in administering New-Fill?
- Can you talk to the surgeon's patients who have had New-Fill?
- How many treatments will you need to achieve a benefit?
- What will be the total cost, including costs of consultations?
- What are the chances of scarring or other complications?

Contact details

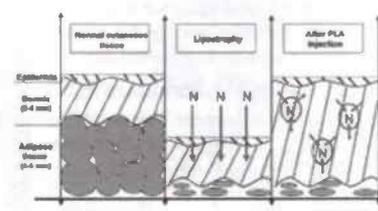
Surgeons

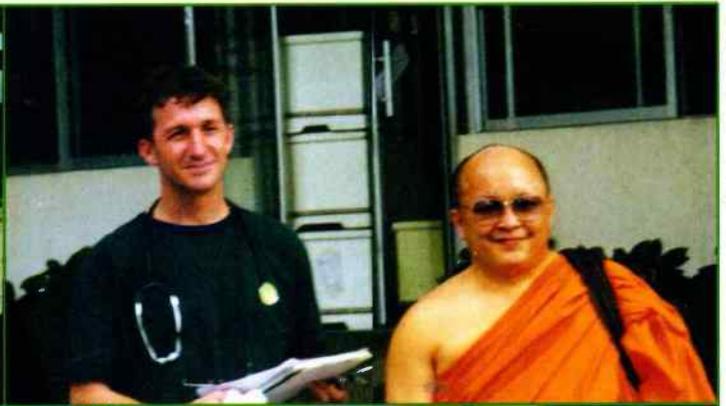
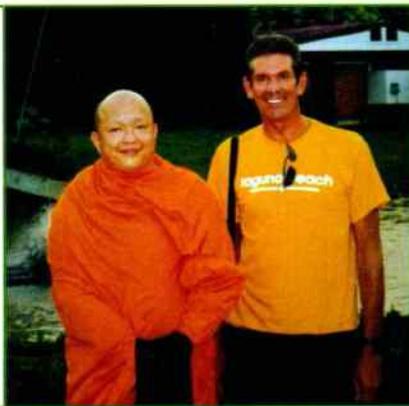
- Dr Brett Archer (Melbourne)
ph 03 9686 9344
email plasticsurgery@bigpond.com.au

Distributor

- Vexinsouth (Adelaide)
ph 08 8267 6266

Newfill® : Mechanism of action





Above left: Venerable Dr Mettanando Bhikkhu, of Wat Phra Bat Nam Phu (aids hospice) visiting Ayutthaya, in Thailand, with Ray Hansen, PLWH/A (NSW) member.

Above right: Dr Yves Wanna is the only doctor at the hospice. He has been working unpaid for two years, despite no hiv-specific training.

Left: Dr Steven Oppenheim MD, Director of San Diego AIDS Hospice, stands next to an hiv/aids memorial at Wat Phra Bat Nam Phu – an aids hospice – in Lop Buri, Thailand.

Below: The temple at Ayutthaya Ray visited.

Cover: AIDS Patient Boned Hill – a museum – at Wat Phra Bat Nam Phu houses the bones and ashes of people who have died of aids, not wanted or returned by relatives because of superstition and naivety about how aids is transmitted.

Pics: Ray Hansen

