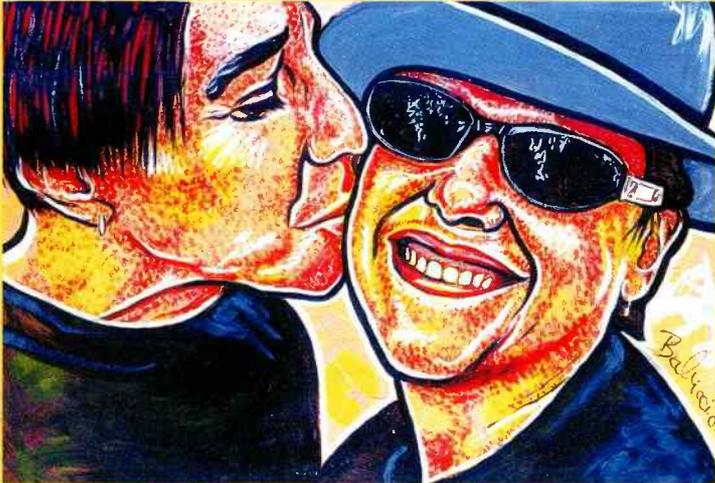


The Magazine of People Living With HIV/AIDS NSW Inc.

No. 114 April/May 2001

Talkabout

◆ Where We Speak for Ourselves ◆



this month, **pep**, vaccine trial, **year of the volunteer** and positive writing

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

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ជំនួយនិងការដឹងចិត្តចុះ

ΑΡΟΥΟ Υ COMPRENSION HIV AIDS Assistenza e Comprensione

ХИВ/СИДА YARDIM VE ANLAYIS PODRŠKA i RAZUMIJEVANJE

ΣΥΜΠΑΡΑΣΤΑΣΗ ΚΑΙ ΚΑΤΑΝΟΗΣΗ HIV-AIDS الايدز

ช่วยเหลื่อและเข้าใจ Trợ Giúp Thông Cảm VIH/SIDA

المسانده التفهم... HIV & AIDS 支持與理解 ऐश.ओ.वी/ऐदस

ПОДРШКА И РАЗУМЕВАЊЕ ПОМОС I ZROZUMIENIE

HIV/AIDS 愛滋病病毒/愛滋病 APOIO E COMPRENSÃO

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YARDIM VE ANLAYIS

التفهم... والمسانده

ΣΥΜΠΑΡΑΣΤΑΣΗ
ΚΑΙ ΚΑΤΑΝΟΗΣΗ

ជំនួយនិងការដឹងចិត្តចុះ

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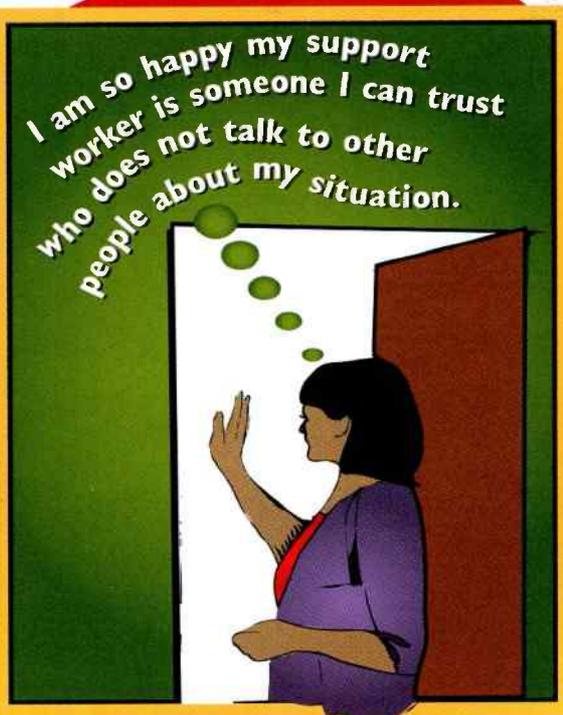
ВИРУСОТ HIV И СИДА-ТА

Assistenza e Comprensione الايدز

ПОДДРШКА И РАЗБИРАЊЕ

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FEATURES



This month's cover images feature couples from all walks of life supporting the full range of happy healthy relationships. The placards were devised and painted by Anthony Babicci for the 2001 Sydney Gay and Lesbian Mardi Gras Parade AIDS Council Of New South Wales entry. Anthony is a local Sydney artist who teaches scenic art at NIDA. *Talkabout* and PLWH/A (NSW) thank Anthony, the SGLMG and ACON for their generosity in sharing these images.



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DISCLAIMER

Images of people included in *Talkabout* do not indicate HIV status either positive or negative.

from the publications working group

This issue of *Talkabout* could be longer – eight pages longer – but it's expensive putting out a magazine of this quality. This year we've had to tighten the purse strings so until we find an extra sponsor or a new way to raise funds from an already generous public, *Talkabout* will stick to 28 pages. That's the bad news but there's plenty of good news!

Talkabout is a unique public forum in which PLWHA speak for themselves. There are many barriers to PLWHA speaking out, discrimination and isolation for instance. In the last eighteen months the Publications Working Group and I have focused on encouraging a diversity of PLWHA to share a little about their lives with our readers. In this issue HIV positive people or people affected by HIV have written three quarters of the stories. Half of the stories document personal experiences and half discuss issues of community importance. There are stories from gay men, straight women, and older married couples. Our readers will each have a different response to these stories. To me it's about empowerment and respecting difference. What is excellent is that these stories are read by HIV positive people and others all over Australia and now, thanks to <http://www.webcentral.com.au>, all over the world.

We hope our writing group will kick off another season of fortnightly meetings this month. Contact me 9361 6750 for details. Terry's moving contribution in this issue is an example of the wonderful work that this group has encouraged. There is talk in the air of another writing competition...stay tuned.

Thanks to all the writers for their contributions, and thank you also to Rosi Okeno for the advertising, Will Klaasen the Publication Assistant, David Urquhart our proof reader and Georgia Willis our designer.

PS. In the previous issue a photo on page 19 was incorrectly captioned as the NAPWA committee. The photo is a promotional shot used in NAPWA publications and includes some members of the committee and other HIV positive people.

Also in the previous issue the email address given for Michael Riches, Convenor of the PLWH/A (NSW) Rural Working Group, was incorrect. Michael can be contacted at ragsta1@aol.com

My apologies to readers.

Kind regards

feona studdert

Editor
Talkabout



In 2001, the Year of the Volunteer, community organisations will acknowledge and thank the thousands of people who volunteer their time and skills to community services and many more areas of Australian life. Jorge Gascon is a volunteer at the Sanctuary, the community service in Newtown offering free holistic health care to PLWHA. He is just one of the many people who volunteer in the HIV/AIDS sector. Jorge's contribution was recently acknowledged at a ceremony to mark NSW Volunteers Appreciation Day. Pictured (l-r) are Robert Ball, Sanctuary manager, Rachel Ward, actor and director of the centre, Jorge Gascon and Richard Riley, Manager of the Community HIV/AIDS team at Central Sydney Area Health Service.



pos action

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

In 2001 we celebrate International Year of the Volunteer and if ever there was a group of organisations that should get down on their collective knee and thank the universe for volunteers, it is the HIV sector. It was volunteers who, ten or more years ago, created organisations like PLWH/A (NSW), the Bobby Goldsmith Foundation and the AIDS Council of NSW. With our volunteer boards and committees, grass roots volunteers doing cleaning, caring and emotional support and the numerous volunteers who help collect tens of thousands of dollars each year, the HIV Sector is truly indebted to its volunteers.

At PLWH/A (NSW) the list of volunteer involvement is long and admirable. Volunteers sit on our Management

If ever there was a group of organisations that should get down on their collective knee and thank the universe for volunteers, it is the HIV sector.

Committee; raise funds; mail out *Talkabout* and Contacts; write articles for *Talkabout*; help in the office; answer our phones; sit on our working groups; provide services at parties in the PLWHA Time Out tent; and speak in public about their lives as a positive person. With our volunteers the organisation achieves a great deal more than it could with only

paid staff. In terms of cold hard cash, volunteers at our organisation are probably worth close to \$100,000 each year.

Many community groups could not survive without the dedication and support that their volunteers provide. Many of the smaller organisations consist entirely of volunteers. This issue of *Talkabout* features just a few of the sector's volunteers.

At the Mardi Gras Launch in February, at the Sydney Opera House, our dedicated volunteers, committee and staff raised close to \$12,000 for the organisation. Such efforts are incredible and only achieved through the selfless act of giving money to the cause, and your time and energy. All of us at PLWH/A (NSW) thank you for the great effort and thank the Sydney Gay and Lesbian Mardi Gras for their continued support. ●



Crossroads

Robert Almond is at another crossroads in his life. After a torrid four years of failed treatments, AIDS-related illness, and hospitalisation Robert is contemplating his future. Not bad for a 28 year old diagnosed HIV positive four years ago.

"I'm a strong person, and my future is looking bright. Hopefully I'll go to TAFE later this year, with perhaps a career in the computer field."

With the help of his doctors, family and friends Robert has stabilised his health and is considering a return to work.

"I used to work in retail and I want to get back into the work force and test my energy levels. I've completed the Positive Decisions program and three short courses in computing. I'm retraining myself and with help from services like the Positive Employment Service and the Ratten Fund I'm setting different goals in life. I don't want to spend the rest of my life on the pension. One thing that gets me through is my sense of humour, and being able to laugh at myself. That's the key."

Warning on garlic supplements

A presentation at the 8th Conference on Retroviruses and Opportunistic Infections has shown that garlic supplements may lower the levels of saquinavir in the blood. A study, using healthy volunteers, revealed that one garlic capsule taken twice a day reduced blood levels of saquinavir by up to 50%. It is unknown if garlic affects other protease inhibitors. People taking any protease inhibitor are advised to seek medical advice before taking garlic supplements. www.thebody.com

Pregnancy caution

The US Food and Drug Administration and Bristol-Myers Squibb have issued a warning that pregnant women receiving stavudine (d4t) together with didanosine may have an increased risk of developing a potentially fatal condition called lactic acidosis. Lactic acidosis is a condition where lactic acid (a by-product of metabolism), accumulates in the body and causes damage to certain organs such as the liver and pancreas.

The warning follows the death of three pregnant women taking stavudine and didanosine in combination with other drugs. Several cases of non-fatal pancreatitis have also been reported in pregnant women taking only stavudine and didanosine. It is recommended that these drugs are prescribed to pregnant women only when the potential benefits outweigh the risks; for example, in cases of limited treatment options. Doctors should monitor patients closely for early signs of lactic acidosis. The statement advises that only physicians experienced in treating HIV infection should make decisions about using stavudine and didanosine during pregnancy. www.hivandhepatitis.com

Change to guidelines

The US Department of Human Services has released new guidelines for the treatment of HIV that recommend delaying antiviral treatment until the viral load is higher and CD-4's are lower than previously recommended. The new guidelines recommend that antiviral treatment of chronic HIV infection should be delayed until CD-4 cells decline to 350 cells p/m (previously, 500 cells p/m) and the viral load has risen to 55,000 copies p/m (previously 20,000 copies p/m). Patients with symptomatic infection should receive antiviral therapy regardless of viral load and CD-4 count. www.hivandhepatitis.com



talkshop

with Glenn Flanagan

PLWH/A (NSW) Community Development Project Worker

Glenn Flanagan profiles what's happening in NSW.

New housing resource

ACON has produced a comprehensive booklet outlining housing assistance options for PLWHA. It's called 'Give me Shelter' and is available from service providers.

Planet Positive at the movies

Planet Positive film club is a safe space for HIV positive people to view movies on the wide screen. 'The Talented Mr. Ripley', is one of many films planned. Call 9206 2000 for details.

Women's space at the PLC

The Positive Living Centre will host a barbecue and get together for Women on Friday afternoons. All positive women are very welcome. Alternative therapies and social engagement will be on the agenda. For details call Amelia on 9206 2000 or the PLC on 9699 8756

Fun and Gaymes

If you are thinking about a return to work, then volunteering may be a good way to increase your skills (with computers for example), confidence and work readiness, and help the community at the same time. One community organisation, with interesting volunteer work, is the Gay Games. They can be contacted on 9235 7002.

Drop into the Western Suburbs Haven

The Western Sydney drop in centre for PLWHA, The Haven, is also looking for volunteers to help with maintenance work, transport and caring. In April the Haven will host a workshop on drug and alcohol issues and hepatitis C. Ring Pat Kennedy on 9672 3600 for further information about volunteering and the workshop.

You can be part of PLWH/A (NSW)

Would you like to join the friendly, busy office team at PLWH/A (NSW)? We need people to volunteer for a morning or an afternoon as receptionists. Duties include answering the phone, greeting visitors, some typing and general office work. Training is available. Contact 9361 6011.

Positive Decisions

Another way to build and test your skills is with the PLWH/A (NSW) Positive Decisions program. Positive Decisions includes work experience in our office two days a week for three months, accredited courses through TAFE and career development and support assistance with the Positive Employment Service. Ring Glenn on 9361 6011 for details.

Put your life down on the page

Interested in writing? If you like the idea, but haven't the discipline or inspiration, a short course in a supportive environment might help you get started. In June I'll run a series of workshops for six weeks on life story writing. Give me a ring on 9361 6011 to enrol. And remember, the Positive Writing group is also here to offer support to budding writers. Contact the Editor, Feona Studdert on 9361 6750 for details.

Finally ...

A big, big thank you to all our volunteers, members, sponsors and staff. We've put together a small tribute to your efforts on the inside back cover of this month's *Talkabout*. 📖



poz writing

by Terry

*"Monsters in my head.
Crash and run in hell.
Worry, worry, worry, my
wild, wild heart."*

I have been HIV positive for ten years. I'm also schizophrenic, mentally ill, disturbed, call it what you like. It means I feel pretty screwed up all the time and I have to rely on medication to get through each day. That's HIV medication as well as handfuls of psych medication. My partner/boyfriend is Indigenous and positive and he finds it difficult to cope with all my unpredictable mood swings, nullified brain as well as his own predicament (being Indigenous and gay and HIV positive is not an easy road).

When you can't get your words out let alone your thoughts, it makes for a very messy and confused personality. Trying to get help isn't always easy. Help isn't always available. Doctors prescribed one and a half million anti-depression tablets last year, I have lost count of how many I've taken over the past thirty years but it wouldn't be far off 262,800; I should be rattling as I walk.

"My soul dies, my heart cries. I'm feeling depression creeping upon me."

According to the writers group I attend and without knowing exactly how it's happening I'm producing poetry as I speak.

"I worry about my lover. I can't sleep at night. I worry about not having enough to live on. Can't even have a holiday. No respite."

I'm always tired and angry with myself, feeling lonely in a relationship. Lonely amongst my positive peers at times, and dealing with my parents who don't understand how their boy became the man I am today - dysfunctional.

"Monsters in my head. Crash and run in hell. Worry, worry, worry, my wild,

wild heart."

I have an HIV doctor, a psychiatrist, a social worker, a mental health nurse, immunologist, and parental support (I put them through hell, and I know it, but I can't always help it). If I didn't have somewhere to go and talk with people who are positive, to chill out and participate in programs I'd be locked in my Housing Commission flat seven days a week doing nothing besides going out to shop. The Protective Office takes care of my finances (they pay my bills, but don't give me enough money to live on).

I have an HIV doctor, a psychiatrist, a social worker, a mental health nurse, immunologist, and parental support.

"Where's that million dollars?"

I listen to music to escape my nightmarish head. In the future I want a quiet passive brain, a fifty-dollar increase in the pension, happiness, sexual happiness and no discrimination for being HIV positive.

In the meantime I want to start a peer group for positive people with a mental illness. If anyone has the same problems and wishes for the same things please let me know via the Positive Living Centre. ①

The Positive Writing Group will kick off another series of fortnightly support meetings this month. Everyone is welcome. For details call feona at PLWH/A (NSW) 02 9361 6750

the waiting game

Progress on the trial to sell specialist anti HIV drugs from community pharmacies in New South Wales is slow. **Derek Walker** reports on why PLWHA are still waiting?

The current system dictates that only doctors who undertake and maintain education in HIV can prescribe specialist HIV drugs and that these drugs are dispensed through hospital pharmacies only. The opening hours of hospital pharmacies are often inconvenient for patients who do not live or work close to a hospital, and who are not able to get to the hospital pharmacy during opening hours.

Community organisations such as PLWH/A (NSW) and ACON have long argued that allowing pharmacists to dispense HIV drugs will enhance the lives of PLWHA. Peter Canavan, is the president of NAPWA and represents PLWH/A (NSW) on the NSW Ministerial Committee on AIDS Strategy, the key forum for the debate. He believes the issue is about assisting PLWHA to live as regular, a life as possible.

"Antiviral drugs offer substantially improved health opportunities for HIV positive people, and allow many of us to return to work and lead fuller lives. If we have to regularly go to a hospital pharmacy to pick up our drugs it is harder for some of us to live a normal life."

Community organisations hope that expanded access to antiviral medications will increase drug compliance among PLWHA who take treatments. Doctors constantly reinforce the message that PLWHA should take their HIV drugs as advised. But what happens when you run short on the weekend? What if you can't get away from work during pharmacy hours?

Community organisations have long complained that the current system raises potential threats for PLWHA confidentiality. PLWHA report their concerns that work colleagues may question why an apparently healthy person needs to go to a hospital pharmacy to collect drugs.

Cost and quality

Despite giving the Ministerial green light to the trial in December 1999 there are still

delays on the ground. One stumbling block is the concern to maintain the quality of health care. Community pharmacists cannot call upon the body of knowledge available to pharmacists in hospitals and most are not trained in possible drug interactions or aware of a client's medical history.

There are also bureaucratic implications, which are of little concern to patients, but important for health care professionals. The additional costs and clerical work involved

The benefits to patients versus the costs to the public health system will determine the success of the trial.

may outweigh the benefit to patients. In short, the public health resources required to establish the scheme may be better spent.

Stumbling blocks

According to Levinia Crooks, the Executive Officer at the Australian Society for HIV Medicine (ASHM), the involvement of many different parties in the trial is a logistical nightmare.

"The fact that the specialised drug program is a Commonwealth program, administered by the State, and we have health services involved on the hospital side and the private sector on the community pharmacy side, means that just about every level of government is involved. I think there is strong commitment from all sides to assist people to access drugs however."

The NSW Health Department is concerned that the State may find itself responsible for ongoing costs. According to a spokesperson, the Department needs approval from the Commonwealth.

"In the absence of the (Commonwealth) subsidy, NSW Health would have to meet the full cost of drugs for which it isn't currently funded."

All systems go

Alison Cunningham, Director of Services at ACON admits progress is slow but believes the starting date is in sight.

"We have experienced delays, particularly concerning logistical arrangements for ordering and storing the drugs. Most of these problems are now resolved. We expect the trial to start in the second half of the year."

A requirement of the trial is that a hospital pharmacy provides the medications to the participating community pharmacies. Hospital pharmacies are reluctant to take on the additional costs, clerical work, and legal responsibility but the Albion Street Clinic, categorised as a hospital for dispensing purposes, recently agreed to host the trial. Professor Julian Gold, Director of the Clinic, is an enthusiastic supporter of the trial and agrees that it is set to go mid-year.

"This trial has the potential to be popular. We are keen to be involved in innovative approaches to health care."

Other good news is that ASHM will prepare training packages in HIV drugs for community pharmacists. The training is a criterion for taking part in the trial and will ensure the quality of the service.

The six-month trial will – if successful – continue in the longer term. The benefits to patients versus the costs to the public health system will determine the success of the trial.

Community pharmacists, such as Chris Ireland from Sharpes Pharmacy, are confident that they will provide a good service to HIV patients.

"Local pharmacists will provide a better overview of the whole range of medications being taken by patients, including pharmacy over the counter drugs."

But even if the trial is successful in the metropolitan areas there remain serious doubts about the viability of a similar trial in rural areas of NSW. ●

Derek Walker is the PLWHA (NSW) Policy and Research Officer.

passion and action

ACON's new CEO believes communication is the key. **feona studdert** profiles a man who finds inspiration in listening.

At the top of Iain Gardner's wish list for his term as ACON CEO is to find a cure for HIV/AIDS. "Wouldn't it just be delightful if we could find a cure and we didn't have to worry about this for much longer."

Not much chance of that – not with estimates of an effective and safe vaccine still pegged at ten years or more. In the meantime it's down to the tricky business of managing the implementation of ACON's three-year strategic plan. It's tricky because the strategy, and its cohort the business plan, attempts a balancing act between direct services, prevention work and addressing the social health issues that underpin the continuing spread of the HIV virus. A shrinking HIV/AIDS dollar doesn't help either.

"Our communities are saying: 'we want you to deliver some improved and some new services and we also want you to continue to do health promotion and education – the more traditional community health – as well.' There are tensions between those, which is why most community health centres stand-alone. I think we can do both. We just have to listen to all the voices and make the hard planning decisions about where to put tight resources."

The states peak HIV/AIDS agency employs 130 staff in Sydney and five regional centres. It manages seven percent of the total HIV/AIDS spending in NSW. As it's key spokesperson Gardner will have to navigate the fault line of what happens at a service level and what is acceptable in terms of outcomes and budgets at the board level.

"I think I'm tough but fair. I can make tough decisions but I like to be thought of as fair. Passion and action inspire me. It amazes me that people can be passion-less about HIV. Great speakers inspire me as well. I like to be challenged to think about things in a different way."

Gardner's resume is extensive. He comes to Sydney from a senior executive position with Caulfield General Medical Centre, a



ACON CEO, Iain Gardner

public hospital in Melbourne where he managed community services and allied health. He has wide experience in the health industry across different sectors, and qualifications in sociology, social work, psychotherapy, management and education.

"I've got a deep and wide tool bag of experience, knowledge and qualifications that I can pick and choose from, as I need them. There aren't many industries that I haven't worked across either as an employee as a manager or a consultant."

There's little doubt he'll be calling on all his skills. 2000 was a watershed year for ACON. It completed two years of navel gazing including intensive community consultations that revealed a mixed bag of achievements. Probably the most significant of the revelations was that only about 25% of NSW PLWHA use ACON services. To Gardner what is especially significant about the low user rate is who isn't using the services and why.

"It's a personal challenge for me that we embrace multicultural races including Indigenous people, and we haven't embraced mental health as well as we could have. I think we don't service people in the rural community well. I grew up in a country town and know the difficulties of confidentiality. This year's business plan addresses those issues.

"Passion and action inspire me. It amazes me that people can be passion-less about HIV."

"On the other hand the majority of PLWHA are treated by their doctors and are now living with HIV rather than dying with HIV. To be relevant ACON must be integrated with all the players in their lives – their doctors, medications, pharmacists etc. The number of HIV/AIDS organisations and groups in Sydney is astounding and it's important we work in collaboration. Our Enhanced Care project will put ancillary support workers in GP clinics and make an almost mini-private community health service for PLWHA. That will also give us a different research base, which is important – there are gaps in the social research."

Mid-way through the financial year Gardner reports that the business plan is on track. He's excited about that but he also has his own interpretation of what ACON needs.

"My top priority after being in the job for three weeks is communication both internal and between ACON and our stakeholders, clients and community groups. Most conflict is the result of miss-communication so we need to get our communication strategy right.

"There's an increasing need for a new round of awareness education. A large number of our population still don't know the very basics about HIV/AIDS. You know how you don't see a brand of car on the road until you decide to buy one – suddenly you see hundreds of those cars. It's like that with HIV – people live almost in denial until confronted with it personally." ●

feona studdert is the Editor of Talkabout and Senior Project Officer, Publications at PLWHA (NSW)



pep me up

Sero-discordant couples are the targets of a new campaign about PEP. **Antony Nicholas** reports.

So you've seen this campaign around the venues and in the newspapers: 'I think I have been exposed to HIV. Now there is a treatment that may prevent infection,' and you're thinking to yourself, "Too late... honey." Well, don't be so sure. Post-exposure prophylaxis (PEP) will not help you if you are HIV positive, but it may be quite a bit of use to your sexual partner if they are HIV negative. Remember that under NSW legislation, the onus is on the HIV positive individual to inform all sexual partners of their HIV status, whether they are having safe sex or not. The personal stories in this issue (page 9&10) demonstrate the value of PEP for sero-discordant couples.

The Facts

There are around 670 people newly diagnosed as HIV positive annually. Around 300 of these are estimated to be new infections i.e. infected within the past year. Approximately 80 percent of these infections are among gay men and a large percentage of those occur between sero-discordant couples. Unfortunately there is low awareness amongst the PLWHA communities about the availability of PEP for incidents of HIV exposure that occur outside the workplace (e.g. between couples). This is partly because the criterion varies state-by-state. The PEP Awareness Group (PAG) launched an education campaign in late January that specifically targets sero-discordant couples about the availability of PEP.

PAG is a good example of what can be

achieved when a cross section of government and community organisations get together to achieve a common goal. The group includes representatives from non-government organisations, the National Centres in HIV Research, several Area Health Services, the NSW Health Department, and several community-based organisations including PLWHA (NSW).

Cost to the community

PLWHA (NSW) regards the low awareness about PEP in NSW as a social justice issue. Government may be concerned about the cost of people presenting inappropriately for PEP, but the cost of treating PLWHA for a lifetime will cost the health system far more than a four-week preventative course. A preventative course of triple therapy is approximately \$A800¹.

Many different concerns were expressed among PEP Awareness Group members, including the experimental nature of PEP, limited research into efficacy, and the belief that people would use PEP as a morning after pill and indulge in unsafe sexual practices. A recent study² in San Francisco has shed some light on the concerns around safe sex practices.

The research

The study showed that after receipt of PEP, most men who have sex with men did not practice unsafe sex more often. Instead, most participants exhibited a decrease in high-risk behaviour. An increase in risk-taking behaviour did occur in some men, although the study could not definitively attribute this to the availability of PEP. The campaign in NSW also tried to address this by focusing on the fact that PEP is a course of pills rather than one morning after pill.

Personally, I find the diversity of views and concerns expressed on behalf of HIV negative people who may need to use PEP

People forget that PEP treatments are identical to those that many PLWHA must take every day on a long-term or life-long basis.

interesting. It seems to me that people forget that PEP treatments are identical to those that many PLWHA must take every day on a long-term or life-long basis.

PEP is a four-week course of antiviral HIV drugs. There is no guarantee that PEP will work. PEP is not similar to the morning after pill used to prevent a pregnancy. As most PLWHA already know, a course of PEP means taking several drugs that often have unpleasant side effects. Around 67% of people enrolled in the PEP Study³ reported side effects; many also reported trouble with maintaining compliance. ●

Antony Nichols is the Executive Officer of PLWHA (NSW). The campaign is a joint project of ACON, PLWHA (NSW), NAAA, SEAHS, CSAHS, NSH, WSAHS, NSW Health, AFAC, ASHM, NCHFECH and the NCHSR. For references used in this article please contact the Editor.

It is best to go to sexual health clinics and doctors who specialise in HIV/AIDS for your PEP treatment. (Phone: 1800 737 669) It is also available 24 hours a day from all Hospital Accident and Emergency Departments within NSW. Information on where you can get PEP is found on the back of the PEP brochure or at the following websites.

- www.acon.org.au
- www.afao.org.au
- www.health.nsw.gov.au
- www.wdp.nsw.gov.au

For detailed information about PEP visit any of these sites:

The PEP Campaign at:

www.wdp.nsw.gov.au/pepinformationSheet.pdf

Self-directed learning package at:
<http://www.wdp.nsw.gov.au/peppowerpoint/pep.ppt>

Feedback on the Campaign. at:
<http://www.wdp.nsw.gov.au/pepevaluationform.htm>

pep me up

Sexual intimacy is a challenge for sero-discordant couples, like **Tom** and **Dave**.*

How do you navigate intimacy?

Tom: Sexual intimacy is a challenge. I associate intimacy with fucking without condoms. For me it's a sign of closeness to my partner, unlike casual encounters where you insist on a rubber. It has led to arguments at times depending on how sensitive I feel.

There are times when I'm OK about using a rubber, particularly when I feel guilty about unprotected anal intercourse or think we're pushing things too far. If Dave fucks me with a condom I sometimes feel as if I could be just anyone and that the rubber is some kind of barrier between us. Of course that's exactly what a rubber is meant to be.

Dave: I'm one of those freaks who don't have a problem with condoms. It feels better without one but people exaggerate the difference. My difficulty is that as a positive guy I feel responsible for transmission, and I feel especially responsible for transmission when I fuck with someone I care about. So for me a more intimate act is putting a rubber on.

Having said that, I can't make all the decisions for my partner and I don't want to be overbearing. Who am I to make decisions for someone (even my lover) if he wants to fuck without a condom? There's an issue about respecting his independence. Of course I like a raw fuck as much as the next person as well. It's a tough one.

What led you to use PEP?

Tom: Do you mean the first or the second time? The first time was on day one of our relationship. I can't explain why I let Dave put his cock in my arse without a condom even knowing that he was positive. It was a crazy time of my life and I was pissed and excited at the same time.

"I'm one of those freaks who don't have a problem with condoms. It feels better without one but people exaggerate the difference...for me a more intimate act is putting a rubber on."

The second time we were on crystal and fucked a fair bit without condoms. Dave had taken himself off his pills a month earlier and we realised that since his viral load was no longer undetectable the risk was greater.

Was your experience of PEP easy or hard to navigate?

Tom: I was used to seeing Dave take his own medication on time every day. I appreciated the need to time the dosage according to meals etc, even though I wasn't positive. The side effects the first time were pretty horrible. I remember looking at the container full of pills and thinking "shit, I'm going to have to consume all these pills". I remember weird feelings around AZT too, something to do with the early days and the effect on people.

Now it's my second time on PEP and I'm sitting here with a rash all over

my body and a bit of a headache from a bad reaction to Nevirapine (which was not part of my first PEP combination). I'm annoyed about that.

Would you consider using PEP again?

Dave: We stopped worrying about it when my viral load was undetectable. We fucked without condoms because we figured it was a risk we were prepared to take. Now that I'm off the pills it's difficult to get into the routine of using condoms again, hence the second PEP incident.

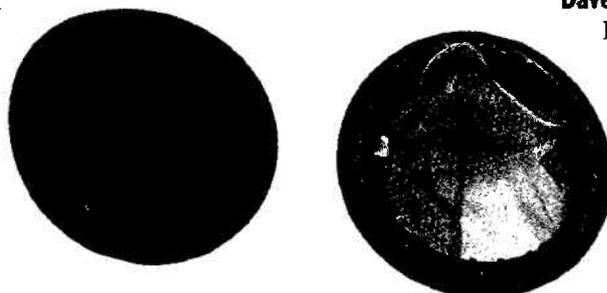
We still don't worry too much when I'm copping it, rightly or wrongly. I think as a positive guy, when you're a bottom the responsibility is clear (his). I've always felt uneasy about topping without a condom, whether I'm undetectable or not.

Has the PEP experience affected your relationship in any way?

Tom: There's always some sense of stress when I'm on PEP because it probably reinforces the risks we've taken in sex. There's always the waiting for test results as well. I guess we try to live our lives normally – we don't like HIV to dominate our lives – but PEP can still reinforce that 'difference' between us. Dave is very loving and supports me 100%. Sometimes I think *she wishes she* were a nurse.

Dave: I'm relieved that Tom has taken PEP. To me it means he's taking some sort of precaution, in contrast to the general state of anxiety I feel about his status. Just call me *Florence*. 🍷

*not their real names





pep me up

Rachel won't be rushing to take PEP again.

the doctor hurriedly issued a course of PEP, assured me that my breast-feeding baby would be unaffected and rushed off to his mates

I f you say "sero-discordant" to the uninitiated, you are greeted with a "Huh? What's that?" After you explain that your partner is living with HIV and you are not, then there is a flash of realisation as the full story sinks in.

I wonder if they think I am mad or stupid or both to continue in such a relationship, but like race and religion, love runs deeper than HIV status. Our love certainly does.

Yes, I have been exposed ... lots of times and yes, each time I have spent months with a knot in the pit of my stomach waiting for results.

Only once though, after an accidental exposure, did I feel the need to rush for treatment. The situation proved ironic.

At the time I was run down and strung out from breast-feeding my second child. After the exposure I panicked and raced to the clinic. It was a Friday evening and the doctor hurriedly issued a course of PEP, assured me that my breast-feeding baby would be unaffected and rushed off to his mates in the waiting room. No ceremony, no counselling, nothing. It was lucky for me that I knew about the HIV virus.

I started the course and was immediately struck with a bad case of diarrhoea and generally felt bloody awful. I also choked several times on the blue chalky tablets. It took a while to discover that milk helped them go down.

Despite the general discomfort, I completed the course dutifully, hating every minute. I certainly identified with people on full time treatments after that.

The irony that I mentioned earlier came a couple of months after finishing the treatment. I had missed my menstruation cycle but thought nothing

of it as I'd heard that treatments could affect your period. When I asked my regular doctor about it she handed me a jar and sent me to the loo. Five minutes later she announced I was indeed pregnant (again). It turned out that I was nearly 12 weeks pregnant, which meant another exposure towards the end of the PEP course! You could have knocked my husband and I over with a feather!

Baby number three came along happy and healthy and still I remain negative.

I have other friends who are also in sero-discordant relationships. One woman I know couldn't handle the constant uncertainty of whether she was still negative. Although this couple loved each other very much, they decided not to have sex any more so that she could regain a level confidence that she could live with.

I understood that. It is frightening to never be absolutely sure. But having sex is part of expressing our love. We practice safe sex, (though you may think us lax), we are now adamant that no matter how tempted, we must do it.

A while after doing the PEP course my husband told me that he felt rejected and almost "unclean" when I rushed off to seek treatment. All I could do was apologise and try to reassure him that this was not the case. He was and is very much loved and I hoped he could understand my need to protect myself.

Despite knowing now that I have had at least one more exposure since the PEP, I don't think I'll rush to have it again. Perhaps I have a natural resistance or perhaps it is just plain and simple luck. I certainly don't feel complacent about it, but some thing or some one is there protecting me and I can only hope it continues. ●

year of the volunteer

Ankali is just one of the many HIV/AIDS organisations that relies on volunteers. In 2001, the year of the Volunteer, we say thankyou.



Making a difference. Ankali volunteers left to right, Graham, Penny and Tony.

*we got on like a house
on fire. I went from a
state of shattered
expectation to an
unforgettable experience.*

Surprise me! by Graham Steer

When you begin as a volunteer with Ankali you expect to support an individual in need and to work with a diverse bunch of co-volunteers. I personally expected to support a gay man. To my surprise, my first client was a straight woman in her sixties who was in an advanced stage of illness.

Margaret was a gem: strong minded and courageous, witty and eccentric. A long time student of music and literature, her political views were, to me, quite radical. Yet we got on like a house on fire. I went from a state of shattered expectation to an unforgettable experience.

When we met, Margaret was isolated. She'd lost contact with friends and family as the years rolled by. She had learned of her HIV status a year or so earlier and lived alone in a dark and dingy rented flat in Stanmore.

In a short time though with the help of Kate, her much loved social worker, Margaret and her two cats moved into a bright Erskineville terrace with a garden. She loved the place and gradually became involved socially with many groups centred around people living with HIV/AIDS, such as Positive Heterosexuals, Myrtle Place, & The Luncheon Club. I used to say to her that she had a busier social life than me, which at times was true.

Margaret passed away after a long bout of illness on 14 February last year. I miss her terribly at times, (like when I'm writing this!).

I have a new client now who is closer to my original expectations: a male, around 30 and recently sero-converted. Over the past six months we have gradually got to know each other.

Margaret was a unique and special person whom nobody can replace. It was only because of my work with Ankali that I had the privilege of knowing her.

continued over page

year of the volunteer

continued . . .

Pick me up by Penny Darroch

In my time as an Ankali volunteer I've supported a number of people living with HIV/AIDS and there are moments in each relationship that will stay in my memory forever.

Let me tell you a little about my friend Jeremy – a name he has chosen for this occasion.

Jeremy has suffered some serious health problems during our two years together but he is the most determined person: optimistic and with a great sense of humour. We discuss just about anything you can think of and I've come to rely on his advice on more than one occasion.

Our friendship isn't just talk; we've had plenty of fun together.

One day in early October – not exactly high summer – Jeremy suggested a swim. We couldn't resist the challenge

leaping down the beach came this dazzling man covered from head to toe in colourful tattoos

and set out. He was unsteady on his feet at that stage and as we staggered towards the water disaster struck and my mate overbalanced in the soft wet

sand at the water's edge. Have you ever tried to lift a laughing, wet and slippery dead weight while you are struggling to keep your own balance? We must have looked funny but the situation was awkward and no amount of tugging seemed to shift the lump. Then leaping down the beach came this dazzling man covered from head to toe in colourful tattoos. He righted Jeremy and saw us safely into the water whereupon Jeremy, still chuckling, struck out towards the passing ferries! Our illustrated friend kept an eye on us until we emerged exhilarated from our swim. Afterwards Jeremy confided, "Now there's another good way to pick up a cute guy!" Glad to be of service, Jeremy.

We still have heaps to talk about and laugh over and more outings to enjoy. Together we go from strength to strength.

Friendship is a trip by Tony Arthur

Brian said he was hosting a 'murder party' for a small group of close friends and that he would like me to join them.

His invitation meant several things to me. I took it as a compliment that he ranked me among his friends. A 'murder party' also seemed at odds with his gentle and passive nature. I was concerned that meeting Brian and his friends in a party atmosphere might alter the dynamics of our relationship. Would we see each other in a different light and like what we see? Would I relate to his friends? We often

Brian said he was hosting a 'murder party' for a small group of close friends and that he would like me to join them.

talked about them – did they know anything about me?

Eventually I accepted the invitation with faith in our ability to distinguish between a social occasion and the nature and purpose of our Ankali relationship.

About a week later, Brian and I met as usual for coffee and a chat. He gave me an envelope with my instructions on how to participate in the murder. This included a profile of my character for the night, and his connection to the other characters/suspects. We would don our characters from the moment of arrival and dress according to their profile. What was I in for?

In the end, the concept was a brilliant answer to all my concerns. We forgot about our real selves and embraced our characters with gusto losing all idea of what it is normally like when we get together. The evening was a hoot and I won a prize for adopting my character so completely!

When we met next on the Ankali-client level I felt a new strength in our relationship. We had learnt to distinguish between work and play. Many Ankali relationships develop into a rewarding mix of both, like most quality friendships.

After all, Ankali does mean "friend"! ●

National PLWHA Conference Melbourne April 16-19.

For many PLWHA it is their primary care doctor who provides the central – often only, reference point for HIV information. This relationship is one of the most challenging, and potentially rewarding, aspects of the HIV lived experience. The upcoming National NAPWA Conference will feature a hypothetical forum – tentatively titled "Maximising your relationship with your GP – without a gun!" Hopefully, the forum will offer a funny and descriptive examination of the point of contact between PLWHA and their doctors. Hope you can join us.

Jo Watson,

Executive Officer, National Association of People living with HIV/AIDS.

it's my life

Darryl has learnt to take an active interest in his health

When I was asked if I planned to go to this month's NAPWA conference in Melbourne I must confess my first thought was NAPWA who? A strange feeling of guilt closely followed this thought, which I put down to the observation that there seems to be this feeling out there in HIV land that we should all have some sort of ownership about our own illness and I for one don't yet feel that way.

When I sero-converted, I made a decision that since I knew little about this virus I would leave it in the hands of the experts. They would handle the virus and I would handle my life. That worked for about all of oh, lets see, two minutes.

One of those doctors

First of all, the doctor to whom a dear friend referred me is – I now realise – one of those doctors who like to attack aggressively, throw everything at the virus and side effects be damned. I was concerned when I sighted the number of pills I was expected to swallow and my concern increased when the doctor made a negative mention of side effects, (you know, vomiting and diarrhoea are normal things in everyone's life along with sudden weight gain, aren't they?). Shortly after, when the Ritonovir changed from pills to a liquid form, I jumped ship. Still, I decided to learn from this episode and joined a gym to change my shape rather

than leave my shape up to the unexplained side effects.

Finding the right doctor

I also asked around my friends about doctors whom they trusted. My, oh my, what a can of worms! It seems that many of us change GPs quite a lot and it's not just because we know what we want from our doctor. Through anecdote, I've learnt that some doctors motivate the change themselves. That is, when our knowledge of the virus and treatments is equal to or

When I sero-converted, I made a decision that since I knew little about this virus I would leave it in the hands of the experts. They would handle the virus and I would handle my life. That worked for about all of oh, lets see, two minutes.

greater than the doctors they become edgy. Perhaps PLWHA will start a new trend in doctor-patient relations: that of partners rather than keeper of all knowledge and obedient dependent.

On a knowledge scale, I have more information than my friend and my partner knows more than I, but my doctor's knowledge is between all three of

us. The good thing for me is that my doctor listens and I understand from my partner that his doctor listens to him.

About six months ago, I encouraged my partner who was experiencing ghastly side effects to look at alternative medication. He presented his 'wish list' of medication to his doctor and as a team they changed his medication.

My life as a guinea pig

I now know more than when I started and I am taking back control of what medication I ingest. I need to know more about side effects and I am far more interested in finding out than my doc. It's not that my doctor isn't interested, it's just that it isn't their life that is altered so drastically by antiviral medication. I do not want to suggest that doctors are not dedicated, because most are, but ultimately I believe we must control our lives. The circumstances of this virus mean that we are guinea pigs for ourselves, those who follow, and for our friends and strangers. Of course, our current knowledge base is built on the lives and wisdom of those people, living or dead, who have experienced this virus and who shared with doctors, researchers, health professionals and each other.

I still don't know enough about this virus. I am coming to grips with the names of the pills rather than referring to the colour or shape to describe my medication (no quizzing me now). You can certainly believe that I know what the side effects are!

The best way for me to add and build on this huge knowledge base is to have an active relationship with knowledge and with my doctor. After all, my life depends upon it. ●



educate myself

In regional New South Wales finding a trained and sympathetic doctor is a lottery.

Patricia tells her story.

When our first GP told us he did not wish to treat the numerous skin cancers we had because it would use up too much of his nitro, we decided to change to another GP. There was other discrimination. He had charged my partner higher consultation rates because he was on treatments and I wasn't.

At our first appointment with the new GP we set it all out: "This is us and this is what we need." We tell him that sometimes we just need to talk; discuss side effects and treatment interactions because, since we are both over 60 it's difficult to tell what is an interaction or side effect and what is just old age.

A little goes a long way

"He'll be there for us," he tells us. "It will be a learning process for him, and the close monitoring will be useful, particularly when you start treatments," he says.

He's there for us alright – but only if we wait three days for an appointment or run the gauntlet of questions from the receptionist who decides if we need an urgent appointment or not. They think they're gods this lot – and they don't even know what our problem is.

We live 300km from Melbourne and 600km from Sydney and as you can imagine, it's unnerving and frustrating in a crisis – where do you turn?

Incident 1

It's January. The plan is to go camping, on holiday, have a good rest. We started a

new treatment regime in October to avoid previous side effects. The literature warned us about these new drugs, 'Watch for a measles-like rash and flu-like symptoms – these side effects are known to cause death.'

In early January the symptoms duly

At our first appointment I gave the new GP back copies of *Talkabout*, *Positive Living* etc. Six months later I asked him and his nurse what they thought – they hadn't read them.

appear. We're one hour's drive away from home camping, having a good rest.

We ask our GP, "Is this a measles-like rash? Are these flu-like symptoms?"

GP doesn't know – we ask again on Sunday because the rash is worse.

Community Nurse, a Sydney-based immunologist who visits fortnightly, phone support in Sydney and Melbourne. It sounds like plenty of resources – but none are available in January.

Fortunately we have an appointment with the dermatologist department at Alfred Hospital in Melbourne for a skin cancer check up, so I call and they book Dr Anne Mijch. She is helpful and thorough – does a skin biopsy and tests for the rash. The outcome is eczema from

the dust of camping under trees. Easy and what a relief. While we're there we have 16 skin cancers burnt off. Dr Mijch hugs us both as we leave. For a minute we don't feel like lepers.

Incident 2

Yesterday. We go to our GP for flu injections. The doctor urges us both to have a pneumonia inoculation. As he's talking, I'm thinking "But I've already had the flu." I hear distant warning bells. I call the STI Nurse who phones the Sydney immunologist who tells us bluntly that inoculations are no use to my partner who has only 60 T-cells. I'm just about to start medication and he mentions emerging evidence that suggests the pneumonia inoculation may increase viral load. We tear up the scripts.

Educating the professionals

We rely on the various publications about treatments and living with HIV/AIDS. Living in the country means confidentiality is essential, ignorance and fear is high.

At our first appointment, I gave the new GP all the back copies of *Talkabout*, *Positive Living* etc. Six months later I asked him and his nurse what they thought – they hadn't read them. We understand that a country GP may have only one or two HIV positive patients. Finding time to stay informed with such a complex and fast changing area is difficult. I don't know what the answer is but there must be one because too much is at stake.

It's a case of educate myself so I can educate the professionals who make the decisions about my health. Scary isn't it? ●

wanting more

Evert has turned the push to get PLWHA back to work to his own advantage.

How do you cope after such a long time in the employment wilderness? It's a difficult question to answer.

When I went on the pension in 1989, I didn't expect to think about employment again, let alone fulfil it. Like most people infected in the 80's my options were limited. I was fortunate, or perhaps unfortunate, to volunteer as a telephone counsellor on the AIDS Hotline in 1988. In those early years, even the so-called experts knew little about hiv and aids. I was still coming to terms with my own grief around diagnosis but here I was, thrown into the deep end as a volunteer with no professional training, giving out information to other hiv positive people.

It was also a time when many of my closest friends, an employer and even a doctor of mine, who were all convinced that we could beat this disease, passed away.

Time and place

I didn't expect to be around long so went on the pension to support myself. I had no superannuation after years of cash-in-hand under-the-counter work. Of course, this was pre-G.S.T. and it was still possible to supplement your benefit with undeclared work and income.

In 1999 there was a lot of talk about the ethics of PLWHA going back to work. At the time a peer support officer at ACON told me that, in his view, people shouldn't be forced into working. I've long opposed such government inspired schemes as Work For The Dole or the more recent

proposal, that we should work for the pension.

Motivation

My decision to return to work was not out of a sense of obligation to the government, although I did say to Centrelink that in a way I was doing the government a favour. I went back to work for financial reasons and lifestyle; I wanted a better quality of life. I'm sure anybody who's tried to survive below the poverty line on a pension can sympathise. Let's face it, I

My decision to return to work was not out of a sense of obligation to the government, although I did say to Centrelink that in a way I was doing the government a favour.

remember when schooners were \$1.20 each and the bar scene was important to me as a means of socialising. Also, I couldn't go out very much for coffee or afford very much in the way of clothes and I am proud and hate to ask for charity.

Back into gear

Going back to work was a heck of a

culture shock. I can't pretend it was an easy transition. After thirteen years I was rusty and, since the advent of computers and the Internet, my clerical skills were outdated.

The solution was an Information Technology Course For Mature Men (over 25 years old) at Randwick College of TAFE. Staff were friendly, the course was fun and my teacher was dynamic. The course cost nothing and my employment agency reimbursed my travel costs. They also helped rewrite my Resume (not showing dates worked) and helped with interviews.

I was fortunate to get the first job I applied for. I love working as the CSN Transport Officer. The part-time hours suit me and I earn enough from 42 hours a fortnight to go off the pension. I also enjoy a much better lifestyle.

Disadvantages

There are financial disadvantages to going back to work. My rent with Department of Housing has gone up and, after a year, I will lose my Concession Card and have to pay full fare and more for medication.

The greatest benefit is that my self-esteem has soared to incomparable heights. I still have as many, if not more friends and, scary as it may seem, I am coping well with my workload.

Though working is not everyone's cup of tea, I found that in my case it was just what the doctor might have ordered. ①

i love stalking

John Douglas on a novel entertainment sweeping the countryside.

Homosexuality may be an innate trait but Gay Culture is for sale

I love stalking. I always have and I always will. It used to be that only celebrities and Linda Ronstadt had stalkers. Now everybody has one! In the 21st Century it is as essential for the discerning HIV Positive Groover to have your own Stalker, as owning a City Gym membership was in the nineties. I don't know if I have any steadfast Stalkers, CMV has been cruel. So I stalk myself.

Everyone needs a hobby, and self-stalking is a fascinating lifestyle choice for those of us who 'live' on a pensions. If you happen to be homosexual, hoorah! As a Self-Stalker you'll satisfy your compulsive narcissistic tendencies. And you thought having HIV was as good as it got! (Is Inverted Oedipus Complex an OI?)

I live in the country and consequently my own stalking generally involves a cracked hand-mirror and a day at a deserted beach walking backward to hide my tracks. "How Long Till I Find My Way Home From Here?" is an interesting variant to delight the Demented Self-Stalker. Like budgeting on the Disability Pension, the only limit to self-stalking is your imagination.

Of course there are no budgeting problems when you self-stalk because it's free. Something we may well consider post Mardi Gras Inc., as we ponder our bare bank accounts and aching heads.

Maybe it's my biased country hick viewpoint, but it seems that these days the gay/queer lifestyle of urbanites exists in a totally commercial ecosystem. Homosexuality may be an innate trait but Gay Culture is for sale.

Many of us probably had our first non-sexual exposure to gay culture through a gay bar. Of course bars exist to sell drinks. Our first public identification as a proud homosexual was likely a t-shirt with a cute slogan such as 'So many Men, So Little Cock'. If we were a Proud Positive Person the

caption might say 'My Friend Went to Ward 17 & All I Got Was This Lousy T Shirt'.* Worst of all, maybe you bought those Freedom Rings – little rainbow-coloured symbols of Gay Culture's bondage to commercialism.

Gay CDs, Queer theory books, rainbow flags, Mardi Gras party tickets, Mardi Gras merchandise ad nauseam, furniture from Ikea because all the gay gang go there.

Getting your first tribal tattoo or your first Viral Load wristband tattoo, paying higher rent to live in a gay neighbourhood, paying for over-priced groceries to live around that neighbourhood, or paying for entry to a nightclub because you haven't made friends with the manager. Costs incurred by stalking Courtney Love and Kylie etc.

How much stuff related to gay identity doesn't involve cash transactions? Attending a few protest marches, cruising at a beat perhaps. Shoplifting nail polish. Catching HIV.

Now that raises a digression – thanks to the Pharmaceutical Benefits Scheme, finding the cash to pay for medications is only a minor fortnightly drama. The real nightmare is the cost and inconvenience of travelling to an HIV prescriber or pharmacy. It's an hour's round trip for me, a breeze compared to some of my friends. Those who are ill or without transport rely on the kindness of our Area Health Service community nurse who runs a drug shuttle service. Ah yes, the bliss of rustic living.

Being a (distant) part of gay culture can be fun. The best parts cost nothing.

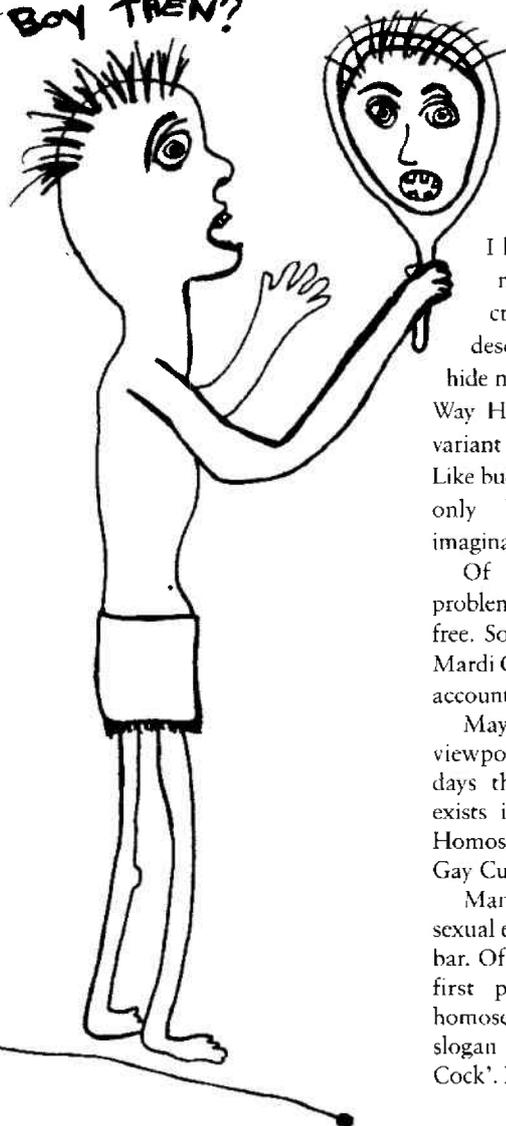
Self-Stalking is not only easy on the pocket, it has liberated me from the quagmire of endlessly searching for Me. Tonight I am going to take pictures of myself whilst in bed so I can see what I look like when I'm asleep.

Now it's your turn.

Try doing something Gay Without Pay every day. ①

*Copies of the T-shirt are available from the author. Send rural anecdotes to dragon@coolgold.com.au

WHO'S A PRETTY BOY THEN?



Mother Helen's Miscellany

Epistle-Ette #7 by **Mother Helen Highwater** OPI (ret*)

Blessings and a perpetual indulgent new Millennium to you all gentle readers.

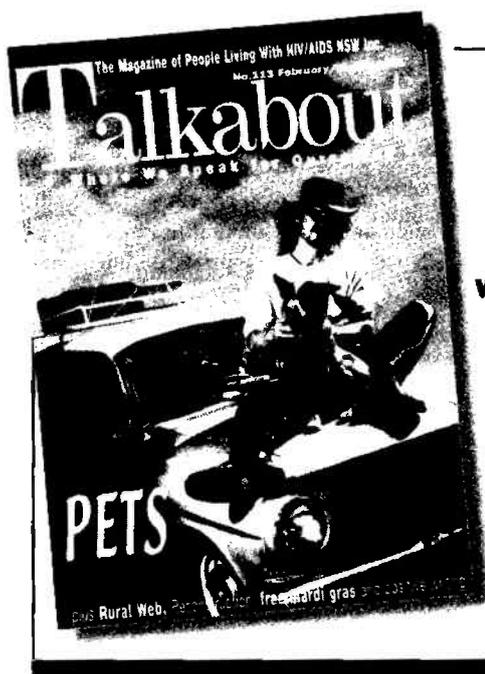
The much-awaited CSN Client Forum was held in the Grand Ballroom of the glittering ACON Palace on Wednesday, February 14th – Valentine's Day. After much grovelling, back-slapping and obligatory thank-yous the serious issues of what this service should provide was discussed at length – about 35 minutes, in total.

Approximately fifteen clients attended and issues such as transport and carer/client relations were aired. Allocating a carer to a particular client need was seen as most important. Due to the small number of volunteers available this is not always possible and, as this humble nun pointed out, it surely is the responsibility of CSN, or its master, ACON, to take advantage of advertising the very existence of this worthwhile and essential service to the broader community. Correct me if I'm wrong but I honestly don't remember ever hearing anything about CSN on the electric

wireless. Oh well! Too late now. Perhaps the next Client Forum on Wednesday, August 15th will see action taken on behalf of client needs and concerns.

On a more positive note (no pun intended), after my annus horribilis, (losing both parents, the defection of a much-loved acolyte and being forced to move convents), we still have much to be grateful for. It beggars belief that CSN functions as superbly as it does. Where on earth would we be without BGF? The Sanctuary, still providing free complementary therapy and the PLC doing whatever it is it's trying to do? Without these dedicated people this frazzled old nun wouldn't be quite as sane as I obviously am!

I hope everyone had a faaaabulous February Festival and have recovered sufficiently to prepare for the 20th anniversary of the Order of Perpetual Indulgence (Sydney House) in November. 'Till next time, gentle readers; remember that I love you all. 🙏
(* retired/retarded).



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the impossible ask – revisited

Alan replies to Tim Alderman's article *The Impossible Ask* published in our December 2000 issue.

Now people are complaining that we do not know the long-term side effects of the drugs we were asking to be fast tracked. Sorry, we can't have it both ways!

What a tragic, depressing and blaming article. It is rare that I read *Talkabout* as I live my life as a person who happens to be HIV positive – not an HIV positive person. My emphasis is on person first, HIV-positive second.*

I am tired of hearing PLWHA go on about the word "compliant". What is the issue here? It is a word. The interpretation of compliance as: "READ: you are a naughty boy and should be caned", is in our own heads – nowhere else! I don't see the word 'compliant' as judgement, but purely a word to ask/describe whether medications are taken correctly for maximum effectiveness and minimum drug resistance. I think the buzzword is adherent/adherence – what – do I stick to things? – it makes me feel like a postage stamp.

Everyone acknowledges that the drugs we take, day in day out, have disgusting side effects, ruin the spontaneity of life and are revealing previously unknown but very nasty long-term side effects on our bodies. How can there be long-term knowledge about something that has only been in use for a few years. HIV positive people are not the only people who have to live with this approach to medications and their illness. It happens in other disease processes as well. As knowledge improves so does treatment. It is that simple.

In fact in one sense we are lucky, as HIV drugs are often fast tracked for use in Australia without years of trials like so many other drugs. Not so many years ago there was an outcry from the positive community demanding that HIV medications be released for use in Australia as soon as possible. "Don't let our men and women die!" Now people are complaining that we do not know the long-term side effects of the drugs we were asking to be fast tracked. Sorry, we can't have it both ways!

Tim comments that we've had, "Years of promises ... for the absolute minimum of health". Who has ever promised anyone anything in the field of HIV medicine?

Another comment relates to the progression of our T-cell count. "How's your

viral load and T-cell count? The big nowhere, undoubtedly!"

Well, for me, the "big nowhere" is a lot better than my T-cell count going down. Stable / the same / no improvement is not great emotionally to hear, but still better than, "sorry your T-cells have dropped again".

Another comment: "You can never return to full time work". Please, is there anyone out there with 170 T-cells that is doing full time work? I know there is.

The one term that Tim didn't use, which surprised me, was 'guinea pig'. Was that term forgotten? I'll add it to the list. I acknowledge that I am a guinea pig and consent to the use of new drugs whose long term side effects are unknown. The best of what my doctor knows at the time is offered to me in the good faith. I'm confident my doctor has my concerns at heart and admits when he doesn't know the answers to my questions.

Everyone's experience with HIV is different, and I too am fed up with being positive so of course I understand some of the fear and frustration. But I feel Tim's frustration is misdirected. We do the best with what we have. Live your life. Be a person first and HIV positive second. Take a structured treatment break Tim. Sounds like it would do you the world of good. ●

*** I had my first AIDS diagnosis six years ago, only 2 1/2 years after sero-conversion. I have been on treatments since then. I proceeded to have a number of opportunistic infections and other aids defining illnesses and my T-cells slowly but very surely declined (to 40) despite antiviral treatment. After many combinations of treatment we finally found a combination that increased my T-cell count significantly and dropped my viral load. I consider myself exceedingly lucky and grateful of the improvement in my health, the quality of my life and my ability to be in the workforce.**

This is an edited extract of Alan's original response to Tim Alderman.

informed consent and vaccine trials

Douglas Barry reports on pitfalls and guidelines to experimental trials.

An effective therapeutic vaccine is obviously of immense benefit to positive people. But it is vital that we know as much as we can about participating in these trials. Understanding the concept of informed consent is vital to those HIV positive people who may join these research efforts.

The process of obtaining the informed consent of participants in research trials is essentially a protective one. After their murderous 'medical' experiments, Nazi doctors were brought to trial in the town of Nuremberg. In their judgement the judges set down ten principles for the conduct of future experiments involving humans. The ten principles are necessary to satisfy moral, ethical and legal concepts.

Principle One of *The Nuremberg Code*, as the judgement became known, stated: "The voluntary consent of the human subject is absolutely essential."

The subject should have: "Sufficient knowledge and comprehension of the subject matter involved as to enable him to make an understanding and enlightened decision."

The Nuremberg Declaration was modified over time to accommodate the needs of modern medical research. But the basic protection, which the concept of informed consent was designed to provide, remains the foundation of all ethical guidelines regulating the conduct of medical research involving people.

Much is written and said about 'informed consent'. It springs from thinking about research participants as rational, independent human beings, capable of making their own decisions about our their lives and health. For these reasons, research participants deserve the respect of medical researchers. Mental

Much is written and said about 'informed consent.' It springs from thinking about research participants as rational, independent human beings, capable of making their own decisions about our their lives and health.

illness or intellectual disability or circumstances such as imprisonment, can diminish our capacity to make those rational decisions. People with diminished capacity are still entitled to respect and to careful measures to protect them.

In practice what does informed consent mean? First, research participants must have information, at their level of comprehension, about the purpose, methods, demands, risks, inconveniences, discomforts and possible outcomes of the research. So if you are asked to join a trial of a therapeutic vaccine, you are both receiving treatment from your doctor and also taking part in a medical experiment designed to obtain knowledge about the vaccine. Therefore you should have sufficient material about that research to enable you to make your own decision about joining the trial and receiving that treatment – a decision you should feel comfortable with.

Secondly, you must give your consent voluntarily – your decision is an act of free choice. On no account, should you consent out of fear or as a result of coercion or any improper inducements – for example, the offer of large sums of money to welfare

recipients is improper. If you are running out of effective combinations and you think the vaccine is a measure of last resort, you may find it difficult to make a decision. In those circumstances, seek further advice.

The process of seeking and giving informed consent has an added role. In the Nuremberg Declaration, the words 'research subject' were used. These days, we speak of 'research participants'. People involved in research should think of themselves as partners in a project that may have benefits for themselves and can increase the store of knowledge we must have to combat the blight of HIV/AIDS. The provision of information and the act of free choice can heighten that sense of a worthwhile collaboration, develop trust and foster cooperation.

As well as the requirement for informed consent, there are other standards of conduct and procedures designed to protect the welfare and the rights of people involved in research trials. These are available in published ethical guidelines, binding on all those conducting medical research. For Australian research, the National Statement on Ethical Conduct in Research Involving Humans can be found at www.health.gov.au/nhmrc

PLWH/A (NSW) Inc., in consultation with NAPWA, is presently developing its policies on the conduct of therapeutic vaccine trials in New South Wales. Our goal is to ensure that the interests of positive people in NSW are safeguarded and advanced and to empower the HIV/AIDS community with information and advice. ●

Douglas Barry is a member of the PLWH/A (NSW) Management Committee and convenor of the Association Legal Working Group.

the australian vaccine trial

Dr Neil Bodsworth reports on the forthcoming trial

Australian HIV doctors enthusiastically welcomed the announcement in October last year that the first clinical trials of an Australian developed HIV vaccine had received the go ahead from both the St Vincent's Hospital Ethics Committee and the Federal Government.

A Melbourne-based biotechnology company, Virax, developed the Australian vaccine, which is one of about a dozen HIV vaccines currently, or soon to be studied, around the world. Two factors have prompted this flurry of vaccine activity. First, results from animal studies have shown that similar vaccines can prevent illness in monkeys, and secondly, the toxicity that most patients taking HAART long-term experience.

This immunity based style of treatment is particularly exciting for me as it holds out the holy grail of keeping PLWHA healthy with just one or two needles a year. No one likes to, and few people can, take these tablets regularly for years on end without a break. HIV drugs have always had lengthy lists of side effects. As distressing as these side effects are, the newly recognised problems of increased risk of heart disease and bone thinning associated with long term HAART threaten perhaps a majority of PLWHA with these serious conditions.

The Australian vaccine has an interesting design. It is basically a chicken flu virus (avipox) plus one human gene and one HIV gene added by genetic technology developed at the ANU. The HIV-gene codes for proteins on the surface of HIV and so provokes an HIV-specific immune response. The human gene codes for interferon gama, a coordinating molecule of the immune system (or cytokine), greatly enhances the specific anti-HIV response by stimulating T-cells. People philosophically opposed to genetically modified (GM) foods may want to think twice before being vaccinated with this 'Frankenstein virus'.

The first trial of 36 patients is limited to the small group of PLWHA who began treatments within six months of getting HIV and have remained undetectable for at least six months since. This is because patients treated early in HIV infection have the best chance to retain the natural anti-HIV immune response that the vaccine is designed to boost. If the vaccine can boost anti-HIV immunity in this population then it will be studied in PLWHA with longer term HIV infection (with hopefully less need for HAART) and later as a preventative vaccine for HIV negatives.

Injections are at zero, one and three months. The study is randomised on a 1:1:1 ratio with 12 patients receiving vaccine with interferon, 12 get vaccine without interferon, and 12 a placebo injection. Specific anti-HIV immune responses are measured by blood tests over 12 months. Unfortunately there is currently no guarantee of later vaccine for patients initially assigned placebo. (See frequently asked questions below)

It is hoped the study will begin in the middle of the year at several general practices and hospital sites within Sydney. ①

Dr Neil Bodsworth MD, MM, MB, BS, FACSHIP is at the Taylor Square Private Clinic.

preventative and therapeutic vaccines

There are two types of vaccine: *preventative and therapeutic.*

Preventative vaccines are for people not infected with a disease and therapeutic vaccines are for people who are.

The type we are most familiar with is the preventative (or "prophylactic") vaccine such as the needles we got as kids to prevent childhood illnesses like whooping cough.

The other situation is when we give a vaccine to someone infected with the disease to boost the body's immunity against that particular germ.

In the case of the HIV vaccine this will first be trialled as a therapeutic vaccine in HIV positive people.

Another immune-based therapy is interleukin-2 (ESPRIT and SILCAAT trials) that increases T-cell counts.

frequently asked questions

The Virax VIR201 trial is a phase I/IIa clinical trial testing for safety in humans, and to evaluate the gene co-expression technology. This has only been tested in-vitro and in animal models to date. It is urgent research asking is it safe and does it suggest any significant immune response in humans?

The issue of access to this vaccine for those on placebo, or outside of these strictly monitored and small studies, would be one that treatment advocates

from NAPWA and other organisations would not see as warranted or responsible until further research analysis and data was available for critical review.

In Australia advocates generally negotiate the programs of special access to HIV treatments only after drugs and agents reach a Phase III clinical study level.

Information supplied by NAPWA, the National Association of People Living with HIV/AIDS.

trials and tribulations

by John Cumming

T-20 is the first of a new class of experimental drugs to be trailed in Australia. T-20 is a fusion inhibitor, so-called because they stop HIV from binding to and entering the human cell. T-20 binds to protein on the surface of HIV called gp4. Gp4 is the 'key' used by HIV to bind onto and enter CD4 cells. By blocking gp41, T-20 blocks the infection of cells by HIV.

T-20 has shown strong antiviral effects when studied alone. Previous researchers studied the effect of the drug in sixteen trial participants. Four out of four patients receiving the highest dose (two 100 mg doses per day) had their viral load drop to below 500 copies within 10 to 14 days.

The Australian trial is aimed specifically at people with drug resistance. Because T-20 targets a different part of HIV's reproductive cycle than those targeted by currently available drugs, it should also work against resistant strains of HIV.

To be eligible people must have more than three month's experience of non-nucleosides, nucleosides and protease inhibitors – (or resistance to all three classes) and a viral load above 5,000 copies. People on the trial will receive resistance testing in order to determine what is the best background regimen (ie, the combination of HIV medications that is most active against HIV), and they will then be randomised into 2 groups. (Two thirds of trial participants will receive T-20 in combination with other antiviral drugs and the other third will receive just the antiviral drugs without T-20).

The background regimen must consist of three to five drugs. After forty-eight weeks those on the background regimen alone will be offered T-20. In NSW, the trial sites are at St Vincents Hospital,

Taylor Square Clinic and Holdsworth House General Practice. Recruitment is expected to start at the end of March.

Side effects

T-20 has to be injected twice a day. If it is taken orally, stomach acids break down its protein structure. The only significant side effect reported so far is the development of reactions around the injection site. These have been reported in two-thirds of those who have taken the drug so far, and have followed a number

of patterns including itchy rash, red swollen or puffy skin, hardened skin, cysts or nodules forming at the injection site (this may be more common if injection occurs in the legs). ●

John Cumming is a Treatment Officer at ACON Treatment Unit. For more information contact participating clinics or ACON Treatment Unit on Freecall 1800 816 518 or 02 9206 2013 / 2036. Email treatments@acon.org.au

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the bare bones

In the first of a regular column about nutrition, **Simon Sadler** reports on osteoporosis.

Over the past ten to fifteen years we've heard a variety of health messages about the importance of bone health to prevent osteoporosis. These messages are primarily targeted at women and until recently have only included younger to middle aged men. What relevance is this to PLWHA, I hear you ask? Current research suggests that we will hear a great deal about this issue in coming years.

Osteoporosis summarised

Osteoporosis is a debilitating weakening of the bones that can increase the risk of bone fractures and breaks and thus affect mobility.

Recent research may suggest that some PLWHA experience an accelerated progression to osteopenia and osteoporosis. Dietary and lifestyle factors are important in bone health at all life stages. Daily intake of calcium is one of the single most important factors in bone health.

New research

The past twelve months has witnessed a gradual increase in the volume of research into the area of Bone Mineral Density (BMD) and people living with HIV. The initial observations by some researchers were that the incidence of osteoporosis was much higher than in the general population. Although the understanding of what causes this problem remains clouded there are a number of factors which might contribute to the problem, including: age, HIV status, other diseases such as cancer and diabetes, certain medications, diet, activity and other lifestyle factors such as smoking, drug and alcohol abuse.

In general terms, osteopenia and osteoporosis are terms used to describe a condition where the strength or density of peoples bones becomes weakened. This occurs through a gradual loss of bone

mineral tissue or bone demineralisation. The process can take many years to develop and usually starts when people are in their mid 20s. Symptoms of the disease in most cases are not evident until the person reaches their mid to late 50s. Anecdotal reports suggest that this may occur earlier for some PLWHA. Declining bone density increases an individual's risk of experiencing bone fractures and breaks, particularly in the weight bearing parts of the body such as the legs and lower back.

Although the gradual loss of bone tissue begins early, it is never too late to take steps to help slow or prevent symptoms from occurring. Some active steps include:

- incorporating calcium rich foods into your diet and
- participating in regular weight bearing exercise

See our table for the calcium requirements for adult men and women.

Weight bearing exercise

Including regular weight bearing exercise in your day to help promote stronger bones. Ideal exercise for bone health is 45-60 minutes, three to four times a week, including walking, light jogging, dancing, tennis and squash. It's important to first discuss your program with your doctor.

This is a simple and delicious recipe from the *Weight Gain Cookbook* that can help add calcium to your diet.

- 1 cup milk
- 2 tbsp skim milk powder
- 1 scoop ice cream
- 1 - 2 tbsp flavouring
- Nutrients Per Serve
- Energy 1125kJ (270cal)
- Protein 15.4g
- Calcium 530mg

Method: Combine all ingredients in a blender. You can substitute soy milk for dairy milk, but it's important to get soy milk that is fortified with calcium. Soy milk is not a good source of calcium. To reduce the fat in this recipe use low fat milk; this would actually increase the calcium. ●

recommended daily calcium

Men 19 years and over	800mg
Women 19 - 54 yrs*	800mg
Women older than 54yrs*	1000mg
Pregnant women	+ 600mg

The best sources of calcium include:

Low fat milk:	350mg/250ml
Full cream milk:	300mg/250ml
Soy milk with added Calcium:	300mg/250ml
Yoghurt:	340mg/250ml
Fish with edible bones (eg. salmon/tuna):	300mg/100g
Cheese:	182mg / 30g slice
Almonds:	70mg / 30g
Broccoli:	70mg / 1/2 cup

meat, eggs, fruit, bread and cereals all have around 30mg per serve.

Around three serves of foods from the best calcium sources will provide the recommended intake for calcium. If our calcium requirement is not met our bodies will release calcium from our bones further contributing to bone loss.

*After menopause women should have more calcium in their diet. See your doctor or dietician for details.

Simon Sadler is a nutritionist at the Albion Street Clinic. Email Sadlersi@sesahs.nsw.gov.au

For further information about the issue of bone health and HIV or any of the other issues raised in this article please contact your doctor, health care provider or an accredited practicing dietitian.

human GROWTH HORMONE for HIV weight loss



Taylor Square Clinic is studying injectable human growth hormone as treatment for weight loss (>10%) in HIV infection. Earlier studies have shown significantly increased muscle mass with this therapy.

Injections are daily with either active growth hormone or placebo (2:1 ratio) for 12 weeks then all participants receive active therapy.

For further information contact David Wheatley,
Joanna Clemons (Study Coordinators)
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In the June/July issue *Talkabout* features the 7th National NAPWA Conference, more creative writing, treatment updates, clinical trial information and much more. Deadline for contributions is May 1.

For more information please call the Editor, feona studdert on (02) 9361 6750, or email your story to feonas@plwha.org.au.

Deadline for the June/July
issue is **May 1, 2001**

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



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The HIV/AIDS Legal Centre is a community legal centre. We provide free legal advice and referral to people living with and affected by HIV/AIDS in NSW. A staff solicitor is available Monday to Friday from 10.00am to 6.00pm. Alternatively HALC holds an information night on alternate Monday evenings where volunteer solicitors give free advice sessions. We deal with topics such as superannuation, discrimination, social security, wills, power of attorney and more.

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olga's personals

Guy Ryde area, 54, HIV+, 6ft, 80 kg, healthy, likes movies, live shows, dinner, watching tv at home. Seeks female similar with GSOH for friendship or relationship. I have no ties, once married with two adult children. **Reply 030401**

43y.o. Gay guy HIV+ 14 yrs. Independent, self-reliant. Looking for a guy for fun and occasional sex. Friendship possible relationship. **Reply 020401**

38y.o. HIV+ guy, living in Glebe, seeking solid relationship. Enjoy reading, cafes and pubs. I'm English with a good sense of humour. Soulmate please respond. **Reply 050201**

Male 38y.o. HIV+ gay. Australian born, fair skin with brown hair & eyes. Well proportioned body 6'1", 88 kgs. Cultural interests, politically motivated and live in Sydney. Love good food and sex. Seeks same for long term (Please include phone number). **Reply 040201**

40y.o. gay, long-term survivor, seeks guy/s for friendship/relationship. Enjoy beach, ten pin bowling, country drives, and quiet lifestyle. DTE/GSOH. Hear from you soon, I hope. Pen/WWW friends welcomed. **Reply 030201**

HIV+ hetero guy seeks girl to be crew and companion on 35' yacht presently cruising Barrier Reef, Whitsunday Islands and Queensland coast. Sailing experience not necessary just an interest in having a good time, even if it's just a holiday. **Reply 020201**

25y.o. HIV+ gay guy. 6'3" not bad looking. Looking to correspond with other uninhibited guys and meet later. I'm extremely open-minded. Want friendship, possible relationship. **Reply 010201**

Sincere. romantic HIV+ gent, 41 good build/health, likes fitness, movies, eating out, try dancing & almost anything. GSOH. No ties. Seeks sincere female age/nationality open, to share good experiences with view to permanent friendship/relationship. **Reply 011200**

Good looking 37 HIV+ het male living in Sydney, I'm a sharing and caring person, wants to meet a HIV+ female for friendship/relationship. My first advert. **Reply 011100**

Hot 30y.o. Gay HIV+, smooth, slim, well-defined gym fit body. Seeks attractive HIV+ guy to 35 to share life/bed. Must be honest, fit, healthy, looking for 1-1 relationship. I live in Potts Point. **Reply 021100**

HIV+ woman 42 looks younger. Intelligent, easy going, warm hearted, attractive, and petite. I have a nice style about me. Love walking, movies, swimming, music and writing. Healthy lifestyle, passionate about life, also realistically optimistic, confidentiality important North Coast NSW. Would love to connect with a man who could appreciate these qualities. **Reply 031100**

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.

diary

social and events

Art Gallery of NSW is in full swing for the 2001 Archibald Prize from the March 17 - May 13, view the entries, guess the winner. ☎ 9225 1744 or www.artgallery.nsw.gov.au

Parramatta Heritage Centre presents *Women with Wings*, a past and present perspective of Australian Women Pilots. FREE. 346A Church Street Parramatta Mon - Sun ☎ 9863 6922

A stroll around **Circular Quay** should always include a visit to Customs House with Emerging Artists from Manchester showcasing the best new craft and design March 10 - April 29, ☎ 9247 2285 for details or www.sydneycustomshouse.com.au

Outings from the **South Sydney Community Transport** team for April/May include The Easter Show and lunch in the Blue Mountains. For more information & to book ☎ Jane or Robbie on 9319 4439.

Check out **Southern Cross Outdoor Group's** new website, for details of their up coming social get togethers, including walks, dances and trips away. Website www.scog.asn.au or ☎ John on 9907 9144.

support

Cheltenham Place offers respite care for people living with HIV/AIDS, their partners and carers. (\$20 donation) For more information about Cheltenham Place, ☎ 08 8272 8799 or david.fitzsimons@aidssadelaideadac.org.au

South Sydney Carers Support Group, A support group for carers of PLWHA. Meets 3rd Tuesday of each month at Sutherland Hospital. Guest speakers and information. Contact Terry or Emma ☎ 02 9350 2955

Friends of Waratah. A support group for PLWHA who live in Southern Sydney. 1st Monday each month, at Kogarah. Emotional support, information and social activities. Emma or Terry ☎ 02 9350 2955

Pozhetwest, Western Sydney peer support and education for men and women living heterosexually with HIV/AIDS. ☎ 02 9671 4100.

Grief Support and Youth Suicide Project for Youth The Project provides individual counselling, support for schools after a suicide, community education and a schools program promoting mental health. This is a free service available for young people aged 15-25 living in the Eastern Suburbs. ☎ 02 9360 3232

Support Group for Significant Others of People with HIV/AIDS related Dementia. The group offers respite care, company and support. Meets last Wednesday of every month at the Tree of Hope cnr Riley and Devonshire Sts, Surry Hills. ☎ Angela Kelly 02 9829 4242 and Carol Knox 02 9580 5718, the AIDS Dementia Outreach Team 02 9339 2078 or David at The Bridge 02 9552 6438.

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 \$4.00 and available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville and Darlington. ☎ Diana on 02 9516 4755.

Living with Loss. Evening groups (six weeks) for people who have had someone close to them die within the last two years. If you are interested ☎ the Sacred Heart Hospice on 02 9380 7674.

HIV Living Peer Support Join a support group, meet other positive guys and share experiences of living HIV positive. For details ☎ HIV Living Project at ACON on 02 9026 2037.

relax

Fit X Gym at the Community Pride Centre, Hutchinson St, Surry Hills. Positive Access Project offer qualified instructors, free assessments, nutritional advice, individual programs and session to try out gym. \$2 a session = \$18 for a 10 visit pass. ☎ (02) 9361 3311 4pm - 7pm M-F.

Yoga for PLWHA Free weekly classes at Acharya's Yoga Centre M - F 12.30pm to 1.30pm, ☎ 02 9264 3765 for more information.

The Sanctuary offers free massage, acupuncture, therapy information, social work and shiatsu. ☎ Robert for details and bookings on 02 9690 1222

Complementary Therapy Advice Advice and referrals for PLWHA interested in complementary therapies available Mondays and Fridays at the Sanctuary. ☎ Mac on 9519 6830 or email complementarytherapies@hotmail.com.

learn

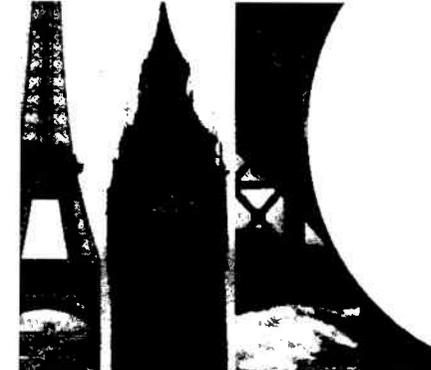
Randwick College offers free Outreach training programs. Information Technology for Mature - Aged Men, Work Opportunities for Women - Computer Skills and Introduction to Computers for Workers & Volunteers in Community Centres, for info on entry and eligibility ☎ free call 1300 360 601 or www.sit.nsw.edu.au

Community Garden, learn how to grow your own vegies. ☎ Carolyn for Waterloo on 9382 8374, Robert for Newtown 9690 1222 and Barrie for Woolloomooloo on 02 9206 1222.

Newtown Neighbourhood Centre has a number of groups ranging from Ninja Warrior Arts, Women's Kick Boxing, Exotic dance classes and Shaja Yoga Meditation. ☎ Charlotte on 02 9516 4755 for more details.

Diary is designed to promote volunteer-based and/or unfunded projects that benefit PLWHA. We especially encourage items from rural and regional NSW. Items of 30 words or less are welcome. Send your diary item to Will Klassen at *Talkabout Diary* PO Box 831 Darlinghurst 1300 Fax 02 9360 3504 Email willk@plwha.org.au Ph 02 9361 6750

For a comprehensive site about the arts, including free entertainment listings see *Qstage Digest* <http://www1.loom.net.au/home/dpj>



hyperactive 17

... anywhere in the world with **Tim Alderman**

International AIDS Society

<http://www.ias.se/>

RATING: Not much for the PLWHA. A dry site obviously designed for healthcare professionals.

The Tour IAS link opens to historical information on the non-profit organisation, and its mission – which is extensive. Activities informs of their custodial status for international AIDS conferences in Africa, Asia, The Pacific and Latin America; their educational programs on HIV Clinical Care and Prevention; articles from their newsletter, information about the Young Investigator Award; the charity account: For the Children in the World, and their caucuses.

And finally there's the International AIDS Conferences page, which speaks for itself. The site does have a direct link to <http://caho.aegis.com/womenatdurban/index.html>, which is in a number of languages, and contains discussion areas and abstracts from the Durban Conference.

Albion Street Centre

<http://www.sesahs.nsw.gov.au/albionstreetcentre>

RATING: This clinic is still at the heart of the HIV/AIDS epidemic. This is a large, informative site that I reviewed in part for the November 2000 issue of *Talkabout*. This month I look at the other half of this useful site.

The index page contains the site index,

plus their Mission Statement, a spiel on what ASC is, and links to the Clinic's comprehensive services and projects.

Clinical includes services for PLWHA, such as dermatology, dentistry, oncology and nutrition, as well as Immunological and Viral Load Monitoring, access to clinical trials, and their pharmacy service. A list of links to the right of the page takes you to related areas.

Information and Education takes you to the Information Line, Library, a Journal List, Video List, an On-line Database, and a heap of other resources including a request to join their mailing list.

Ankali is the worthwhile project next door to the Clinic that provides emotional support for PLWHA and significant others. Access to the Ankali page is available via the ASC site. ARCHI (Australian Reference Centre for Hepatitis C Information) has a large page with links to information on Hepatitis C, and a FAQ.

Compliance/Adherence has links to a good selection of resources on this sometimes-controversial area of PLWHA health.

International Consultancies includes links to HIDNA (HIV/AIDS International Development Network of Australia). ASC is linked into networks of care and development in places as diverse as Thailand, Indonesia and China, and provides consultancy to UNAIDS, WHO and UNICEF. There are links to HIDNA resources such as monographs, periodicals,

pamphlets and journal articles.

'Infection Control Resource Centre' was established in 1995 in accordance with NSW Health Department directives, guidelines, policies and regulations. Links to the right of this page give access to an Articles List, Video Catalogue, Resource Packages, Training and Information, and a Newsletter. The last remaining Index links speak for themselves, with 'Needlestick Injury Hotline', and 'Links to Other Sites' which will link you to many sites already reviewed in Hyper-Active over the last 12 months, as well as other interesting and informative links.

SPAIDS

<http://www.zipworld.com.au/~josken/spaids.htm>

RATING: A specific site for a specific service, and one well worth supporting.

SPAIDS (Sydney Park AIDS Memorial Groves) was started seven years ago, and has had 14 tree-plantings. The main page gives a personal touch, with a history of the project. Links are provided to similar projects in the USA. Some photos of the St. Peter's Grove are provided. the SPAIDS project is seeking a new coordinator. If you are interested please contact the previous coordinator via the site.

Tim Alderman is a member of the Publications Working Group. This is Tim's final Hyperactive. Many thanks to Tim and good luck with your writing course. Ed.

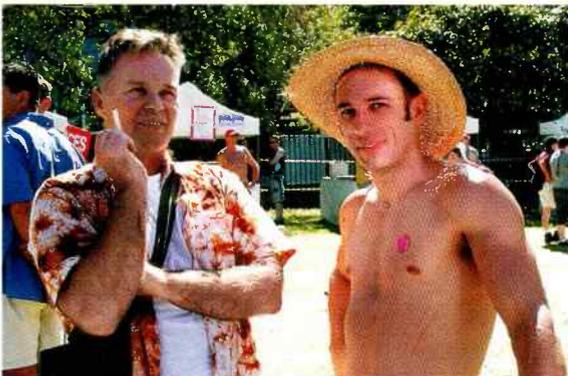
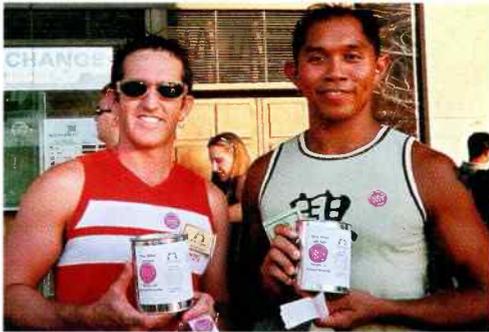
QUICK CLICK

http://www.fda.gov/oc/buyonline/buyonline_ads/fdabannerads.html (don't forget the underscore between buyonline and ads) is a site put up by the US Food and Drug Administration with banner ads on it, pointing people to their site to check out the validity of food or drug products that are sold online. You can post the banner ads on your own site as a way of informing people of hoaxes etc. Despite this being an American site, if the article is available there it is available everywhere.

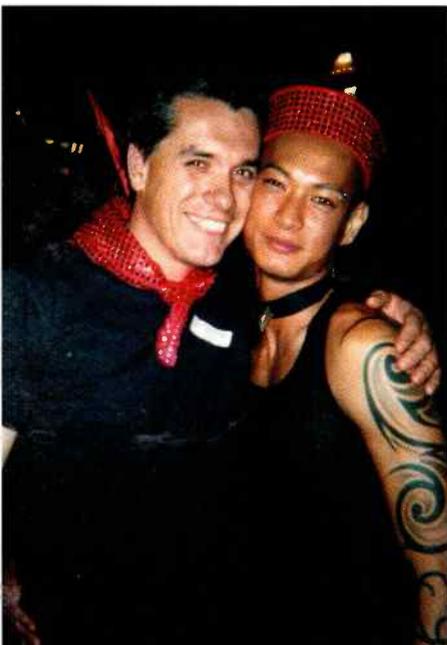
Correction – The site for marijuana as medicine in Quick Clicks, *Hyperactive 16*, in the February/March *Talkabout* had an incorrect site address. It should have read <http://mojo.calyx.net/~olsen/MEDICAL/medical.html>. Our apologies for this error.



Thank you to all
our volunteers



A big, big thank you to all the volunteers and staff of PLWH/A (NSW) who helped the organisation raise just under \$12,000 at the Sydney Gay and Lesbian Mardi Gras Launch and Fair Day. Pictured are a selection of shots taken at the launch, fair and at the annual SGLMG Parade. Best wishes to all xxx



Australian AIDS Memorial Quilt



*Remember their names
Keep the love alive*

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Sat 21 April 10am - 5pm

Sun 22 April 11am - 4pm

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