No. 64 April 1996

Talkabout

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

◆ Where We Speak for Ourselves ◆

CUT THE RED TAPE

Convenor's Report

OVER THE PAST few weeks there have been a number of developments which could have an impact on Australia's response to AIDS and on our lives as HIV positive people.

The first is the election of the new Federal Coalition Government.

Prior to the election both parties committed themselves to continuing a bi-partisan approach to AIDS and to putting a third National AIDS Strategy in place. The National Strategy is very important to us, because the Strategy contains Government funding for treatment, care, education and research. PLWH/A (NSW) will need to work closely with the new Commonwealth Government to ensure the best possible standards of treatment, care and research.

The appointment of Dr Michael Wooldridge as the new Commonwealth Health Minister is a pleasing development. Dr Wooldridge has a good understanding of AIDS issues, and when in Opposition was always prepared to listen to the concerns of PLWH/A and AIDS organisations. We will be presenting Dr Wooldridge with information about some of the AIDS issues we think he needs to act on. High on that list will be the need to reform Australia's elephantine drug financing systems so that they work for — not against — people with life-threatening illnesses like HIV/AIDS.

On that subject, PLWH/A organisations reacted angrily to the recent decision by the Pharmaceutical Benefits Advisory Committee (PBAC — the Government committee which decides whether or not to pay for our treatments) on funding of 3TC, d4T and AZT for use in combination treatment. Among a number of bizarre decisions, the PBAC have imposed a 500 CD4 limit on these drugs, meaning that people will have to wait for their immune system to be markedly damaged before being allowed to begin treatment. How absurd! Would you wait for someone to become very ill with tuberculosis before beginning treatment? Of course not.

AIDS organisations will need to fight hard to overturn the PBAC decision, which is ridiculous and immoral. All people with HIV must have the right to begin treatment when they and their doctors decide this is appropriate for them.

We are meeting with the PBAC on March 18 to discuss their decision and where we go in the future, because there are a range of new drugs nearing approval (Saquinavir, Ritonavir, Crixivan and various drugs to fight AIDS related opportunistic infections). We must ensure that these drugs are funded quickly and fairly.

On a brighter note, it is pleasing to report that the NSW Health Minister and the NSW AIDS/Infectious Diseases Branch have agreed to increase the annual government grant to PLWH/A. We have been funded to employ a full-time HIV Community Development Worker. We will use this position to reach out and involve more positive people in PLWH/A. This position will also be helpful in ensuring that as many people with HIV/AIDS as possible are aware of available services and their rights.

Funding has also been provided for a Research Officer. This position will assist our voluntary committee and working groups to research issues like housing, legal issues, treatment and so on. This research work is important, because if we're going to obtain the best deal for positive people we need to present strong, well researched policies and arguments.

We have also received additional funding to upgrade and expand *Talkabout* and to produce the Contacts section of *Talkabout* as a separate, quarterly booklet.

In conclusion, I would like to thank all those who helped us ensure that PLWH/A had a strong presence in the Gay and Lesbian Mardi Gras Parade, and at other events of the Mardi Gras Festival. These events provide us with an excellent opportunity to promote our work and to provide important information on treatment, care and support to people with HIV and those affected.

— Bill Whittaker

People Living With HIV/AIDS (NSW) Inc.

Current committee

Bill Whittaker: **Convenor**
Claude Fabian: **Deputy Convenor**
Vivienne Munro: **Secretary**
Rolf Petherbridge: **Acting Treasurer**
Chris Hordern, Stuart McEacharn, David Nicholas, John Trigg, Kath Vallentine, Larry Wellings

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This month's cover

By C. Moore Hardy. PLWH/A's float in the Mardi Gras Parade attacked inefficiencies and delays in Australia's drug approval and funding systems. Its key message was to cut the mountains of red tape denying access to important new treatments. The float, fabulous as it was, was not PLWH/A's only involvement in Mardi Gras of course — see page 10 for our pix from Fair Day and the Time Out Room at the Party.

Talkabout

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

- A recent survey found that about 20% of "homosexual AIDS deaths" in Amsterdam [in the group surveyed] were by euthanasia. The Netherlands have liberal euthanasia guidelines; euthanasia is permitted when repeatedly requested by lucid patients who have unbearable and irremediable pain. Apparently, about 72% of those who chose euthanasia would have died within a month anyway. *(Australian Doctor)*
- Latest figures from the World Health Organisation show that 1.3m cumulative AIDS cases have been reported world wide, a 26% increase on last year's figures. Some 34% of these come from Africa. Some of the luckier countries are Algeria, reporting only 244 AIDS cases, Tunisia: 255, Morocco: 290 and Mauritania: 16. *(AIDS Analysis Africa)*
- *Washington Post* writer Christine Brennen's new book, "Inside Edge: A revealing journey into the secret world of figure skating", shows that AIDS has affected male figure skaters more than any other athletes and that the epidemic continues to endanger top skaters. The book claims that the US Figure Skating Association (USFSA) has not responded with adequate urgency to the disease. USFSA disagrees. *(BCPWA News)*
- Canada Post will issue an AIDS stamp before the 11th International Conference on AIDS in Vancouver in July. HIV+ philatelist, Blair Henshaw, has been lobbying Canada Post for four years to issue the stamp, which will be unveiled in early May. Henshaw's collection of AIDS stamps, which includes about 130 stamps from 60 countries, will be on display at the Vancouver conference. *(BCPWA News)*
- In early March San Francisco became the first city in the world to begin wide scale free distribution of internal condoms to gay men at city health clinics. Although the FDA has not given approval for the "so called 'female condom'", Reality, to be used for anal sex, the device was tested six years ago by gay men in Chicago — apparently with a favourable response from the users. If the FDA gives the go-ahead, Reality could undergo further tests for anal use. *(Bay Area Reporter)*
- Of the approximately 1 million children affected with HIV world-wide, 90% live in sub-Saharan Africa. In developing countries, rates of mother to child transmission are twice those reported in Europe and the US. Nearly 80% of those infected will die before they're 5 as a result of HIV aggravated malnutrition, diarrhoea and respiratory infections. *(Medical Alert)*
- An Indonesian minister has predicted that 2.5m people in Indonesia could be HIV+ by the year 2000 unless serious action is taken. The number of annual reported cases is 300. *(AIDS Analysis Asia)*

FDA approved

The United States Food and Drug Administration (FDA) embarked on a spate of drug approvals earlier this year. First off the block was ddC, fully approved for use in combination with AZT as initial therapy for treatment of HIV disease.

Also approved was the promising Abbott protease inhibitor (PI) Ritonavir. The Merck PI, Indinavir (Crixivan), has been recommended for FDA approval following the presentation of studies which found that 40% of people who took the drug alone and 90% of those who took it in combination with AZT and 3TC, had their HIV load fall below detectable levels.

Saq's OK

Saquinavir has been in the news following comments by Professor David Cooper in the *Sydney Star Observer*, that using the drug too soon could cause cross resistance with other, better PIs. This statement, accompanied by the assertion that HIV treatments are in chaos, attracted censure from the National Association of People with HIV/AIDS (NAPWA).

In a statement issued on March 11, NAPWA said that Professor Cooper's comments were "counterproductive and a gross misrepresentation of the views and actions of AIDS activists". NAPWA was also concerned that Cooper did not raise his concerns formally with the relevant organisations and individuals before making public statements.

On Saquinavir, NAPWA has pointed out that while the development of resistance is a factor in all anti-virals, the development of PI resistance appears to be relatively slow. Preliminary data presented by the drug's manufacturer, Roche, suggests that up to 90% of people taking the drug will still be sensitive to Ritonavir and Indinavir after one year. Other studies support this view, although NAPWA notes there is some disagreement between PI manufacturers.

In late February, Roche announced that in partnership with Abbott, it would be conducting a trial of a combination of Saquinavir and Ritonavir. It is hoped that in combination the two treatments will be more effective than when used alone. (It is not advisable to combine Ritonavir with other anti-virals).

NAPWA rejected Professor Cooper's claims that AIDS treatment is "in chaos", that treatments are being used in an inappropriate manner, and his criticisms of compassionate access programs. NAPWA stated that it has only called for compassionate access programs for drugs such as Saquinavir, where benefit has been clearly indicated in overseas trials, primarily for PLWHA whose health is failing and who are finding other treatments ineffective

NAPWA stated that the AIDS death rate has fallen significantly during 1995 and 1996 and that access to drugs provided compassionately, such as 3TC, are likely to be a main contributor to this.

KM1 launch

The KM1 Herbal Formula was well and truly launched at the beginning of March with a press conference at the Darlinghurst Community Health Centre. The subsequent media blitz about the trial was highly successful, with both the profile of the trial substantially lifted and a swag of new participants — especially women and people from country areas — recruited as a result.

Although the mainstream journos, predictably, went over the top in their descriptions, this trial is, on most counts, indeed a first. It's the first scientific complementary therapy HIV/AIDS trial in Australia. It's the first time such a broad spread of people living with HIV/AIDS have been invited onto a trial. The first women's specific case record forms. The first community (as opposed to government, university or international drug company) organised scientific trial in Australia . . .

One of the interesting aspects of dealing with the media was their difficulty in grasping even the basics. I lost count of the number of times I was asked "... yes, but who do you work *for?*". The idea that we, the community, not some body or institution, could actually organise something scientifically legitimate is obviously hard for people to grasp.

Another unfortunate aspect was the disinterest in our specific targeting of marginalised groups (because it's the right thing to do and because it will guarantee a better sample). The presence of HIV positive women at the press conference was ignored.

Nevertheless, and despite some mistakes, the coverage was not dismissive. In other words, we have established our credibility with most of the cynics.

Now comes the hard slog of actually running this highly complicated trial on our own resources. Mailouts, getting the herbs to country people, phone bills — this comes to thousands of dollars and out of the pockets of people with very little to start with! We, as yet, have no funding, although a submission has gone to the AIDS Trust. Other money will be sought but any ideas from *Talkabout* readers on this vital cog in the wheel will — seriously — help ensure that this trial, *our* trial, is successful.

Spaces on the trial are still available. Participants are being placed on in 'waves'. One has gone on, another will follow in May — so it's not too late. But remember, being on this trial does require *active* participation. For more info please call us on 552 2243.

— Paul Canning,
KM1 trial media officer

$25,000 was raised for BGF in their annual Shop Yourself Stupid on February 24. Snappped in Oxford Street were celebrity collectors John Fowler and Clover Moore with Stephen Buzzacott. Over $42,000 was collected for BGF at the Mardi Gras Parade and the Reserved Seating area was a huge success, raising over $90,000. PHOTO: MAZZ IMAGES

PBS out of step

IN EARLY MARCH THE PHARMACEUTICAL Benefits Advisory Committee (PBAC), recommended the subsidy, under the Pharmaceutical Benefits Scheme (PBS), of 3TC and d4T for use in patients with CD4 counts of 500 or less. The PBAC has recommended to the Government that this be fast tracked so that the drugs should be available within four months.

The PBAC decision met with anger from both NAPWA and the Australian Federation of AIDS Organisations (AFAO). NAPWA described the PBAC decision as "immoral" and "arbitrary".

NAPWA Treatments spokesperson Bill Whittaker said the PBAC decision meant that people with HIV must wait until their immune systems are substantially damaged before being allowed treatment. "PBAC is asking people to accept an inferior standard of treatment and to sacrifice their health," he said.

Both NAPWA and AFAO say there is considerable evidence to suggest that people with HIV should be treated early and aggressively with HIV anti-viral treatments and that the PBAC decision is out of step with current knowledge and practice. The Australian Drug Evaluation Committee (ADEC) recently approved 3TC and d4T for use at any stage of HIV disease where clinically indicated — regardless of CD4 counts.

"PBAC requested expert advice on this matter from the Clinical Treatment and Trials Advisory Committee, but do not seem to have taken the advice that they received", said Bill O'Loughlin, National President of AFAO. AFAO has called upon PBAC to abolish the CD4 limits. A meeting with PBAC on March 18 was inconclusive.

NAPWA will be seeking a meeting with the new Health Minister to discuss the PBAC decision, as well as other treatments issues.

Ritonavir shock

THE FRENCH GOVERNMENT HAS allowed the marketing and funding of Abbott's new protease inhibitor, Ritonavir, without requiring the company to formally supply any evidence of its efficacy. They have approved the drug solely on the basis of the approval in the US, by the FDA. There are 18,000 people with AIDS in France, and 150,000 HIV positive people.

Unfortunately, Abbott Pharmaceuticals did not anticipate the

Briefs

- The Positive Speakers Bureau is holding its second training program at the end of April. We need positive people who identify with the following groups; women, NESB, Aboriginal and injecting drug users. If interested please contact Luke or Larry at PLWH/A on 361 6011.
- Queen Bunny and her entourage will be visiting HIV/AIDS services on Easter Sunday distributing Easter gifts and cheer. Volunteer delivery bunnies, or anyone wishing to donate money or Easter eggs, can call 550 5577 for more info.
- Staff at Telstra's International Telephone Exchange in Pitt St will be delivering Easter baskets to Cahill 17 (St Vincent's) and the Marks Pavilion (Prince Henry). Items in demand include shampoo, toothpaste, T-shirts etc. To make a donation call Peter Bomford on 231 3316.
- The Community Support Network offers a training course for people interested in becoming carers. Interested? Go to an information session — the next two are Wednesday April 17 and Wed May 15, 1pm or 7pm. For details, call 206 2032.
- ACON Mid North Coast and Northern Rivers Branches invite country people to enter a poster competition. The incentive: Three glorious days at Turtle Cove Resort for the lucky winner (and partner). They want you to come up with a poster that rural people can identify with, that will be produced and distributed throughout rural NSW. For more information call Colin (066) 51 4056 or Sue (066) 22 1555.
- PRIDE is undertaking a photography project which aims to capture Sydney's gay and lesbian community groups on film. The project focuses on what "community" means and how we are (or are not) coping with HIV/AIDS in 1996. Photographs will be in an exhibition later this year. If you'd like to be involved, call Amanda on 331 1333.
- The Fitness Exchange Community Gym, located in the PRIDE Centre, is to trial a Positive Access project over the next 6 - 8 months. The project aims to provide participants with a supportive and fun community environment in which to develop a personal exercise program. The Gym instructors are undergoing training in relation to HIV so they'll be better placed to offer a specialised program designed to assist each person in maximising their health and well being. Membership fees are kept to a minimum and are negotiable for people experiencing severe financial hardship. Confidentiality and respect are assured. For more info call Amanda on 331 1333.
- The Sydney College of Traditional Chinese Medicine (TCM) is presenting a seminar, the Treatment of HIV with Chinese Herbs on Sunday, April 7. Cost: $100 for the day; $30 per session. For more info call Henry Liang, 9955 8801.

sudden demand for the drug which followed in the wake of the FDA approval of Ritonavir, in the fastest drug approval process in US history, nor the unprecedented French decision to license the drug.

Abbott stated that it has evidence that three other European governments are about to approve the marketing and funding of Ritonavir within the next few days: Sweden, the Netherlands, and the UK.

All this makes it highly unlikely that Australian PLWHA will be able to obtain access to more of the drug than will be available through the 40 or so places already allocated on the compassionate access scheme. There seems very little chance that the Government will have licensed Ritonavir before September!

— Henry Forester

NAPWA news

TREATMENTS ACCESS, SKILLS BUILDING, poverty and education for people with HIV are among the main priorities identified for action in 1996 by NAPWA at its executive meeting held in Melbourne on February 18 and 19.

"Treatments access and education have to remain our number one priorities", said NAPWA President Alan Brotherton. "The vastly improved outlook around treatments hasn't resulted in many more people accessing them. This is largely because the approval system is so slow and treatments so hard to get, especially combination treatment, but also because important new advances simply have not been widely enough promoted."

NAPWA plans to run a National Treatments Roadshow to try to renew interest in treatments around the country and to explain the importance of recent advances and new discoveries to what may be a sceptical audience.

"Perhaps the over-hyping and subsequent disappointment around AZT may have made people more wary about new treatments", said Brotherton, "But that doesn't explain, for example, why the recent SMASH survey shows positive gay men in Sydney using less alternative *and* allopathic therapies. This is a disturbing finding which suggests a growing disenchantment with any form of therapy right at the time when things are looking better than they have for some years. This only underscores the need for more and better funded education around health monitoring and maintenance."

NAPWA will also be focusing on issues of poverty, legal reform, prisons and skills building for PLWHA groups throughout the year.

Dubbo talkfest

AS *TALKABOUT* GOES TO PRESS, THE HIV/AIDS Rural Conference is being held over four days in Dubbo. With numerous opportunities for formal and informal presentations and discussion, the Conference outcomes and recommendations could provide the basis for future developments across rural NSW.

Rural HIV positive, Aboriginal, gay/lesbian and health care worker perspectives should make interesting reading in the May issue of *Talkabout*.

— Larry Wellings

Day Centre update

JANUARY 1996 MARKED YET ANOTHER birthday for the Day Centre. Bashfulness makes me not want to reveal our age. It's a lady's prerogative after all!? Within the first two months of 1996 the Day Centre has already begun its program of addressing the needs of PLWHA at a community level.

The introduction of Saturday opening has filled the gap of a missing lunch service, making meals available Monday — Sunday. Saturday opening has also allowed those people who work, access to the Centre. Lunch numbers are swelling and an overflow on the dining floor is imminent!

Our monthly newsletter, *First Edition*, is now informing PLWHA about the Centre, its services and events planned. We welcome views from the community and will be delighted to publish any letters or comments. Copies can be mailed directly or you can pick one up at the Day Centre or at various services around Oxford St and Newtown.

Fundraising has begun well with our Mardi Gras Fair Day Raffle raising $1,100. More, bigger and better fund-raisers are being planned. The money will be used by the Day Centre Social Club (DCSC) to aid and assist its members. The DCSC is a group of clients who have a direct input into our services and programs.

An Activities Program aimed at skills training has begun to take shape with pottery, Spanish dance, Spanish language, spinning and cosmetic care classes being run from the Centre. Also, the Centre runs a Certified Massage School which only costs $10 for the unwaged. Courses run quarterly (February, May, August and November). You can take part in our training/volunteer programs, particularly in the kitchen or reception areas.

The hairdressing service has expanded now to two hairdressers per week. The gym facilities have expanded following the donation of a gym station from a gentleman in Potts Point. We have also received our dates and times for complimentary tickets for the Australian Opera's dress rehearsals and for plays at the New Theatre, as well as the listing of free performances at the Belvoir St Theatre — all these will be listed in *First Edition*.

See the *Talkabout* Contacts list, P14, for details of how to get to the Centre, or call me on 357 3011.

— Robert Attwood

Day Centre float volunteers take a break before the Mardi Gras Parade gets under way. PHOTO: Mayu Kanamori

"+"

WHEN AUSTIN OAKMAN DIED OF AIDS related illness in February this year, he left a remarkable range of artworks resting against his bedroom wall. The few friends who had seen these extraordinary installations were dazzled and begged him to exhibit them. In his typically self deprecating manner, Oakman always said that if he exhibited his art, he'd probably just hang it for an hour or so in some fence in an abandoned alley.

Oakman had worked as an artist from the 70s, exhibiting in group shows, but it was an intricate and striking series of drawings, illustrations and sculptures that would preoccupy him for his final years. The collection, now brought together under the title "+", comprises largely of totems, lean timber structures that work as elaborate frames for panels bearing a constantly changing and personal iconography.

"+" will be exhibited April 16 - 27 at the Tap Gallery, level 1/278 Palmer St, Darlinghurst. Opening night will be Thursday, April 18, 6 - 8pm. Proceeds from "+" will benefit *Talkabout*.

For more information call 356 2260.

— Bruce Carter

PLWF

[ED: THAT'S PEOPLE LIVING WITH Fashion, for the style-challenged among you.] PLWF was a packed out fund-raiser for Gay Men Fighting AIDS (GMFA) on February 20. The night, which featured six sensational fashion parades, raised over $1,400 for GMFA. There were also performances by Damaged Stock and erotic piercings by Polymorph Art.

Since this overwhelmingly successful event, GMFA celebrated our first birthday on March 12. The project has quite a bit to celebrate, including our gay men's health promotion campaign featuring Ian Roberts, the GayLife information sessions, and our advocacy activities, which focused on street safety in the Newtown area and the issue of poverty and skills development for PLWHA.

Thank you to all the gay men, businesses and venues who have supported us over the last year. We look forward to continuing to develop GMFA for many more years to come.

— Greg Millan, Co-ordinator

Fairfield fight

FOLLOWING THE ANNOUNCEMENT that Fairfield Hospital's HIV/AIDS services will move to the Alfred Hospital while its infectious diseases facility goes to the Royal Melbourne, Victorians face a splintering of the integrated services developed at Fairfield.

Briefs

- Injecting drug users have been excluded from most clinical trials, but a Johns Hopkins study shows that IDUs can be reliable study participants. "This study refutes the notion that IDUs should be summarily excluded from clinical trials on the basis of preconceived impressions of difficulties in their recruitment, enrolment, comprehension of informed consent or follow-up", wrote Katherine Harrison in *JAIDS*. *(Positively Aware)*
- US: The Centers for Disease Control and Prevention (CDC) recently released a report on how race and ethnicity are related to opportunistic illnesses (OIs). The CDC study of data for 203,470 PWA concluded that while some OIs were more common among certain racial and ethnic groups, race and ethnicity were not, by themselves, risk factors for those illnesses. The report concluded that factors such as exposure to disease causing agents, diagnosis and reporting of conditions and access to medical care are the most likely causes of the differences. For example the higher rate of toxoplasmosis of the brain among HIV+ African Americans and Hispanics was consistent with a higher prevalence of toxo in those populations. *(Positively Aware)*
- Curcumin, a component of the spice turmeric and popular herbal medicine, has no anti-HIV activity in people, according to a study reported on at the 3rd Conference in Retroviruses in February in the US. An earlier, smaller study had shown a reduction in viral load. *(GMHC Treatment Issues)*
- A US study of 403 adult men with AIDS (1984 - 94) found large differences in survival depending on physicians' HIV experience (measured in large part by how many PWA they had cared for). Patients cared for by doctors with the most experience had a 31% lower risk of death compared to those cared for by doctors with the least experience. Patients with experienced doctors had more CD4 monitoring and more prophylaxis against PCP. *(AIDS Treatment News)*
- A recent Houston study of 125 women has found that miscarriage in the first trimester is 3 times more likely in positive women, perhaps due to early HIV infection of the foetus. *(AIDS Alert)*
- Thalidomide effectively and safely heals severe mouth ulcers in people with HIV, according to an interim analysis of a placebo controlled NIAID study. Thalidomide is the first treatment shown to heal these painful ulcers, which can make eating difficult and contribute to weight loss and dehydration. The study will continue (with all participants receiving thalidomide) so that researchers can further evaluate the drug's effectiveness and long term toxicity. *(PWAC NY Newsline)*

The first blow was State Health Minister Marie Tehan's announcement that a decision about the future location of the Victorian Infectious Diseases Reference Laboratories (VIDRL) would not be made for at least twelve months.

"The apparent lack of certainty over the future of VIDRL is an ominous sign and suggests a possible down grading of HIV/AIDS services in Victoria", said Alan Brotherton, NAPWA President. "The integration of clinical and research facilities at Fairfield Hospital provided a service of national significance. The decision to close Fairfield was misguided in the first place. The decision to now break up the services is a disaster for the effective Australian response to HIV/AIDS".

The future of HIV services north of the Yarra is unclear at this time. Despite recommendations from the PLWHA program and the Victorian AIDS Council that St Vincent's Hospital become the 'new Fairfield' (taking over the integrated services in full, with the service currently offered by the Alfred continuing at increased capacity), it will not be possible for St Vincent's to run an HIV service of any size now the services are to be split between the Alfred and the Royal Melbourne. It is believed that the Royal Melbourne may expand HIV/AIDS designated beds in its infectious diseases unit.

There has been ongoing industrial strife at the Fairfield site since its closure was announced, as remuneration for retrenched staff was in some cases inadequate and in others discriminatory.

Volunteers are ensuring the hospital remains operational in consultation with the unions, who do not want work bans to force an early closure.

— Bridget Haire

Asia/Pacific women to meet

In January this year the AIDES Federation Nationale held a meeting in Paris of peak international PLWHA groups and members of UNAIDS, to address the Global Initiative for the Greater Involvement of PWA (GIPA). The French Government has pledged money, through UNAIDS, to networks such as GNP+ and the International Community of Women Living with HIV/AIDS (ICW), to facilitate their work in developing countries. Africa, Asia/Pacific and Latin America were each granted $29,000 for meetings. GIPA regional sessions determined how this money would be spent.

The GIPA proposal for the Asia/Pacific region focused on the need to strengthen existing networks. In order to do this, contacts with individuals must be strengthened and PWHA must be supported within their own countries and communities.

It was decided that the money would fund a women's regional meeting in Manila later this year. This is good news for ICW, as it will be a first in this region and go a long way towards increasing the emerging voice of positive women, developing advocacy and building relationships both within ICW and with the Asia/Pacific network of PLWHA(APN+) and the Asia/Pacific Council of AIDS Service Organisations. It will also provide the opportunity to develop a clear plan for the future.

— Vivienne Munro

Notice

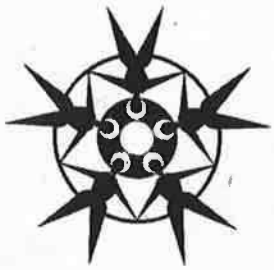
Endora, the Sea-Witch, Dies of The Curse

Eric Sleight, Treasurer and Committee Member of PLWH/A (NSW), died at the Sacred Heart Hospice on Tuesday March 19.

PLWH/A staff and Committee will miss Endora's smile, his laugh (or was that a scream?), his charm, his bitchiness — but most of all, we'll miss Eric's optimism, warmth and love for others.

The next issue of *Talkabout* will include a tribute to Eric.

Positive Women's Retreat



The second Positive Women's Retreat was held at Kyabra in late January. ***Emma King*** *reports that a good time was had by all.*

PHOTO: JAN KNEEN-MCDAID

Positive women, their carers and families made a spash at Jamberoo.

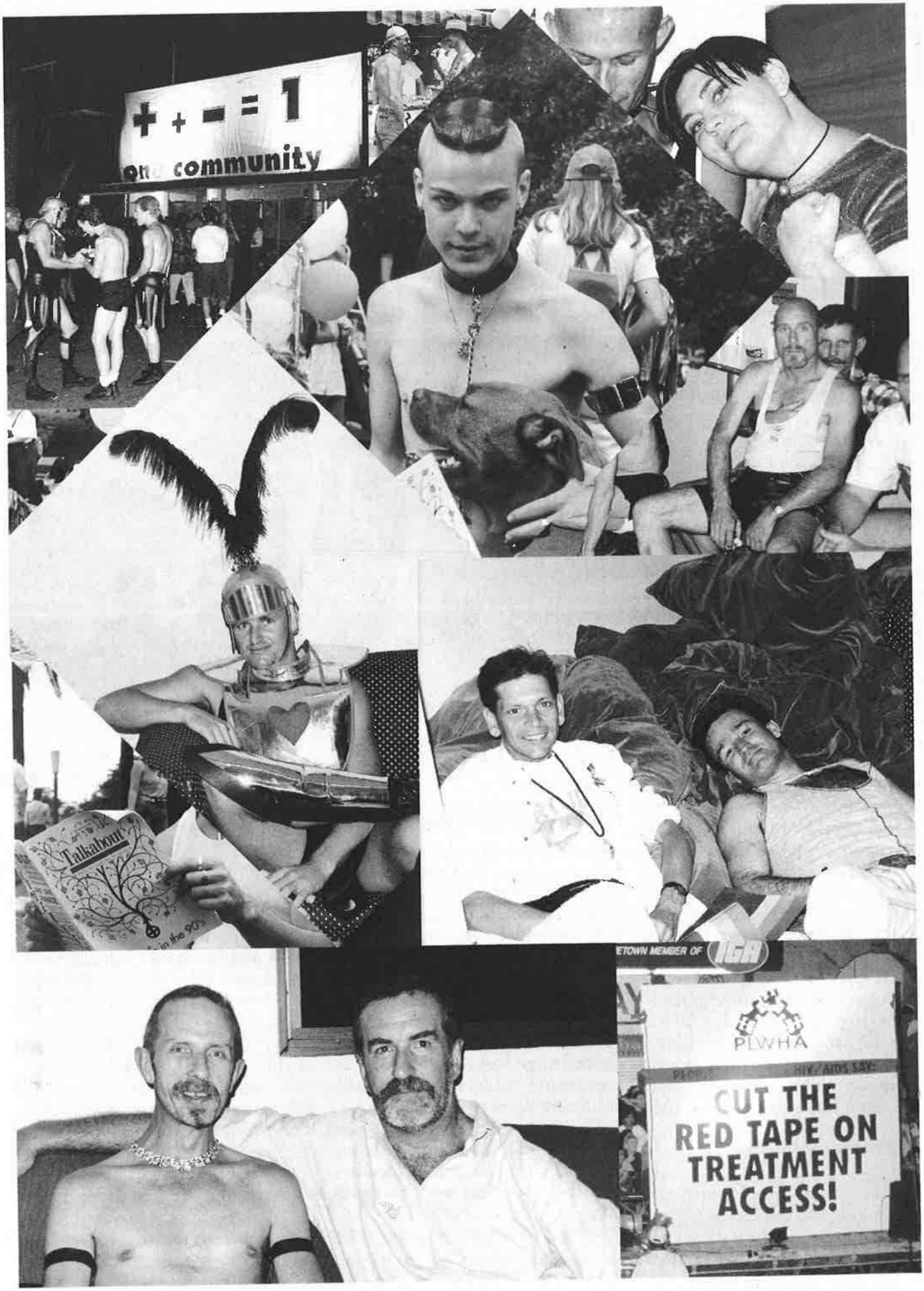
KYABRA, SITUATED APPROXIMATELY halfway between Sydney and Canberra, is a beautiful property containing a small group of houses with names like 'willow' and lots of sheep! The two busloads of women, partners, carers and children en route to Kyabra were filled with fun. After arriving, most of us decided to settle in by swimming and reclining near the very picturesque pool. Unfortunately this was the only day we could enjoy real sunshine as the rest of the time it spat rain onto the Retreat.

Once again Helen's cooking was superb — all of us probably put on a few extra kilos with the huge amount of food she dished up. It seemed like the focal points for the retreat were the kitchen and the therapists. We had a range of therapies to chose from: reiki, naturopathy, massage and polarity therapy to name a few. This came in handy as many women chose to horse-ride at the retreat and those tender muscles needed massaging the next day after that kind of exercise!

Jamberoo Recreation Park was probably the highlight for this girl. Us big kids went with the smaller kids and the Camp Goodtime volunteers to the park where we ran a-literal-muck! We jumped off the fake cliffs, rode the waterslides, drove the cars, smashed into each other with the speed boats and sped down the toboggan run. One big kid (who will remain nameless) went down the fast track of the toboggan run so fast she collected herself and broke the speed limit at the same time. A few burnt fingers and a red face later she came down slower next time. All of us who elected to go had a ball! I think at any future Retreats we should definitely do that again!

The rest of the Retreat was much needed quiet time, sharing stories and experiences or just indulging in a massage or two! Many thanks to the therapists Jan, Liz, Noddy and Rebecca who did an excellent job of soothing our tired bodies. The only real 'work' as such that we did was formulate a women specific data sheet for the KM1 Trial. This was a really important step for positive women as this type of data collection will be instrumental in forming a body of information about how HIV specifically affects our bodies. Let's hope this will begin to occur on the drug companies trials so that finally at some point in the future (hopefully sooner than later) we positive women will be able to at least have some idea what these drugs will do to our bodies.

Overall the Retreat was a great success and it exposed those closet bingo players in the process! Let's hope for another in the near future, creating well rested and well informed positive women. ◆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one community
Talkabout
in the 90's
PLWHA
CUT THE
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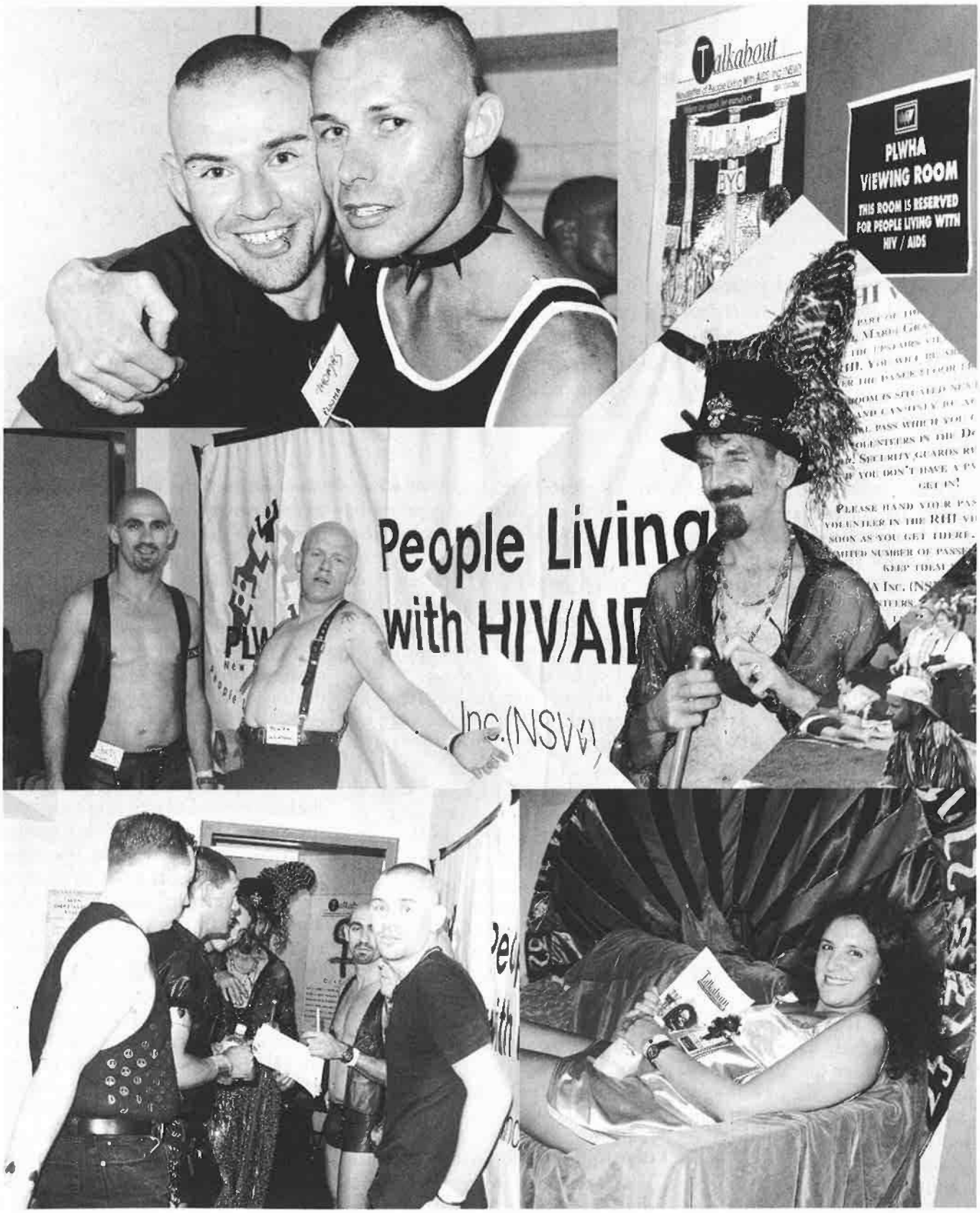
TREATMENT
ACCESS!



Yep, PLWH/A NSW Inc. did Mardi Gras in a big way. Some of our main activities are pictured here: Fair Day – smart canines read* Talkabout *... our hard-hitting float ... and of course, the assorted, understated guests at the Party Time Out Room – lurve the headwear – watch out for the spikes doll!

Photos: Paige Slan

Doctor, doctor — *friend* or **foe**?

Can you trust your doctor to put your needs before the needs of any clinical trials you may be enrolled in? Many doctors are caught between their commitment to their patients and their desire to contribute to the 'greater good' of advancing treatments knowledge. ***Rolf Petherbridge*** *discusses the problems created by this conflict of interests and puts forward some solutions to this 'apparent' ethical dilemma.*

IN AUSTRALIA, IT IS TYPICAL FOR A positive person to have been diagnosed around eight to ten years ago and since then subjected to a number of cycles of treatment depression and hope, fatalism and optimism. We have, in various ways, been battling for our lives for a decade and many of us have exhausted the benefit to be gained from currently licensed HIV drugs. Additionally, most of us have suffered substantial loss of friends and associates. Our dependency on our medical practitioners is of an exceptionally high order. We are entitled to expect that our personal doctors are our strongest allies in the battle to stay alive and we must never lose sight of this fact. This is the right of every person with a life-threatening disease.

In the recent past many of us, myself included, have begun to wonder whether our doctors are allies or enemies. We have begun to wonder whether we are people whose lives are cherished or whether we are mere experimental animals whose lives are being sacrificed by doctors so that they can save the lives of others.

In the complexity of evolving knowledge of HIV treatment there are a number of situations where the needs of individuals imperilled by HIV are in conflict with the needs of doctors and society. In any such situation, where a personal interest is in alignment with a greater good, it is very difficult for that person to separate the two. A further complication exists in that the societal and professional needs are paralleled by the need of some parties to further their academic careers through the successful conduct of rigid clinical trials. As a general ethical principle, such conflict of interest should disqualify the party concerned from decision making. However it is not practical to take the power to make decisions about treatments or clinical trials away from the physician — *nor is it necessary.*

It is *un*necessary because the profession's own ethical principles require that the physician elevate the needs of the patient above the needs of society. This imperative is expressed in the World Medical Association Declaration of Helsinki: Recommendations Guiding Medical Physicians in Biomedical Research Involving Human Subjects (current form) thus: "Concern for the interests of the subject must always prevail over the interests of science and society."

The medical profession's repeated prioritisation of society's needs over our individual needs, where access to 'unproven' HIV therapies and the conduct of HIV trials are concerned, has created an atmosphere of disillusionment, distrust and feelings of betrayal.

PLWHA volunteer for trials for two reasons; the altruistic desire to contribute to a cure for all and the selfish desire to survive themselves. The proportions of the two vary between individuals and at different times in each individual. But both are present at all times in all people so that when circumstances arise in which these desires conflict they cause considerable distress.

Treatment flexibility

Clinical research physicians, by dictating rigid restrictions on using other drugs while on a trial, are insensitively making participants agonise over sticking to the protocol for the sake of others and sacrificing their own chances of survival in the process, or using the prohibited drugs to give them a better chance of surviving.

One of the consequences of the development of a new generation of HIV treatments which have substantial effects on CD4 counts, is that blinded trials are effectively impossible because CD4 results indicate whether or not an individual is on the new treatment. To blind these trials would require concealing the CD4 results from patients and doctors. Since CD4 counts are essential in clinical management this is ethically unacceptable.

Current standard therapy is failing many trial participants. Often, and quite understandably, they resort to using other drugs

when they can get their hands on them. Increasingly they can. All participants would like to obey the protocol and those with the security of high CD4s will almost always do so. But all would like to survive and so many in the control arm will secretly augment their treatment. Thus in practice, the differences in extra drug use between the active and the placebo arms which follow, render the restrictions counter productive.

Clinical trials are but a tool in a search for knowledge. It is impossible to achieve accurate data and correct interpretation if we do not know what trial participants are doing. Intelligent management avoids penalising or otherwise inhibiting self-relevation, if that revelation is in the public interest. An absence of restrictions would reduce the moral anguish and internal conflict, result in accurate data recording, and, by allowing for combination use in the more effective arms as well as the control, would give randomisation a better chance to do its job.

Steps in this direction are already being taken in the United States.

Washout times

Some trials require that participants stop taking their regular anti-viral treatments for a certain period (a washout). On the Merck Protease/d4T trial, this was up to three weeks; other recent trials have required washouts as long as 12 weeks. The studies of Ho and of Shaw have established that HIV is highly active daily but this is partly balanced by a huge daily cell production. The natural history of HIV has been likened to a sink with the tap running but the plug out. Nucleoside therapy in this model may be seen as the sink strainer. Obviously suspension of therapy for even a short time will affect this balance of cell depletion and cell replacement to the detriment of the patient.

I cannot see that nucleoside washouts longer than four days can ever be justified and I am appalled that they have not faced active resistance from the medical profession. Whether these prolonged washout times exist to serve society's and doctors' interests by providing 'clean' trial results or whether they primarily serve the companies' interests by pushing the trial population closer to the edge, providing more and earlier illnesses and deaths and shortening the time to significant results, is open to debate. To compound the injury, examples have occurred where patients have suspended their treatment in order to qualify for a trial and then discovered the trial was full or they were for other reasons ineligible.

Ethics Committee approvals

HIV community organisations have criticised institutions for running trials which they perceive to be unethical. This criticism has been uniformly countered by the trial's organisers with the response: "This trial is ethical because it has been approved by an EC (or two, or three ECs)".

The facts of the matter are that the doctors' responsibility for ensuring patients do not participate in unethical trials cannot be sloughed off onto ECs. They have the responsibilities of their profession and they are the gate keepers between the companies and their patients. The understanding of HIV possessed by most EC members is necessarily limited. They are heavily dependant on the submitting investigator for advice and this negates their ability to carry out their task of independent assessment. A national HIV research ethics committee whose members are knowledgeable in the particulars of HIV and consult with HIV community organisations is really the only satisfactory model.

Changing knowledge

It is likely that during the course of a trial, new information will be released relating to the therapy under trial, alternative (i.e. mainstream but alternate) therapies, or the course and mechanism of the disease itself. A predictable result of such new information is that some modifications in treatment regime will occur, along with withdrawals from the trial. It is my observation that investigators are reluctant to communicate information which may have this result.

It is necessary to have a process for promptly notifying both ECs and participants of any new information — including any relevant discoveries about the course or mechanism of the illness — which might affect willingness to participate or probable best treatment. This process should not be solely relient on the investigator for such communication. Ethics committees must be open to consideration of submissions from the participants and their representative organisations.

New drugs

CD4 counts and viral load measures have come to be referred to as surrogate markers. This nomenclature has served to devalue them. They are direct quantitative measures of the primary pathology (damage done) and of the pathogen (germ causing the damage) itself. It would be more accurate to call them semi-surrogate measures. In relation to drug approval and marketing, antivirals whose 'semi-surrogate' marker benefit is demonstrated but whose clinical benefit was still in question, should be licensed and funded for use in HIV infection on the basis that they inhibit HIV replication and lessen CD4 depletion. It then becomes a matter of joint decision between the patient and his/her doctor whether these effects were worth the attendant and as yet unmeasured risks.

I do not oppose clinical-endpoint trials being conducted as confirmatory trials after benefit on semi-surrogate markers has been shown, but I do object to some of the circumstances in which they have been conducted. Where enrolment is of a person's free will, i.e. other means of access are available, I support them.

Early use

Requests for access to unproven drugs frequently meet with opposition from doctors. This opposition is usually based on three arguments.

Firstly, "Access should be denied because it makes it more difficult to conduct clinical trials." This argument clearly elevates the common good above the individual good, and as such is an unethical position for a doctor to take. I do not question the predicted consequence. I am saying that manipulating availability so as to herd people into trials through a lack of alternatives is unethical. The fact that a predictable price might be paid, or has been paid in the past as a result of adherence to ethical principles, is no reason to flout them.

Secondly, "Patients should be denied use of these drugs because not enough is known about them." If a drug is under development then the most informed and expert opinion is that the probability favours its usefulness, were that not so the company would have abandoned it.

Thirdly, "The ancient medical tenet which says "Above all do no harm." justifies the doctor in denying access". This proposition is totally specious. When a fatal outcome is looming and the use of a promising but unproven agent is an alternative, to do nothing is to do harm.

It is unquestioned that useful and reliable treatments will be developed for HIV if PLWHA are prepared to take some risks with their lives for the sake of others. But to do so must at all times be their decision, not someone else's — particularly not their doctor's.

Conclusion

It seems there is a pressing need to remind doctors that they are not scientists; they are agents of their patients using science for their patient's benefit.

The patient has traditionally been told (and still is told) by the doctor: "Trust us. We know more than you do." They do know more than we do, but unless we can have absolute confidence that they are rigorously applying the basic ethical principles, their superior knowledge is of itself no reason for trust.

I do appreciate the pressures doctors are under as a result of a genuine and noble desire to use their power towards a cure, and the accumulated frustration from many years of impotence. Furthermore I realise that paternalism in the profession, unquestioned by patients until quite recently, is so heavily enculturated that it is difficult for doctors to recognise it in their actions. But it is plain to me that many of the positions taken by the medical profession, both individually and collectively, are inconsistent with the accepted ethics of the profession.

To abandon ethical principals for what is credited to be a greater good is to fail to understand and accept the reason for their existence and their necessity. When faced with a situation where the accepted ethics do not appear to fit the needs of the situation, one must either abide by them or change them. To decide individually or collectively to ignore them is, in essence, a criminal act.

Rolf Petherbridge is a PLWH/A Comittee member and the HIV positive representative on the Clinical Trials and Treatments Advisory Committee of the National Centre in HIV Epidemiology and Clinical Research. This article is based on a discussion paper Rolf presented to CTTAC in November 1995.

Olgas Personals

Sydney East — straight 28 yo positive guy. Bit chubby and shy — 180cm tall, outdoors type but not a greenie, likes surfing, fishing, photography, movies, all types of music, coffee shops, pool playing. Non smoker, non drug taker — occasional drinker — seeks positive lady with similar tastes for friendship/relationship.
960405

Gay Guy — New to Lismore area, would like to connect with guy 30 to 45yo, who enjoys holding, hugging and intimacy. I am mid 30s, slim build, blue eyes, HIV+, passive and quite healthy. I enjoy diversity in people, cultures, and alternative healing approaches. I am a smoker and like occasional rage. Let's connect.
960410

How to respond to an advertisement:

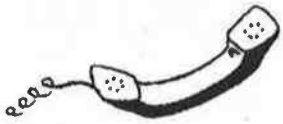
- Write your response letter and seal it in an envelope with a 45c stamp on it.
- Write the Box # in pencil on the outside
- Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst NSW 2011 and you can be assured that it will be passed on.

How to place your advertisement:

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

Pull Out

Contacts



AIDS Council of NSW (ACON)

Commonealth St, Surry Hills
(near Museum Train Station)
Tel: 206 2000

ACON Western Sydney 9 Charles St, Parramatta. 204 2400.

ACON Illawarra 129 Kembla St, Wollongong. (042) 26 1163.

ACON Mid-North Coast 93 High St, Coffs Harbour. (066) 51 4056.

ACON Northern Rivers 147 Laurel Ave, Lismore. (066) 22 1555.

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

Community Support Network (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.

CSN Western Sydney Pat Kennedy 204 2404.

Counselling Professional counsellors available for anyone living with or affected by HIV/AIDS. Free and confidential service, including: One-to-one counselling; home or hospital visits; telephone counselling. Call 206 2000 for appointment.

Fun and Esteem Workshops For gay and bisexual men under the age of 26. Groups in Parramatta, Campbelltown and city. 206 2077.

Gay & lesbian Injecting Drug Use Project (GLID UP). Outreach, information & referral. 206 2096.

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

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

Positive Asian Men's Project Looks at the needs of all HIV+ Asian men. Arnel Landicho 206 2080.

Positive Women Individual or group support for and by HIV/AIDS positive women. Non-judgemental and completely confidential. Women and AIDS Project Officer or Women's HIV Support Officer, 206 2000, TTY 283 2088.

General

AIDS Trust of Australia 221 2955.

Albion Street Centre Information Line 332 4000.

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

Australian Federation of AIDS Organisations (AFAO) 231 2111.

Australian Nurses in AIDS Special interest group for nurses. John Miller 339 1111 or Maggie Tomkins 332 1090.

Civil Rehabilitation Committee Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Joanne Wing 289 2670.

Complementary Trials Incorporated Currently conducting the KM1 Herbal Formula Trial 552 2243.

Gay Men Fighting Aids Gay Men Fighting Aids offers social support and health information for gay men. A volunteer driven project of Central Sydney Area Health Service. Ring 519 5202 anytime.

Gender Centre (The) Services for people with gender issues. Counselling and support, outreach, printed information, accommodation. Provides referral to a range of specialist counselling, medical, HIV/AIDS, education, employment, legal, housing and other community services (02) 569 2366.

Kids With AIDS (KWAIDS) and parents of KWAIDS. c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772.

Hands On Project Community based HIV/AIDS training program for youth workers 267 6387.

Innerskill Needle & syringe exchange, information & referral. 810 1122.

Metropolitan Community Church (MCC) 638 3298. Sydney 332 2457.

Multicultural HIV/AIDS Education and Support Project Workers in 15 languages who provide HIV/AIDS information. Also provides cultural information, training & consultancy. Peter Todaro 515 3098.

National AIDS/HIV Counsellors Association 206 2000.

National Audio Visual Archive of PLWA Royce 319 1887 (after 1 pm).

National Centre in HIV Epidemiology & Clinical Research 332 4648.

National Centre for HIV Social Research (Macquarie Uni) 805 8046.

National Association of People Living With AIDS (NAPWA) 231 2111

NorthAIDS Community-based support, information, counselling and social activities for all living with HIV/AIDS North of the Harbour. Small and friendly. Bill Evans 9982 2310.

NSW Anti-Discrimination Board Takes complaints of AIDS related discrimination. 318 5400.

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

NSW World AIDS Day Project For information on the World AIDS Day program or contacts in your area contact Michael Reid (02) 588 6777.

NSW World AIDS Day Education Office The World AIDS Day NSW project provides HIV/AIDS education using the Australian AIDS Memorial Quilt. Contact Sue Clark (02) 331 4758.

Quilt Project Sydney Memorial project for those who have died of AIDS. 360 7669.

Sex Workers' Outreach Project (SWOP) 319 4866.

Silk Road Social and support group for Asian gay and bisexual men. Workshops, discussions, social activities. Arnel 206 2000.

Social Workers in AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Also acts as a lobby group for people affected by HIV/AIDS. Andrew Harvey, Social Worker, R.P.A.H., Missenden Road, Camperdown 515 3196.

Sydney Sexual Health Centre

Sydney Hospital
Macquarie St
(near Martin Place Station)
For an appointment or information
382 7440
For recorded information
11646

Services provided:

- *Bodyline clinic Wed 6.30pm - 10.30pm*
- *Counselling*
- *Free condoms, dams and lube*
- *Hepatitis B tests and vaccinations*
- *HIV/AIDS tests and care*
- *HIV eye clinic*
- *Multicultural information and interpreter services*
- *Needle syringe exchange*
- *Safe sex information*
- *STD test, treatment and information*

**no medicare card required*

People Living With HIV/AIDS (NSW) Inc.

Tel 361 6011 Fax 360 3504

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

Feeling lonely? Feeling down?

Just need someone to talk to . . ?

Try our **'Phone-A-Friend'** Buddy Line ♦ Our computer can match you with a buddy ♦ Male, female, gay or straight, S.O.P.Y. doesn't discriminate ♦ Confidential ♦ **Call 360 2945** ♦ Support of Positive Youth ♦ 26 Hutchinson Street, Surry Hills ♦

POSITIVE TRANSGENDER SUPPORT

A support network has been established for HIV+ transgender people. For more details contact The Gender Centre on (02) 569-2366

Are you an HIV Positive Woman?

Screamline 1800 630 075 *(Toll Free)*

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

TAYLOR SQUARE PRIVATE CLINIC

Dr Robert Finlayson ○ Dr Ross Price ○ Dr Mark Robertson
Dr Linda Dayan ○ Dr Neil Bodsworth ○ Dr Debbie Couldwell
Fellows of the Australian College of Venereologists
Dr John Byrne ○ Dr. Emanuel Vlahakis
8am to 8pm Monday to Friday ○ 10am to 12 noon Saturday

302 Bourke St Darlinghurst

331 6151

Call for appointment ○ Health Care Card Holders Bulk Billed

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

SYDNEY PLWHA DAY CENTRE A safe place to relax amongst friends. Services include: lunches Tuesday-Saturday, therapies, pool table, computer game, library (books, videos and cassettes), pottery class, spanish dance class, spanish language class, haircuts, day trips and much, much more. 14-20 William Lane Woolloomooloo. Tel 357 3011, Fax 356 4547.

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

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

TROY LOVEGROVE FOUNDATION Provides financial assistance for children living with HIV/AIDS. Sam Corrie 018 290 889.

VOLUNTARY EUTHANASIA SOCIETY OF NSW INC. 212 4782.

CLINICS & HOSPITALS

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

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

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

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

HAEMOPHILIA UNIT Royal Prince Alfred Hospital. 516 7013.

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

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

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

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

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

PRINCE OF WALES Children's Hospital (Paediatric AIDS Unit) High St Randwick. 382 1653. Dental Clinic, Avoca St, 399 2369.

ROYAL NORTH SHORE HIV outpatient, day treatment, medical consultations, inpatient services, counselling, support groups, sexual health clinic, testing. 9926 7414/7415. Needle & syringe exchange 9906 7083.

ROYAL PRINCE ALFRED (AIDS Ward) Missenden Rd, Camperdown. 515 6488.

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

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

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

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

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

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

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

EMOTIONAL SUPPORT

ACON COUNSELLING SERVICE Call 206 2000 for appointment.

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

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

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

FRIDAY DROP-IN for PLWHA at ACON Western Sydney. 204 2402 for confidential information.

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

PARENT'S FLAG Parents and friends of lesbians and gays. Meets 2nd Mon of the

month. Heather, 899 1101, or Mollie 630 5681.

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

QUEST FOR LIFE FOUNDATION Emotional support and education for people with life threatening illnesses, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. (048) 83 6599.

RELATIONSHIPS COUNSELLING A free and confidential counselling service for anyone with HIV, their family, partner or friends. Contact Helen Golding 361-2213 (St Vincent's Hospital).

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

SUPPORT OF POSITIVE YOUTH (S.O.P.Y.) INC. Support, information, advocacy and referral for young people living with or affected by HIV/AIDS. PO Box 919 Darlinghurst NSW 2010. 26 Hutchinson St, Surry Hills. For assistance or a chat please phone 360 2945 or fax 360 5206.

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

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

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

PRACTICAL HELP

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

BOBBY GOLDSMITH FOUNDATION A community based, registered charity providing direct financial assistance to people disadvantaged as a direct result of HIV illness. 360 9755.

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

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

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

NORTHAIDS ACCOMMODATION at Des Kilkeary Lodge, Dee Why. Respite and stepdown support for PLWHA and their carers. All NSW residents eligible. Small day centre. Carrie 9982 2177.

THE SANCTUARY Centre for complementary Thearies focussing on relaxation therapies. Tuesday & Friday 1.00-5.30pm. Gebe Neighbourhood Centre. Transport can be arranged. Bookings essential. Phone Robert 019 906 949 or 690 1222.

STANFORD HOUSE provides short term crisis accommodation for people living with HIV/ AIDS and their loved ones. Referrals through ACON 206 2000 or social workers.

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

OUTSIDE SYDNEY

PENRITH, HAWKESBURY & BLUE MOUNTAINS

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

BLUE MOUNTAINS PLWA CENTRE INC Wed 12noon-4pm (lunch) & Fri 7.00-10.30pm (dinner) (047) 82 2119 or Sue (047) 591611 or Franc (047) 821853.

CSN BLUE MOUNTAINS Hands on practical help for people with HIV/AIDS. Pat Kennedy, (02) 204 2404.

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

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

NEPEAN HIV/SEXUAL HEALTH CLINIC Nepean Hospital. Monday 3pm - 8pm, Thursday 9am - 5pm. (047) 24 2507 for appointments. Counselling & Support (047) 24 2598.

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

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

CENTRAL COAST & HUNTER

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

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

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

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

HUNTER LESBIAN AND GAY INTERAGENCY INC PO Box 3111, Hamilton Delivery Centre, 2303. Contact Jim Ennis, Male Co-Convenor (049) 336 240.

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

KARUMAH DAY CENTRE. First floor, 101 Scott St, opposite Newcastle Railway Station. Open Tues 6-9pm (games night),

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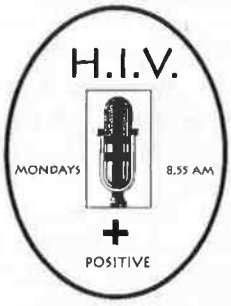

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NEW ENGLAND & NORTH COAST

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

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

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

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

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

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

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MID NORTH COAST HEALTH SERVICE — SEXUAL HEALTH TEAM Primary Health Care Centre, Cnr Boambee & High Sts, Coffs Harbour. Free & Confidential Service. Nursing (066) 591 424; Counselling (066) 591 424; Aboriginal Health (066) 591 489; NSEP (018) 661 723.

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

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

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

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

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

TBAGS (Tamworth Boys & Girls Society) Bernie (067) 85 2147.

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

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

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Area/District Health Service HIV/AIDS Coordinators

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

CENTRAL SYDNEY
Lesley Painter
Ph: 550 5366

CENTRAL WEST
Dave Breckenreg (Acting)
Ph: (063) 32 8576/8538/8571

EASTERN SYDNEY
Marlene Velecky
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HUNTER
Marilyn Bliss
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Chris O'Reilly
Ph: 843 3118

WESTERN NSW
Dr Michael Douglas (Acting)
Ph: (068) 81 2222/2242

WEST

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

DUBBO/MUDGEE SEXUAL HEALTH/HIV SERVICE Robert Baldwin. HIV/STD Worker. Community Health Centres Dubbo (068) 85 8937 & Mudgee (063) 72 6555.

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

ORANGE COMMUNITY HEALTH CENTRE Sexual health info, referral and support. Central West HIV/AIDS Task Force, contact Shirley-Ann Bailey (063) 62 6422.

PLWH/A (NSW) INC THANKS YOU

RED RIBBON — MARDI GRAS LAUNCH

Sydney Gay and Lesbian Mardi Gras, The Luncheon Club, Vaucluse High School, Sydney Opera House, AIDS Trust of Australia

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Sydney Gay and Lesbian Mardi Gras, dc's PINK PRINT, Zulu Advertising and Design Pty Ltd., Tim Clift

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PLWH/A MARDI GRAS FLOAT

Sydney Gay and Lesbian Mardi Gras, David Corbett, Rob Lake, Rob Judd, Paul van Reyk

OTHER

Powerhouse Museum, Yellow Pages Social Club, BGF, South Sydney Council, Darryn Hahn, Paige Slan

A special thank you to Claude Fabian, John Trigg, Larry Wellings, Chris Horden, David Williams, Robert James, Richard Capuano, Wendy Kootoofa and the PLWH/A staff for their extraordinary efforts in ensuring our Mardi Gras involvement was a success.

Also a warm thank you to all other volunteers and supporters who assisted in many ways.

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HIV Community Development Officer
35 Hours Per Fortnight

ACON Illawarra is seeking to fill the above position to initiate and support a range of community development activities for PLWHA (people who are HIV positive and their carers) in the Illawarra and Shoalhaven. The officer will ideally have knowledge and ability in community development, awareness of social issues concerning HIV/AIDS, demonstrated capacity to act as an advocate and to develop and implement education and/or support programs. Sound written and oral presentation skills and skills in liaison with service providers are also necessary. Applicants must also demonstrate sensitivity and a desire to work with PLWHA.

Salary Range: $28,418-$34,607 pro rata per annum

Closing Date: 19 April 1996

Essential criteria for the above position includes a sensitivity and a desire to work with people with HIV/AIDS. A position description, terms and conditions of employment and selection criteria must be obtained before applying. Please telephone (042) 261 163 after 10am Monday-Friday. ACON Illawarra is located at 129 Kembla Street Wollongong.

No agencies please
ACON has a policy of non-smoking in the workplace.

No regrets

It's well over a year since Ricky Brooks died in a Darlinghurst hotel. Ricky, who had AIDS, was helped to take his own life by his lover, Les Hoddy. Les was later charged with manslaughter and aiding and abetting suicide, after he told the police he had helped Ricky die. In November last year, Les was acquitted of manslaughter and given a good behaviour bond on the other charge. The Judge was lenient in view of the fact that Les is himself HIV positive and taking into account the "tragic circumstances" of the case.

Following the judgement, Executive Director of ACON, Don Baxter, called on NSW politicians to enact voluntary euthanasia legislation, saying "This is a clear message from the judiciary to the politicians to reform the [relevant] law". But ***Les Hoddy*** *doesn't want to be a hero. He just acted as many others would in the same circumstances. This is his account of what happened.*

Tell me about your decision to help Ricky to die.

We'd talked about it before and I'd said that I'd be behind him, and that if it got to the stage that I was not well enough, we'd do it together.

We'd had a bit of a disagreement because he'd just got out of the Hospice, and he wanted to go to Sleaze Ball. I didn't think he was up to it, he was still quite ill. So I hadn't heard from him for a while, and next thing, I got this phone call, it was Ricky: "Les, I've just stuffed up . . ."

I went over, he'd booked himself into a hotel. He was determined. He'd taken, I'd say, quite a few bottles of codeine. You could see that he was tired, tired of having to take all the different drugs, tired of going to see the doctor three or four times a week.

When I got there we talked. He was rambling on a bit, but lucid. I had to think, do I help him any further? He said "I need help, I want to . . ." So I did. Then we just sat on the bed and talked.

I gave him the option of ringing the ambulance. We cried I think, and we held each other, and I left. It was not until late that evening that I found out from the police that he had died. The police took it down as being suicide.

Why did you go to the police three weeks later?

I don't know if it was guilt or what, that came over me, but I decided that people should really know the truth. Why should people have to go and hide in hotel rooms? Why couldn't he have done it at home?

That night I was feeling so down. I rang Ankali and they said don't go to the police. I rang a really close friend, who said, think about it, wait until tomorrow, when you're sober. I was quite mad, I'd drunk quite a lot and taken a lot of anti-depressants. I thought I'd ring the police and just talk about it hypothetically, and of course it all just blurted out. They came around to my home and questioned me for about half an hour, then said, we'll just go down to the station, you'll be at home in your own bed in a few hours — next thing I was charged with manslaughter, aiding and abetting a suicide. And I was placed in a cell and I was going to appear in court that morning. Then I spent two days over at Long Bay, waiting for Bail.

The police had said nothing would happen — I didn't realise I was going to be charged. I made it quite clear — I don't think I killed him, I helped him. I would consider doing it again, if the situation arose. I've got it planned for myself. I'm sure I'm not the only one.

Do you regret going to the police, now that it's all over?

No, I don't think so. I think we've opened up a door. I'll admit there wasn't much support around at that time. I went through ten months of no support, then suddenly ACON turned up and took over everything. They were quite happy to do all the talking to any media.

Where did you look for support?

I had the support of my Ankali. I went to the Inner City Legal Centre and they're the ones that got me onto David Buchanan, my barrister, who has a lot to do with ACON. I feel I was used by ACON to push their barrow. I feel that I was also being used as their guinea pig. I didn't plan to be an activist on this issue. A lot of people have commented that they felt I was being used.

Because ACON was developing the Voluntary Euthanasia Bill at that time?

I wished I'd had more support from ACON for the whole period of the court case. The support only started coming quite late in the case, after the manslaughter charge was dropped. *

What was it like going through the last year?

Well, I had to appear at the police station every day. I spent the year seeing psychiatrists. I ended up having a stroke in January through all the stress. I was on all these different drugs.

There were times when I'd just leave the answering machine on or pull the phone out of the wall. I tried to kill myself a few times. It was like I had nobody left. I thought, I'm going to be lonely for the rest of my life. It's very hard to find somebody when you're HIV positive. But then I started getting supportive letters from places like the SIDA Centre in Perth — I come from Perth.

Once the manslaughter charge was dropped, it was a lot off my mind. They changed the charge from aiding and abetting a suicide to aiding and abetting to assist a suicide and it seemed a lesser charge, although it wasn't, it was still a maximum of ten years in jail. Then it took quite a few months until court came up.

Through all this, my health has now deteriorated and I've gone into AIDS. I was quite healthy when I met Ricky.

There's also the people that persecute you, the right to lifers — I've lost a few friends through their Christian beliefs. I got a few phone calls that were quite nasty, so I decided that my phone number should be changed and taken out of the phone book.

My flat was broken into. People found out that I was HIV positive and didn't want me in the building. I was persecuted to the point that I had to leave. Someone had painted "killer" on the wall, "poofter", or "AIDS Carrier". I had my door smashed in. That's when I had a stroke. I'm better now, but it has downgraded my health. It's only now in the last couple of months I've started getting on with my life.

PHOTO: JAMIE DUNBAR

Do you feel like you've had a chance to grieve for Ricky properly, with all this other stuff going on?

Not really. I was working at the time and I found I had to give my job up. I have to move out of where I'm living now, the media still know where I am. I've got a place to move, so I feel like it's all going to be a new start.

I feel that I can talk easily about it now. Not that a tear doesn't come to my eye — I can still remember the day that it happened. Now I can look back on the photo album. It's getting easier. It's good actually — I never volunteered in my whole life, now I help with BGF, I volunteer with the Luncheon Club. It's got me up and doing things, instead of feeling sorry for myself. Because I could have either kept going down, which I was, or start coming up.

I don't want to be seen as a martyr. Maybe it was about time somebody came out and said something, but it's now time for the government to do something. I don't want other people to go through what we did. Ricky may have had another year in him, but it could have been a year of hell. I think what he chose in the end was very brave. Maybe he did botch up, but I'm glad that I was there with him. I want the government to listen.

* The manslaughter charge was dropped because it was found that the amount of medication Les gave Ricky could not have caused his death alone.

Interview by Jill Sergeant

Kosmetic Survival

Kaposi's sarcoma (KS) remains a significant problem in people with HIV, although it appears that the overall incidence is declining and it is tending to occur in later stages of HIV infection. ***Dr Mark Newell*** *outlines your treatment options.*

BECAUSE IT IS HIGHLY VISIBLE, KS can cause considerable anxiety in those affected. As the disease can be both physically and psychologically distressing, a sensitive approach is required by the treating doctor.

The overall situation with regard to KS therapy has improved recently due to the increasing availability of more effective therapies. Also, new evidence that a sexually-transmissible herpes virus is involved in causing KS may lead to innovative diagnostic, prevention and treatment strategies in the future.

Kaposi's sarcoma presenting at an early stage, where the disease is only confined to several small skin lesions, can be dealt with by using local therapy or, if you prefer, simply left alone and observed, the lesions concealed with cosmetic camouflage cream. However, it is advisable to confirm the clinical diagnosis of KS with a biopsy. This can easily be performed in a doctor's surgery under local anaesthetic. A small piece of the KS (about 4mm across) is removed and the area closed with a single stitch. The laboratory can then confirm the diagnosis. This is important as very occasionally a lesion resembling KS may be caused by a bacterial infection which can easily be treated with a conventional antibiotic. Malignant melanoma may also resemble KS.

Local treatment of early KS is becoming more common as there are presently at least three options for treatment. These are: local injections of a dilute solution of the anti-cancer drug vinblastine directly into the KS lesion (intralesional injection); freezing with liquid nitrogen spray (Cryotherapy); or radiotherapy.

Intralesional vinblastine (see next page) is one method of treating small, uncomplicated KS skin lesions and is best reserved for those less than 1.5 cm in diameter. Local anaesthetic cream can be used beforehand, but some people experience some pain at the site during the injection and for a couple of days afterwards. Such pain can be easily managed with over the counter pain killers.

The same procedure can also be used to treat lesions of the oral cavity, using local anaesthetic spray beforehand and regular antibacterial mouth washes afterwards to reduce any chance of local infection.

After treatment, the lesions usually flatten and become paler in colour over the next couple of weeks. Occasionally some lesions become moist several days after injection due to the breakdown of the KS. If this occurs, simple cleaning with saline and dressings can help. It is advisable to cover such lesions, as the fluid will contain HIV. Any which have not completely cleared up can be reinjected once they're healed.

Some specialist HIV centres also use liquid nitrogen cryospray from a special canister. In this procedure, the lesion is sprayed until frozen. One US AIDS cancer specialist prefers this method to intralesional vinblastine as, in his experience, the patients experience less pain.

Alternative local treatments presently under research include retinoic acid derivatives and the sclerosing agent sodium tetradecyl sulphate; the latter is used in some centres for lesions affecting the mouth.

If the KS lesions are still few in number but larger than 1.5 cm and therefore unsuitable for the above methods, they can be treated effectively with a course of radiotherapy, which is done in specialised hospital centres. This procedure is especially useful if there is swelling of the lesions causing discomfort and/or there are several lesions close together in a cluster that can be treated using a single radiation field. Local redness similar to mild sunburn can result and the lesions usually flatten and become pale over the next few weeks. However lesions in the mouth are often not suitable for radiotherapy due to local reaction and treatment of the feet requires special care.

The most important decision you'll make in managing your KS is when to start systemic intravenous chemotherapy. The usual indications are a large number of lesions, rapid appearance of new lesions, large lesions causing symptoms — especially pain and swelling — or any evidence of

lung and/or gut involvement. The standard regimen (bleomycin/vincristine) is generally well tolerated without the usual side effects associated with chemotherapy such as hair falling out or nausea and vomiting but may be only partially effective. However vincristine can cause reversible pain and tingling of the hands and feet after some doses and should therefore not be given if you already have these symptoms from HIV itself or other anti-HIV therapies such as ddI.

The situation has improved with the availability of cancer drugs encased in microscopic fat globules called liposomes which help to concentrate the drug in the tumour where it's needed. One of these drugs uses an established anti-cancer agent (doxorubicin) encased in a liposome. This drug (liposomal doxorubicin) has been licensed in the US (DOXIL) and is available in some HIV centres in Australia on a compassionate basis, usually for KS that is not responsive to conventional chemotherapy.

There is good evidence that these new agents are more effective than the drugs previously used, As with many anti-cancer drugs, the main problem is bone marrow depression leading to a fall in the white cell count. However another relatively new drug, G-CSF, can be used in conjunction with chemotherapy to help maintain the white cell count and thereby prevent infection. In addition, other drugs causing bone marrow suppression may need to be stopped or have their doses reduced if possible.

In general, KS, although still a very distressing condition, can now be controlled in the early stages and therapy is improving for the more advanced cases. If the disease is not under control, it is important to get an early referral to a specialist in HIV cancers who can then discuss the various treatment options with you.

Mark Newell is the Clinical Trials Co-ordinator for HIV/Oncology at the National Centre of HIV/AIDS Epidemiology and Clinical Research.

Vinblastin' KS

GRAPHIC: JIM CHAN

*When **Max Spears** developed Kaposi's sarcoma in 1994, he sought effective treatment that had few side effects. Based in South Australia, Max was at a disadvantage, not having access to the latest and most effective treatment options. However, his determination paid off when a dentist and oncologist suggested he try vinblastine injected into KS lesions.*

IN 1988, I WAS LOOKING THROUGH an AIDS medical book when I found a picture of an intralesional (directly into the lesion) injection of a Kaposi's sarcoma lesion. The lesion was on the man's penis. I remember thinking, "I hope it doesn't happen to me".

In 1994, I developed nodular KS lesions. My local doctor cut them out and later my AIDS specialist referred me to an Oncologist (cancer specialist) at Royal Adelaide Hospital. She treated me with radiotherapy.

I rang Sydney and found I could have alpha interferon, but not in Adelaide. I sold my flat and moved to Sydney and was told of the side effects. I refused the treatment as I was not yet sick and not used to night sweats and flu like symptoms. The cost for this treatment was $50,000 per year. I did not want to have AIDS clearly stamped on my body; I was not yet sick.

In Sydney, on the pension, I tried a number of different treatments for the KS lesions.

1. Trental to reduce Tumour Necrosis Factor.
2. Radiotherapy from a begrudging oncologist.
3. Cryotherapy.
4. Systemic chemotherapy (vincristine/bleomycin). The poisonous side effects that went on for the next year were attributed to HIV. I lost my sex drive and I was sick and exhausted most days.

I went back to Adelaide to die with my cosmetically damaged body. But I survived, received lots more radiotherapy in small doses every morning for a week. And still they came, six to eight lesions at a time. And still more radiation, at great cost to the hospital and to my stress levels.

The oncologist, working with a brilliant dentist at Adelaide Dental Hospital, assumed that oral KS treatment would also work on the skin. That is, she suggested we use vinblastine as intralesional treatment. I agreed to try, having asked to have it two years previously. [Vinblastine has been available for treating KS since 1957, but because the injections can be extremely painful, it has been left alone].

After initial trouble in working out how much vinblastine to use, we followed the dentistry experi-

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➤ FROM PREVIOUS PAGE

ence and used 0.1ml of 0.1mg/ml. The pain was too much, as even the lignocaine pain killer hurt with injection. I introduced EMLA cream, applied to the lesion at least two hours before the injection and felt no pain. It worked, although I continued to have problems with the lesions on my feet. [EMLA cream is an S2 item made by ASTRA Pharmaceuticals].

After treatment, the area around the lesions should turn red in two days, indicating an inflammatory response. The vinblastine will numb the region for about three to four weeks. As the lesion heals, the dry skin will disappear. The important point is that it looks dead.

Practices in Sydney and Melbourne have been using intralesional vinblastine for some time. The process should be quickly adopted by local GPs throughout the country, with referral to specialists.

Other factors to consider:

1. Your doctor can dilute the Vinblastine, which cuts costs — it doesn't have to be done in a laboratory.
2. Medical insurance will cover this procedure.
3. At commercial rates, vinblastine costs around $40-$70 for 20ml.

While intralesional vinblastine is considered 'standard treatment' in some parts of Australia, some people with KS have no access to this treatment. My search for an appropriate treatment highlights the need for formal standards of best practice. Thanks to Doctors Liz Coates and Linda Swainey from Adelaide and no thanks to the National Treatment Project (NTP), for failing to inform people about this treatment.

***Ed:** The NTP has taken note of Max's criticism and will be publishing his article on vinblastine in their next edition of* HIV Herald.

Dr. Mark Robertson, from Taylor Square Private Clinic, comments:

I HAVE USED VINBLASTINE WITH six patients and four others have been treated at this clinic. Of the five I've spoken to recently, three of them found it quite helpful, but two others had to go onto chemotherapy.

We only use vinblastine to treat lesions which are less than one cm. across. (This is standard in the UK, where the procedure is used a lot). This means we often do it as soon as a lesion comes up, just as part of a regular visit.

Using a multi-dose vial (and of course observing infection control procedures) it works out to be quite a cheap treatment. I've only had to inject lesions once, occasionally a second time. If someone has multiple lesions, we usually refer them to St Vincents for an assessment.

Vinblastine is good as a cosmetic treatment for small lesions when the person is otherwise well. If they're very unwell and have a lot of lesions, there's not much point in using it. It's not a 'cure' for KS, but we have had no problems with lesions recurring on people who are treated with Vinblastine. It's a good alternative to radiotherapy as a cosmetic treatment for KS.

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- Equipment Lending i.e. Wheelchairs, walking aids, spence mattresses & other home comfort aids Ph HIV OT 690 1222
- Gym/Exercise & Hydrotherapy Classes Ph 515 6111 pge 6861
- Injecting Drug Users Counselling Ph 660 5455
- Mental Health Counselling Ph 560 4500
- Multicultural Support & Education Ph 515 3098
- Newtown Needle Exchange Ph 515 3138
- Pain Management/Palliative Care & the On Call Nursing Service Ph 515 7744
- Relaxation, Stress management & methods for maintaining your energy levels Ph 515 6111 page 2550
- Sexual health advice & Screening Ph 560 3057

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PROVIDING QUALITY CARE IN THE INNER WEST

What's viral load really mean?

By Alan Strum

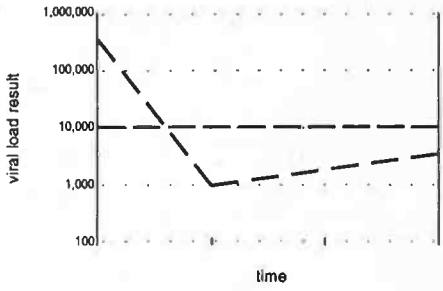
THE VIRAL LOAD TEST TELLS YOU how much virus is in your blood. This is a highly specialised test which has been made relatively simple for labs to use.

Because the virus itself is too small for us to count, a special technique is used that amplifies the genetic material of HIV (HIV RNA). This means that the test provides very specific conditions in which the HIV genetic material is copied, and copied again and again until enough of the HIV genetic material is present to the point that it can be easily counted. Once the genetic material has been counted the lab then calculates back to how much HIV genetic material was present in the first place. Thus we are able to determine the actual amount of HIV genetic material, which we call 'viral load'.

A confusing aspect to the results of a viral load test is that they are often expressed in terms of 'log' values. Many of us would not have a clue what this really means. Some might be able to remember back to school days when we used log tables and log graphs (does this sound familiar?).

Using log values makes it possible to fit small figures and large figures onto graph paper. Thus it is possible to make graphs of results from say ten up to the millions on one piece of paper. This is done by using a scale of ten. Log can be expressed to base 10. So the first multiple can start at 10, then 100, then 1,000, then 10,000, then 100,000 and then 1,000,000 etc.

Charting Viral Load
using a log scale



Consequently, if you have a viral load of say 500,000 and you reduce this by using some of the new drug treatments that are becoming available to say 1,000, then you have reduced your viral load by about 2.5 logs (see graph).

If you decide to get your viral load tested then it is possible for you to graph out your results over time by using a log graph sheet that you can buy from newsagencies. This way you can check to see what's happening in your body with the virus. If your viral load is high (greater than 100,000 copies) then you might want to consider starting antivirals. If your viral load is low (below 10,000 copies) then maybe you don't need antivirals.

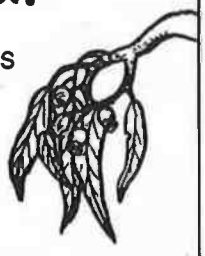
A high viral load is associated with an increased risk of disease progression. Conversely a low viral load is associated with a decreased risk of disease progression. Using viral load tests will also be a useful tool for letting someone know if their antiviral drugs are working. This will be seen by a reduction in the viral load after commencing antiviral therapy. If, after a period of time, the viral load goes back up it could be time to swap to a different antiviral regime.

In the future viral load results will become an integrated part of HIV management, indicating whether someone is at risk of progressing with HIV disease, whether they should consider using antiviral treatments and when to change antiviral treatments.

Alan Strum is NSW Treatments Officer at ACON.
For futher reading see PI Perspective, *Number 17, December 1995.*

Talkabout Goes Bush

Our second rural special issue will hit the tracks in May. Send in your contributions now . . .
stories, poems, reflections, drawings . . .
to: PO Box 831
Darlinghurst, 2010.



Tiredness tactics

Too tired to lift a finger? It's not just post-Mardi Gras blues. Almost everybody living with HIV will experience fatigue at some stage of their illness. Everybody has different strategies to help them cope. ***Mary Jackson*** *offers some ideas and suggestions to help manage your fatigue.*

FATIGUE IS DIFFERENT FOR EVERYbody and what works for some people will not work for others. Fatigue can be experienced due to a variety of reasons ranging from the HIV disease process, to stress related and medication related reasons. The important thing to remember is that it is affecting you and your lifestyle and so it is important to try and manage it.

Activities that you have to do every day can often cause fatigue which may prevent you from doing the other things that you want to do. Many people find showering and dressing can be very fatiguing. If you sit down to shower and dress and undress it can often make it easier as you are not having to support yourself — the chair or stool is. Having a hot shower creates a very humid environment especially if the room is not well ventilated. Humidity can tire you, just like a humid day, so a lukewarm shower in a bathroom that is well ventilated will help conserve your energy. If you find showering does really exhaust you have the shower last thing at night so you can go straight to bed.

Do you have any other tips for handling fatigue? Send them in to *Talkabout*, so other readers can benefit from your ideas. Our address is on page 2.

Having breaks throughout the day — time out and even taking rests during tasks can help. For example, take a five minute rest to just sit and read the paper and then go back to whatever you were doing, rather than trying to do the whole thing in one go and exhausting yourself. If you can, take regular rests before you actually start to feel tired. Make sure your workspace or environment is user friendly so that work isn't more difficult than it has to be. You will probably have good days and bad days so try and put off some things until you are feeling better or ask somebody to help.

As already mentioned, sitting rather than standing can help because the chair supports you. Try sitting down when you are doing tasks like washing the dishes or preparing a meal.

Exercise can also help with managing fatigue — gentle water exercise like hydrotherapy is a good way to start — talk to your local physiotherapist or contact Mark Zacka at Royal Prince Alfred Hospital regarding the hydrotherapy and exercise programs they run there.

Managing your fatigue is really about balancing your workload and routine — work out a schedule that works for you, not for somebody else.

Mary Jackson is an occupational therapist with Northern Sydney Area Health Service. The ideas in this article come from people living with HIV and AIDS and other people Mary has worked with who also experience fatigue as part of their illness.

If you would like more information on how to manage your fatigue or want to have a specialised program worked out for you, contact your local occupational therapist. Occupational therapists work at major hospital units in Sydney and also through community health centres.
Royal North Shore - 9926 7103;
Clinic 16 - 9926 7414;
Prince Henry - 694 5448;
Sacred Heart - 361 9444;
St Vincent's - 361 7361;
Redfern Community Centre - 690 1222;
Darlinghurst Community Centre - 360 3133.

GRAPHIC: PHILLIP MCGRATH

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SHIT SCARED

By Alan

I WAS VERY ENTERTAINED BY Annoner Muss's "Pack yer daks" tips (*Talkabout*, February). Well, entertained til about 18 hours later. There I was, standing chatting to a friend, a slight twinge, the eyes went wide, wider, *"Oh no, no!"* and the entire contents of my 23 feet of intestine deposited itself in two and a half seconds on the *outside* of my body. Into my boxers and shorts, albeit momentarily, before running or glooping down my legs and filling my runners. I would like to say Nike runners but on a pension they are more your Dunlop Volley type of Nike. One good thing about country living is that brown spattered Dunlops don't raise an eyebrow.

Annoner Muss was right, boxers don't hold much. In fact — nothing! And maybe instead of the runners, gum boots might be the go — a new fashion trend, (well, they appear popular with Russian housewives).

Also praise the lord for the change in home styles in the 90s — it's all polished floor boards and tiles now and no longer the shag pile or berber. "Oh that's an interesting coffee stain — over your entire lounge room."

My 'Pack yer Daks' tips include a repertoire of nonchalant comments, e.g. "I appear to have had a little accident." (Oh, really.) "I just might pop into the bathroom to freshen up a little before coffee", and my favourite: "Oops".

Or if you wish to be a touch witty and lighten the situation (and why not — you're suddenly five kg lighter): "The wind seems to have picked up", or "I love the smell of Napisan in the mornings", or even better, accusingly point at your friend and say "Did you fart?"

Other tips:

- Never, never ignore even the slightest twinge.
- Don't ever fart.
- Keep an ice cream container (empty) by the bed and in the car. But not the Streets Blue Ribbon chocolate container, it's a bit off putting and let's not lose hold of all our illicit pleasures.
- Carry a pack of Wet Ones at all times.
- Don't go out.
- If you do go out stand close to the toilets at bars. Have you ever tried getting from one side of the Oxford to the other in two and a half secs?
- Don't let anyone squeeze your butt (no matter how cute they are — actually, especially if they are cute.
- Don't eat for 48 hours before getting fucked.
- Don't fuck on a loose day.
- Don't fuck.
- Buy pantie shields — ask your sister!
- Never squat.
- Move your telly into the bathroom.
- Wear a yashmak so no-one will recognise you.
- Sit down for a few minutes more *after* wiping your bum.
- Burn incense in your undie drawer.
- Consider a colostomy — with the extra large bag. The floral patterned bag is quite nice . . . but finding the shoes to match — yes, yes, an oldie (but a goodie)!
- Insert an extra large butt plug. It won't help but at least you will have a smile on your face for half the day!
- Get a baby and blame it for that odd odour that now permeates your entire home.
- Don't, don't let anyone serve you dhal.

GRAPHIC: PHILLIP MCGRATH

So those of us 'flatulent with follow through' go quietly and keep the tips coming in. A new title perhaps: 'shit scared'.

. . . and finally, into the bathroom, walking very gingerly, lean your head against the wall and sigh! Coz there is sweet fuck all else you can do about it!

***Ed:** This takes our 101 tips for living with diarrhoea up to around #53. Keep them flowing in! (And tips you've found helpful for dealing with any other HIV inconveniences.) PO Box 831, Darlinghurst 2010.*

COMMUNITY PROJECT WORKER

PRIDE is committed to providing services for the social, cultural and political development of the Sydney lesbian and gay communities. PRIDE engages in fundraising activities and community outreach programs and is committed to facilitating and supporting the lesbian and gay community response to HIV/AIDS focused community development programs. The activities for this project support the National HIV/AIDS strategy which endeavours to increase awareness of HIV/AIDS issues within populations at risk. The PRIDE community HIV/AIDS mobilisation project is a grassroots community development initiative designed to increase the visibility of community commitment to safe sex and safe injecting among gay men and will be for an 18 month period. This position, specifically targeting gay men, will complement an existing project targeting lesbian / gay / queer / transgender users of the PRIDE centre.

The project worker must be able to demonstrate a commitment to the gay community and possess knowledge of issues affecting gay men, in particular, NESB, Aboriginal and Torres Strait Islanders or differently abled. The position involves collaboration with gay community groups to ensure that safe sex and safe injecting practice messages are visible within existing activities. The position would suit a person with experience in co-ordinating community development activities, or a recent graduate in Social Work, Behavioural / Social Sciences or Nursing.

PRIDE is committed to coalition policies and gender parity in all areas of its operation. The organisation is also committed to anti-discriminatory practices in relation to sex, disability, age, ethnicity, race and HIV status. The position will be worked over a 35 hour week. Salary $29,425. Applications must be received by Friday April 19, 1996

For a copy of the selection criteria and position description contact: Bronte Morris at PRIDE, Monday - Friday 10 am to 6 pm on (02) 331 1333 or fax (02) 331 1199

The AIDS Council of NSW (ACON) is a community-based organisation providing a range of services for people living with HIV/AIDS and affected by HIV/AIDS. ACON services include preventative education, support, legal and advocacy. ACON is an equal opportunity employer and encourages people with HIV to apply for positions.

HIV Women's Support Officer

40 Hours Per Fortnight

This position will provide information, education, peer support and referral to women living with HIV. The Officer will develop strategies and services to ensure that Positive Women are provided with services which are sensitive to their needs and the needs of people close to them. The Project also works collaboratively with ACON's Women and AIDS Project to ensure successful outcomes for Positive Women.

Under ACON's HIV employment policy this position is designated to be filled by a person with HIV. We are seeking a HIV positive person for this position. The successful candidate should possess good communication skills, along with a direct knowledge of HIV/AIDS to be able to provide support to Positive Women. Project planning and the development of new services are also an important part of this project.

Salary Range: $33,548-$34,607 pro rata per annum

Closing Date: 19 April 1996

Essential criteria for the above position includes a sensitivity and a desire to work with people with HIV/AIDS. A position description, terms and conditions of employment and selection criteria must be obtained before applying. Please telephone reception on (02) 206 2000 after 11am Monday-Friday. ACON Sydney is located at 9 Commonwealth Street, Surry Hills.

No agencies please

ACON has a policy of non-smoking in the workplace.

NEW HIV EYE SERVICE

Sydney Sexual Health Centre
Sydney Hospital in conjunction with Sydney Eye Hospital

Eye Clinic
Thursday mornings 8:30 to 10:30

(to expand with demand)

- Eye checks for people without eye symptoms with CD4 counts less than 50 or with AIDS
- Eye symptoms in PLWHA
- Full opthalmic service
- Management or prophylaxis of CMV retinitis:
  - IV induction (inpatient or outpatient)
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  - Latest trials
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- Shared care and liaison with private doctors
- Confidential, no Medicare card required, no referral necessary
- Consultant: Dr Mark Gillies PhD, FRACO

For an appointment or more information telephone 382 7440

The Blue Mountains PLWHA Centre Inc.

WE ARE A SUPPORT CENTRE SITUATED at Katoomba in the Blue Mountains. Originally called the "Haere Mai" Day Centre, the Centre was formed in May 1990 and became incorporated as the Blue Mountains PLWHA Centre Inc. on December 24, 1992. The Centre registered as a Charitable Fundraising Organisation in September last year, so all donations of $2.00 and over are tax deductible. We are not connected with any other PLWHA organisation.

Services provided by the Centre include:

Direct financial assistance for food, heating and phone bills etc. Living in the mountains can strain finances for PLWHA, especially in winter with the added costs for heating.

Lunch on Wednesdays and dinner on Fridays We endeavour to provide two nutritious meals a week at no cost to positive people and for a nominal donation to friends and others. Rostered volunteers (members, friends or organisations such as CSN West) cook the meals. Costs are reimbursed by the Centre. These meal days are a time when people can come together for companionship, peer support and any of the activities that the Centre may provide such as video nights and bus trips. We also occasionally get visits from other groups e.g. the Sydney Day Centre.

Pharmaceuticals prescribed by the Woodlands Clinic at Katoomba Hospital are paid for by the Centre if dispensed at the hospital pharmacy.

Fortisip and Ensure supplements are made available for free through the Woodlands Clinic to those needing them. The Centre covers the cost.

Franc with Sue, PLWHA Centre President, at the Jungle Fever fundraising party.

These are just a few of the areas which our budget covers.

Household items for loan from the Centre. We have a limited number of household items which we can supply to members who need them, including bar fridges, heaters, electric jugs and TV sets (numbers are limited). We also supply pre-loved warm clothes, curtains etc.

The Medlow Bath Park is also a project of the Blue Mountains PLWHA Centre Inc. In 1992 a sub-committee of the Centre was formed to conserve the Medlow Bath Park as a living tribute to those who have passed on due to HIV. People have planted an avenue of flowering Cherries, a Maple grove, a Camellia grove and a Pittosporum hedge, and lined the perimeter with Rhododendrons. Most of the trees and shrubs planted have commemorative plaques.

The premises are provided by the Blue Mountains City Council. At present the Centre receives no Government funding. We have in the past received a funding grant from Western Suburbs Area Assistance Scheme which enabled us to purchase the necessary items to set up our office and to employ a part time co-ordinator for part of 1995.

Services are now administered by a management committee of four and our working budget comes entirely from donations and fundraising events. The Centre tries to hold between three and four dance parties a year. Our last party was the "Jungle Fever" dance held in February. Our next party will be "Let it Snow" in May. Last August the "Rainbow Fantasy", a formal dinner and evening of entertainment and celebrity auctions, raised a substantial amount of money earmarked for financial assistance.

Another popular fundraising event, held three times so far, is the Cottage and Country Garden Weekend on the third weekend of October each year. A selection of private gardens are opened to the public and the money raised is distributed between the Woodlands Clinic at Katoomba Hospital, CSN West, Karuna, Medlow Bath Park and the PLWHA Centre.

For more information call the PLWHA Centre (047) 82 2119. See also Contacts list p.17.

— Franc Hancock, Secretary

Talkabout

WHERE WE SPEAK FOR OURSELVES

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

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

PLWH/A membership

Yes! I want to apply for membership of PLWH/A (NSW) Inc. **$2** per year as a:

- ❑ Full member (NSW resident with HIV/AIDS)
- ❑ Associate member (NSW residents affected by HIV/AIDS)

Disclosure of HIV status entitles you to full membership of PLWH/A, with the right to vote for all management committee positions. Membership status is strictly confidential.

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  - ❑ *(Extra copies **$30** each per year)*
- ❑ Concession (PLWHA organisations, non-funded community based groups etc.) ***$40*** per year
  - ❑ *(Extra copies **$15** each per year)*
- ❑ Overseas ***A$120*** per year
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