

No. 78 August 1997

Talkabout

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

◆ , Where We Speak for Ourselves ◆



Treatments and Lifestyles

Introducing Paul Maudlin

Positive Speakers Bureau Co-ordinator



DEDICATION. THAT'S WHAT COMES across when you talk to Paul Maudlin. Twenty years dedication to the Royal Australian Navy (which resulted in him being decorated with the Order of Australia). Dedication to the Positive Speakers' Bureau (PSB) ever since it started in 1994. And most recently, dedication to his new role as Co-ordinator for the Bureau. Since his HIV diagnosis in 1993, Paul's done HIV Peer Support Facilitator training, facilitated support groups and worked with Ankali. He first heard about the PSB at a positive support group in 1993 and attended a ground-breaking community meeting in April 1994 to toss ideas around about what the PSB could do. By the time the PSB was launched on World AIDS Day 1994, Paul was already trained up as a positive speaker and actually missed the launch: "I wasn't there," Paul says, "because I was doing my first talk in Tullamore, near Dubbo". By then, Paul had

left the navy and was working for an electronics company. "I'd say to my staff, 'Well, look. I've gotta go off for a couple of hours, you know, cover for me.' And so I'd be all over the place doing talks, sometimes a couple a week." Since then, Paul has clocked up nearly three years worth of community talks on HIV. "The talks I give are pretty much the same", he says, "although you vary it depending on the audience. I tend to do my personal story which is a brief history of pre- and post-HIV diagnosis. It never ceases to amaze me just what they come up and ask." One of PSB's goals is to dispel myths about people with HIV and Paul can see that happening during his talks. "The myths are blown away because they see you as a real person. I mean, I was married, got two kids and they look at that and say, oh wow, this is not your typical gay man syndrome, he's got kids our age. It becomes all so much more real to them." At the end of last year he found the demands of working full time, being in a permanent relationship and running between various meetings for one organisation or the other was all too much, so he dropped everything except the PSB. Paul and other PSB colleagues have just put together a promotional pamphlet for the PSB and their next step is to figure out promotional campaigns and target audiences. "I'd like to reach a huge audience but I just don't think enough people know about us. People, like service clubs, Lions, Rotary . . . I'm sure if people were

aware of our service they would use us. Even the gay community doesn't seem to use us as well as the general community."

What about the personal side of Paul? He's *almost* a born and bred Sydney boy (he was born in England but came to Australia at the age of 2). He lives in a federation cottage in St Peters with his partner Nicholas in a domestic arrangement that sounds nicely balanced; Paul does the handyman stuff around the home and Nicholas is a great chef! Paul reads a lot and keeps a journal about HIV which he wants to use as the basis for a book. Music, ten-pin bowling and the gym help Paul to relax. He is also training as a telephone counselor with the Gay and Lesbian Counselling Service and hopes one day to complete a professional counselling course. Is Paul good value or what? I say book him for a talk soon!

- John Cumming



If you would like to use our services or be involved as a speaker ring Paul on 9361 6011



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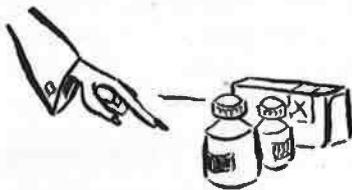
PLWHA Email: plwhagen@rainbow.net.au
Research Email: plwaha@rainbow.net.au
Fax: 9360 3504
Office: Suite 5, Level 1, 94 Oxford St
Post: Box 831, Darlinghurst NSW 2010
Phone: 9361 6011
Talkabout: 9361 6750
Freecall: 1800 245 677

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This month's cover

By Phillip McGrath, is a playful look at the interplay between doctors who insist on the importance of regular dosing, and their patients, who may feel trapped by dosage regimes. Turn to page 12 to see some opinions about the "C" word!

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Contributions: John Cumming, PO Box 831
Darlinghurst NSW 2010
Tel: (02) 9361 6750

Advertising: Sandy Thompson
Distribution & subscription enquiries:
Paul Roberts, Wed & Fri.

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● In a recent issue of *Antimicrobial Agents and Chemotherapy*, the National Cancer Institute in the United States reported on the discovery of a protein extracted from blue-green algae that has been shown to inactivate HIV in test tubes. According to researchers, the protein (CV-N) not only irreversibly inactivates diverse strains of HIV-1 and HIV-2, it also inhibits cell-to-cell as well as virus-to-cell transmission of the virus. Enthusiastic about their discovery, the researchers were led to conclude that (CV-N), the first antiviral protein to be extracted from a blue-green alga "provides a novel lead for further investigation of new potential therapeutic and preventative strategies against HIV infection."

● The US Food and Drug Administration (FDA) has warned doctors in the US about the possibility of protease inhibitors causing a new side effect - diabetes. This side effect has been noted across all of the four protease inhibitors currently available. The risk of developing diabetes appears to be low - less than 1%, and of the cases reported, on average it took about 76 days of protease inhibitor use for symptoms of diabetes to appear. Those who did develop diabetes were able to control it with insulin or oral drugs. With the risk at such a low level, it is believed that the benefit from protease inhibitors outweighs the risk of developing diabetes.

● A study published in *The American Journal of Psychiatry* this year has shown that severe stress speeds up the decline of the immune system. Over a period of three and a half years, 93 HIV positive men (symptom - free) were followed, and it was documented that "the more severe the life stress experienced, the greater the risk of developing symptoms". For every severe life stress in each of the six month intervals, the risk of developing symptoms of HIV infection doubled. This study documents for the first time the links between the brain and the immune system, which enable these different parts of the body to influence each other.

● At least 75 percent of the world's AIDS cases are found in sub-Saharan Africa, according to the World Health Organisation. Since the discovery of the first case of AIDS in early 1980s, about 4.5 million of the world's 6 million cases have been diagnosed there. Sexual contact is the major mode of transmission; multiple sex partners for men continue to aggravate the rate of transmission. However, an estimated 70 percent of males in Zambia and Zimbabwe now use condoms to prevent HIV transmission and pregnancy.

(Xinhua News Agency)

Hey Minister!

THE NSW COMMUNITY SERVICES Minister Mr. Ron Dyer has come under fire from HIV/AIDS groups. The groups say that he has failed to clarify whether people living with HIV/AIDS (PLWHA) are entitled to services from the Home and Community Care (HACC) program. The groups say that a report funded by the Department into access and equity issues in Eastern Sydney HACC services shows that many service providers are completely unaware of this entitlement. In an area where 56% of the State's PLWHA live, front-line HACC services such as Meals On Wheels, shopping and food services and personal care and cleaning services would assist to maintain basic needs and therefore keep many PLWHA out of the hospital system. PLWH/A (NSW) Convenor, Phillip Medcalf, said, "In July 1994 a clarifying statement on eligibility for people with episodic conditions was issued by the Department. This said that 'episodic conditions are those which from time to time may cause some degree of functional disability. Such conditions may include multiple sclerosis and in some cases HIV/AIDS . . . these people are also eligible to receive community support services provided by the HACC program'. This is why the report's first recommendation is that the Minister clarify entitlement. Most PLWHA and service providers clearly are not aware." Project auspice spokesperson, Botany Neighbourhood Centre Coordinator, Barbara Delcasse, noted that the Minister had been asked twice since April for the statement. "Each time he's simply referred it back to his Department," she said "They have failed to answer". Medcalf also added that, "PLWH/A (NSW) is concerned that this excellent report is stalling at the first recommendation. The report provides practical ideas which would help many PLWHA but it clearly needs leadership and support from the top - which the

Minister is not providing at present."

The report, entitled *Us & Them*, was undertaken last year following community concern about poverty amongst PLWHA. Its 55 pages contain twenty recommendations covering changes to policy, information provision, training, funding, service delivery and follow-up issues. On July 17th Bill Rigney, steering committee member of the HIV/AIDS Access & Equity to HACC Services Project, attended an Anti-Discrimination Board discussion evening and brought the Minister's lack of response to Chris Puplick's attention. "From this point I can only hope that the further recommendations of the Report will be acted on by individuals, committees and organisations with a little more haste and without discrimination to achieve all twenty of the Steering Committee's recommendations," said Bill. "I call on the Minister to immediately release a statement detailing the entitlements of PLWHA concerning the Home and Community Care Program."

Us and Them, the Report into Access and Equity in Home and Community Care Services, is available at this internet address: <http://www.geocities.com/WestHollywood/Heights/5227/access-equity-report.htm>. For further information please call Paul Canning on 0412 112 553.

- Paul Canning

ACON West's new recruits

I AM PLEASED TO JOIN THE STAFF of ACON Western Sydney as HIV Positive Community Development and Education Officer. We have recently restructured services for PLWHA to allow for more educational and support activities as well as Community Support Network home based care services. My project was developed to expand information resources in the

Western Suburbs and to co-ordinate more peer support programs.

I am currently consulting with PLWHA and their service providers to identify what educational and support services are needed. Our initial plans include a New Treatments Information Session in August and new educational activities at the Western Suburbs Positive Drop In. For further information or suggestions on these activities, please call (02) 9204 2402.

— Scott Rutter

NorthAIDS News

NORTHAIDS INVITES ALL POSITIVE people on the Northern side to meet informally over lunch a new key worker in HIV. Angelo Morelli, late of CSN, is the new Northern Sydney Area HIV Community Liaison Social Worker and will join us at lunch on Friday 22nd of August. This is your chance to check him out at close quarters, hear his point of view and share yours. There'll be the usual delicious lunch, and good company, plus the chance to get to know someone who will be important on the Northside HIV scene. Do join us! Our next information session for local positive people will be on a Sunday afternoon, 10th August from 2pm to 4pm, with the subject "Housing, DSS and the whole damn thing" and some qualified, lively speakers. Get directions from us on 9929 4288 and get the insights and information that may help you. NorthAIDS Myrtle Place Volunteer Induction begins soon. If you want to support the Northern Sydney HIV community get access to information, support and social activities, please let us know. Tasks will include cooking, helping to run lunches, massage, organising excursions and information sessions. Volunteers are also needed for our Northern Beaches supported accommodation house — talk to any of us at NorthAIDS, 9929 4288.

— Bill Evans



Dot Dingle and company strutting their stuff for the Boys' Own Bake Off at the Oxford Hotel on June 29. The event raised \$30,000 for the Bobby Goldsmith Foundation.

PHOTO: MAZZ IMAGES

Vaccine for Hep A & B

THE WORLD'S FIRST COMBINED vaccine against hepatitis A and B is now available in Australia. In a media release on 9 July, Dr Basil Donovan, Director of the Sydney Sexual Health Centre, said, "The combined vaccine will be great for gay men who are at increased risk of both hepatitis A and B." The vaccine is called Twinrix and involves a course of three injections over six months. It will cost the same as the two separate vaccines but will entail fewer doctor visits. Clinical trials have found the combined vaccine is well tolerated and is highly effective in stimulating a protective immune response. "Half of all gay men will acquire hepatitis A at some time in their lives and three quarters will acquire hepatitis B," Dr Donovan said. "The combined vaccine will mean fewer needles, fewer doctor visits and less hassle, which should hopefully see more people protecting themselves against both viruses. It's also important to remember that safe sex doesn't protect against hepatitis A. It probably provides some protection against hepatitis B which is many times more infectious than

HIV. But vaccination is the way to go," he said. The new vaccine is also expected to be useful for various occupational groups, including the armed forces, certain health care workers and day care staff, as well as patients with chronic liver diseases, recipients of liver transplants and recipients of blood products.

Tropical Fruits Vindicated

THE REVIEW OF THE ACON Northern Rivers Branch commissioned by ACON vindicates the position of Tropical Fruits, the largest and broadest gay and lesbian community group in the Northern Rivers. The detailed report was released in June by David Lowe Consulting and confirms the need for ACON to work more closely with community organisations. Aiming to "identify the service areas and delivery arrangements most appropriate to ACON meeting the needs of those most affected by HIV/AIDS in the Northern Rivers", the review was commissioned in Lismore in March this year following a community meeting. A key finding in the report is that the branch's strategic plan had failed to identify the most appropriate

Briefs



● The NSW Ageing and Disability Department has just issued the NSW Government Disability Policy Framework (Green Paper). It contains limited reference to people living with HIV/AIDS, and PLWHA (NSW) will be analysing the paper and participating in community discussion sessions with the Department at the end of July. More information will appear in the next issue of *Talkabout*.

● The Sydney PWA Living Centre has secured premises in Bourke Street, Surry Hills to which it plans to relocate. "It's taken 18 months of hard negotiations with various organisations. In the process we have built up mutual trust and respect, which doesn't happen overnight," Centre President Drew Mollineau told *Talkabout*. The Centre has recently appointed a new catering manager and is advertising to fill the position of Centre Manager. A series of public forums is planned to consult with the community about the direction of the Centre.

● A Master of Visual Arts student at the University of South Australia plans a large scale memorial clock commemorating Australia's AIDS/HIV casualties. Leith Semmens has chosen a large marble clock as a project for his final Masters assignment and expects to complete the project by 1998. He is still seeking a major sponsor and can be contacted on ph 08-8234 9149.

● Earlier this year ACON's home-based care project Community Support Network embarked on an accreditation program with the Australian Community Health Association under their Community Health Accreditation and Standards Program. (CHASP). The report is now available from ACON's Sydney and Western branches. The review involved a range of people including staff, CSN clients and carers. If you are interested in obtaining a copy of the report please contact Jim Belford (Sydney) 02-92062038 or Michael Erwee (Western Sydney) 02-92042407.

● Our Pathways Inc, (OPI) the drop-in centre for PLWHA in the Illawarra/Shoalhaven region, recently celebrated its first birthday! The Centre has received a grant from the AIDS Trust for internet access. Two terminals will be set up in Wollongong and Nowra over the next few months. Members up and down the coast have been busy bowling in Bomaderry and barbecue-ing in Culburra. Up coming events: a bus trip to Ulladulla on August 16, the Annual General Meeting on August 30 at 2pm, and a fundraising stall at Berri markets on the first Sunday in September.

priorities and had adopted a general community focus that was too broad. This broad community focus had caused resources to be spread too thinly, with consequent loss of services to those most in need of ACON services. The report also found inappropriate Branch activity for which other agencies had primary responsibility, activities such as community education and support for Hep C for which ACON was not funded, and inconsistencies with the ACON strategic plan.

The report highlighted the need to link service delivery with community development, especially in the area of gay men's education where 'initiatives targeting gay men and all PLWHA should be given the highest priority'. Other recommendations include making ACON more responsible for professional supervision of service delivery staff, referring requests for low priority services to other appropriate agencies, and streamlining administration. Overall, the recommendation was for fewer resources to be devoted to administration and more to core care and education services. As part of the process of re-prioritising gay education, the report recommended placing high value on working with local gay community organisations in a community development context. "Particular efforts need to be made to repair relationships with the Tropical Fruits group and to develop closer relations with Camp Clarence" the report said.

The report is certainly a win for the gay and lesbian community. Gay men (positive and negative) will be the top priority for HIV/AIDS education services delivered by the branch. A redirection of staff from administration to direct client services should help to make this a reality. Upgrading the educator's position to full-time, making it a peer position and shifting responsibility for training volunteers to client service staff will greatly enhance the potential of the position. The report also acknowledged the im-

portance of a number of lesbian services conducted on ACON premises such as Lesbian Line, and recommended that they be maintained. It recommended a review of the administration of the vitamin service and suggests relocating or redesigning the ACON premises to match its service delivery needs. Relations between Tropical Fruits and ACON have been at an all-time low. The community hopes that staff occupying positions following the restructure will be able to focus on the issues and take a positive attitude towards working with the Tropical Fruits. Copies of the report are available from ACON Sydney and the Branch. (ph 066 221555)

— Basil Cameron

This article first appeared in Tropical Fruit Juice, the newsletter of Tropical Fruits, a non-profit support and social group for gays and lesbians in the Northern Rivers. For further information about Tropical Fruits ph Victor (066) 899 352 or call their information line: (066) 224 353.

CSN West

COMMUNITY SUPPORT NETWORK (CSN) Western Sydney and Blue Mountains is now staffed with two part-time Care Liaison Officers, Brooke Hill and Anne Clapham. Anne has extensive experience in community service, having worked in the field of domestic violence and as a gay and lesbian liaison officer for the Police Service. Brooke has worked for the AIDS Council for the past two years in various administrative positions and has been involved with CSN as a volunteer for three years.

Both Brooke and Anne have had over 10 years experience in the customer service field, and are dedicated to customer client satisfaction. CSN West offers supportive home based practical care to PLWHA in Western Sydney. Those who wish to use our services or who want to join the volunteer team can phone Brooke or Anne on (02) 9204 2404 weekdays between 9am and 5pm.

ACON out and about

BASED ON RECENT FEEDBACK from community consultations and from the service survey which followed, ACON is creating the position of Manager Regional Services to oversee operations in the Mid North Coast and Northern Rivers areas. The person in this position will fill a place on the ACON management team and will represent the interests of regional NSW in a much more focused way than has ever been the case in the past.

There will be two ACON officers located in the Mid North Coast, one focusing on gay men's education and the other on care and support. It will be their responsibility to determine what services are needed in the communities and to arrange for the delivery of those services either by importing expertise from the Sydney office or by organising something locally. Each officer will be assigned specific locations for which they will be the focus for feedback, suggestions, complaints, etc. to the Manager Regional Services.

Anyone who needs to get suggestions to ACON will have a specific name and telephone number to call. While they will have a small office, these officers will be in their cars, out and about in the area. ACON officers will now go out to the people. Position descriptions are being written for these two positions and the vacancies should be advertised in early August.

— Jim Belford, Manager,
Client Liaison and
Information Unit,
ACON Sydney

Safety Net

GERALD LAWRENCE, ACON's Positive Educator, has noticed that some people are missing out on free prescriptions. "A number of clients are not recording the cost of their hospital scripts," he told *Talkabout* in mid July. "People on



The Luncheon Club Larder volunteers lined up and ready to serve. The Larder is open Wednesday and Friday afternoons at Sydney's Pride Centre.

PHOTO: MAZZ IMAGES

multiple drug combinations who record all their medications should be approaching the safety net limit over the next month or so." Pensioners and DSS beneficiaries with a Card pay \$3.20 for each prescription until they reach the safety net of \$166.40, after which their prescriptions are filled free of charge for the rest of the calendar year. People in full-time employment pay \$20 per script till they reach \$600.

Because some prescriptions are filled at pharmacies, and others (e.g. protease inhibitors) can only be filled at hospital pharmacies, people can go over their safety net limit without realising it. It's important to record the cost of every prescription, wherever it is filled. If you want further advice about how to minimise your prescription drug costs, speak to your pharmacist or ring ACON's HIV Support Project on 9206 2011.

Larder Open for Business

THE LARDER, NOW OPERATING out of Sydney's PRIDE Centre in Hutchinson Street Surry Hills, aims to give practical help to pensioners in financial difficulties. Under the guiding hand of Luncheon Club dynamo Carole Ann King, the larder is open every

Wednesday and Friday from 12pm to 4pm, providing basic food and household items to pensioners in need. Volunteer and ex bank manager Paul Tansley is also available to listen to pensioners' financial problems, provide advice and refer them to other services. Paul has been HIV positive for 13 years and previously involved in ACON, CSN, Leather Pride and the Candlelight Rally. "I think people can relate to me because I know what their problems are," he told *Talkabout*. Carole Ann and Paul have noticed a need for this advice. "I see people spending money on takeaways when they could make the money go so much further if they knew how," said Carole Ann. The Larder needs money to buy supplies and urgently needs a fridge with double glass doors.

Carers Conference

AFAO, THE PEAK NATIONAL organisation representing Australia's community based HIV/AIDS response, will be hosting the First National Conference for Carers on September 27 and 28 in Sydney. The conference will be open to all workers and volunteers in community based HIV/AIDS care and support services. Brochures will

Briefs



● Reports of dwindling supplies of Nelfinavir in Australia should not be a problem for those people already enrolled on the Special Access Scheme. The distributors, Roche Australia, have experienced supply difficulties with the manufacturer, Agouron Pharmaceuticals, but have guaranteed continued access to those already receiving this drug. Others wishing to enrol on the program may experience a wait of 3 - 4 weeks, before being able to start using Nelfinavir. NAPWA, AFAO & PLWH/A (NSW) are monitoring the situation closely.

● Doctors in the US have recently published the results of a study using Fluconazole, an antifungal agent, 200mg a week, to prevent the appearance of candidiasis in women with HIV infection. Overall results indicated that use of once weekly Fluconazole appeared to be safe and effective in preventing candida infection in HIV+ women by a difference of approximately 50%. (CATIE)

● Highly active antiretroviral therapy (HAART) can greatly reduce lymph-node HIV levels, but even a short interruption means starting all over again, reports the US publication, AIDS WEEKLY. With the advent of HAART, hopes that HIV can be eliminated or permanently suppressed depend on whether the drug combinations are able to reduce viral burdens in the lymph nodes as well as they do in the peripheral blood. The good news, announced Joseph K. Wong of the University of California, San Diego, is that HIV in lymphoid tissues is reduced by 4 log [10] in patients whose plasma viral loads remain undetectable after a year of HAART. However lymph-node HIV levels remain high in patients with relatively low-level plasma virus levels. Perhaps even more disappointing is the finding that lymph-node virus levels rebound back to pre-treatment levels during brief interruptions of therapy. "Even modest plasma virus levels during therapy can be associated with very significant virus loads in lymphoid tissues," Wong said. (AIDS WEEKLY July 1997)

● Last month saw the US release of two sets of guidelines on the best use of anti-HIV drugs. These guidelines will inform the work already being carried out in Australia to update the 1996 Clinical Treatment and Therapies Advisory Committee (CTTAC) guidelines. The revised guidelines are expected to also reflect the monitoring guidelines of the US Department of Health and Human Services on prescribing anti-retrovirals to women.

be available after the second week of August from ACON and PLWHA organisations, and from Steve McIntyre at AFAO (ph 9281 1999).

Sydney Water monitors Crypto

SYDNEY WATER ANNOUNCED IN A media release on July 17 that their reservoir at Potts Hill had recently shown low-level readings of "cryptosporidium-like organisms". Cryptosporidiosis is caused by a parasite and can be a serious challenge to the life and well-being of immunocompromised people. As a result of the readings, the reservoir has been taken out of service. Managing Director Mr Paul Broad said further tests of the reservoir had not detected any organisms, and he added that Sydney's water remains perfectly safe to drink.

New Herbal Treatments Centre

A CENTRE INVESTIGATING THE benefits of herbal treatments opened at Sydney University on July 22. The centre's director Professor Basil Roufohalis said, "There's a range of conditions that the medical profession is less able to help, and there is potential for herbal medicine to complement the therapies available."

The Sydney Morning Herald quoted the professor as being keen to explore the benefits of herbal remedies for illnesses such as HIV, AIDS and Hepatitis C, "In actual fact", Professor Roufohalis told *Talkabout*, "it was written to sound as if we are working on this, but unfortunately we are not. If there was an opportunity in the future to investigate plant materials as a source of new drugs we would be pleased, but as yet I personally don't have any tangible suggestions."

Hand in Hand disbursements

IN MID-JULY ACON RELEASED A total of nearly \$18,000 to community groups servicing people with HIV/AIDS. The external disbursements came from the profits of its Hand-In-Hand dance party. Contributions of \$2000 went to the Amitayus Hospice Service, the Blue Mountains PLWHA Centre, CLASH (now known as Positive Heterosexuals), Corrective Services GLRL, Friends of Waratah, Tropical Fruits and the Western Sydney Positive Drop-in. Other community groups received amounts of between \$700 and \$400.

Housing Project Open

THE BOBBY GOLDSMITH HOUSING Project is up and running! Occupation of the premises in inner Sydney had been delayed by structural problems, but these have been resolved. The Bobby Goldsmith Fund's Alison Cunningham told *Talkabout* that five tenants moved into the housing project in mid July. Half of the units are now occupied and the remaining units will be occupied gradually over the coming months. *Talkabout* congratulates Alison and the Bobby Goldsmith Foundation - an outstanding achievement!

Positive Heterosexuals

CLASH, THE SUPPORT GROUP FOR HIV positive heterosexuals is now known as Positive Heterosexuals. The group recently received \$2000 from ACON, which will be used to fund workshops on positive treatments and health maintenance.

For more information about Positive Heterosexuals, including a copy of their newsletter, ph 1800 812404 or write to PO Box 1311 Darlinghurst 2010.

Talkback



ACON smooth talk?

I NOTICE THAT ACON HAS advertised for community feedback about ACON services. In Oct/Nov 1996 when I was employed by ACON as Coordinator for CSN Western Sydney and Blue Mountains, ACON in Parramatta conducted a similar survey but they ignored the survey's positive response and implemented the strategies of a questionable report. The Beats Project was disbanded around October 1996 to be replaced by a new Education Strategy. To my knowledge, some eight months after the abandonment of the Beats Project that replacement is not yet operational. The ACON Committee itself adopted these strategies - are they aware that they have not been implemented? The Beats Project was dropped while not even halfway through its funded year - the staff being left in limbo, not knowing where they fitted into the plans of head office (if they fitted in at all) and what was to happen to the remaining funds of that project.

Eventually I felt forced to resign, in the interests of both clients and carers. After my resignation, members of the community wrote to the Executive Director in protest. I understand a petition was also delivered, yet weeks later there has been no response.

The community in Western Sydney and the Blue Mountains is entitled to the same services from ACON as in the city. Can ACON really expect response to their survey when they have ignored their own surveys and changed the services to suit their plans? Why has the Parramatta office been cleared

of all experienced staff - with the exception of the part-time Youth Peer Educator? Why does the community still shun the office? Positive people face the same discrimination and issues, no matter where they live. The community in the west will not continue to swallow the smooth talk of ACON bureaucrats telling them how much they are doing for them. Spending funds on advertisements asking for opinions only adds insult to injury when ACON ignores letters of objection.

- Pat Kennedy

No Response

I REFER TO PAT KENNEDY'S LETTER concerning ACON Western Sydney which appeared in the Sydney Star Observer dated July 10. You may like to know that I protested about ACON's treatment of Mrs Kennedy, CSN clients and carers to its Executive Director, Bernie Coates back on May 1. It took numerous phone calls and a follow-up letter to elicit a response from Mr Coates (after six weeks) but even then, he did not address the problem. On June 16 I wrote again and to date have had no response. In view of ACON's apparent lack of interest in its Western constituents, I notified the Star, the Capital Q and my Federal MP, Daryl Melham on June 17 by letter, but again have had no feedback whatsoever.

- Peter Mahoney

ACON Responds

ACON WELCOMES COMMENT ON its programs but Pat Kennedy's

disgruntled comments about the ACON Western Sydney office require a response. There is no doubt that Pat has contributed a good deal to the development of ACON's Community Support Network (CSN) program in Western Sydney over many years. As the CSN co-ordinator until April this year, Pat has had a clear commitment to positive people and developed many close relationships and loyal supporters in the West. As part of a broader view of CSN, an evaluation of services in the West was conducted in 1996/97 which recommended a number of changes and improvements. Unfortunately Pat did not support the changes and chose to resign. The review and its implementation were conducted in a standard and professional way and I was both surprised and saddened that Pat experienced the process she describes in her letter. I can assure all, clients and carers, that CSN Western Sydney will continue to provide good services for HIV positive clients and support for carers as we have always done. Two new CSN workers are now in place, an already successful recruitment drive for new carers is under way and this will lead to an expansion of the program. ACON has a strong commitment to the West and the changes we have made are all about expanding and improving services to the area. We have recently increased the budget in our Western Sydney office for both the gay education and CSN projects, created a new HIV Community Education position, and we'll soon be recruiting a second gay educator and providing better offices and meeting space. By the time *Talkabout* is published, we would have also held a public forum at the Western

Sydney branch to discuss these changes. Anybody in the West who wants to know more or is interested in becoming a member or volunteer is encouraged to ring the branch on 9204 2400.

**- Bernie Coates
Executive Director
AIDS Council of New South Wales**

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



*Talkabout, PO Box 831
Darlinghurst 2010*

Correction

The art on page 24 of the May/June issue of *Talkabout* should have been credited to Robbie Blackwell, not Robbie Blackmore.

Notice

WITH REGRET THE PLWH/A (NSW) committee has accepted the resignation of John Trigg. We thank him for his contribution to the organisation during his time as a committee member, especially for the dedicated work he contributed to the Complementary Therapies Working Group. The committee invites expressions of interest to fill the gap left by John. Ideally applicants will have an interest and experience in complementary therapies and/or positive education.

Please submit applications to my attention.

**- Phillip Medcalfe
Convenor
PLWH/A (NSW) Inc.**



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"THE TIMES THEY ARE A'CHANGING"

The Committee of PLWH/A (NSW) Inc are considering a change of name for the organisation and seek your views.

The acronym of PLWH/A can lead to confusion for the identity of this organisation, and it has been suggested that a new profile and identity for us would be a dynamic lift into the next phase of the HIV/AIDS epidemic.

We want to hear from you, the members, before the next Annual General Meeting, and any possible changes are introduced.

All comments and suggestions are welcome.

**Come on
It's your organisation
Have your say**

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**Contact Marc on 9350 2959
Waratah Clinic call Terry White CNS/HIV on 9350 2955
Carers Support Group call Terry on 9350 2955**

Elation and Devastation

Among the rush of stories from people whose lives have been turned around by combination therapies, some voices are not being heard.

I FEEL KIND OF STRANGE WRITING about my experiences with combination therapies because I am one of the 3 out of 10 who are not responding to treatments. Some people will judge me as failing the available treatments. I perceive my situation to be one where the available treatments are failing me. I am writing my story to contribute to a more balanced debate about treating with combination therapies. My experience with combination treatments has been one of elation and devastation. I am disappointed that my viral load cannot reach undetectable levels but I am not defeated by my experience. My challenges in living with HIV have armed me with a sense of cautious optimism. I have learnt that my life is not going to be lived according to computerised pathology printouts. I have not worked since retiring in December 1994. In 1995, I was hit by a MAC attack, then CMV Retinitis in my left eye and finally Karposi's Sarcoma. I isolated myself to enable me to direct all my resources into staying alive. I slowly ventured back into life after successfully treating my most alarming problem, the KS. At about the same time, combination therapies were becoming available and as my T-cells had plummeted to twenty, I was eligible on compassionate access grounds. I started with 3TC and Saquinavir, (as I had used all other drugs in sequential monotherapy). Taking pills was, by now, no problem for me because I was already taking about 20 a day for the CMV and MAC. I didn't respond to 3TC and Saquinavir so I added Ritonavir. The side-effects were

pretty awful for me. Lots of nausea, tingling in and around my mouth, vomiting, and hot flushes, four hours after taking the dose. One month in and the results were good, (viral load 8,200) but I felt like shit. Two months in and the viral load skyrocketed to 180,000. So what to do? Here I was taking medication that was affecting my quality of life, I was down to 52 kilos and living on Maxolon. But I had exhausted all my available drugs. I chose to continue to endure this Ritonavir until some-

"I am but one person who is not getting benefits from combination therapies. My plea is simple and is aimed at the undetectables; please don't abandon us."

thing new came along. I did so for five long months. Then good news was on the horizon. I had not used d4t and I was able to combine it with Delavirdine and eventually Nelfinavir. Finally, I had all the drugs and commenced my new regime. No side-effects. One month into treatment, a miracle happened, viral load 5,100. I was overjoyed! In all my years of living with HIV, this was the first time that I had had a positive result. I could have screamed out at the top of my voice - I am alive! But I didn't. I told nobody. I needed to be sure, so I waited. I took my 52 pills per day and my life continued. 7am pills, 3pm pills, 7pm pills, 11pm pills. Two months. I did another blood test which showed that my viral load had gone up to 168,200. I felt winded. Bill, my doctor, sat with me in silence as I tried to absorb this information. But I feel good and look the best I have looked in three years. Why me? For the next week I closed myself off from the

world. I felt numb and empty. I needed to think. So what now? I have used all available combinations and yet no response. New drugs are on the horizon or in developmental stage. But do I have that long to wait? And then I read about a shortage of Nelfinavir and I think to myself that I am taking medication that is giving me no benefit and in effect depriving somebody else of a drug that could benefit his or her life. And that's where I am at. My motivation for writing this piece is three-fold:

- I am but one person who is not getting benefits from combination therapies. My plea is simple and is aimed at the undetectables; please don't abandon us.
- Survival is not solely dependant on drugs. It has been shown that issues of stress, depression and grief contribute to deteriorating health. To maximise survival it is important to seek out support, develop assertive abilities and have an awareness of one's life purpose and goals.
- All drugs have side-effects but not all people experience them. People choose to take medicines they believe will benefit their longevity. People also choose to use alternative therapies to increase their chance of survival. All people with HIV/AIDS live with hope in their hearts, hope that what they've chosen bears some reward.

Whatever the choice you make, commit yourself to it, maximise the benefits that you can gain from your choice. Be vigorous in your pursuits of a better quality of life. And have the kindness to respect others who may choose differently. Seek advice as needed, have an open and trusting relationship with your doctor as you will need it. Once it develops, it will be of great comfort to you. Good luck on your journey.

- Philip Nelmes

with all this political correctness. After all, if you do NOT take your protease inhibitors in 'compliance' with the manufacturer's and your doctor's instructions, you could very well become resistant to it and have lost one of your avenues to wellness . . . and this is a truth, whether or not you complied or acquiesced with/to their instructions.

Norman

WHEN I FIRST HEARD PEOPLE were being called 'non-compliant' I thought how dare they label me just for not taking some pills. I'd like to use another word, but I've looked it up in dictionaries and thesauruses, and that's the most accurate word. That's the word the medical establishment uses so why not use it? It's like we're reclaiming it for our own use.

Vivienne

I HAD BEEN QUITE HAPPILY ENJOYING a drug free holiday for eighteen months, and then combination therapy was offered. After twenty seconds consideration, I agreed. At this time my viral load was 100,000 and the T-cells 380. The first combination of drugs offered was Saquinavir, Stavudine and Lamivudine. All went well for two weeks and then it was like being on AZT again. Life consisted of headaches, nausea, diarrhoea, lethargy and generally feeling like the morning after the night before, except I had not had the pleasure of the night before. Indinavir was substituted for the Saquinavir. The physical symptoms lessened within a week and then the mental anguish began; when to take the wretched stuff in accordance with the instructions, how to fit it in with irregular shifts, irregular meal hours and irregular sleeping hours? I determined the combina-

tion therapy wasn't going to give me a nervous breakdown. So now I compromise. I take the Indinavir three times a day, but not always strictly correctly spaced. Often I have to get up at 4:30 to start work. If I eat breakfast, I find I usually forget to take Indinavir. So I tend to take the pills straight away and eat later on when I feel like it. I am told that this is not good enough, but it is my way of taking some control back over my life. Because I also take medications for other problems I take handfuls of tablets three to four times a day. I try to rule them rather than the other way around. Latest blood tests eight months down the track show viral load not detectable and T-cells 860.

Bruce

PHOTOS: C. MOORE HARDY

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The Centre is open for appointments every Monday from 6.30pm to 8.00pm. You need an appointment to see a lawyer. Appointments can be made by contacting the Centre on the numbers below, Monday to Friday from 10.00am to 6.00pm.

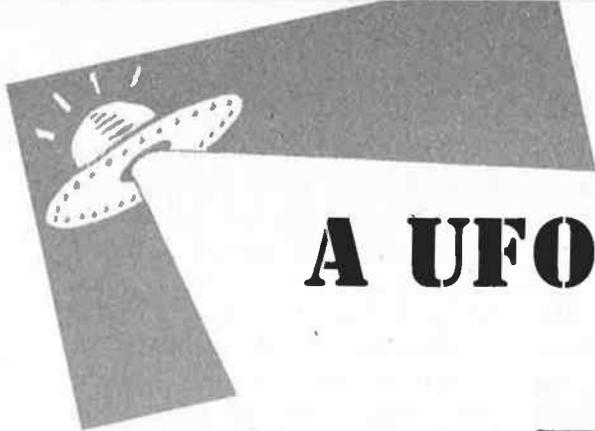
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All information is kept strictly confidential.

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A UFO ABDUCTION

Paul Roberts has previously been too angry to write for Talkabout but following something akin to a UFO abduction or a religious experience he lets flow with some observations on being sick, getting well, and a potentially fuller life and makes a plea for tolerance of his erratic "acquiescence".

- ... **THEY SAID** THAT I WOULD BE DEAD BY NOW.
- ... **THEY SAID** THAT I WOULDN'T NEED TO WORRY ABOUT SUPER OR BUYING A HOUSE OR A CAREER.
- ... **THEY SAID** JUST TAKE CARE OF THE PRESENT BECAUSE THERE IS NO FUTURE.
- ... AND YOU KNOW IT'S TURNED OUT THAT **THEY** LIED TO ME.



GRAPHIC: PHILLIP McGRATH

I'VE BEEN INFECTED FOR 12 OR 13 years now. Last year I nearly died, not from anything special but just from my body being tired of having to fight for that long.

Then it happened. I got well. My graphs went in the right direction – you know, T-cells up, viral load down. I finally shifted pneumonia off my chest after three years of having it. I put on 20 kilos in a very short time. Basically, I was a miracle – well according to some of my friends I was anyway.

I went from preparing for my end to planning my future – very quickly! My legacy of these 13 years is a weak chest and total blindness in one eye and really poor vision in the other. CMV is just vile – you wouldn't wish it on your worst enemy.

But I do feel like a knight of old, who had slain the dragon for his princess – unfortunately I had to

wait for the drug companies to give me the sword now the princess is getting on a bit!

After dealing with varying degrees of pain and discomfort for three years plus psychologically preparing myself for the end, getting well again has had a profound mental effect on me.

Without pain, I am able to cope, able to salvage my friendships and other relationships prior to their total disintegration. I've lost my anger, I've become calmer. I am able to forgive. It's like having a religious experience or being abducted by UFOs – not that either of these experiences have ever happened to me. BUT something certainly happened!

I feel now, having been close to death, that when it gets close again – as it most certainly will – that I will be very different. Next time,

I won't alienate my friends, or hide myself in my room, or hate the way I physically appear and build up that anger – that anger that overwhelms you and takes over normal-thought processing.

I say that I will be different, but in the way that each sexual experience is unique, I'm sure that each near-death experience is unique and the stresses and worries are different each time. But surely you must learn something on this death/life merry-go-round!

As a result of getting well, I've started to enjoy life again. I don't puff when I run for the bus. I've started socialising again. Friends have started to enjoy my company for my company's sake rather than doing their duty. Most importantly, I have hope for the future.

But what now? A friend who is 33 has a web site that shows a pro-

jection of when, according to the available data, he is supposed to have zero T-cells. It used to be when he turned 36, now it is when he turns 58. Based on this totally unscientific formula that I have decided to believe in unconditionally, this means I've got an extra 20 years – and who knows what special pills we will all have to kill off our HIV by then – I could have 40 or more years left. Now that's even more spooky than preparing for your own death at 34. I never expected to get old!

So I find myself at a crossroads. Do I embrace the workplace? Maybe move, now that the services in Sydney available to me as a person with AIDS are not so important to me? Do I start a *relationship* after avoiding them for so long – it wouldn't have been fair to any prospective life partner, would it? Do I take what money I have and get a mortgage? Or

spend it on that big overseas trip? Or go into business or invest it? Or leave it as super and plan on actually retiring at 65? How do you know? It was easy when I was told categorically that the maximum I had was 10 years. Now it's anyone's guess.

I still worry, only now it's about "compliance" cause I'm bad (*read not perfect*) at that, and I worry that because of or in spite of my bad "compliance", I might not have those 20 or 40 big ones left.

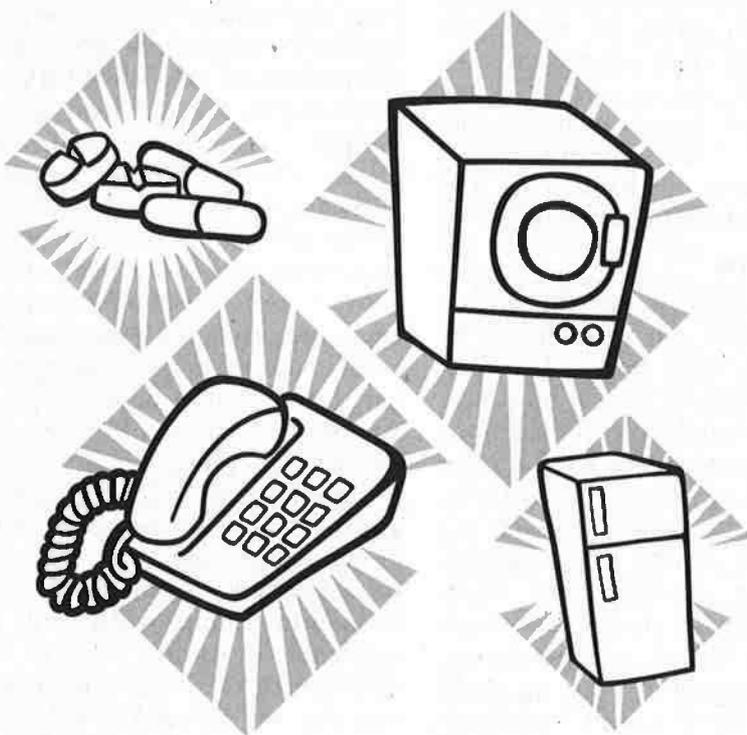
I'm trying to be good with my "compliance" – I have a system and a dosette box and a drug therapy that is relatively side-effect free and is not too obtrusive in my life, a good doctor, a supportive environment etc., so I'm doing the right things but I'm still bad sometimes. Getting well seems almost to be a hindrance to good "compliance" because I don't need them anymore – do I? **WRONG!**

Is it possible for doctors, drug companies, activists and bureaucrats to do the pre Howard/Hanson politically correct thing, and rather than lecture me on "compliance", create an environment that assists me to embrace, celebrate and enjoy my **acquiescence**? After all, isn't that's what most of them are paid for?

Preferably drugs that mix well with common recreational substances like alcohol! Perhaps a full range of antiretrovirals needs to be made available behind the bar of every pub, club, sex on premises venue and restaurant! Now there's a marketing idea whose time has come!

Anyway, when are they going to come up with drugs where "compliance" is not my problem? **Better drugs now**, is what I say!

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Routines & Rituals

The National Centre in HIV Social Research (Macquarie University) surveyed 35 people living with HIV/AIDS about their experiences of combination therapy. Social researcher Kane Race summarises the survey's findings.*

MOST READERS OF THIS MAGAZINE will know combination therapies work effectively when drug levels are consistent, preventing HIV from replicating – and that the way to do this is to take the pills as prescribed and on time. But this knowledge isn't much use when you're out and about and the pills are safe at home. What works best for one person may fail another completely. Just as one person may be able to tolerate certain side effects better than the next, specific drugs are associated with specific practices which may suit one person's lifestyle but not others'. People who carefully consider how the proposed regimen will fit in with their lifestyle seem to have better luck with dosing. If they haven't been able to discuss these issues with their doctor, they consider finding a new one. Many respondents spoke of how helpful it is to talk to other positive friends, close friends generally, and staff at PLWHA/AIDS organisations about combination choice and dosing.

Rituals

Ritonavir and Saquinavir must be taken with hearty meals, while Indinavir and ddI should be taken on an empty stomach. Indinavir should be taken with lots of water, while ddI should be mixed with water or chewed. The survey shows that when pill-taking is embedded in other daily practice, there is less chance of forgetting a

dose. Participants in the survey developed routines by associating dosing with daily prompts, and even by a sort of ritualisation of the dosing process. By ritualisation I mean developing a set of simple processes that make taking the pills a familiar event. Okay, stirring your ddI into water might not seem particularly ceremonial, but it may make you more familiar or routine with the procedure of dosing. People's use of containers or pill boxes is a sort of ritual in this sense. It also helps to solve the question of 'Did I or didn't I take them?' Many of the people we interviewed developed particularly creative 'rituals' around dosing. Some people placed their pills in places made significant in the course of the day (by the bed, on top of the tele, on the kitchen table). One participant spoke of 'the rigmarole' associated with Indinavir and ddI: "You become very much aware of when you have to eat; when you have to take the tablets and so on." On the other hand, he occasionally forgets ddI: "It's a more simple system. You only have to put it in your mouth and swallow it."

Prompts

Drugs with no specific dosing requirements can nevertheless be associated with certain prompts. 'Living rhythms' appear most useful to prompt dosing: for example, sleeping patterns, eating patterns, and arriving home from work. Generally, the dosing time acts as a scaffolding around which particular living rhythms are built. Combining the dosing time with waking or fasting prompts dosing. Choose prompts that are (or could be) most significant in – and consistent within – your lifestyle. Often a combination of prompts are used. When living rhythms and routines might be upset (e.g. on weekends, or when travelling)

this is particularly important. People in our study often found themselves in social situations where taking HIV pills was embarrassing or just easy to let slip. On the other hand, some social situations encouraged people to dose – for example, the expectation of a partner or friends at meal times.

Planning ahead

Planning ahead is a common strategy for taking pills discretely, if necessary. For others, being up front with their dosing could signify something positive to their friends: that they are taking charge of their health. It is natural to be concerned that pill-taking will indicate 'illness' to the company you're in. But the meaning of pill-taking can be negotiated socially. The connotations are not always negative. In some circumstances, taking pills in company could provide the perfect opportunity to build up a supportive network of friends around issues like HIV.

One of the biggest challenges to the pill routine is the occurrence of side-effects. We are currently analysing the strategies people use to manage side effects. A community report with more detail on the above issues and people's experience, use, and understandings of combination therapy is being prepared and should be available in August. If you would like more information, please contact myself or Philippa Cristaudo on (02) 9850 8046. Thanks to everyone who participated in the study and who helped with recruitment. The information you provided will be invaluable in gaining a better understanding of effective treatment use, and will be used to help others in their own treatment choices and health maintenance.

** Research was conducted by Kane Race, Rob Wilkins and Philippa Cristaudo*

The Pill Count

Can I do it?

Alan Strum, ACON Treatments Officer, summarises some issues people present him with concerning treatment regimes.

"COMPLIANCE" IS NOT MY FAVOURITE word of the year. I prefer to say whether or not a combination of drugs is easy to take. If a treatment regime is not easy, then someone is likely to miss doses or not want to take up treatment in the first place.

When someone first talks to me about taking treatments, they refer to not wanting to be ruled by the drugs. That's fine. Looking at daily routines, finding patterns and then fitting the drugs into those patterns can help people to feel more in control and less ruled by the necessity of following strict dosing schedules. Once a good dosing regime is sorted out, then people need to be aware of other factors that crop up when someone first decides to start a particular treatment. Please remember that the issues and responses can be very complex – more complex than I can place on paper in one article.

If I take the drug then it reminds me I have HIV

HIV is in your body taking control of your immune system; taking the drugs is your way of taking back that control and kicking the virus in the butt. (Some people will need counselling about this before being comfortable about taking the drugs.)

I'm scared, I don't know how I'll feel if I take the drugs

This indicates you might need counselling. However you can pick up the drugs, take them home and leave them on the shelf for a while. Open the bottles, look at

the tablets, put them in your hands. Then see how you feel. Just because you pick up the drugs doesn't mean you have to take them. (Remember to take a backpack with you to the hospital pharmacy because the containers can be quite large).

I miss doses when I go out and don't get home in time (i.e. I got lucky at the bar)

Always take a small pack of at least 2 doses with you wherever you go. That way you don't have to go home and you can stay out and have your fun.

It's hard to remember to take the drugs when I feel so well

Try to think of HIV as another type of disease or illness. If you have diabetes you always have to take insulin otherwise you get sick instantly. Or maybe think of HIV as having a heart condition – if you miss a dose your heart might stop. I know this sounds melodramatic but HIV does replicate if you miss doses.

I have too many tablets to take too many times a day

If you can, change to a twice a day regime. Some regimes only consist of 6 tablets a day. Otherwise if you have been on the drugs long enough you might be able to cut back to a maintenance regime with less drugs (this idea is in clinical trial at the moment to see if it is possible). Some drugs are now being used once a day but you would need to talk to your doctor to find out if you can do this (research is now underway to confirm this with some of the drugs.)

I have niggling side effects

If you have side effects then taking the pills can be off-putting and can be a good excuse to miss

doses. Try to find a way to deal with the side effects such as complementary therapies. Otherwise, you might be able to change your treatment to one which is gentler on your body without side effects.

I miss doses when I want to take recreational drugs and party

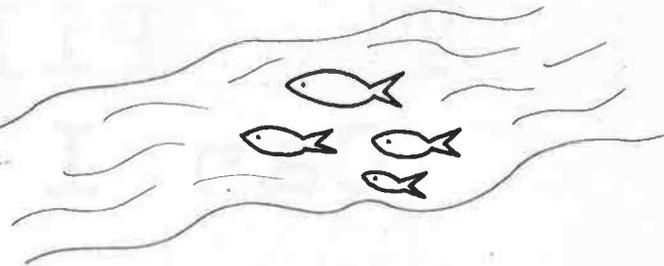
The recreational drugs can interact with protease inhibitors (dangerously). Take the recreational drugs a few hours before taking your antiviral drugs. (Separate out the drugs to minimise the interaction.) Only use really small amounts of the recreational drugs at a time to reduce the chances of an overdose and hospitalisation. Experiment a little with small recreational amounts until you find the right "high" you're looking for – but be careful. You might need to experiment a few times before you get it right, so don't rush to get your high.

I ran out of pills on the weekend

Always keep a small separate emergency supply, enough to see you through a weekend. Otherwise try and see who else is on the same drugs as you so you can set up an emergency supply mechanism among friends. This will help to prevent any last minute panic attacks.

The most important aspect to always taking pills is to feel completely comfortable with the idea of taking them. Making sure it's what you really want to do is the first step to ensuring that you won't come up with excuses, reasons or situations for missing doses. Remember, the pills are your investment in your long term future. Be comfortable. Do it right. Use everything at your disposal as a reminder to always take the pills and plan for a healthy tomorrow.

A Different School of Fish



A young man, who recently contracted HIV writes about his life.

MY NAME IS PAUL AND I AM 23 years old. I have been living with the virus biologically for just over six months. I belong to a different school of fish. I grew up in a poor family with an Aboriginal mother and white stepfather from whom I have three younger sisters. Alcohol abuse, domestic violence and poverty ruled the roost in my childhood and adolescence. Exercise became my drug while growing up. I was different. I held regard and respect for the human body. Leaving the Queensland home for Sydney when I was 18, recovering from a traumatic sexual experience that left no room to believe I was still HIV-, I worked as a stripper on Oxford Street. Overcoming grave fears, I eventually went for a HIV test which returned an equally traumatic negative result. After an assault in Darlinghurst that smashed all my front teeth, I came out to relatives about sexual abuse in my infancy by an uncle recently departed. Relatives castigated me and were vindictive and vicious at the announcement of my confession. Soon after, I learnt that I was born out of a rape. Relatives had maintained an inviolable vow of silence amongst themselves up until my disclosure. They absolved themselves of all responsibility. My ideal of tracking down my father disintegrated before my very eyes and led me to sink into unfathomable depths of loneliness and aloofness. I was completely immersed in pain and sorrow. I felt unloved. I felt ugly. And I hated myself. Love had deserted me. I

was shot to pieces and descended into the valley of darkness. I could not live knowing that my father was at large. As a consolation prize, I frequented the Matthew Talbot Hostel for meals, to be in the company of older men. I read a lot, watched daytime TV and wandered the streets at night. This carried on for about a year. I was lost. I felt defeated. The three initials that characterised my life were SOS. Eventually, I felt that the only way I could haul myself out of my misery was to change the shoes I was standing in. I had to separate myself from the past and create a new life for myself. So I became the master of my own destiny and set out to become HIV+, visiting sex clubs week after week, month after month. I was relentless and unscrupulous. I believed HIV was the only ticket out of the hell my life was. I bartered my immune system to the world for an opportunity to become human once again. Health and fitness kept me alive, as did the re-affirmation of my faith all this while, when love tried in vain to break me.

I seroconverted last year in November and immediately about turned on commitment to my life. From the few I told, there was overwhelming pressure to go onto drug therapy. However, I was not willing to compromise on my anti-chemical morals. I was back with a vengeance. I felt immune to the antagonism and ridicule that the world comforts fresh seroconverters with, because from where I was trapped, it was a career move in my life. Though I've had tiny twinges of regret at what I did to myself, I am back in the driver's seat of my life. I'm no longer diffident. I'm no longer

isolated. As I've always done, I'm holding my own hand through the trials and tribulations of life. Standing alone has never felt strange to me.

My doctor has thankfully never pressured me to start drug therapy. We laugh and lecture each other about health. He's not fickle and I'm not flippant. We have a strong foundation from which we work. After research, I commenced dietary supplements in January and aligned myself with a herbalist in May. The instigation of health protocols to fuel my body is accumulating. I'm hitting hard and hitting early in my own regimes, living what I believe. Needless to say, I've become fitter and leaner than ever in response to how the world is shaping me this year. I am living quite frugally and commit to a stringent health and fitness regime.

I have little family support and am really out on a limb at the moment. But right from the start I've been different and unconventional, and it comes easy to me to follow my heart and intelligence. Despite sexual confusion, I'm in more fertile pastures now. I'm reticent to divulge an anti-chemical lifestyle in an age where HIV treatment results are so stratified throughout society. However, for those statisticians reading, the viral load has abated from 360 000 (5.56) to 58 000 (4.78), and CD4s steadfast at 18%, 745 to 28%, 510. CD8s elevated at 65%, 2500 to 55%, 1000, with tender armpits and groin joints. Those are the lucky numbers that have spun up on the grand wheel of life the past six months. The dust of seroconversion is settling. Sure, I'm committed to lowering my viral load, but not being an 'unde-

"OH MY GOODNESS

What kind of issues come up when you "retire", then recover your health and want to work? The Positive Employment Service (PES) in Northern Sydney aims to enhance quality of life, well-being and health for PLWHA by addressing issues of employment. Guy Taylor spoke to Sarah Yallop, the Service's occupational therapist.

Could you tell us a bit about yourself and how PES came about?

The employment service came about from my work on the HIV clinical team in Northern Sydney Area Health Service and in the Eastern Sydney Area Health Service. I was coming into contact with a lot of clients who, because of new therapies, were now starting to look at issues of returning to work. There didn't seem to be anybody systematically addressing those issues and they didn't seem to be satisfied with the services they were receiving from agencies like the CES etc. I suppose, it's a very new issue and we're not used to people with HIV going back to work. People just didn't know what to do. So I came up with a proposal for a service and was then funded to develop that service, which has been running since the middle of March this year. It has been set up in response to new therapies. It's hard to say how long that will last and whether that need will continue to be around but I thought it was important that something was set up in response to that quite quickly.

What services does the PES offer?

It's really a first step for people who are thinking about returning

to work. PES is also for people who are currently in employment whose HIV is impacting on their ability to perform their job and also for people who may not be looking to get back into traditional paid work, but are looking at some other options like volunteering. It's really looking at guiding people through the decision making process of returning to work; looking at careers, identifying what they've done in the past and how they can use those skills in the future. Have their values and what they want out of work changed? How does that impact on their return to work?. It's a process of becoming more self-aware and giving people a framework to work this out and when appropriate linking them to some services that might be useful to them.

What do you think the labour market is looking for at the moment?

The labour market is changing. The greatest increase in jobs is in part-time work, which is quite positive for people with HIV because a lot of them wanting to go back to part-time work will have that flexibility of being able to fit in other things during their working time. One of the major difficulties is that there are so many people competing for jobs, so I guess that it is difficult for people who've been out of the work force to then get back into it. I wouldn't say it is impossible, but the labour market is quite harsh because employers have a lot of people to choose from. So it's easy to dismiss people who have been out of work for a while. But I think that the labour market is becoming more flexible and that's definitely a plus.

Do most people that you see disclose their status to their prospective employer?

The majority of people don't want to disclose and I think that in today's labour market it's probably a very wise decision. When I developed the service I actually did some interviews with employer groups and large companies to get a feel for what employers felt about people with HIV going back into the workforce. For a start, the majority of those people weren't aware that this was an issue, that HIV+ people were returning to work. I guess they still thought that when you get HIV you leave work and die. These employers also said that "People would find it very difficult if they disclosed within our organisation". Even though there's anti-discrimination legislation, there are still some very conservative attitudes in the workplace. And why should people disclose? The only thing the employer needs to know is whether they can actually perform that job. Some people I'm seeing are concerned that they may have health relapses, and that's something I talk about with people. We go through the different places where it's possible to disclose to your employer. I wouldn't advocate any one decision on disclosure, I think it's everyone's own choice.

How do your clients work that through? What advice do you give about that?

I think it is one of the major issues. It depends where you're working. I suppose a lot of people look towards the gay and lesbian friendly organisations, and the HIV positive friendly organisations because they know that they'll be a little bit more accepted. But for other people it's a process of going through things: What if you disclose to your em-

I'VE GOT A FUTURE!

ployer on your application letter? What do you think would happen? Why would you do it? Why would you not do it? What if it came up at the interview? How would you deal with it? What about disclosing on the job, what would be the pros and cons? What if you never disclose? How do you explain gaps in your resume? I don't think people have to come up with a concrete answer when we go through that process but mentally they have gone through all those different scenarios. Then if those scenarios happen they can think back to what we talked about, and they have a few strategies already in mind. I don't think you can ever be fully prepared for that type of situation. It's totally up to them, what ever feels right for them at the time. I would certainly be there for that client, before or after they disclosed. I see that as part of the service. Disclosure is a really big barrier and age is another barrier that some of the clients feel. Often when I first talk to people they say "Well I want to get back into the workforce, but my age is the big thing".

Is age a factor when they're changing jobs, or just generally?

A lot of the clients have been saying to me, "I want to change into a totally different area". It's like they've had this transformation through having HIV. It changes their perspective on life and their values. I think it's very difficult to start from scratch and retrain all the way up but I think it can be done. I get a list of all their past jobs and find out what they did and didn't like, what they learnt, so that they know the past is not 'the Past'. A lot of people say, "I don't have skills in certain areas" but they really do. It's a matter of selling yourself to an employer. Many of the clients

have done some amazing and creative things in the past which is great to hear about.

What about people who contracted HIV when they were young and don't have a career base to work from?

For them in a way it's easier to do things like training because it's more expected at their age. Society expects older people to be set in their career, whereas younger people are expected to be training. With someone younger I would look at what kind of training they wanted to do. There have been lots of people in their 40s who wanted to do some training, but they've also had a lot more life experience that they can draw on.

How do you feel your clients are coping with the stress of going back into the workforce?

It's difficult to say because the service has only been running for a short time. I've seen about 50 people. A lot of them are just starting work again, but because they have spent more time thinking about choice, they choose something that is suited to them, which makes it a much less stressful transition.

Is your service helping to reduce that stress?

I think the service helps because it makes people a little bit more self-aware. I've seen people jump into a job and then come to see me afterward because it's been quite stressful. They had a false expectation of what they could do and they didn't think a lot about how much they could physically handle. When you've been out of work for a while you forget about work patterns and how demanding they can be. So I think people who use the PES are a little bit more prepared.

Are you seeing people who want to work because they need the money?

Finance is something people like to talk about, but once they sit down and talk about it they realise that work is a lot more than just money. For some people it is a driving force because they're used to a certain lifestyle and they just can't have that anymore. If they're just looking for money it's different because they don't expect more out of their job. A lot of people I see are saying, "I want to get off the Pension, I feel guilty, I want to contribute to society, I want to express myself through my work." It's also a sense of returning to normality; now that people are feeling well, there's a huge sense of "oh, I should be working". People really need to think before they rush into work, especially if they've been out of the workforce and have been so changed from having HIV. The most important piece of advice I give to people is not to rush it. I think people feel this real sense of guilt, that they're the age they are and they're on a Disability Support Pension, and they think, "I should be at work, I'm not sick any more". And OK, they aren't sick but they still have a chronic condition which has to be taken into account when they're working. The typical scenario I see is someone who's been out of work for a number of years, up to 11 years in one case, and retired because of HIV, and is on a pension and waiting to die, and has now benefited from treatments. And the issues that go along with that are just incredible. You really need to take it slowly because there are so many things to think about. It's that whole life-change of, "Well, I'm going to die" to "Oh my goodness, I've got a future!"

Sarah Yallop - ph 9926 7855

The Ripple Effect

In May this year, Sharon Snir, a counsellor at ACON, ran a six-week-long experiential therapy group for couples affected by HIV. She writes about the impact of HIV on relationships.

RELATIONSHIPS PROVIDE US WITH companionship and many feelings such as anger, hope, joy, shame, pain, fear and guilt. When HIV affects relationships, these emotions are usually intensified. In order to look at how HIV creates and destroys aspects of relationships, we must first understand the meaning of relationship. The invasion of HIV into any relationship creates a ripple effect, altering the relationship on physical, emotional, behavioural and spiritual levels. As a therapist who works holistically I cannot separate one part of a person from another part. As I see it, we are embodied spirits who experience life through our thoughts, our bodies and our feelings. The physical interacts and influences our emotions, behaviour and spirituality, and the way we behave impacts on our thoughts, feelings and beliefs.

Physical

For the person with HIV, the act of having sex has changed forever. Couples who were spontaneous in their sex lives now face the need to safely explore desire, trust, fear, rejection and loss. All these areas can be discussed and negotiated and yet the very act of discussion and negotiation brings about changes. When I speak to some positive women, they describe dramatic changes in their body image. Their genitalia,

formerly a source of exquisite pleasure, have now become a danger zone. Positive people ask themselves: Does my partner really want me now? Am I still desirable? Will s/he get fed up with me and leave me? Will anyone else ever want me? How do I say, "I'm too tired, too frightened, too uninterested", without pushing my partner away? The side effects of treatments create a whole range of physical issues. Some people put on weight, leading to heaviness and discomfort. Others may lose weight or lose control of their bowels. Deciding to go ahead with drug treatments means living with a constant reminder of HIV. The very act of swallowing tablets at specific times, regardless of where the person may be, means they now have to plan their days around treatment. Some choose to keep their status private and therefore need to find privacy to take medication. The partner who is HIV negative experiences the stress of having a partner with a chronic life-threatening illness who may die. For both partners this anxiety may result in sleeplessness, loss of appetite, apathy, irritability, impatience, despair and depression. All these things impact physically on the positive partner and on the relationship. On the other hand, many people describe a newfound strength and a new lease of life through the use of treatments and a return to a feeling of health and enjoyment in the physical aspects of life previously lost through illness related to HIV.

Heightened Emotions

When one or both partners are HIV+ the normal undulation of emotions often becomes more like

a roller coaster ride. A niggling irritation can quite unexpectedly turn into rage. A feeling of slight envy can suddenly become overwhelming jealousy, and one thoughtless word can leave you eating yourself up with guilt, regret and even resentment. The other side of the coin however, is the feeling of freedom some people describe in knowing they can now do things they have only dreamed of because HIV has set them free from procrastination, free from the shackles of other people's opinions, free to take risks they never dared take before. One of the main aspects of HIV is the losses it brings into the lives of those it touches. The loss of health, money, work, dreams, plans, hopes, friends, lovers and freedom. HIV brings a world of paradox. It may bring a new freedom or a feeling of being trapped and overwhelmed. When one partner experiences feelings that the other partner may not understand or be fully aware of, the relationship can become rocky and very challenging. The fear of losing a partner can overshadow much of the relationship, and yet the denial of that very issue can drain the relationship of much of its energy. The importance of sharing what each partner wants and needs and of expressing how different situations are experienced by each partner can relieve the pressure that builds up through fear, misunderstandings and the making of assumptions. We all need to be reminded at times that the primary reason we are in a partnership is because we want companionship.

We all need to feel connected in some way with our world and one

A Generation Gap ?

Robert Baldwin has been working for HIV organisations since 1992 and currently co-ordinates the HIV/Sexual Health Program of the Mid North Coast Health Service. He wonders if the experiences of newly infected positive people differ from those of people who've had the virus for longer periods.

THE "POST AIDS" DEBATE OF late last year had the potential to encourage divisions between HIV positive and negative people. Coined by social researcher Dr Gary Dowsett to describe the changing experiences of the epidemic, the term "Post AIDS" suggested that decisions about HIV are now more considered, rather than a "crisis mode" response. Others have misinterpreted the term to mean 'the crisis is over'. During the debate it was very clear to me, no matter how much reassurance was given, that this misinterpretation was a real possibility and could be further fuelled by the release of even more effective HIV medications and treatment vaccines. Now, as many organisations attempt to grapple with the changing face of HIV/AIDS in a rational and sensitive manner, the debate appears to have calmed down. The changes are being influenced by the release of new combination treatments and sophisticated monitoring techniques, a monumental new understanding of the way this virus affects the body and a view that further positive developments are imminent.

During a recent discussion with a newly seroconverted friend, my thoughts about the impact of these changes on the community now and in the future were rekindled. One thought was not to do with the differences between HIV positive and negative people but the 'generation gap' developing between recently seroconverted HIV positive people and those who have been living with HIV for years. When people talk of generation gaps, they refer to a difference between groups of peo-

ple based on age. However, groups form for lots of other reasons: large families versus smaller ones, computer phobics versus computer literate, hippies versus rappers and people who became HIV positive pre-1996 versus the newly seroconverted. People who became positive in the 1980's and the early 1990's were often promised solutions, with only limited delivery of them. I can still hear my voice, both professionally and personally, saying to keep hope and that things would get better. I



GRAPHIC: PHILLIP MCGRATH

often had trouble believing what I was saying. The early days of monotherapy with AZT (especially high dose) promised great hope of an effective treatment but this hope was not realised. Maintaining a sense of real hope was often difficult. Even bipartisan political support, anti discrimination and vilification laws, dual therapies and effective prophylactic treatments such as Bactrim only ended up providing glimmers of hope.

For HIV positive people, especially for those who have recently seroconverted, life has changed. They are being offered new, largely effective treatments, that have the potential to suppress this virus to levels previously only dreamed

of. Regular monitoring is able to confirm the treatments' effectiveness and provide real indicators of their sustainability. Certainly many people who have been HIV positive for years are also taking advantage of these treatments. In many cases these are proving effective but there are fundamental differences. One of the main generational differences, besides immune system status, is the degree of hope. It is difficult to change a mind-set built around bravely coming to terms with chronic illness and a shortened lifespan to a mind-set that can once again believe in a 'normal' life. My friend saw a difference between his feelings and those of the 'older' generation of positive people - and I mean 'older' in terms of years of living with HIV. Instead of a sense of past battles lost, of fighting against the odds with a severely limited armoury, he has a definite sense of optimism and faith that everything is going to be OK.

But what is the problem with having a generation gap? Issues of separation, misunderstandings, non co-operation and animosity spring to mind. With an HIV generation gap, the specific issues might be differences in levels of access to treatments and compliance, safe behaviours, healthy living and a divided 'community'. To bridge a generation gap there generally needs to be movement on both sides towards understanding and acceptance. But what are the possible benefits? A chance to learn from each other and provide a larger supportive network? Where to now? I'd be interested in hearing other people's thoughts on this issue. ♦

Complacency is not the cure

Last December, Colin Clewes wrote an article for Talkabout titled "Why I Hate World AIDS Day". Currently Manager of the NSW World AIDS Day (WAD) Programme, he suggests a re-evaluation of World AIDS Day to keep it relevant.

SOON WE WILL AGAIN THINK OF World AIDS Day. For many people it's little more than an irrelevant talkfest, for others an additional burden on their workload. But I see it as having a constructive role to play within the HIV/AIDS community and industry. World AIDS Day can and should play a central role in maintaining community support for HIV/AIDS services and programs. I believe that HIV/AIDS awareness is slipping right off the public agenda through a combination of erroneous beliefs and the growing climate of intolerance currently sweeping the country. For example, there is a belief that the advent of combination therapy represents the end of the HIV/AIDS crisis. This belief may undermine the protective behaviours of some at-risk communities. There is concern that the needs of people living with HIV/AIDS will be forgotten. And from a broader social perspective, there is a very real danger that HIV/AIDS initiatives will be given less priority than in the past. The Third National HIV/AIDS Strategy contains some elements of this approach as it maps out future HIV/AIDS strategies "in the context of sexual health and related communicable diseases." As we lurch ever deeper into the culture of moral re-armament and scapegoating, there will be an inevitable

questioning of the value (or values) of the more controversial education/prevention initiatives such as needle/syringe exchanges and explicit sex education for gay men. Indeed this is already happening on a significant level; some needle/syringe exchanges have had their operations restricted because of antagonism within their local communities. Last year's banning of the Queensland AIDS Council's "bubble boy" cards is another manifestation of this trend.

I feel WAD offers an appropriate platform for re-launching HIV/AIDS onto the public's



agenda. Regardless of how opposed we may feel towards the concept, the reality is that there is an annual time slot allocated in the public/media world for the recognition of HIV/AIDS issues. WAD and, more recently, AIDS Awareness Week will roll across the news desks whether we like it or not. My proposal therefore attempts to capture and develop this presence into a programme which truly conveys the HIV/AIDS message. That message consists in my view of the following:

- ⌘ that the HIV/AIDS crisis is not over – it continues to impact severely on the lives of many people and also sustains the risk of new infections
- ⌘ that we do not yet have a cure for HIV/AIDS and this is not a time to reduce our vigilance on

either education/prevention or treatment and care issues.

I further propose that we convey this message under the slogan "Complacency Is Not The Cure".

Quite how we convey that message is very much a matter of individual choice but herewith a few possibilities:

- ⌘ that World AIDS Day is used to release reports, studies and other data on the current state of the HIV/AIDS crisis (eg. issues of poverty, living with HIV/AIDS, access to treatment, continuing education needs). As part of this proposal, I am suggesting that anyone currently working on such information either delays or expedites its release to coincide with World AIDS Day week.
 - ⌘ that other WAD activities around Australia focus on spelling out the current realities of the HIV/AIDS crisis.
 - ⌘ that World AIDS Day week is used as a platform to launch new education, treatment and lobbying initiatives (ACTUP, where are you?)
 - ⌘ that HIV/AIDS workers and activists co-ordinate a regional, day-by-day media campaign based on the above message. (I realise that's asking for a lot given the state of HIV/AIDS politics but let's at least try for one week out of the year!)
- In summary, I'm suggesting that, like it or hate it, World AIDS Day – the Concept, will be around for a while. It has the potential to be tokenistic, bureaucratic, and irrelevant. It also has the potential to be focussed, educational and influential. In the current social and economic climate it very much needs to be the latter.
- ⌘

Gay Educators:

Breaking Down The Walls

by Greg Allen



I OFTEN APPROACH CONFERENCES with a cynical mind, questioning their purpose and practical application to the issues experienced by positive people. Yet the fourth National Gay Educators Conference held in Melbourne in June should be considered a great achievement. It attracted a variety of 'educators', from community workers (like me), to people with vast adult education skills and experience. The participants were drawn from AIDS Councils, PLWH/A groups and included individuals from all over Australia. I attended the same conference in 1995 and found it quite different, with far fewer participants, a narrower focus, less agreement and little co-operation. In contrast, the 1997 conference eroded the walls separating AIDS Councils and PLWH/A organisations and those between PLWH/A organisations and the gay community. All the participants were generous and patient and strove to communicate on a level that was accessible to all.

Many subjects were discussed and 'workshopped', but the focus quickly moved to positive education and, within that area, the issue of compliance.

We have been living with the idea of 'Treatments Compliance' in some form, for three and a half years. In 1994, a campaign in the gay press used the slogan "Take Bactrim, Bitch". In 1996, Sydney's PRIDE Community Development Project produced "Keeping It Up", an innovative performance piece. Later that year, we were introduced to the term "compliance" and now we have a new term that has flown across the sea from the UK and USA - "concordance". Huh? I hear you say.

No matter what the word or term, the meaning is clear. The debate at the conference over what word should be used, was sometimes spirited and sometimes humorous, but the message has urgency, and many agreed that it was a priority in the education strategies of all organisations.

Many elements make this a vital issue in the lives of people living with HIV/AIDS who choose to use combination therapy. Taking the maximum advantage of the treatment's potential means taking every dose as advised by the prescriber. This message is repeated by every research and medical professional when talking about protease inhibitors and combination therapies. At the conference, after debating that subject, we moved to what we do so well in AIDS Inc, 'discussion'. The subject of using 'compliance', 'concordance' or something altogether different, bounced around the conference starting spot fires of controversy sometimes leading to red faced white knuckled debate. I ask, does it matter as long as it communicates

with the target groups? Well, apparently it does. Unlike at the Academy Awards there was no winner here, only an agreement that you say 'tomato' and I'll say 'tomatoe' but let's *not* call the whole thing off.

Many issues were identified as factors influencing compliance. Some were lifestyle-related, including recreational drug use, disclosure, career and eating habits and some were less personal, such as distribution of information and access.

To some, the debate is a little redundant because compliance issues can be immensely personal and often depend on the quality of information supplied by the prescriber.

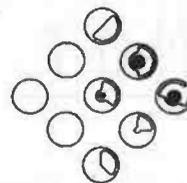
Compliance is only one issue faced by PLWH/As, and this was recognised at the conference. As a result, a move is afoot to include 'Positive Education' in the peer education and gay men's education strategies of the AIDS Councils. This was agreed in 1996 yet no action had been taken to instigate the move. At ACON, at least, this is changing, with many NSW educators being the most vocal advocates for this plan at the conference.

The individuals who steered this drive for inclusion of positive education at the conference were Aldo Spina, Alan Brotherton, Scott Berry and Stephen Gallagher . . . all from NSW, good news for some in Australia. Now the strained relationship between positive and negative gay men in Sydney may dissolve into history. Let's hope so.

Greg Allen is PLWH/A's
Community Development Volunteer
Co-ordinator

AIDS IMPACT

3rd International Conference



In Melbourne on 22 June several hundred people from Australia and overseas came together for four days to discuss and exchange ideas and information about the psycho-social impact of HIV/AIDS. Jo Watson shares her impressions of the Conference.

THIS WAS A BROAD-RANGING programme, for the potential topics and issues are endless, especially considering the length of time communities have been living and working within the epidemic, and the different stages of crisis that have marked the last decade and a half. I won't go into all the details of the programme, but will try and give a broad overview. If anyone is interested in more information regarding papers or presentations please let me know and I'll be able to refer you on to the appropriate sources.

Sunday was the first day, with the opening ceremony, marked by speeches from the Governor-General of Australia, the President of the National Association of People Living with HIV/AIDS (NAPWA), the Executive Director of UNAIDS in Geneva, and the President of the Malaysian Council of NGOs on AIDS. This day saw presenters discuss the diverse scenarios between countries, and even communities within a country, and how such different cultural environments can require unique responses.

The second day was taken up with presentations covering topics which included mental health, changing patterns of risk among gay and homosexually active men, travel and sex work, homophobia, injecting drug users, positive living, indigenous people and

HIV/AIDS, families and children, and sexual relations.

To give you an idea of the number of presentations over the four days, there were 74 in total this day, obviously with different sessions running concurrently throughout the conference. This makes choosing your day quite a mix and match exercise, with the result that many people were playing musical chairs throughout the sessions to try and hear as wide a mix of papers as possible.

Tuesday included papers on social research within HIV communities, models of health care, public policy, new treatments and therapies, art therapy, Australian ethnic communities, and negotiated safety. Two papers were of particular note, in my opinion. One was from a team of Social Workers at St. Vincent's Hospital in Sydney, looking at the impact of new treatments on a group of HIV patients, and how their Unit can change their service in response. The other was presented by Keith Gilbert, a Gay Educator from the Australian Federation of AIDS Organisations (AFAO), proposing different approaches to the communication between researchers, educators and the gay community.

On the final day, themes covered included culture and community, international responses, prevention interventions, healthcare economics, HIV testing, HIV counselling, and an excellent workshop was presented by Gerald Lawrence and Tim Wong from ACON, looking at the psychosocial impact of new treatments, with the objective of encouraging and assisting service providers to identify issues and influences relevant for positive people.

In summary, this conference was a mixed bag for me. Some of the 'academic speak' used by presenters was frustrating, especially when this conference was meant to be inclusive, not only for overseas guests, but also community sector and public delegates. The criticism many of us have of scientific and medical language overwhelming the positive community can also be directed at academia when they communicate with unnecessary jargon to groups outside of their 'tribe'.

Another comment heard often throughout the four days was that this conference, with claims of community focus, was definitely priced and located way out of the reach of many people who would have been interested in attending. For those of us who were able to register, there was a nagging question as to the benefit when measured against the costs and resources involved for our respective organisations sending us there. Many papers were dated, or clearly of little practical application to the community groups. On the other hand, they will look good on academic publication lists.

On a brighter note, those sessions where excellent papers featured, were like striking mother lode, and challenged many of us in the community sector to produce and present more of the grassroots experience and reality to such forums in the future. This will support the specified objective of the National HIV/AIDS Strategy, that all collaborative partners are working together for practical outcomes, based on quality research. Collaborative research needs active listening, as well as good communication, too often hard to find at conferences of this size and design. ◆

NOT YOUR AVERAGE TRIAL

THE KM1 HERBAL FORMULA trial is not like your average HIV therapeutic drug trial. It uses herbs, not drugs; it doesn't discriminate against women, pregnant or otherwise; it doesn't restrict entry to people with a certain number of cd4 cells; and it allows participants to use any other drugs they like. After being approved by the South Eastern Sydney Area Health Service Ethics Committee the trial opened in March 1996, operating from the Sydney PWA Living Centre in Woolloomooloo. Since then, the running of the trial has been overseen by Jan Kneen McDaid, who recently displayed a poster about the trial at the International AIDS Impact Conference in Melbourne. The poster included photos of trial participants, one of whom is an eighty year old man. Jan said, "People who looked at the poster were really interested. They said 'It's really beautiful', commenting on the Aboriginal artwork. People picked up on the graph at the bottom of the poster and said, "how come there's only a few women?" I said, "how come indeed." I feel that women have very particular problems with confidentiality on trials and can't trust that confidentiality won't be breached. I can understand that, because it's a very delicate subject for women, much more so than for men. One person was very intrigued with the whole idea of a very old man on the trial and I explained that he had come onto the trial because he didn't want any drugs. When he started the trial in March 1996 he had 200 t-cells and he's now got 600 t-cells."

The trial is uniquely community organised and run, and has received limited financial support from HIV/AIDS agencies, gay & lesbian community bodies and complementary therapy companies. Jan says participants have been agitated by the fact that

there's been no interim analysis, which isn't surprising as the trial is over a year old. "The reason for that is because I made an agreement with CHRN (the Community HIV Research Network) that we wouldn't have one. Because it's the first herb formula trial in Australia for HIV, they wanted as many people as possible to analyse, to the detriment of getting results through, stopping the trial and then getting it marketed so people could buy the formula in health food shops." Jan has also been hampered by lack of funds and resources. "I can't work any faster. I don't have



Jan Kneen-McDaid, co-ordinator of the KM1 Herbal Trial

PHOTO: JOHN CUMMING

any funds to pay people to enter my data. It takes time and it's very sophisticated work and it's got to be done properly. Consequently these are the hiccups of the trial." The work has taken its toll on Jan's health and she plans a long holiday when the trial concludes early next year. Once her energy is restored, she is enthusiastic about more trials. "It's the first one like it and I hope to do some more. I'm going on holiday for at least six months, and then I'm going to bring out a breast cancer trial and a Hep C one." The lack of restrictions on trial participants means

analysing the results will be more complex than usual. "Most people in the trial are using triple combination therapies and consulting orthodox doctors," Jan said. "And then there's other people who are IVD users and who smoke marijuana. So when you're looking at people's health those things really need to be taken into account. If you're going to do a naturopathic symptoms analysis, that's what every good practitioner should do."

Matthew Law from the National Centre in HIV Epidemiology and Clinical Research is aware of the difficulty in assessing the results of the trial, given that many of its participants are also on combination therapies. He is confident that sound conclusions can be drawn from the results. "The important point is that the KM1 trial is a double blind randomised trial - participants do not know whether they are receiving the herbal formula or the control. This means that any changes to combination treatment will be independent of the randomised treatment and should balance out between the two arms. So long as the herbal formula is still of benefit to people receiving combination treatment, comparing those participants randomised to the herbal formula with those participants randomised to the control will still give a valid assessment of the effect of the herbal formula."

Despite the current publicity about combination therapies, many people are unable to take them. Jan sees her trial filling a gap for these people. "The trial has allowed people a little bit of choice in what they do, especially people who can't do the triple combos. For people on the triple combos, it also helps with some of the toxic effects."

John Cumming

HALC News

ACON's HIV/AIDS Legal Centre (HALC) provides legal assistance to people whose legal problems relate to HIV/AIDS.

HALC wins Payout

A CLIENT OF HALC RECENTLY had his claim for Total and Permanent Disability (TPD) settled in full by an insurer, MLC Life Limited, who had initially refused to pay the claim. He started work on 16 April 1994 and joined the MLC Employee Retirement Plan at the same time. The Member Information Booklet he received on joining the Plan stated, "if you die or become totally and permanently disabled within two years of becoming a member . . . then no insurance benefit will be payable." He received a table of Transaction Details which recorded his employer's contribution "paid to" 30 June 1994. On 12 May 1996, he retired, believing the two year exclusion period had ended in April 1996. MLC refused to pay his claim, however, on the basis that it was lodged within the exclusion period. While the payment covered the period from April 1994, it was only actually received by the insurer on 29 June 1994. An inquiry by HALC's Paul Garde revealed that under a private agreement between MLC and its insurer, the two year exclusion period was interpreted as running from the date on which the beneficiary's employer's contributions were credited (29 June 1994) rather than the date when HALC's client commenced employment. Through HALC, the client lodged a complaint under section 101 of the Superannuation Industry (Supervision) Act 1993. HALC also assisted him to complain to the Australian Competition and Consumer Commission (ACCC) that MLC

had engaged in "misleading and deceptive conduct" prohibited by section 52 of the *Trade Practices Act 1974*. The ACCC agreed with the complaint and passed on its opinion to MLC. Soon after, while the first complaint was still being considered, MLC settled the claim in full on a "no admissions" basis. Since then HALC understands that the ACCC has required MLC to reconsider any claims which may have been refused on the basis of the exclusion period when calculated from the date of payment. This outcome shows that Trade Practices law and the ACCC may be used even where there are other more obvious avenues of redress.

HIV positive tenants can oppose harsh evictions

Provided 60 days notice is given, the Residential Tenancies Act 1987 has allowed NSW landlords to terminate a continuing residential tenancy agreement without stating a reason. If the tenant does not vacate the premises, landlords have been able to obtain eviction orders as a matter of course from the Residential

Tenancy Tribunal. Although the Tribunal is obliged to consider "the circumstances of the case", until recently, the impact of an eviction on the health of HIV positive tenants has never been a consideration. In one such recent case, although the rent was up to date and the tenancy agreement had not been breached, the Tribunal granted an eviction order to the landlord of an HIV positive tenant. The tenant then sought HALC's assistance in appealing to the NSW Court of Appeal against the eviction. The Court ruled that the Tribunal must have regard to all relevant circumstances, including the age and state of health of the tenant, the tenant's need to live in a particular area and the inability of the tenant to find other suitable accommodation. This decision establishes an important precedent and provides protection to some HIV positive tenants who are threatened by hostile eviction. Such tenants can argue against an eviction order to the Residential Tenancy Tribunal because of their poor state of health and need for access to medical and community support which is more accessible in some areas than in others. ♦



GRAPHIC: PHILLIP MCGRATH

Hydrotherapy: A different way to exercise

By Belinda Weir

HYDROTHERAPY . . .

HYDRO . . .

WHAT IS IT?

WHERE DO YOU DO IT?

IS IT GOOD FOR YOU?

BASICALLY, HYDROTHERAPY IS A type of exercise that is done in a heated pool. The temperature of the water is around 31°C. A physiotherapist runs the exercise classes so he/she can specifically look at your needs and requirements and give you the most appropriate exercises. Hydro is similar to aquarobics but the exercises are little easier (and the water a little warmer!) The exercises at hydro can be gentle or more strenuous depending on the individual need. So if you want to exercise but even the thought of it causes you pain and fatigue, then hydro is the place to start. The warm water has a soothing effect on painful joints and muscles and you will find it much easier to stretch and move. The buoyancy of the water takes away some of the weight effect of gravity so you feel lighter. However, hydro does work your muscles, particularly if you work against the resistance of the water. With regular hydro, you can get improvements in muscle tone and strength. In 1994 Mark Zacka, physio at Royal Prince Alfred Hospital, did a study looking at the benefits of hydro for people with HIV. He found that there were significant increases in measures of strength, endurance and cardiovascular fitness. There were also improvements in immune function in some participants. A similar trial has also been conducted in Melbourne with people living with HIV and AIDS. Probably, the best way for



Hydrotherapy can be useful for a variety of HIV-related conditions.

PHOTO: PAIGE SLAN

hydro to be recognised as beneficial is for those who have participated to speak for themselves. All the people I spoke to are HIV positive and have participated in hydro classes regularly. Colin, who has not had any HIV-related symptoms since becoming positive many years ago, states, "It is the only pain free exercise for the orthopaedically challenged positive person." Laurie, who has experienced HIV wasting and peripheral neuropathy feels his walking and balance have improved greatly since starting hydro six months ago. Robert had HIV-related myopathy which meant he experienced considerable weakness, particularly in his leg muscles. He feels hydro maintains a beneficial level of fitness for him and has paved the way for him to start exercising with weights in the gym. David suffered with swollen legs as a result of KS blocking the lymph nodes. He feels hydro gave him a lot of confidence by improving his mobility to what it was prior to the swelling. It also improved his energy levels and helped to drain the

fluid from his legs. He says, "After the exercise your body glows and you feel quite blissful." Well, he said it! Andrew likes hydro simply because, "it is the only exercise I feel like doing when I'm sick." Five different people, five different views. All those who participated liked the group atmosphere, finding it supportive, motivating, de-isolating and fun. As one said, "It is a social outing as well as an exercise class." Currently in Sydney there are four classes running at two locations specifically for people living with HIV and AIDS. This includes a class just for women. These hydro groups are at Royal Prince Alfred Hospital, Camperdown and Royal South Sydney Hospital, Zetland. Partners and carers are also welcome to participate. Also, general hydro classes may be available at your closest hospital hydro pool. Please contact one of the physios listed below for more information. Helen Kindness and Mark Zacka on 9515 6111, Anita Ulman on 9360 3133 or Belinda Weir on 9690 1222. ◆

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