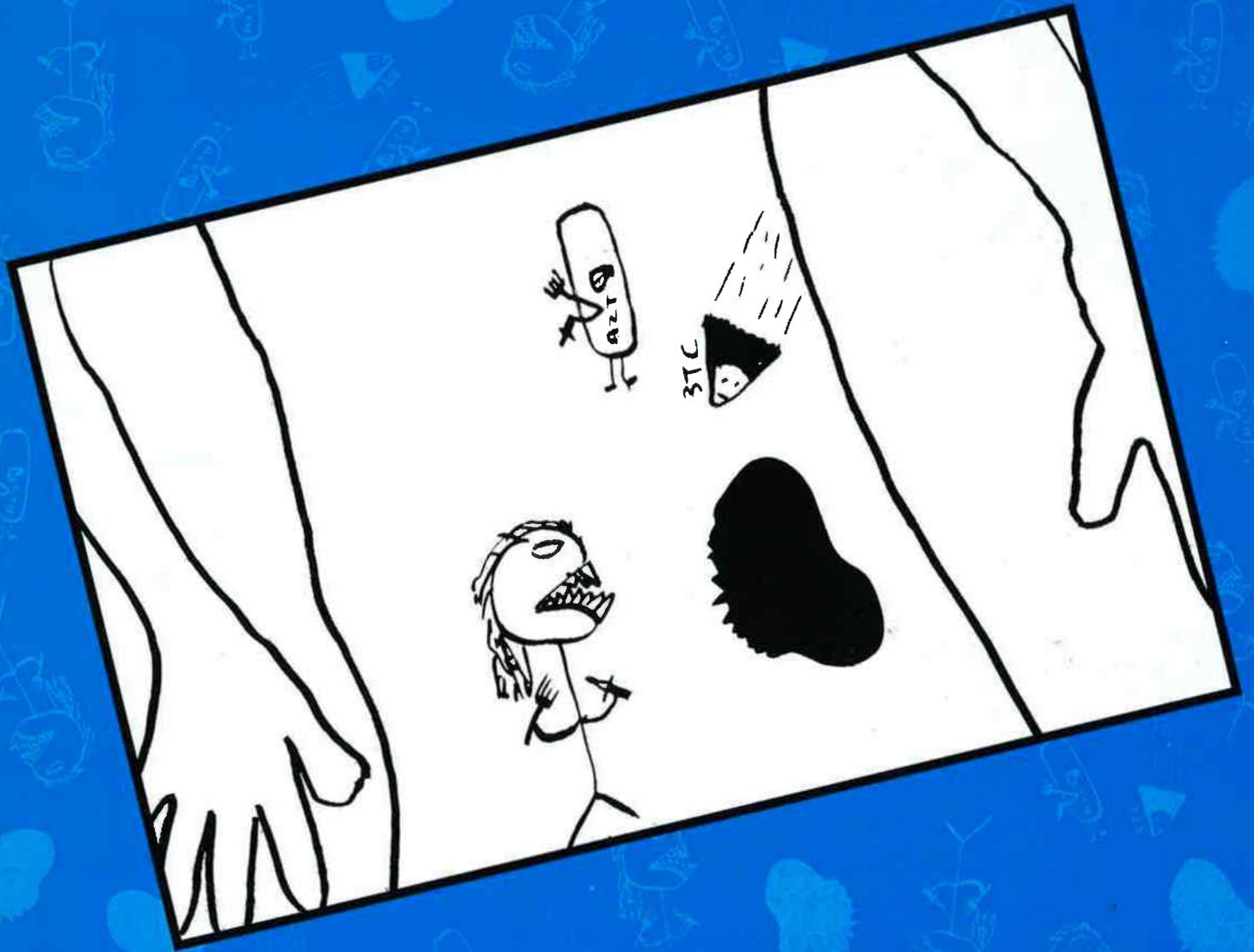


No. 80 October 1997

# Talkabout

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

◆ Where We Speak for Ourselves ◆



## Combination Kids

*lighten*

# *your load*

Nowadays by lowering your viral load, it's possible to control HIV for longer than ever before. But to ease your viral load takes more than sheer determination. It also takes practical support. A free booklet is now available to help you get the most from your treatment. It has information on how to manage side-effects and tips on making the drugs easier to take. Pick up this booklet and reduce your load.

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service outlets  
and venues  
or call:



Brought to you by the AIDS Council of New South Wales

# Contents

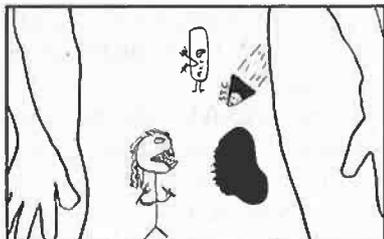
|                                    |     |
|------------------------------------|-----|
| Poetry .....                       | .11 |
| Kids in a world with AIDS .....    | .14 |
| Combination kids .....             | .15 |
| Mary Poppins, where are you .....  | .17 |
| Julie & Amanda and the pills ..... | .19 |
| White roses, blue ribbons .....    | .20 |
| Different strokes .....            | .22 |
| The Coláo Project .....            | .23 |

## Regulars

|   |     |
|---|-----|
| News .....  | .4  |
| Requests & notices .....                            | .9  |
| Gloria's Food .....                                 | .26 |
| Legal Update .....                                  | .28 |
| Service Update: The Troy Lovegrove Foundation ..... | .29 |

### This month's cover

**By an HIV positive boy aged 15.** The image represents the boy's hope that his treatments are working. 3TC and AZT are dive bombing the virus, which is the figure with the knife and fork about to eat up a Tcell. As a proportion of the epidemic in Australia, kids may not account for much, but this may actually make them more vulnerable, because their concerns are taken less seriously and there is less information available to them. Our special feature on children and treatments starts page 14.



**Talkabout** is published every month by People Living With HIV/AIDS (NSW) Inc. All views expressed are the opinions of the respective authors and not necessarily those of PLWH/A, its management or members. *Talkabout* is produced by the Newsletter Working Group of PLWH/A (NSW) Inc. Copyright for all material in *Talkabout* – text, graphics and photos – resides with the respective contributor. Contact Jill Sergeant, the editorial co-ordinator, for information on reproducing articles or illustrations.

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If you would like to be involved with *Talkabout* call Jill on 9361 6750 for the date and time of the next Newsletter Working Group meeting.

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**Deadline for the next issue: October 17th 1997**



● The majority of HIV+ individuals in the United States have been tested, according to new research from the Centers for Disease Control and Prevention. At an infectious diseases conference in Toronto sponsored by the American Society for Microbiology, the CDC's Patricia Sweeney said that out of an estimated 650,000 to 900,000 HIV+ persons in the US, between 509,000 and 545,000 know about their infection and thus can seek treatment.

● The Uganda AIDS Commission has reported that at least 400,000 people have died from AIDS-related diseases in the country since 1984. The figure is the commission's first estimate of the overall toll AIDS has taken on Uganda's population. During testimony to a parliamentary committee, Commission Director-General Omwiny Ojwok also noted that about 90% of Uganda's current population of 18 million now know how to avoid contracting HIV. Some 1.5 million Ugandans are currently HIV+, Ojwok added. (*CDC Daily Summaries*)

● *Knowledge, Action, Health*, the first ever HIV treatment guide for women, was launched by Women Alive in September. The guide, in pocket sized format, is written to equip women with the most up to date information possible, to enable them to actively and knowledgeably participate in making treatment decisions with a trusted doctor. It includes colourful illustrations, charts and worksheets to enable readers to better understand the various treatment options and analyse their CD4 counts, viral load tests and side effects. A scorecard helps you to evaluate potential combination therapies. To get a copy, contact Women Alive, 1566 Burnside Ave, Los Angeles, CA, 90019, USA. (*AEGIS*)

● Legislators in Kenya have adopted a new bill that addresses the nation's rapidly intensifying AIDS problem. According to recent data from Kenya's Ministry of Health, AIDS has killed approx. 230,000 Kenyans between the ages of 15 and 39 since 1984. That number is expected to reach 1 million by 2000. The bill marks the government's first public acknowledgement of the scope of the epidemic. Sessional Paper No. 4 of 1997 calls for a nationwide program to enlighten citizens to the dangers of casual sex, and it recommends that anyone who intentionally transmits HIV to another person be arrested on charges of manslaughter. Many health experts and government officials criticised the bill for not going far enough. It does not address the issue of polygamy, which is a leading cause of the prevalence of HIV in Kenya; and it is not as harsh on intentional HIV transmission as many would like. (*CDC Daily Summaries*)

ALTHOUGH THERE HAS BEEN quite a lot of sickness in the team over the last month, a lot has happened. Two more working groups have been established: the Care and Services Working Group under the leadership of PLWHA (NSW) committee member Shane Wells; and the Legal & Euthanasia Working Group, which has its first meeting on October 27.

Margaret Duckett, Convenor of the Treatments Working Group, is taking a break whilst she is in Geneva, Switzerland, having taken a short term position as the Co-ordinator of the Community Forum at the 12th World AIDS Conference. We all wish her every success with this challenging position.

Kathy Triffitt, an art therapist, has become the new Convenor of the Complementary Therapies Treatment Working Group. Kathy has been the Co-ordinator of the highly successful 'Self Imaging, Self Documentation Project' for people living with HIV and AIDS since the late eighties, and more recently has been involved with the Positive Retreats. We welcome her commitment.

PLWH/A has received a small recurrent grant from the NSW Department of Health to run campaigns and forums. The working groups will be developing strategies to keep you up-to-date with the latest information. Watch out for future notices about these activities.

Luke Smith, our Finance/Administration Officer has been upgraded to working five days a week. This has coincided with the fact that as of October 1, PLWH/A has formally taken over its own funding from ACON. This is a great leap forward for the organisation.

Paul Maudlin, Acting Positive Speakers Co-ordinator has also been upgraded to working five days. This is to include co-ordinating the pilot 'Versa' project (see page 5). Now this position has been upgraded PLWH/A will be looking to conduct the third PSB

training course in the early part of 1998.

Since our latest promotional campaign of advertisements and brochures the number of speaking engagements has gone up from around nine to over 20 a month. This speaks highly for the exposure of the PSB.

Over 7,000 "Getting the most out of your HIV treatments" booklets have been distributed, and because of this huge demand a second print run has been done. You can get more copies by phoning Jo or Robert on 9361 6011.

Finally, I would like to remind all members that it's nearly that time of the year again - AGM time! So please remember to update your membership, think about becoming a committee member and come along to the meeting, which will be around the first week in December. The date will be confirmed in the next issue.

- Phillip Medcalf

## New look NAPWA

AT THE ANNUAL GENERAL Meeting of the National Association of People Living with HIV/AIDS (NAPWA), held in Melbourne on September 13, the new Executive Committee was formally ratified.

It's farewell to Alan Brotherton, who decided not to stand for re-nomination as President. Alan said, "It's been a year of strong growth and many new challenges for NAPWA. The end of it sees the organisation in a strong position to meet the challenges of the future. It's satisfying to leave the organisation in such great condition. I wish the new Executive the best of luck".

Welcome to new President Ian Rankin from Canberra. Ian has a background in the public service and considerable involvement in union work. As for the HIV world, well, you name it, he's probably done it - at least in the ACT. He's been Convenor of PLWH/A ACT 94 - 95 and President of the AIDS Action Council ACT in 96-97.

During that time Ian was also a NAPWA and AFAO delegate and involved with the Ministerial Advisory Committee on AIDS.

Ian wants to ensure that NAPWA is truly the voice of positive people by creating an environment that encourages them to have input into the organisation.

The other executive positions are: Vice President, Mark Reid; Education Spokesperson, Stephen Gallagher; Legal Spokesperson, Les Szaraz; Indigenous spokespersons (alternating), Neville Fazulla and Rodney Junga; Treatments Spokesperson, Peter Canavan; and Care and Support Spokesperson, David Menadue.

NAPWA has called for expressions of interest in filling the position of Women's Spokesperson to the NAPWA Executive. More information is available from Russell Westacott or Andrew Little, ph. 9281 1999.

## PIE report

THE POSITIVE INFORMATION AND Education (PIE) Project is about to publish and distribute its Consultation Report. The Consultation, which began in January this year, aimed to determine the most important education and information issues for people with HIV/AIDS in Australia. The consultation interviewed service providers and volunteers in the HIV community sector, as well as some people with HIV/AIDS who use community services. Also interviewed were doctors, specialists, social workers, complementary therapists and nurses.

*Issues covered in the report include:*

1. **Antiviral treatment, testing and new HIV information.** The report highlights the importance of new treatments, blood tests and new understandings of how HIV works in the body. These issues are named by all consultation participants as the priority in PLWHA education



*Journalist Jane Singleton launched a new support program for people with HIV on September 16. The program, which aims to make the new treatments regimes easier for people to manage, includes the Coláo Project (see P23), a chat line (see below), and a kit containing information and snappy pill boxes. The program is funded by Roche Pharmaceuticals through an educational grant.*

PHOTO: C. MOORE-HARDY

- and information provision. Differences between States and Territories are discussed and recommendations made about acknowledging these differences. Recommendations are made about education on sticking to treatment regimes, the role of PLWHA in treatment education, using advertising campaigns and outreach among other issues.

2. **Health Maintenance and Monitoring.** The report observes that health maintenance has been re-prioritised in the minds of service providers across Australia. The importance of keeping diagnosis, prevention and treatment of opportunistic infections on the agenda is highlighted and recommendations are made about monitoring the impact of antivirals on disease progression.

3. **Living with HIV/AIDS.** A number of lifestyle and human rights issues for PLWHA are addressed in the PIE Consultation Report: positive sexuality and relationships, integrating work

- and retirement, disclosure of HIV status, human rights and HIV, illicit drugs and alcohol among others.

4. **Particular groups of PLWHA.** Throughout the PIE Report consideration is given to different groups of PLWHA and their specific needs in relation to education and information, including indigenous people, NESB people, women with HIV, families and children, drug users and gay men.

The PIE Project is managed by NAPWA and the Australian Federation of AIDS Organisations (AFAO). For a copy of the report call Phillip on 9281 1999.

— Scott Berry

## Chat line

A NEW FREECALL NUMBER FOR positive people, Versa, will be open to calls from November 28 for three to four months. Versa will focus on providing treatment information to callers between 8.00pm and 12.00am Thursday to Sunday. Callers will have the option of either joining a live phone

## Briefs



● Welcome to Barbara Delcasse, who starts work as the new Centre Manager at the Positive Living Centre in Woolloomoollo on October 20. Barbara, previously Co-ordinator of the Botany Neighbourhood Centre, has been involved with a range of HIV/AIDS services and projects including the Food Distribution Network, the Quilt Project and the HIV/AIDS Access and Equity project, which was an important outcome of the Poverty Sucks campaign.

● A lunchtime support group for positive women in Sydney that's so confidential we don't even know where it is, starts on October 9. It is guaranteed to be a safe space. For more details call Shellee or Erycka on 9206 2000. Speaking with other positive women makes a world of difference. Try.

● Our Changing Lives is an experiential workshop aimed at people who have started treatments and are now looking at issues related to their sense of hope and future, e.g. changing relationships, body image, choosing to return to work, etc. The workshop, to be held on the weekend of October 25 & 26, is being run by the HIV Living Project at ACON. Interested? Call Gerald on 9206 2011.

● Anyone wishing to make a donation to the Diana, Princess of Wales HIV/AIDS Appeal, can do so by calling 1800 689 188 during business hours or by mail to: Reply Paid 560, AIDS Trust of Australia, PO Box 1030, Darlinghurst, NSW 2010.

● The next tree planting in Sydney Park, St Peters, is scheduled for Sunday, October 12, 10.30am - 3.30pm. Sponsored by the South Sydney Council, SPAIDS invites you to plant a young Australian native tree to commemorate the life of someone who has died from HIV/AIDS. The groves are next to Barwon Park Rd. For more info call Mannie De Saxe, 9718 1452.

● Key Group Health Care in Woollahra/Bondi Junction are offering naturopathic consultations for \$15 (save \$30) to Health Care Card holders. Medications are sold at the normal price so the total fee would not exceed \$35 - \$40. Consultation times are Tuesdays and Fridays from 1.00pm - 5.30pm. Please call 9369 2482.

● In a first for Victoria, a web site is now on line which aims to offer a comprehensive reference directory of services and resources for people living with HIV/AIDS, their partners, families, friends and carers. Called "Positive People Victoria", the site also offers news and an opportunity for discussion of issues relevant to positive people. <http://home.vicnet.net.au/~positive/>.

forum, or talking one-on-one to a Treatment Information Facilitator. The kinds of topics discussed may include: when to start therapy; how to minimise side effects; what drugs are available, etc.

The Project is funded by Roche Pharmaceuticals, however it will be directed by a group of community representatives, including PLWH/A. The technical support such as information technology, will be provided by TeleTech, an international company which specialises in this kind of service.

The initiative was announced at the launch of the new HIV therapy support program on September 16 (see photo p5).

## Futures success

AN EXTRAORDINARY RESPONSE TO the HIV Futures survey of PLWHA has made it one of the largest studies of its kind in the world. Over 900 people have completed detailed questionnaires.

The study, conducted by the National Centre in HIV Social Research at La Trobe university, explores social aspects of living with HIV/AIDS, and covers areas such as housing, work, finances, treatments, relationships and sex.

Chief investigator of the study, Dr Doug Ezzy, has said he was delighted by the response. Ezzy applauded the work of community groups such as PLWH/A (NSW) and the Bobby Goldsmith Foundation (BGF), and health care workers in making the study recruitment a success.

"The findings from the study will significantly influence HIV/AIDS related policy and will be a major source of information for government, community organisations, health care workers and people with HIV/AIDS", Dr Ezzy said. Initial results are expected to be available within a few months.

## Home care

THE COMMITTEE STEERING THE Access & Equity project for PLWHA has expressed pleasure in Minister Ron Dyer's agreement that people living with HIV/AIDS

are entitled to home and community Care (HACC) services.

In late August the Minister stated that "I wish to confirm that people living with HIV/AIDS who have a functional disability arising from their condition are eligible to receive the basic maintenance and support services provided by the HACC program".

The Minister promised that the Department would "be investigating in detail the recommendations made in the report on HACC services, "Us & Them", in order to formulate any necessary policy response and action."

The report will be launched on October 31 at the PRIDE Centre. The full text of the report is located at: <http://www.geocities.com/WestHollywood/Heights/5227/access-equity-report.htm>

## Costs of care

A NEW STUDY HAS SHOWN THAT half of the primary, home based carers of people with AIDS had no preparation for becoming a carer, with many teaching themselves the skills required 'on the job'.

"Yet care-giving for a person with AIDS involves managing a complex and changing array of symptoms, as well as providing physical assistance and emotional support", said researcher at the National Centre in HIV Social Research, La Trobe University, Diana McConachy.

The study found that care giving had a negative impact on carers' lives in many areas, including finances, employment, health and leisure. In spite of this, most saw their role in a positive light.

Peter Grogan, President of AFAO, launched the report at the AFAO National Carers Conference on September 27 - 28.

"Home based carers are often overlooked within the health care system. Yet they save governments millions of dollars each year, make real improvements to people's lives and allow people with HIV/AIDS to remain in their own homes during periods of illness and to die at home if they chose", said Grogan.

“One of the great successes of the world class HIV/AIDS strategy in this country has been to resource the community sector and carers. While this report makes it clear we need to find better ways of helping carers, the model is a great one and should be repeated in other areas.”

## Straight summer fun

POSITIVE HETEROSEXUALS HAVE just launched a new summer program of exciting events. Highlights include:

The Southern Highlands to the Sea Experience – a steam train journey in the traditional style of the 1940s (November 1);

Open House meetings for members, partners and significant others at the Tree of Hope Centre at the end of each month. Speakers and topics include HIV/AIDS humour, and hobbies and pastimes;

A December Workshop on Positive Treatments and Health Maintenance where positive heterosexuals learn about managing new treatments and accessing other health programs;

World AIDS Awareness Week. Positive Heterosexuals will staff their own stall in King St, Newtown, providing HIV/AIDS information to the general public;

Support group meetings every month and the next issue of our newsletter.

Full details of the Positive Heterosexuals Summer Program are available. Call our Freecall phone line, 1 800 812 404 (staffed and open every Wednesday 10.00am - 3.00pm, or write to Positive Heterosexuals, PO Box 1311, Darlinghurst, 2010.

– David Barton

## Kids' on Hope

THE SEVENTH IN THE PERFORMANCE Positive series is to feature a banner containing kids' thoughts about the event's theme – 'Hope'. “We ‘hope’ that this will get people thinking about the many and different ways this theme can be interpreted and understood,” said



*The Diana, Princess of Wales HIV/AIDS Appeal was launched on September 12 by British High Commissioner to Australia, Sir Roger Carrick (2nd from left). The fund is off to a good start with a donation of \$7,565 raised at the Manor House on September 10. Also pictured, (from left), President of AFAO Peter Grogan, owner of the Manor House Tim Berry, and Chairman of the AIDS Trust of Australia, Chris Puplick. For details of how to make a donation, see Briefs, p6.*

PHOTO: MAZZ IMAGES

Performance Positive curator Victoria Spence.

On Sunday October 19 between 10.00am and 4pm, the PRIDE Centre will be alive with children adding their story to the banner. Refreshments will be available.

“It’ll be fun”, said Spence. “We’re inviting all kids with a direct or indirect relationship with HIV/AIDS to come along.”

PRIDE Executive Officer, Bronte Morris, said “Performance Positive is again timely. At a moment when the epidemic and our relationship with it is rapidly changing, it seems fitting to provide a space where we get dramatically different perspectives on the future”.

The banner has been donated by South Sydney Council. Carers of children are encouraged to ring in advance if they have special needs. Assistance getting there may be available.

If you can’t make it to PRIDE, the banner will also be at the regular support group held at the Sydney Children’s Hospital on Saturday October 18.

Performance Positive VII: Hope, is to be held at the PRIDE Centre on October 24 & 25. Call Paul Canning or Bronte Morris on 9331 1333 for more information.



## Art from the heart

THE THIRD ANNUAL “ART FROM the Heart” exhibition in association with the AIDS Trust of Australia, will be held during AIDS Awareness Week, November 23 - December 1, at Bondi Pavilion.

Art from the Heart is about giving everyone an opportunity to express themselves. The exhibition is open to anyone who has lost someone they love to AIDS. All forms of art are accepted – painting, sculpture, poetry, photography . . .

The exhibition seeks to assist all Australians express their grief at the loss of a loved one in a meaningful sense. It plays a real role

## B r i e f s



● The Pharmaceutical Benefits Advisory Committee (PBAC) has recommended that HIV combination therapies be made available to more people with HIV. Under the new indications, HIV+ people with a viral load of more than 10,000 copies can also be prescribed anti-retrovirals, irrespective of their CD4 count. According to the PBAC, the recommendation will be implemented early next year.

● The PBAC has come under fire for its decision not to recommend the NNRTI Delavirdine, for listing on the Pharmaceutical Benefits Scheme. Manufacturer, Pharmacia & Upjohn, are resubmitting their application for approval, and in the meantime will supply the drug free of charge. NAPWA will be lobbying Health Minister Wooldridge on this issue.

● Taking supplements of the mineral selenium may improve survival rates for HIV+ individuals. A (US) National Institutes of Health-funded study of 125 HIV+ men and women revealed that patients with selenium deficiency were 19.9 times more likely to die of AIDS-related illnesses than people with healthy selenium levels. Study leader Marianna Baum said selenium's relevance may be connected to its anti-oxidant function or its role in gene regulation. The study also found that vitamins A, B-12, and zinc affect survival rates, but not as significantly as selenium. Selenium is found in grains and vegetables, but can be toxic in large doses.

● New guidelines from the US Department of Health and Human Services recommend giving potent drug combinations to infants born HIV+ as soon as possible to prevent disease progression. The guidelines, established by 64 experts on treating HIV infected children, are being published for comment before they are made national policy. "These guidelines will fill an important gap in our knowledge by recognising the unique treatment needs of infants, children, and adolescents living with HIV," said Health and Human Services Secretary Donna Shalala.

● At the Interscience Conference on Antimicrobial Agents and Chemotherapy in Toronto, Dr. Steven Deeks presented data from a clinic at San Francisco General Hospital which showed a return to detectable virus levels in 53% of 136 HIV+ patients, most of whom had experienced an initial drop in virus levels to undetectable after beginning protease inhibitor therapy. It's unclear whether this is a sign that the virus is developing resistance, or merely a result of patients not following the required dosing schedules consistently. (*CDC Daily Summaries*)

towards healing the scars of the survivors of people who have died from HIV/AIDS.

Entry to the exhibition is by donation, all funds raised go to BGF. For more information, call Grant on 9974 5560 or James on 9356 4586.

## OPI Update

AN EXCELLENT TURN-OUT FOR Our Pathways Inc's AGM in central Wollongong means that we have an eight member board made up of PLWHA from right across the region as well as an exciting action plan for the coming twelve months. Best of all is the close relationship we are developing with Safehaven, the volunteer-run PLWHA/gay/lesbian drop-in centre just recently opened in Nowra.

Over a dozen people joined in the September bus-trip to Milton to a picnic day, and a bus trip is planned from Nowra to Wollongong on October 25 to the Unity Halloween Dance.

Red ribbon production is in full swing for the week of events surrounding World AIDS Day. As well as a variety concert on November 29, over thirty local visual artists (including Bert Flugelman and May Barrie) are donating works to "Passion - the exhibition". Originally planned for four weeks the Wollongong City Gallery has extended the exhibition to eight weeks to cover the summer holiday period, due to the calibre of those exhibiting and because of the exhibition's awareness raising role.

October promises to be busy with the usual 2nd Friday video & pizza night, speakers on complementary therapies, massage, reiki, lunches and the counselling CHAT afternoons on Thursdays.

- Cameron Sharp

## Board Aid

ON THE WEEKEND ON SEPTEMBER 6 & 7 a couple of speakers from the PLWH/A Positive Speakers Bureau (PSB), hauled on the snow boots and swished on down to Thredbo for Australia's first

Board Aid festival. Board Aid, which is now a yearly event in America, first started a few years ago as an event to raise awareness about HIV/AIDS among young people who identified with music, skateboarding and snowboarding cultures. The event raises funds for HIV positive youth and reaches thousands of young people.

The Aussie festival, hosted by *Crank* magazine, included a range of competitions and events, information about safe sex and injecting practices, and several talks by the PSB speakers.

The assignment was a great success for our speakers, who got a standing ovation from 400 people after one of their talks.

## Dollar ethics

THE INTERNATIONAL ASSOCIATION of Physicians in AIDS Care (IAPAC) is sponsoring the first International Conference on Healthcare Resource Allocation for HIV/AIDS and other Life-Threatening Illnesses, in Washington in November. The conference will be focusing on the key question: how do we decide how to humanely allocate resources?

The conference aims to examine the ethical issues that are all too often skirted in policy debates. For example, about five percent of people with HIV/AIDS have access to promising new drugs - what about the other 95%?

Some have argued that government or the pharmaceutical industry should provide free drugs to the millions of people who cannot afford them. Others point out that more lives would be saved by immunising all children, or by focusing on other illnesses. Meanwhile, across the globe, millions face famine and civil unrest, with no access to basic health care or effective sanitation.

Proposals will be offered to reduce the transmission rate of HIV and improve the lives of individuals affected by HIV/AIDS and other life threatening diseases.

(IAPAC home page:

<http://www.iapac.org/conferences/hrac/hrac.html>)

# Requests



## Contributors Fund

*THANK YOU! TALKABOUT* HAS received a generous donation of \$1,000 from Barry Enkelmann. We were thrilled to receive this donation because it enables us to start a project we've had in mind for some time: payment of some of our contributors.

We will pay HIV positive people who are on low incomes (mainly the DSP) for their written contributions when these are published in *Talkabout*. Whether or not an item is published is at the discretion of the Editorial Working Group. We will pay a standard rate of \$35 for any article of 600 words or more, and \$15 per item for poetry, starting with the November issue.

Of course, we will only be able to continue payments for as long

as the money lasts. However, if you think this is a good idea and would like to support it; you can help it continue by making a donation yourself. We hope that enough donations will come in to ensure that we can keep on paying contributors, and perhaps increase our rates at some point in the future. All such donations will be acknowledged in *Talkabout*.

Send donations to: The Talkabout Contributors' Fund, PO Box 831, Darlinghurst, 2010.

## Maasai appeal

AFRICA'S MORTALITY RATES FOR HIV/AIDS are devastating and it would take a cultural revolution plus education to even start to make any impact. A culturally-based silence about HIV and the custom of having multiple wives contribute to high transmission rates in Africa.

I had some experience of this culture in 1993 when I stayed in Kenya with a small group of Maasai on the outskirts of Nairobi. The small wandering groups of Maasai have to travel from bush camp to bush camp, often hundreds of kilometres from each other, in order to feed their cattle. Water was always scarce and had to be carried a great distance by hand. In such arid conditions, flies increased and so did disease.

Since my return, my friend Stanley has written to me and told me of a sponsored bicycle ride he had done in the hot African sun for many kilometres. He raised enough money to start a school. Normally parents would have to sell many of their cattle to send their children to school, so Stanley was very excited. The school's classrooms were made of corrugated iron and Stanley had

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converted one of the classrooms into an office. He receives *Talkabout* and has read lots of articles to the children. The children in turn told their parents, who informed the rest of the village.

Given the cultural reluctance of the Maasai to talk about sex, I felt quite privileged and honoured at Stanley's disclosure in his last letter that his school teaches its pupils about sexually transmitted diseases, including AIDS. However they don't teach children about sex. Instead, the mothers are taught about AIDS and how to prevent it and they then instruct their daughters in the home.

Stanley has appealed to me for money to build proper classrooms for the school, as they are not cemented and the roof cannot keep the rain out.

Many would argue that we need to look after our HIV/AIDS problems here in Australia. Millions of dollars are spent yearly on AIDS. Yet AIDS is a pandemic that affects poverty-stricken continents like Africa particularly severely. The virus knows no state lines or international borders. The pandemic needs global networking and education on a scale that has never been perceived before. Compared to conditions in Africa, each and every one of us in Australia lives in affluence.

Stanley is trying to bring AIDS education to the Maasai and needs economic support from those of you who believe that this pandemic can only be stopped by appropriate education for all. If you believe this is true, please send your donations (in US dollars or UK sterling) directly to: Stanley Sankaire Keduka, PO Box 9, Kiserian, Kenya, Africa.

- Jan Kneen McDaid

## Euthanasia research

MANY PEOPLE IN THE HIV/AIDS community have an experience of euthanasia/assisted death, either through helping someone die, or in considering it as a possible option for themselves.

Little is known about these experiences, particularly since assisted death must generally remain secret for fear of legal sanctions.

The Euthanasia Project, run from the National Centre in HIV Social Research at Macquarie University, is examining the effect on people who help a friend, loved one or patient to die. We are also interested in talking to people who have made plans for their own assisted death. These issues will be discussed in a *confidential* interview that will take one to two hours to complete. For information, please call Suzanne Bermingham on 9850 8624, between 8am and 8pm Monday to Saturday.

**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**



### People Living With HIV/AIDS (NSW) Inc.

#### Current committee:

Philip Medcalf: **Convenor**  
Claude Fabian: **Deputy Convenor**  
Vincent Dobbin: **Secretary**  
Erycka Fars: **Treasurer**  
Chris Holland, Andrew Kirk, Bill Whittaker,  
Ed Moreno, Les Szaraz, Shane Wells

#### Current staff:

Ryan McGlaughlin: **Co-ordinator**  
Luke Smith: **Finance/Admin Officer**  
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DTP/Advertising**  
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Talkabout: 9361 6750  
Freecall: 1800 245 677

## Editorial Working Group

Yes, at last - you can hold us accountable. From now on, each issue of *Talkabout* will include a listing of the people who are involved with the *Talkabout* Editorial Working group. This group meets about twice a month to discuss the content of *Talkabout & Contacts*. If you're interested in joining, please call Jill on 9361 6750.

David Barton, Sarah Bergin, Vincent Dobbin, Bill Evans, Erycka Fars, Stephen Gallagher, Kim Gotlieb, Ryan McGlaughlin, Paul Roberts, Jill Sergeant, Sandy Thompson, Guy Taylor, Jo Watson.

## Olga's Personals

HIV+ 29 year old heterosexual guy, into fishing, surfing, occasionally nightclubbing, coffee shops, museums, bushwalking, books and meditation - seeks a positive strong minded lady with a sense of humour for a long term relationship. Prefer non-vegetarian.  
971005

HIV+ man, 41, retired but now enjoying good health, wishing to return to workforce. Previous occupation bar manager at leading Sydney sports club. Looking for casual/part time work in hospitality industry. I am willing and enthusiastic. Phone Stuart on 9389 2375.

### How to respond to an advertisement:

- Write your response letter and seal it in an envelope with a 45c stamp on it.
- Write the box no in pencil on the outside.
- Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst, NSW, 2010 and you can be assured that it will be passed on. To protect your confidentiality, make sure the envelope is clearly marked *Olga's Personals*.

### How to place your advertisement:

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

## Poetry



### *And if destiny succeeds?*

*With every passing second  
Another of his cells  
Is attacked by an invisible army  
Wreaking havoc and revenge  
For a minor indiscretion  
Which happened so long ago.  
He wastes away  
Drawing useless heavy breaths,  
Getting closer to destiny-  
That wretched guardian of us all.*

*There is nowhere for him to hide  
As this modern Gestapo  
Hunts its victims with indiscretion  
And just as before there is no-one  
To stand in the way of the holocaust.  
I cry my tears in vain  
As his flesh literally turns to dust,  
Drifting away on a wind  
Fraught with harsh words  
And vile contradictions.  
I inject him with as much  
Strength and passion as I can muster*

*But his body rejects the potion  
And I am left to stand hopelessly -  
Neither help nor hindrance  
Merely a useless bystander  
In another of life's bitter injustices.  
And what use is there in praying  
When His words are used  
To justify the annihilation  
Of so many beautiful souls?  
I reject a god who acts so brutally.  
I reject all who cannot understand.  
I reject everything I have ever known of logic.*

*Stumbling through tunnel  
After dark, winding tunnel  
I lead him to the edge of the abyss  
And watch him peacefully fall  
Without wing or cloud  
To break the momentum.  
I am more alone  
than ever before.  
I no longer am.*

- Todd Alexander

### *Where are you my little man?*

*I saw a young boy go by  
He was two years old and green of eye  
Slender like you with straight red hair  
But hard as I looked, you were not there.*

*A group of children playing ball  
Boys and girls both big and small  
I was restless inside and the panic grew  
Because try as I might, I could not see you.*

*You are not really one of them, my little son  
You'll always be a special one  
Here a short while, then gone somewhere  
I could rest inside if I just knew where.*

*As I glanced up at the clouds gliding by  
Floating free in a peaceful sky  
Lovely and light - they have not a care  
And finally my son, I found you there.*

**I love you Hayden  
Daddy  
xoxo**

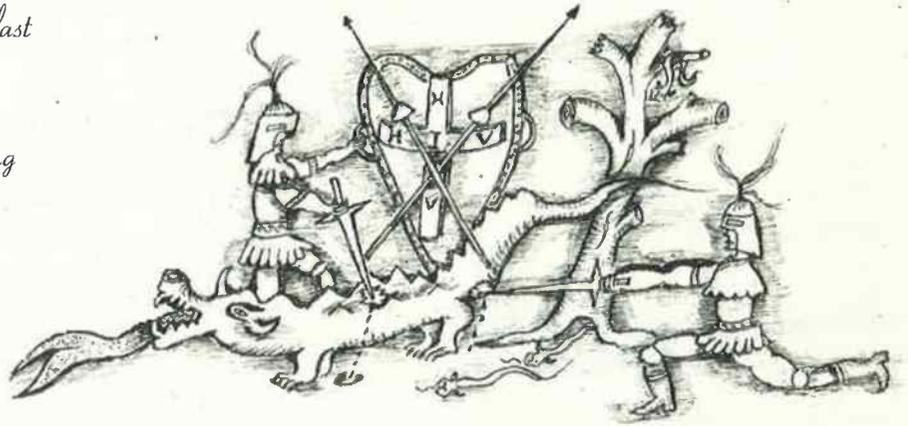
Hayden Brown died  
of AIDS in 1993.  
He was just 27 months old.  
He is sadly missed by his  
Daddy (Gregg Brown).

# The Holy Crusade

In times long past when knights lived fast  
And sported with abandon,  
Using wine and song and powders strong  
They indulged and loved at random.  
Pleasures of an ancient kind,  
Of golden calves  
Of sodom paths  
Enticing uncontrolled and debauched minds  
To worship icons of the devil's kind.  
Oh for sooth!  
What was let loose?

An omen of unholy dread  
Where fear and death become the norm  
If men took other men to bed.  
The Reaper sowed his seeds of horror  
And those knights once bold saw no tomorrow  
As they wrythed in sewers of decaying Gommorah.

But Hark! And Hear!  
A strange and solo monk did thus appear,  
Offering hope in all this fear.  
He preached and was known by all  
As our Holy Brother Retrovir.  
From all accounts it did seem  
He came from the isle of Zidovudine.



From a distant land another came  
A warrior of a warring clan and his name became  
Zalcitibane.  
But still the people grew more vexed.  
So from the ancient isle of Crete  
Travelled the Emporer Didanosine Videx.  
Descendent of a mummy's boy, the ruler known as  
Oedipus Rex.  
Zerit joined the new crusade,  
For Retrovir had had his day.  
Soon another from the Regal House of a different land  
Mightier still with sword in hand  
And different yet than all his peers;  
Rode Lamivudine of Epivir.  
These men had shown their strength  
And wrath against their foe,  
Who still wove anew his cape of woe,

And in the darkness slid and slimed  
His evil toxins through orifices of every kind.

Then the Queen of Arthur's name  
A noble woman and one of fame  
Joined the fight with torch and flame.  
It was Guenavir, a woman clear  
Who summoned maidens far and near.  
For another tactic, a different fight  
Was needed to outwit this force,  
This Grim Black Knight.

The myth of animar rose anew,  
The priestess legend summoned  
The spirit of Esther the Jew.

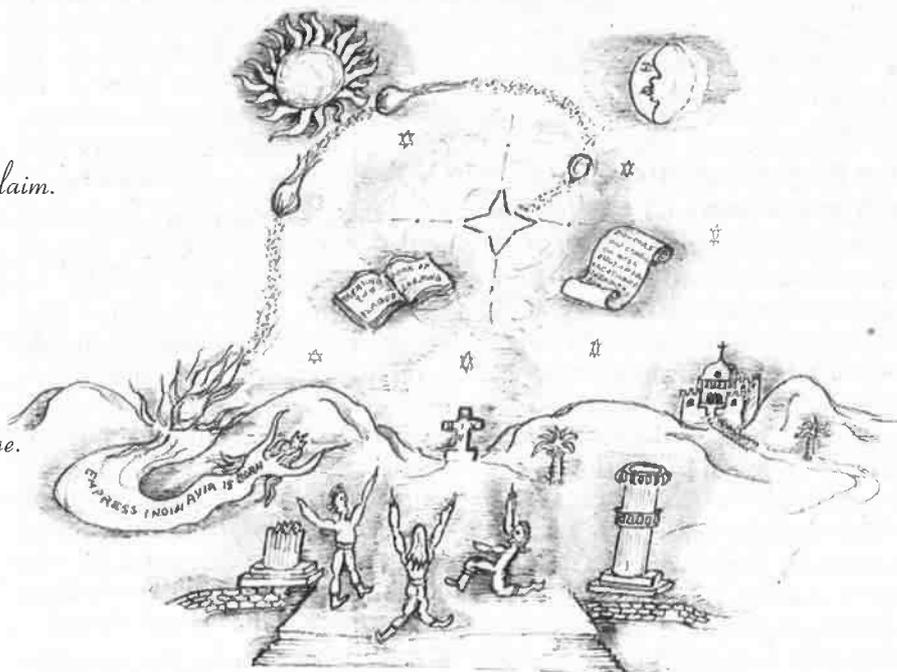
From the mountain kingdom of Nevirapine,  
A wooded land from a far off time,  
Two sisters travelled in a regal train  
On steeds of white  
And through every village received acclaim.  
Arriving first was a princess dear  
Known by all as Saquinavir.  
She joined the fight at Invirase,  
A coastal port where the plague did rage.  
In a barge along the winding Norvir  
Sat the Princess Ritonavir.  
She too offered a mighty blow  
To the plague of doom, this evil foe.

Many had their lesions cleared,  
Yet others grew sicker  
And she became more feared.

Behold above! A star shines bright,  
On a crystal clear and moonless night.  
Three wise men, doctors proud  
With books of learning and voices loud  
Spoke of brews, of potions new  
As they gazed above, a light broke through.

For the Queen of Stars,  
Crixivan, shot forth a comet  
Which on the sickened earth did land  
And from its ashes did appear  
The cosmic empress Indinavir.

— Gregory Zukerman



GRAPHICS: GREGORY ZUKERMAN



# 1997 World AIDS Day

## Children Living in a World with AIDS

- In Australia, 136 children had been diagnosed HIV+ at 31/3/97. Of these, 106 were boys and 30 were girls.
- To that date, there had been 43 cases of AIDS and 30 deaths from AIDS.

– National Centre in HIV  
Epidemiology & Clinical Research

- Every day, 1,000 children become infected with HIV.
- Over nine million children are estimated to have lost their mothers to AIDS. Many millions more are living with an HIV+ parent and face deprivation and orphanhood in the years ahead.
- Nearly one million children are living with HIV and suffer the

physical and psychological consequences of infection.

- Because of HIV/AIDS, millions of children are already experiencing the loss of their parents, educators, health workers, community leaders and role models.
- Children's rights are human rights. By affirming their rights, we help promote human rights for all.

– UNAIDS briefing paper

IN A WORLD WITH AIDS, CHILDREN must become everybody's responsibility. On World AIDS Day 1994, heads of governments from 42 countries, attending the Paris AIDS Summit, called for a global partnership to reduce the impact of the HIV/AIDS epidemic on children and young people.

Through the 1997 World AIDS Day Campaign, UNAIDS and its partners aim to bring to the attention of the international community the many facets of the epidemic's impact on the lives of children. The campaign will offer a platform for children and their communities to voice their concerns and aspirations in relation to the epidemic and to support the development of appropriate responses.

### The Rights of the Child in the context of HIV/AIDS

All children under the age of 18 living in today's world – whether they are themselves infected with HIV, affected by AIDS in their households or communities, or living in the shadow of HIV risk – are recognised by the United Nations Convention on the Rights of the Child.

⌘ The United Nations Convention on the Rights of the Child in the Context of HIV/AIDS has spelled out principles for reducing children's vulnerability to infection and for protecting children

from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed:

⌘ Children's rights to life, survival and development should be guaranteed;

⌘ The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.

⌘ Children should have access to HIV/AIDS prevention education, to information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.

⌘ Children's rights to confidentiality and privacy in regard to their HIV status should be recognised. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.

⌘ All children should receive adequate treatment and care for

HIV/AIDS including those children for whom this may require additional costs because of their circumstances, such as orphans.

⌘ States should include HIV/AIDS disability as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.

⌘ Children should have access to health care services and programs, and barriers to access encountered by especially vulnerable groups should be removed.

⌘ Children should have access to social benefits, including social security and social insurance.

⌘ Children should enjoy adequate standards of living. Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.

⌘ No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.

⌘ Special measures should be taken by governments to prevent and minimise the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

Source: NSW Health Department

# Combination kids

*Deciding when and how to start combination therapy can be tricky enough. When the therapy is for your child, there are just a few more trifling issues to consider... like, are any drugs available for kids anyway? Or... how do I stop her spitting them out? In these pages, Michele Goode gives a rundown of what's available for the under-twelves, as well as some tips on getting the drugs past lips that seem to be welded shut.*

CURRENTLY, MOST antivirals are not licensed for use in children in Australia, but this does not mean they are not available. Children should not be compromised by lack of licensing – drugs that have not been approved can be obtained by your doctor through a scheme called the Special Access Scheme (SAS).

Why have antivirals not been approved for use in children under twelve years? Well, it seems that demand drives the drug companies to license drugs. It costs drug companies about \$100,000 to license drugs and in Australia the number of infected children is relatively low, therefore the demand for antivirals for children is low. So antivirals are dispensed to chil-

dren at the discretion of individual hospital budgets which are left to absorb the cost.

This is of course a less than adequate system and steps are being taken to try to improve it. The Royal College of Paediatrics has put a submission in to the Steering Committee of the Highly Specialised Drug Program requesting a review of the needs of

ment. AZT, d4T, 3TC, 1592, ddI, nevirapine, ritonavir and nelfinavir are all available in a child-friendly form, i.e. in a syrup that's easy to take or a powder that can be sprinkled on food. All these drugs have been trialled in children in USA and have been found to be as effective in children as in adults.

So the drugs are out there. If your doctor is having problems getting them for your child, the Paediatric HIV team at the Sydney Children's Hospital can be contacted for advice.

The parents and the child (if old enough) should be involved in the decision making about when to start taking antivirals, and which ones to use. Find out all of the options, consider the side effects and the practicalities of it all and be honest with your feelings and decisions.

Then there is the big C word, compliance! Are you as a parent willing to give these drugs to your child and adhere to the regimen, knowing that skipping or missing drugs can cause HIV resistant strains to emerge?

Talk about your fears with your doctor, nurse or social worker. It may be that you need more information and more time. It may be that the combination that's recommended is just not practical for you or your child. It may be useful to talk to other parents in



GRAPHIC: KAREN VANCE

children who require specialised drugs under the S100 scheme. Drugs available to children infected with HIV/AIDS will be included in this.

In the meantime your child should still be able to get access to the recommended treat-

similar situations so that you get a better feel for the nitty gritty details.

We recommend starting triple combination therapy when viral loads are consistently over the tens of thousands, or when the CD4 (T cell) count is falling, and that can be hard on children. With an adult, you can rationalise the use of drugs when they feel fine, but children have a basic logic that: if I'm sick I take medicine, if I'm OK, why do I need this stuff? For some tips on crossing that hurdle, see pp 17 & 18.

The next obstacle is the taste! Most of the drugs taste fine – well, not *too* bad. So far children have had no problems with taking AZT, 3TC, d4T and ddI, but—as usual, there are exceptions to everything. One of the protease inhibitors, ritonavir, tastes really bad and I have to say that the only children taking this at the moment (apart from one child who we affectionately call asbestos mouth) are children who already have feeding tubes in and don't get to taste it. We have tried the peanut butter and chocolate before and after the drug as recommended, to kill the taste, but mostly children simply refuse to take it.

Nelfinavir, the other protease inhibitor, is very sweet tasting and the children don't seem to have as much of a problem with it. It comes in the form of a powder which can be sprinkled over food or in milk. Do not put it in citrus drinks like orange juice because the taste apparently becomes unbearable.

Other drugs like ddC and saquinavir can be used in children but they are either tablets or capsules (and in the case of saquinavir, lots of capsules) that most children cannot swallow. Indinavir is just too impractical, it requires you to have an empty stomach for a start. Try telling that to your child who raids the fridge regularly, or your child who does not eat a big amount but fancies a snack at the

wrong time. And you need to drink lots of fluid – about two litres a day for an adult – not easy.

And then there's school. Adults can wear an alarm clock to remind themselves that their tablets are due to be taken. But young children cannot take that responsibility. They are too young and they go to school where often people do not know that they are HIV positive. If your child is on a combination of drugs that need to be taken three times a day, give the middle dose after school. Maybe you can work your own schedule around this if you are having to



GRAPHIC: KAREN VANCE

take the drugs three times a day and you can take them at the same time as your child. This can make the child feel a little less isolated and you are less likely to forget yours. Most parents say that their own health takes a back seat to that of their child. Remember you need to keep *you* healthy to have the energy to keep your child healthy.

Make sure when your child does start treatment that they see the doctor regularly. It is important to monitor the drugs' effect on your child's body to make sure that they are doing a good job and also to make sure no harm is being done. All drugs have the potential for side effects and antivirals are

no exception. Your doctor, nurse or pharmacist can alert you to side effects you need to look out for.

So far, children seem to be tolerating the antivirals really well with the most common side effect being diarrhoea. This is problematic for a child who may not be toilet trained or in the midst of training. It may mean a child wearing nappies for a period of time until control is gained. This of course has implications for schooling. Schools are unlikely to take a child who is still wearing nappies. As well as that there is the potential for the child to be a target of teasing. Speak to your doctor, nurse and nutritionist. Dietary advice may help.

Nausea has been reported to be a common side effect of the drugs, in particular ritonavir. This usually seems to improve as time goes by. There have also been reports of skin rashes. If these occur contact your doctor for advice.

Falling viral loads and increasing T cell counts are often the only indicator that your child is doing well since they may have started medicines when outwardly they were feeling fine, but a blood test revealed the viral load count was high. Remember that the aim of medicines at this stage is to avoid damage to the immune system and keep the child well, so you may not notice a tangible difference to your child's wellbeing.

As for those children who already have damaged immune systems, don't despair, repair can take place and further damage may well be averted. Don't be anxious to get early results.

We recommend doing a viral load test three months after starting the therapy. During that time however, parents often tell us that they can see remarkable improvements in energy levels in their child, so be prepared!

*Michele Goode is Clinical Nurse Consultant with the Paediatric HIV Team at Sydney Children's Hospital.*



# Mary Poppins, where are you?

*If only we all had Mary's charm and skill at making the medicine go down! These tips may help make it a little easier.*

CHECK WITH YOUR DOCTOR OR nurse how much of each medicine to give. Ask them to show you and get them to write it down for you. Find out if the medicine should be given with or without food, and ask about the side effects your child may experience.

If you are running out of medicine, let the hospital pharmacy know at least one week in advance so that it is ready for you to pick up when the time comes.

When giving the medicine, be patient and try not to raise your voice. It can be upsetting and scary when your child won't take their medications, but try not to get angry with them. You may need to get support for yourself so that you can approach the whole situation with a more relaxed attitude. This could mean delaying a dose for half an hour or so while you get on the phone and sob to your best friend or perhaps a counsellor about how hard it is and how you can't stand the little @#&\* for not doing what they're told, etc. (out of the child's earshot, of course)!

A good technique for babies and toddlers:

Prepare everything first. Then sit with your baby on your lap in a comfortable chair and have everything within reach – the med-

icine, towel, bib. If you are right handed put the baby in your left arm. Now hold the baby's left arm with your left hand and put the baby's right arm under your left arm and around your back (as you would when giving your baby a bottle). Hold the baby's head between your arm and chest so the head stays still. Tilt the baby back – gravity may help and you may need all the help you can get! With

a syringe or dropper slide the medicine along the side of the tongue towards the back of the mouth – the baby is less likely to spit it back out that way.

Give little amounts at a time to prevent choking and spitting.

Gently keep the mouth closed until baby swallows. When all the medicine is finished give a big cuddle. Some juice or water at this stage will help to get rid of the after taste.

For older children:

Older children will need a little more encouragement. You may have developed some tricks of your own at this stage but here are some more that may help.

- Never ask your child if he or she wants or will take the medicine. Instead tell them that they must take it but offer choices on how they wish to



GRAPHICS: KAREN VANCE

take it and acknowledge that it is horrible having to take medicines.

- Sometimes kids just need to throw a tantrum about having to take the medication first. If you're able to listen to all their anger and fears about it and let them have a good cry, they may become much more relaxed about the process, and notice that it's not as bad as they thought it was.
- Involve your child in taking the medicines. They may actually want to help you get them ready. Little ones might like to squeeze the syringe or dropper themselves.
- Negotiating about the exact timing of a dose – for example, before or after the bedtime story – will also give the child a greater sense of control (But be-

ware of the “just one more story first” tactic).

- Offer the child a choice about taking it straight or mixed in a milk shake, honey or ice cream.
- Keep trying different foods to cover the taste until you find one that works.
- If there are a few friends and relatives about, smaller children may like to choose who gives them their medicine on some occasions.
- Keep explanations about why the medicine is needed as simple as possible and talk about it in relation to something that the child connects with. (Example: feeling tired is awful but this medicine might help you to run faster).
- If you have to give asthma medication, allow the child to play

with the spacer or mask so that it's not so frightening when you need to use it.

- The taste of some medicines is just too hard to cover up and you may need to talk to your doctor about changing to something else if your child continues to refuse.

Remember the first month will be the hardest and if you have enough support for yourself and have found strategies that work well, it should get easier after that. Stick with it during that period. Get your friends to offer your child plenty of encouragement. Eventually you will find that your child will take the medicines in two minutes instead of the long one hour battle it used to take when you first started.

– Michele Goode & Jill Sergeant



PLWHIA (NSW) is an advocacy organisation. One of our main objectives is to ensure that people with HIV/AIDS have access to high quality treatments.

Our Treatments Working Group advises us on treatment policy and advocacy. The group is made up of volunteers with skills and interest in the HIV treatment area. Lobbying for better treatments, and ensuring that the new drugs are provided to people who need them the most, are some of the activities of the Treatments Working Group.

Due to some members moving out of NSW, the Treatment Working Group is looking for 2 people to join the group. We are looking for people with skills in advocacy and policy, and a knowledge of HIV treatments (or basic knowledge with at least a very strong interest in learning more).

Meetings are held once a month, usually Thursday evenings, commencing at 7pm.

**If you think you have skills to offer and an interest in HIV treatments please contact Jo Watson at PLWHIA on 9361 6011 for more information. Applications close 31 October.**

## Performance Positive

### VII 'Hope' October 24 + 25

Host: Paul Capsis

Performers: The Soul Bitches, Elizabeth Burton, Dean Walsh, Tim Bishop, Martin delAmo, Paul Cordeiro, Heather Grace-Jones + Graeme Gray.

Due to overwhelming interest there will be different performers on each night.

Book your \$5 ticket in advance at PRIDE or 7.30pm on the night.



### Kids to give their take on 'Hope'

Open day @ PRIDE for kids to contribute to a banner being created for *Performance Positive VII*. The banner has been donated by South Sydney Council.

Refreshments + fun + 'Hope'!

Sunday October 19, 10am - 4pm.

Carers of children with special needs are encouraged to ring in advance.

Call 9331 1333 for further information.

This ad sponsored by 'Talkabout' (a project of PLWHIA NSW)

# Julie & Amanda and the pills



*Julie is a positive woman in her late twenties, who lost her partner, John, to AIDS over two years ago. Her oldest child, Amanda is five years old and also positive.*

## **What medication does Amanda take?**

She's on 3TC in liquid form, d4t also as a liquid, nelfinavir, fluconazole, acyclovir and bactrim. She's also prescribed Ventolin and pulmicort for breathing.

## **So what does this mean in everyday terms?**

Well, she takes eight or nine tablets a day, in four batches throughout the day. There's also three sets of liquid medications. I don't push the puffers much, unless she's going to be in a smoky environment, or she needs them because of a cold.

## **Why does she take this combination?**

She was on AZT for two years, and then ddI, but she didn't tolerate that well at all. She's also taken AZT and 3TC for a while. Our doctor has been cautious, and didn't want to rush into the protease inhibitors, until nelfinavir was available, which is apparently better for children. They say when starting the PI it's better to change the other medications and that's why he wanted to change her onto the combination d4t, nelfinavir and 1592. We're still waiting for the 1592 to be available.

## **Have there been side effects?**

She occasionally gets 'itchy bites' from the Bactrim, and there's been a bit of neuropathy too I think, but it's hard to tell.

The other day she said her fingers were tingling, but I knew she'd been watching TV on the floor with her hands underneath her, so I wasn't sure if it wasn't just old-fashioned pins and needles. It's hard for her to put that sort of thing into words anyway.

## **Have the drugs been working?**

She's definitely improved since taking the 3TC. She has more appetite, has gained weight, and is growing. She's also doing more of the things she's supposed to do at her age. I'm concerned about these drugs in the long run, because of possible kidney damage, and that sort of thing. But her viral load has come down, so I'm grateful for that. Our doctor is good, he explains things, and I'm certainly involved in the decision-making.

## **Is it easy for her to take the medication?**

No! It was okay when it was liquids, and I could mix them into fruit juice or Milo, but since she had the bad experience with the ddI it's been harder. She often kicks up a fuss about taking the tablets. Some of them are quite big, and I can halve them, but if you chop them up more than that, it just takes longer to get them down. It puts a fair bit of pressure on me. People say oh well, lots of adults forget to take pills or avoid taking them, but I'm responsible for her, and if I don't make her take the pills, she won't take them. It can be a real battle sometimes. I feel accountable, and it can stress me out sometimes.

## **Do you have any ways of making it easier?**

I wish I knew how. She'll often take them for other people when she won't take them for me, but there's not always someone else.

Sometimes I resort to threats! We did find that there was a better alternative to the usual cherry-flavoured bactrim liquid. It's bactrim in suspension and it tastes a lot better. The chemist had to get it in specially.

## **How are things at pre-school?**

Oh they're great. The staff take her aside and give her the medicine in the kitchen – it fits in well with the nap after lunch. When she started on the tablets, I had to tell them that she was positive. Our CSN co-ordinator was really helpful. She suggested we tell them on a Friday, so that they'd have the weekend to digest the idea, and she made the phone call. They've all been very good, genuinely concerned for Amanda and her health and not frightened or moralistic. In fact I'm more worried that they'll be discriminating too positively – she's always been a bit of a pet with them.

## Amanda

### **Amanda, how do you feel about taking your medicine?**

I took all my medicine.

### **What's good about taking your medicine?**

I already took it today!

### **What's bad about taking your medicine?**

Yucky taste! Not the Bactrim, and not the little round ones but the other ones (Julie: nelfinavir).

### **Do you know other children who have to take medicine?**

Nanna. I help Nanna take her medicine. Mummy's sick too.

*Interviews by Bill Evans*

# White roses blue ribbons

*Chris's son Timothy is 13 years old. He lives with his mum in Sydney and spends most holidays and any weekend he possibly can, with his dad, who lives in the country. Chris reflects on some of the issues that have come up for him as a positive gay dad.*

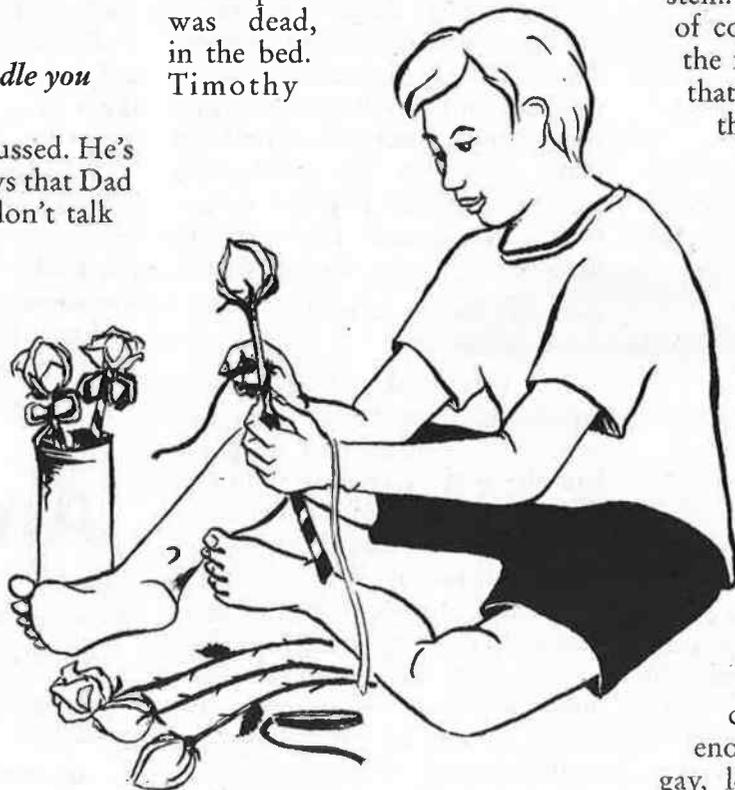
## **How does Timothy handle you being positive?**

It's basically not discussed. He's conscious of it, he knows that Dad has the virus, but we don't talk about it at length at any time. His experience, having watched my lover die and friends die and all of that, is that he equates it with me leaving him. He has this assumption that I will die, because no-one else he knows with HIV has lived.

Of course I did leave him when he was 18 months old. And now the thought that I may leave and he'll never see me again is fairly devastating – if you're just bordering on adolescence and your parents die, that's a fairly traumatic time of your life. Knowing that makes the bond even more special, and the time that we have. We've got a lot of things to resolve, there's no denying that, we've got a lot of talking to do.

When my lover of eight years died, Timothy was there. He knew what it was all about, although initially we tried to hide it from him, we didn't want him to know. He was about nine then. We didn't want him to be – tainted – by the whole thing. I know that's a really rough word . . .

He came around with his Mum and Alphonso was dead, in the bed. Timothy



GRAPHIC: KAREN VANCE

was so good to me, making sure I was okay. Of course he loved Alphonso as well, he'd grown up with him. I'd moved out when Timothy was about 18 months old and I'd met Al within 12 months – he loved Al.

I had said to Tim, listen love will you pick up some white roses for the funeral – just one for Al's

sister, who was coming out from Argentina, myself, Helen, for you and Mum and Ian. He said to his mum on the way home in the car, I've got to go to the shop where you buy ribbons, I've got to buy some ribbons. Anyway, they bought the roses, and Timothy dutifully sat down and on every one of the roses he wrapped blue and white ribbon around the stem. Al was Argentinian and of course blue and white was the flag of Argentina. He felt that was a really important thing to do. I didn't even think of that! Didn't even cross my mind. So here's this fabulous little boy, doing that for me. I was very impressed by his loveliness on that.

## **How public is he at school, and with his friends about you being HIV positive?**

Well he can't really be. He's at a Catholic boy's school, it's really difficult for him. It's difficult enough having a father that's gay, let alone having a father that's HIV.

Although Timothy at one stage, years ago, when we used to get AZT in these huge big bottles, wanted to take it along and talk about it at 'show & tell' at school one morning. I don't think it was hugely appropriate that he do that, but of course it's part of his life, he sees me taking the tablets. I think I told him that I needed it to stay well, and he saw it as a wonderful

thing to talk about, this medicine was keeping Daddy well.

*This interview came about because you contacted the PLWH/A office some time ago, about wanting to get childcare at a positive retreat. Could you tell me about that?*

In May 1995, ACON Northern Rivers had a retreat. It was in school holidays and I asked what provision they were going to have for kids. I got this really stoney silence from everyone. It was, hang on, you're a gay man, this is for positive people. And I said yeah, okay, but I happen to have a child.

I could actually think of six men, very quickly, positive men that I know, who have children. Some of them are sole custodians for the kids. A retreat would be a prime opportunity for us to get

away as positive parents, and have a facility for us to take our kids to.

Anyway, ACON said that they didn't see it as appropriate for children. And I thought that was a very interesting statement! What was going to happen at the retreat that wasn't suitable for children?

As it ironically turned out, Timothy was off on a fitness camp on the weekend of the retreat and I went anyway. But I didn't know that initially, I thought it was the following week.

*Did you feel that there was anything your son couldn't have handled?*

No, there was nothing there I haven't exposed him to, just through watching movies. I can understand that there may have been other people who may have

had difficulties with children being there.

My other argument was that I knew for a fact that the women's retreat always had childcare. Why didn't the men's retreat provide it? It could have been a really affirming experience for Timothy to be at the retreat – for him to see that people are living with HIV, that people are getting on with it.

I think there's a need that's not being addressed – the issues of positive men with children. There are a lot of us out there, I would like just a recognition that we exist.

My son is probably an even bigger part of my life than my gay identity – your children are, they're critically important to you.

*Interview by Jill Sergeant*

## LET'S TALK ABOUT SEX

Appointments  
& info phone 9382 7440  
For recorded information 11646

- \* HIV/AIDS tests and care
- \* HIV eye clinic
- \* STD tests, treatment and information
- \* Hepatitis B tests and vaccinations
- \* Counselling
- \* Free condoms, dams and lube
- \* Multicultural information & interpreter services
- \* Needle syringe exchange
- \* Safe sex information

**SYDNEY SEXUAL HEALTH CENTRE**  
Sydney Hospital, Macquarie St

(near Martin Place Station)

No medicare card required

## The good, the bad and the ugly

Have your experiences in the  
workplace been good, bad  
or downright ugly?

Whatever, we want to hear about it!

The Australian Centre for Lesbian and Gay Research and the Gay and Lesbian Rights Lobby are undertaking research on workplace experiences of Lesbians, Gay men and Transgender people. The information obtained will be used to lobby for changes in workplace practices.

So all you Lesbians, Gays and Transgenders out there, be sure to pick up your copy of the survey from **The Bookshop** (Darlinghurst and Newtown), **Gleebooks** or **The Feminist Bookshop**. If you can't find it or live outside Sydney (as lots of us do!) don't fret, just ring The Australian Centre for Lesbian and Gay Research on (02) 9351-5564 (1800 350507 outside Sydney for rural distribution points) or e-mail us on [acigr@social.usyd.edu.au](mailto:acigr@social.usyd.edu.au) and we'll make sure you get your copy.

Don't miss this chance  
to tell *your* story and  
make a difference!

# DIFFERENT STROKES

*Steven has written this story about dealing with the virus in response to Paul's story, "A different school of fish", which appeared in the August Talkabout.*

I SEROCONVERTED IN MAY 1996. I had been acutely aware of HIV before then, with a number of friends positive or dead, and a brother positive since the early '80s. For me, safe sex meant very very safe sex, but still . . .

I got what I thought was the flu in April 1996, which reminded me to get my regular HIV test. My doctor advised me that my results were unclear and that I should get more detailed testing done. We made an appointment for me to attend St Vincent's Hospital on the next Tuesday.

I did not keep the appointment as such. Instead, over the weekend I got very sick, and got admitted to the hospital on the Monday. Straight to ward 17 - I was stunned. Lots of tests, very sick. Thursday brought confirmation. This caused lots of medical students to come and visit - "look, here is someone with seroconversion illness".

I was vaguely aware of treatments that were available.

Protease inhibitors were very new and little was known. Even so, I was determined from day one to kill the virus as much as I could.

The hospital social worker told me about the various drugs that were available, and the doctor had prescribed some. I asked: "where are my drugs?" The social worker replied that I could start as soon as I wanted but the staff thought I might want to wait for a day or so to get used to the idea of being positive. That was like a red rag to a bull, and an hour later I had taken my first dose of combination therapy.

The first combination was AZT, 3TC, saquinavir. This combination reduced the viral load from 2.2 million to 3,000 over the span of four months. My doctor and I changed the saquinavir to indinavir, and this has provided undetectable results.

There were side effects - diarrhoea and nausea to start with, which reduced over time. Currently there are some skin rash problems, but I'm not letting that stop me from taking the drugs.

I have established a regime of taking the tablets: AZT and 3TC at breakfast (before 8.00am) and dinner (after 7.00pm). The indinavir is taken at 10.00am, 6.00pm and 2.00am. This timetable enables me to have lunch at lunchtime,

and dinner at dinner-time, and thus interact socially at those times whilst not eating for two hours before and one hour after taking the indinavir.

The 10.00am indinavir dose is invariably taken at work and often in front of other people. (I'm a lawyer, and sometimes take them in Court). I'm not sure if people notice that I take the tablets, or whether it sinks in that I do. Certainly no-one has asked me why I take the tablets every day, or why I don't share in morning teas. I think the worst that they might say is "strange guy, drinks a lot of water and takes some tablets".

The 2.00am dose means that I have to wake up in the middle of the night. Most nights I don't even notice: the alarm goes off, I take the tablets (which are beside the bed), I might go to the bathroom, and I fall back to sleep. No big deal.

I also recognise that the drugs may have some long-term effects. So does HIV. For me, the drugs are by far the better of two negatives.

I hate the fact that I'm positive, but it's a fact of my life. I look upon HIV as a medical condition with very severe end results, which the drugs keep at bay. I recognise that the drugs do not work for all of us, and I'm lucky. ♦

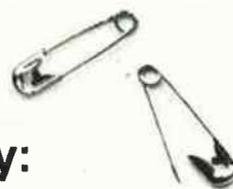


The November Talkabout will tackle an

**alternative theme for World AIDS Day:**

**Complacency is not the cure**

Send contributions to PO Box 831, Darlinghurst, 2010.



# Let's stick together

## The Coláo Project

WELL WE ALL KNOW BY NOW THAT if you're on combination therapy, it can be just a bit – shall we say, challenging – sticking to the prescribed regime. A new program, sponsored by Roche Pharmaceuticals, has been devised to address just that challenge. A key part of the program, which was launched on September 16 by OUT Communications, is the Coláo Project (Coláo is Greek for 'stick').

The project, co-ordinated by occupational therapist Pene Manolas, consists of ongoing workshops in which participants get to discuss and devise ways of managing their treatments and maintaining the motivation to 'stick' to the regimes; and forums where people discuss some of the same topics and feed back to the project about issues they're facing as positive individuals.

You can get into this project if you are already on or considering combination therapy. The first workshop is due to start this month so get in fast. Pene would prefer people to have a letter of referral from their doctor or other health professional. Then, in a one-to-one interview, she will assess your situation to make sure that you'll fit in and benefit from the workshops.

The first workshop will deal with stress management and skills development; the second will focus on goal setting, planning for

the future and prioritising, and the third, about "maintaining the motivation", is primarily aimed at people who are "feeling drug weary". Each workshop group

The other strand to the project, open forums, will, says Pene, "be more trying to gauge where people are at, how people are feeling, and will feed into how the project could develop. We will be monitoring the project fairly closely, it will develop over time."

The Project is a bit different from other community responses to the changing treatments environment because it is based on occupational therapy. But what is occupational therapy, you ask – isn't it just knitting and basket weaving? Well no, there's a bit more to it. In fact in Britain and America occupational therapy is, according to Pene, used quite extensively with people with HIV.

An occupational therapist's role is to work with a person to identify what difficulties and limitations the person faces in their every day living and help them figure out ways of overcoming them. Traditionally, occupational therapists have been best known for their work with people who've had physical injuries. Their work can be extremely practical, at the level of finding special cutlery for people with injuries to their hands or arms, but occupational therapists

will also consider other aspects of a person's life, not just the physical. For example, in the August *Talkabout*, we ran an interview with Sarah Yallop, an



*Pene Manolas, pictured at the Coláo launch.*

***"But what is occupational therapy, you ask – isn't it just knitting and basket weaving? Well no, there's a bit more to it."***

will run once a week for six weeks and if the project is successful and there's a lot of demand for workshop places, the project will consider options for expansion.

occupational therapist who assists HIV positive people to get back into the workforce; and the Coláo Project is using OT to address people's challenges around combination therapies.

"Our belief is that if there's a deficit in one area or another, it can impact on all the other areas of a person's life so we look at how a client functions holistically", says Pene Manolas, "the aim is to promote independence".

Although occupational therapy addresses the emotional aspects of illness as well as the physical aspects, it's different from counselling because it is concerned with the practical skills people need to cope – such as stress management, relaxation techniques, assertiveness, decision making and problem solving.

Pene sees it as "giving [people] the tools to make their own decisions and equipping them a bit more with the skills that they need" to put those decisions into practice. Occupational therapists

can work with people one-to-one or, as in the Coláo Project, in groups, where people get to share ideas and information. The process you're likely to go through is like a series of mental exercises, noticing how you deal with certain situations – for example, do you have problem solving



COLÁO  
GETTING YOU AND YOUR  
THERAPY TOGETHER

skills or do you just go into crisis when a problem arises? – and working out what the solution is, in this case learning some new skills.

Pene has been working with HIV positive people for seven years, most of that time in London,

where an occupational therapist is often part of a multidisciplinary team responsible for a positive person's care and support. She was attracted to the area because "I was looking for an area with a more holistic focus, one that did balance some of the psychology of illness with the physical side of illness." She moved from cancer medicine to renal and respiratory diseases, then to HIV, all areas where there's more opportunity to work with people on a long term basis, rather than just devise their special equipment and then wave goodbye. Another aspect that led her into the area was "that you're working with a young client group that's really motivated towards wellness".

Pene's had "fantastic" feedback from PLWHA she's worked with in London, about the value of occupational therapy. If you'd like to find out for yourself, call Pene at the Coláo Project on 9331 7466.

– Jill Sergeant

## Ugly Toenails?

Thick and crumbling toenails and fingernails due to a fungus are very common in HIV infection.

Taylor Square Private Clinic is studying the antifungal nail lacquer Loceryl™ as treatment for HIV-related fungal nail infections. Loceryl is very effective in HIV-negative people and is licensed in Australia.

Lacquer is applied weekly for 12 months with clinic visits every three months or so. There is no placebo. Lacquer is provided free of charge (normally about \$70) and payment is made to cover your incidental costs.

For information please contact Margaret Slade RN or Dr Neil Bodsworth at Taylor Square Private Clinic, Darlinghurst on 9331 6151 – email: [neilb@clinipath.com.au](mailto:neilb@clinipath.com.au).



## Finding the facts

By Simon Sadler

OVER THE YEARS GLORIA HAS covered many topics ranging from the runs to vegetarianism. But what foods should you be eating to keep you in good health? This is a topic where opinions and information are as varied as the outfits at Sleaze. And some dietary advice is also similar: on the surface it's appealing to the eye but on closer inspection is quite skimpy and full of holes! This may not be a bad thing as long as you keep on your toes to avoid getting into trouble. Some health and diet information (or more appropriately, misinformation) will charm you with promises and health claims, but will ultimately result in a dietary hangover, leaving your health and immune system worse off than when you began.

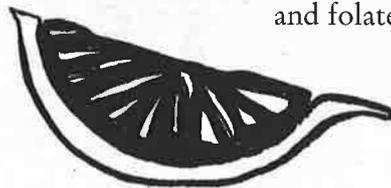
Your diet and lifestyle are important factors in your physical, psychological and spiritual health and they are 'treatment decisions' that you make every day. If you are deciding to start anti-HIV drug therapy, don't you want to know all the possible side effects? Your long-term nutrition is no different. The aim of this article is to give you some basic facts about good nutrition and a healthy lifestyle.

Good nutrition has a number of benefits that are not limited to your physical health. These benefits range from weight maintenance, psychological well being

and improved self esteem, to increasing the efficiency of HIV medication, optimising immune function and actually reducing your risk of hospitalisation.

Many messages from the media tell us that we should all be eating a 'balanced diet'. The term has been used so often it has become a cliché, but what is a balanced diet? It is an eating plan that incorporates a variety of foods from a number of sources. These foods with recommended serving sizes include:

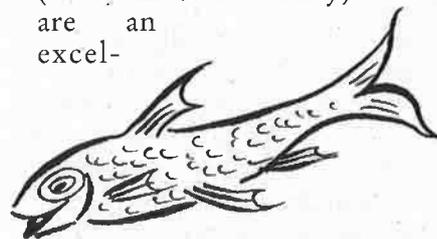
- **Breads and cereals** (at least five serves a day) which provide a number of the B group vitamins, energy in the form of carbohydrate and also fibre. Foods in this group include rice, pasta, breakfast cereals, couscous and all other grain products such as wheat, rye, and oats.
- **Fruit and vegetables** (at least three serves of fruit and four serves of vegetables a day). These are also energy foods and provide a variety of vitamins and minerals, such as vitamin C and folate.



- **Dairy foods** (at least three serves a day) are an excellent source of calcium and also contain protein and carbohydrate.

If these foods cause you bloating and diarrhoea, soy milk and reduced lactose milk offer a good alternative.

- **Lean meat, fish and poultry** (two - three serves a day) are an excellent



lent source of protein, vitamin B12 and iron.

- **Legumes, nuts and pulses** These include foods such as soy, kidney and baked beans, lentils and chickpeas. These foods are an excellent source of protein, carbohydrate, fibre and zinc.
- **Fluids** (at least eight glasses a day) are extremely important in maintaining body hydration and flushing the body of toxins. They include water, juices, cordials and a small amount of soft drink.
- **Indulgences** (one or two a day). These include the foods you treat yourself to every day such as takeaways, eating out, cakes, biscuits and yes . . . *chocolate!* These foods have important psychological as well as nutritional importance.

This all sounds very regimented and serving size variations will be dependant on your age, height and activity level. However, the fact

remains that eating a variety of these foods contributes to a healthy balanced diet.

As the word 'balanced' suggests, too much of any of these groups at the cost of another can cause nutritional problems. For example a diet consisting of a large proportion of takeaways, chocolate, soft drink, etc. is rich in energy but has little in the way of vitamins and minerals, the very nutrients that would strengthen your immune system, improve your energy levels and enhance your feeling of wellbeing. Alternatively, a diet consisting only of vegetables and fruit is low in protein and can become very dull and difficult to maintain (both psychologically and from a health perspective). As the old adage says: 'Man cannot live on bread alone'.

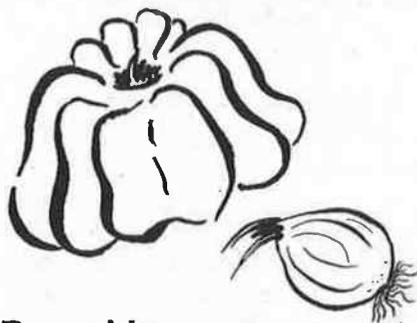
As there is a small amount of malabsorption associated with HIV it may also be wise to consider taking a daily multivitamin and mineral supplement. This will ensure that you are getting all of your vitamin and mineral requirements. It is important to note that megadoses of some nutrients, such as vitamin E and zinc can actually deplete your immune system. Also, doses of vitamin C greater than 2 - 3 grams per day may cause gastrointestinal upsets and diarrhoea.

Exercise is another area where you can improve your health and direct your own HIV treatment. Weight bearing or resistive training such as weights, gym work and exercises such as push-ups and sit ups improve fitness levels and muscularity. These improvements in muscle mass and tone may also avert muscle wasting in the future. However, it is extremely important to note that before commencing any form of exercise to consult your doctor and your dietitian.

A number of these suggestions become difficult when you experience one or more HIV or medication related side-effects. Side-effects such as loss of appetite, nausea, bloating, taste

changes and diarrhoea all contribute to a decreased food intake and weight loss. If you want to find out more about symptom control, diet and exercise contact a dietitian in your area. They will give you other ideas to improve your intake.

Here are a few examples of recipes that promote good health. As you can see it takes much more than an apple a day to keep the doctor away.



### Pumpkin soup

- (Serves 2)  
 500g pumpkin, cubed  
 2 1/2 cups chicken or vege stock  
 1 tspn butter  
 1 chopped onion  
 milk, sour cream, grated cheese and chives (if desired)

Melt butter and sauté onion two to three minutes. Add pumpkin and stock.

Cook until pumpkin is quite soft, adding water or milk as water evaporates. Cool. Mash with potato masher or puree in a blender. Reheat and serve with sour cream and grated cheese if desired.



### Chicken pot pie

- (Serves 2)  
 1 small onion  
 1 tspn butter

- 1&1/2 tspn flour  
 1 cup chopped cooked chicken  
 1 cup frozen mixed vegetables  
 1 cup milk  
 1 tspn chopped parsley  
 pinch pepper  
 pinch tarragon

### Mashed potato topping

- 2 medium potatoes  
 1/4 cup milk  
 1 tspn butter  
 pinch nutmeg  
 pinch pepper

Boil potatoes. Sauté onion in butter and stir in flour. Remove from the heat and add a little milk to form a paste. Returning to stove, stir through the remaining milk. Add parsley, tarragon and pepper. Cook over medium heat until mixture thickens.

Mix in cooked chicken and vegetables. Pour into a small casserole dish. Mash together potato topping ingredients until fluffy. Spread over the top of the chicken with a little butter & cheese on the top. Bake for 20 minutes at 200C or until golden brown.

### Spicy bean casserole

Recipe can be made a day ahead.

- 1/2 cup dried red kidney beans  
 1/2 cup dried lima beans  
 2 tspn polyunsat. margarine  
 1 spanish red onion, diced  
 1 carrot, sliced  
 1 small red pepper, chopped  
 1 clove garlic, crushed  
 1 small fresh red chilli, chopped  
 1 tspn ground cumin  
 1/2 tspn ground cinnamon  
 1/2 tspn ground nutmeg  
 410g can no-added-salt tomatoes  
 1/2 cup water  
 1/2 vege stock cube, crumbled  
 2 tspn no-added-salt tomato paste  
 2 tspn honey  
 1/2 cup canned no-added-salt corn kernels, drained

Cover beans with water in bowl, stand overnight, drain.

Heat margarine in pan, add onion, carrot, pepper, garlic and chilli, cook until onion is soft. Stir in cumin, cinnamon and

nutmeg, cook further minute. Stir in beans, undrained crushed tomatoes, water, stock cube, paste and honey.

Bring to boil, simmer, covered, for about 45 minutes, stirring occasionally, or until beans are tender. Stir in corn, simmer further five minutes.

Thanks to the National Heart Foundation for allowing us to reprint this recipe from their low fat cookery books.

### Fruit salad mousse

(Serves 4)  
 1 can fruit salad  
 2 cup low fat fruit yoghurt (e.g. fruit salad, apricot)  
 1 tbspn gelatine  
 600ml carton custard  
 Drain fruit and reserve 1/2 cup syrup. Puree fruit in a blender or food processor.

Sprinkle gelatine over syrup and dissolve over gentle heat. Add gelatine, yoghurt and custard to fruit and blend until smooth.

Spoon into serving glasses and refrigerate until set.



### Sleaze Ball smoothie

(Makes 1 litre)  
 2 cups chilled low fat milk  
 1/2 cup low fat vanilla yoghurt  
 200g frozen, fresh or tinned raspberries  
 3 ripe peaches  
 1 tbspn honey  
 Place ingredients together in a blender and process until smooth

consistency. Pour into four tall glasses and decorate with fruit.

Recipes are from the Weight Gain Cookbook which can be obtained through the Albion Street Centre ph: 9332 1090.

*Simon Sadler is a dietitian at the Albion Street Centre*

We welcome readers' favourite recipes.

Please send them in to Gloria, c/o *Talkabout*, PO Box 831, Darlinghurst, 2010 or email: plwhagen@rainbow.net.au.



GRAPHICS: PHILLIP McGRATH



## It's time again to say Thank You.

On November 30 at the University of Sydney's Seymour Theatre Centre we will again acknowledge the efforts of those in the community who work tirelessly and often anonymously against HIV/AIDS. Brochures explaining nomination criteria and nomination categories are available from AUSSIE BOYS, THE TOOLSHEDS, THE BOOKSHOP (Newtown & Darlinghurst), OGGI HAIRDRESSERS and most HIV/AIDS community groups. For more information contact Douglas at the NSW WORLD AIDS DAY PROJECT OFFICE on phone 9382 8356 or fax 9382 8158. The NSW World AIDS Day Project is funded by the AIDS and Infectious Diseases Branch of the NSW Department of Health.



# Applying for permanent residence

by David Law

JUST BECAUSE YOU ARE HIV POSITIVE doesn't mean that your application to become a permanent resident in Australia will automatically be rejected. All people applying for permanent residency must successfully pass a stringent health check. Not surprisingly, being HIV positive makes it impossible to pass the health check. However, in certain circumstances, someone applying for permanent residency who is HIV positive can ask for a waiver of the health requirement.

Most people with HIV who apply for permanent residency do so under the "interdependency" category, which is available for people in a gay or lesbian relationship whose partner is an Australian citizen or permanent resident. Other categories include spouse (including de facto), fiancé, dependent child or refugee. When

applying for the waiver, you will need to establish that granting you permanent residency is unlikely to result in undue cost to the Australian community. All relevant circumstances are taken into account including:

- your employment history and occupational skills;
- your medical history, current health and prognosis;
- how much you earn and any savings or assets you may have;
- your likely future use of medical services and social security;
- whether you have private health insurance;
- whether you have financial support from your sponsor, family member or organisation;
- any strong humanitarian or compassionate factors.

The treatment of HIV positive people in your home country may

be relevant. In particular, is there persecution of or discrimination against people who are HIV positive; and can treatment be readily obtained?

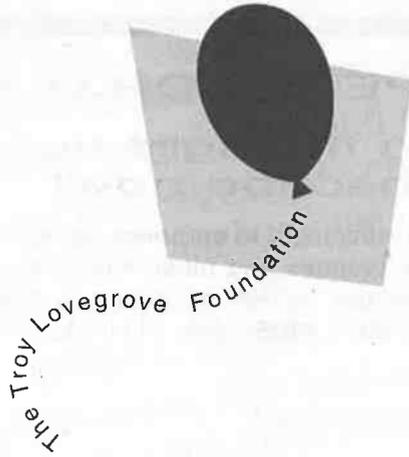
The process of applying for permanent residency is frustratingly slow and involves a huge number of forms and documents. This can be particularly daunting for someone who doesn't speak or understand English very well. Anyone applying for permanent residence, especially someone seeking a waiver of the health requirements, should be advised by an immigration lawyer or migration agent (who will charge for his or her services). Referrals, advice and assistance can be obtained free from the HIV/AIDS Legal Centre on 9206 2060.

*David Law is a volunteer solicitor at the HIV/AIDS Legal Centre in Sydney.*



GRAPHIC: PHILLIP MCGRATH

## Service Update



# The Troy Lovegrove Foundation Ltd.

TROY LOVEGROVE, THE SON OF Vince and Suzi Lovegrove, was well known from the documentaries *Suzi's Story* and *A kid called Troy*. Troy died of AIDS in 1993 and it was his final wish that a charity be established to assist other children living with HIV/AIDS. In 1994 the Troy Lovegrove Foundation Limited (TLF) was incorporated as a registered charity. It is the Foundation's mission to improve the quality of life of children in Australia who are living with HIV/AIDS – children both affected and infected by this illness.

One of the main ways that we strive to achieve this aim is through our Family Assistance Disbursements Policy.

The Foundation understands that families living with HIV/AIDS have many expenses, and we try to alleviate this extra pressure by helping them pay for such things as school fees, retreats, infant formula, utility accounts, white-goods, children's recreational activities (e.g. school camps, sports, extra curricular activities) and welfare expenses (food payments).

Although based in Sydney, the TLF reaches out and assists families throughout the continent.

The TLF will assess any request for financial assistance, forwarded to us by a referring agent (i.e. your case worker, social worker, clinical nurse, etc.) for families who have dependent children and who are living with HIV/AIDS. The referring agent must complete the Application for Financial Assistance form, which gives the Foundation basic information about each family. Because needs and wants continually change in family life, it is our policy that the family (through your agent if you wish) updates this form every six months.

The completed form can be faxed or posted to the Foundation for processing. We will usually assess the request within 48 hours of receiving it and contact your referring agent.

If your family is already on the Foundation's file the only form that the referring agent needs to fill in is the Family Assistance form. If you need assistance with bills it is important that a copy of all accounts be forwarded to the

Foundation along with the application form. If you wish, we can pay the account direct from our Sydney office, but if you prefer to do it yourself, we can arrange that too.

If we're not able to assist your family, we will try to refer you to other avenues and services that may be able to help with the specific request.

Your contact with TLF can be through your agent at all times, unless you would prefer to contact us directly.

If you would like more information about the Troy Lovegrove Foundation Disbursements Policy please do not hesitate to contact me on 9398 5880, fax: 9399 9006.

The TLF is a registered charity and our main source of income is fundraising activities. If you would like to increase the Foundation's vital funds for children living with HIV/AIDS, please send your tax deductible donation to PO Box 624, Double Bay, 2028.

**– Samantha Corrie  
National Manager**

# Talkabout

## WHERE WE SPEAK FOR OURSELVES

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

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

### PLWH/A Membership

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

- Full member (NSW resident with HIV/AIDS)
- Associate member (NSW residents affected by HIV/AIDS)  
Disclosure of HIV status entitles you to full membership of PLWH/A, with the right to vote for all management committee positions.  
Membership status is strictly confidential.

### Talkabout Annual Subscription Rates

Please note that *Talkabout* subscribers also receive *With Complements* Newsletter eight times a year for no extra charge!  
All NSW *Talkabout* subscribers also receive *Contacts* – the directory of services for people living with HIV/AIDS in NSW – quarterly.

#### Individuals

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