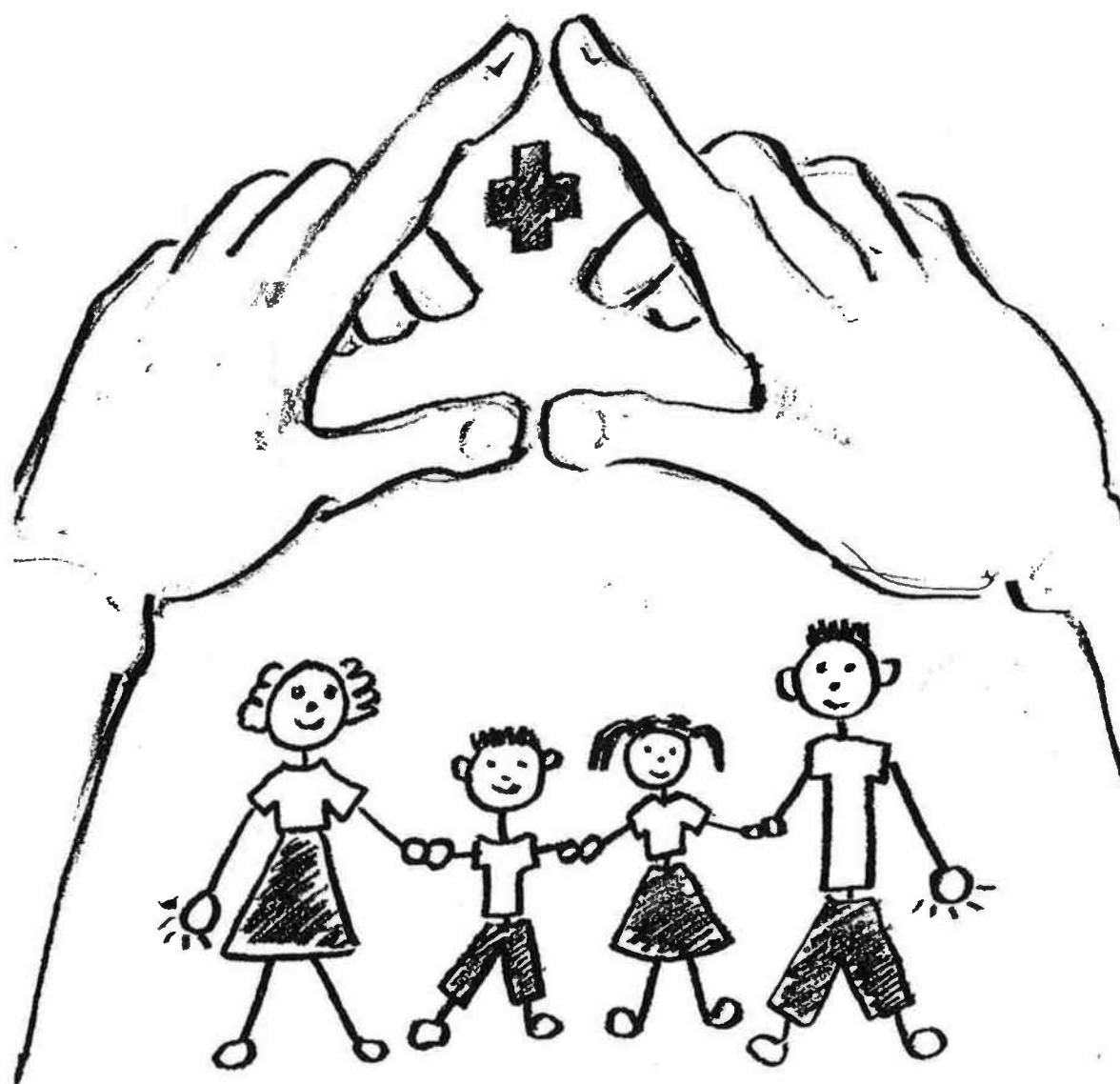


No. 59 October 1995

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆



In The Family

PLWH/A News



LOBBYING FOR BETTER TREATMENTS has taken up much of PLWH/A's time and energy over the past few months.

The current HIV treatment picture is pretty encouraging. We've never had as many new antiviral drugs in the pipeline, both in clinical trials and nearing marketing approval. Usually, it has been a long wait for the next new drug, with the pace of research appearing very slow indeed.

However, in the past year we've seen new antiviral drugs like 3TC and d4T give good results. We also have three new protease inhibitor drugs — Saquinavir, Ritonavir and Crixivan — being trialled, with the likelihood that these very promising antiviral treatments will be approved next year. Still more treatments are in earlier stages of development.

PLWH/A has been working hard to gain access to these new treatments for our constituents. For example, people who are failing on drugs like AZT, ddI or ddC often can't afford to wait for trials to be completed and new drugs to be licensed. So along with other activists and AIDS organisations, we've been lobbying drug companies to set up compassionate access programs to provide new drugs to people who need them most.

This work is usually difficult and demanding, but we are making progress. Abbott Pharmaceuticals have finally announced a compassionate access scheme for their protease inhibitor drug Ritonavir — no doubt as a result of intense pressure from activists locally and internationally. We met with Abbott last week and they have promised close consultation with us in setting up a compassionate access scheme for Ritonavir.

We should be able to give more details about the Abbott protease and about outcomes of meetings with other protease manufacturers — Roche and Merck — in the next *Talkabout*. In the meantime, if you feel you're running out of treatment options, keep asking your doctor or local AIDS Council for any new information.

While PLWH/A has been working hard on new antiviral drugs, there remains a huge amount of work to do on other treatment issues. Some of this work is just not getting done because it's beyond our energies and resources. To address this, PLWH/A has decided to create a new staff position of Treatment Advocacy Support Officer, to help us cope better with the huge treatment lobbying workload. Funding for this position is only possible because of a generous donation from one of our members. The position will initially run for six months and if it proves successful we hope to be able to find funds to continue it.

Another major issue we are focusing on is hospital care in the Eastern and Southern Areas of Sydney. We are particularly concerned about rumoured staffing and service cuts at St Vincent's Hospital, Darlinghurst. We'll be joining ACON in a meeting with area health officials to discuss the situation.

In the last issue I mentioned PLWH/A's response to the draft ACON Voluntary Euthanasia Bill. We understand that Parliament's consideration of the draft Bill has been deferred until early next year. We are continuing to formulate our position on the Bill — helped greatly by input we received from people with HIV. We plan to report on this in *Talkabout* soon.

There have been some staffing changes at PLWH/A. David Wallace has resigned as our Positive Speakers Bureau Coordinator. We wish David well for the future. Welcome to Sandy Thompson — our new Layout and Graphic Design Officer for *Talkabout*. And special thanks to Paul Canning, who leaves us after putting a lot of work into editing and producing *Talkabout* over the past year.

In conclusion, I want to pay tribute to Tony Carden, who died of AIDS last week. Tony was a magnificent AIDS activist. However, amongst all his hard work fighting AIDS, Tony still managed to enjoy life to the full and to find many opportunities to express his wicked sense of humour. There is a message in that for all of us. Thanks Tony, it was a privilege to know you and work with you.

— Bill Whittaker, Convenor



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This month's cover

By Ruth Samuels. Megan Mkwanzizi's 1991 needs assessment of Positive women found that half the women surveyed had children. By March this year, 111 children under 13 had been diagnosed HIV positive, of whom 30 have died. Small numbers, maybe, but HIV/AIDS has a big impact on kids, whether or not they are Positive themselves. That's why this edition of *Talkabout* focuses on children. Our special starts page 12.

Talkabout

Talkabout welcomes unsolicited contributions. However, we cannot accept responsibility for manuscripts and photographs or for material lost or damaged in the post.
Letters submitted to *Talkabout* or its editorial coordinator are assumed to be for publication in whole or in part unless specified otherwise.
For further information contact Jill Sergeant (Tuesday, Wednesday or Friday).
For advertising contact Sandra. Send contributions to:
PO Box 831, Darlinghurst, NSW 2010.

Deadline for the next issue: October 17

If your venue/organisation is interested in distributing *Talkabout*, contact the editorial coordinator. Call the editorial coordinator on 361 6750 for the date and time of the next Newsletter Working Group meeting.

Talkabout is published every month by People Living With HIV/AIDS Inc. (NSW). All views expressed are the opinions of the respective authors and not necessarily those of PLWH/A, its management or members.

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Talkabout is made possible by subscriptions, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* is also grateful for the assistance of the AIDS Council of NSW and thanks the many volunteers without whom its publication would not be possible.

ISSN 1034 0866

Briefs



● Bad news in Norway, where a new law enables doctors to refer to a national board any person they think is capable of putting others at risk of HIV infection. If the board agrees, the person may be isolated in a secure hospital unit for a minimum of three months. A similar law exists in Sweden, where 40 people have been interned since 1989 - mostly drug users and prostitutes. (*AIDS Newsletter*)

● On August 1 the Russian Parliament passed a new law requiring mandatory HIV testing for all foreigners who visit the country for three months or longer. It's not yet clear how this new law will be implemented. The new law has been widely criticised by Russian doctors and AIDS workers. (*Body Positive UK*)

● A new condom that changes colour if damaged has been patented in the US. The condom has three layers; the middle layer is composed of an air sensitive dye that remains colourless until one of the other layers is punctured. At that point, when the air hits the dye it changes colour, a warning that the condom has a tear. The dyes likely to be used would turn the condom purple or green. (*The Body Positive US*)

● The US Federal Drug Authority has issued a warning that people with HIV or liver disease should avoid eating raw oysters because of the risk of infection with a bacterium, *Vibrio Vulnificus*. 40% of infections are rapidly fatal. *Vulnificus* occurs naturally, not as a result of pollution. Proper cooking completely kills it and eliminates the risk. (*AIDS Treatment News*)

● As at June 1995, a cumulative total of 43,574 HIV infections, 8,358 cases of AIDS and 5,667 AIDS deaths have been notified to the Western Pacific Regional Office of the World Health Organisation. In 1994 Malaysia accounted for 43.3% of new infections and Australia 53.7% of the AIDS cases. This region includes Japan, China, Korea, Singapore, Nauru, Vanuatu, the Marshall Islands and Samoa. (*WHO AIDS Surveillance Report*)

● North American PLWHA, who have had to avoid tap water since the Centers for Disease Control warned that it could be dangerous, may have to avoid soft drinks and other flavoured drinks as well, until it's established that beverage companies are using filtered or heated water in their products. ACT UP's Cryptosporidium Working Group has recommended that people only drink water that has been boiled for more than a minute and always wash their hands after handling raw meat or chicken. (*The Body Positive US*)

● South Africa is about to have its first test case of discrimination in employment. A young man is suing the police force for not recruiting him because of his HIV test result. (*Positive Living Vic.*)

My sex

"BETWEEN WOMEN'S PAMPHLETS THAT assume I'm HIV negative and HIV positive pamphlets that assume I'm a man - I've disappeared", says one of the women whose story is recorded in the long awaited booklet addressing issues around sexuality for positive women, *My Sex*.

The booklet, which was launched at a private women's dinner in late August, is not a "how-to" safe sex guide. Rather, it is a collection of Positive women's personal stories about their experiences of sex. The voices in *My Sex* validate the feelings and experiences of Positive Women. The booklet documents a process of one-to-one interviews, workshops and feedback sessions in which women talked about sex and sexuality. Common themes are: sex is important, change, disclosure and negotiation, facts, loss, hope.

"We hope that women will relate to it on a really grass roots level, that they will read it and think 'someone else has felt like me'", says Jacqueline Frajer, ACON's Women's HIV Support Officer.

The booklet is the first of its kind in Australia. Copies can be ordered by or for women with HIV and AIDS in NSW only, from the ACON Information Team, PO Box 350 Darlinghurst 2010. Please respect that this is a limited and expensive resource especially for Positive women and is not available for general education or training.

Go herbal

THE LONG AWAITED KMI HERBAL trial should soon be going ahead, since the trial protocol has been substantially approved by the South Eastern Sydney Area Health Service Ethics Committee. Naturopath Jan Kneen-McDaid, who will be running the trial, is awaiting final approval of amendments to the protocol which would allow people using methadone or recreational drugs to take part.

The trial, which will run for a period of six months, is open to people with a T-cell count of 400 or less who have been diagnosed with HIV for at least six months and have had an AIDS defining illness. It will operate from the Australasian College of Natural Therapies at 31 Bay St, Broadway.

If you wish to participate, or have already registered interest when the trial was first proposed last year, please call Jan on 552 2243 to confirm your contact details. She hopes to start the trial as soon as the 200 places are filled. Please also pick up a memorandum of the trial from either the PLWH/A office, the Sydney PLWHA Day Centre or ACON (addresses in Contacts List).

AZT plus

EARLY REPORTS OF A US STUDY (ACTG 0175) have confirmed the benefit of combination therapy. The three year study of 2,500 people compared single antiviral therapy using ddI or AZT to combinations of AZT plus ddI and AZT plus ddC.

The key conclusion is that the combinations work better than AZT alone. The study also found benefit in starting combination therapy early, and ddI as a monotherapy appeared superior to AZT.

PLWH/A Convenor Bill Whittaker said that combination therapy "must now become the standard antiviral treatment for people with HIV in Australia."

The study results also had implications for the development of future clinical trials. "Some clinical trials . . . which test new drugs against AZT alone should be reviewed in light of this research," Whittaker said. Drugs such as 3TC, d4T and the protease inhibitors currently being trialed should be considered when people are deciding what drug combinations will work best for them.

Whittaker believes that viral load testing should become more readily available in Australia so that

decision making about treatments can be guided by viral load information.

At present, viral load testing is only available to people on the 3TC trial, but the results are not given to participants until the end of the trial. Rumour is that the test can be had — for a price — at certain locations in Sydney. "HIV doctors are keen to have the test made more accessible as soon as possible", says ACON's HIV Health Promotions Officer, Stephen Gallagher.

Screamline

ABOUT 70 PEOPLE, INCLUDING A dozen positive women, attended the launch of Screamline, the new peer support phone line for Positive women, on September 4. Speakers Chris Puplick, Acting Chair of the AIDS Trust and June Crawford, from the National Centre in HIV Social Research, made strong pledges of support to Screamline.

Positive women Kath Vallentine and Vivienne Munro spoke about their personal experiences of isolation and reflected on the added difficulties for women who are geographically isolated from other Positive women. It is hoped that Screamline will do much to counter such isolation.

Screamline is open to calls on Tuesdays and Fridays from 11am to 4pm. It is staffed by trained volunteers who are Positive women.

A Goodtime

THE POPULAR ANNUAL CAMP FOR families affected by HIV/AIDS, Camp Goodtime, took place on the weekend of September 22-24. The camp was attended by 31 families from all over the country, including 54 young people aged from six months to 16 years.

While adults learned how to massage their babies and attended workshops on topics such as disclosure, medical management of children and coping with loss, the children played hard, did craft activities such as mask making, went



Photo: Maz Images

Nurses from Ward 17 South with Brook (centre) at the Ward 17 South Benefit at DCM on Sunday 27 August.

horseriding, abseiling and grass tobogganning. Boomerang throwing, bootscooting and Quilt panel making were also part of the program.

Support groups for both adults and children were held after the Remembrance ceremony and tree planting on Sunday morning.

We hope to run a longer report on the Camp in the November *Talkabout*.

Positive living

REPRESENTATIVES FROM HIV positive communities called for a central role in service delivery and organisations for positive people at a conference organised by NAPWA in August.

Positive Living Centres were seen as the most desirable place to house advocacy, activist information and service needs of Positive people. Conference participants stressed the importance of skills development and national networking to the success of Positive Living Centres.

Ryan McGlaughlin, Executive Member of NAPWA and conference organiser, was inspired by the energy and commitment present at the conference. "The conference was able to create an exciting vision for the future", he said.

NAPWA will be approaching the Federal Government about job skills and retraining programs; looking at ways to address the financial needs of Positive people; and liaising with AIDS Councils, non Government and Government agencies.

Following on from this conference, McGlaughlin hopes that "Positive Living Centres will be the place to go to see Positive people supporting, caring and working for themselves."

A report describing outcomes of the conference is available from NAPWA. For a copy, or for more information call Russell Westcott on 231 2111.

Day service review

THE REVIEW OF DAY SERVICES FOR people with HIV/AIDS is expected to finalise its recommendations by the end of October. Consultations with a wide range of individuals and groups of people have been undertaken during September and a survey has been distributed within HIV treatment centres and in a number of community organisations.

Some of the issues that have arisen in these consultations have been

Briefs



● A coalition of community based organisations, including ACON and NUAA, have adopted a policy on "Prisons and Blood Borne Communicable Diseases". On September 18 Chris Puplick, President of the ADB, launched the policy, which includes a strategy for the appropriate care and treatment of HIV+ prisoners.

● ACON's Vitamin and Nutritional Supplement Service must be packing on muscle after the September fundraising benefits from "Bob Smith — Growing Up Gay" and "A gathering of Vampires". Thanks also to the Beachamp for free drinks donated to the "Vampires" pre-sleaze benefit. The Service sells vitamins, minerals and supplements at wholesale prices. Funds raised subsidise the more costly products.

● To coincide with a rural HIV conference to be held in Dubbo in March next year, Dubbo Regional Gallery is planning an exhibition dealing with related issues. Anyone interested in participating in this exhibition can contact the curator, Grant Buchanan before Friday October 27, at 52 Darling St Dubbo, 2830, (068) 82 5033, or Acting Gallery Director Elizabeth Smith, (068) 81 4342.

● The Gay and Lesbian Roadshow will be visiting Armidale on October 21 and Woollongong on November 18. One of the Roadshow's aims is to strengthen rural HIV/AIDS networks. For more info call the ACON Rural Project on 008 802 612.

● ACON Northern Rivers will hold their Byron Bay Outreach on October 9 and 23 from 10am to 3pm. Mullumbimby Outreach will be on October 16 and 30 from 10am to 3pm. For more information call Kathleen at ACON on (066) 22 1555.

● The Sydney PLWHA Day Centre October Day Trip on Thursday October 5 will be a visit to "Jewels of Fantasy" at the Powerhouse Museum followed by an afternoon at Homebush Aquatic Centre. Lunch provided. Call 357 3011 to book. We hope champagne will be provided for this outing, to celebrate the renewal of the Day Centre's lease for another twelve months. The lease, due to expire later this year, was renewed by SESAHS on September 12.

● The National Centre in HIV/AIDS Social Research urgently needs the help of participants in the 3TC trial or Special Access Scheme. Call Evan Smith or Claire Parsons on Freecall 1800 064 398 if you're interested.

● The AIDS Mastery workshop is for PLWHA, their partners, carers, families and loved ones as well as people working in the field. The purpose of AIDS Mastery is to discover ways to live to the full. The workshop is on October 13 - 15, with an introductory night on October 5 at ACON, room 3. Cost: \$250, no-one turned away through lack of funds. Call Bill, 247 8626 or Scott 368 0168.

the need for careful consideration of the location of the service, the hours of opening, the range of activities and whether the program should be a number of services linked together rather than providing everything in one building.

The consultants, Anne Malcolm and Lesley Goulburn, are seeking comment from PLWHA up until mid-October when they will begin to draft the report. They can be contacted on 564 1174 or 327 8128.

Queerlit

HIV IS "ONE OF THE MOST WRITTEN about diseases in our history", according to David Urquhart, convenor of the 'Writing HIV' panel at Queerlit on August 27. Certainly, there was no shortage of things to talk about at the session.

Speakers Colin Griffith, Dominic O'Grady, Kathy Triffitt and Chris Jones covered the gamut of topics from Positive writing, print media coverage, self documentation and users' writing to poetic responses to the epidemic.

Colin, who said that he viewed his writing as a form of therapy, read stinging and blackly comic extracts from his diary — a week of treatments, waiting rooms, anger and yearnings for rich, expensive food.

Dominic, ex ACON Media Liaison Officer, now with the *Sydney Star Observer*, delineated the differences between how the mainstream and community media identify AIDS as newsworthy. The mainstream media focuses on issues such as new infections, drugs and euthanasia, the gay and lesbian press are more likely to also run stories on poverty, quality of care, education strategies and funding — stories which are important to the affected community.

Kathy, who has been working on the Self-Imaging, Self Documentation project since the late 1980s, explored the importance of personal diaries and autobiographies not only for the individuals concerned, but also as emerging histories of the epidemic. Such writing documents

how people with HIV/AIDS view their own place within the epidemic and create a more authentic history than that documented by the media. She urged the importance of taking the responsibility to record our own histories.

Chris, editor of *NUAA News* and poet, suggested that HIV and Queer writing together cut across mainstream assumptions about the virus and appropriate responses to it. HIV has produced a new literature he said, which must also address issues of oppression and discrimination.

'Writing HIV' was organised by David Urquhart, a member of the *Talkabout* Newsletter Working Group.

The Strategy

THE SECOND NATIONAL HIV/AIDS Strategy, which embodies the Federal Government's commitment to HIV/AIDS care and prevention, expires in June 1996. A report on the Evaluation of the Strategy was presented to Prime Minister Paul Keating on June 27, as *Talkabout* goes to press. This report is likely to influence how Australia responds to HIV/AIDS into the next century. We hope to discuss the report in the November *Talkabout*.

Tree planting

EVERYBODY KNOWS THAT THE 47 DAY drought in Sydney broke on the 48th day. And behold, it was Saturday September 2, the day of the fourth tree planting in the AIDS Memorial Groves at Sydney Park, St Peters.

Project Co-ordinators had hoped to display their special T-shirts for the occasion. Alas, the continuous rain prevented any display and kept away most of the planters.

Nevertheless, some 20 or so did turn up and, looking like rice paddy farmers, planted between 200 and 300 young native Australian trees for people who have died from AIDS related illness.

There will be another planting in November. Dates have yet to be confirmed.

As you have guessed, the HIV/AIDS tree planting Project has plenty of white T-shirts for sale at \$15 each. The attractive tree design is in green and brown.

For information about the Project and T-shirts, call me on 718 1452.

— Mannie De Saxe

Positive mums

A WORKSHOP ON CHILDREN AT THE meeting of the International Community of Women prior to the GNP+ Conference in Capetown, South Africa, earlier this year identified the following strategies for addressing difficulties faced by HIV positive mothers, who may also have Positive children.

Women need to find ways to lift the burden of guilt that so frequently brings them down.

Women need to find an appropriate and workable way to disclose their status to their children.

Women need to be supported themselves so that they can live better and not feel that they are making their children suffer.

Women need to be supported and assisted in finding a reliable support network.

Society needs to get away from the taboos of death and realise and accept that dying is a natural part of the process of life.

Both HIV infected and HIV affected children need access to counselling — they need their own support. We all need to be allowed to talk openly about our feelings — it's okay to cry — but cry with your eyes not your heart. Cry — let it out and go on with life.

Positive kids

FINDINGS FROM A STUDY INVOLVING 42 children from 9 to 15 years old who had been born with HIV infections and were being treated at the Children's Hospital in New Jersey in Newark were reported in the journal *Paediatrics*.

Children infected at birth with HIV may live years without symptoms and without anyone realising



Photo: Maz Images

Craig Patterson, Commonwealth Department of Health (left) and Paul Kinder ACON Deputy director (right) pictured with Safe Sex Slut and Cindy Pastel at the launch of ACON's Gay Men's Education Strategy on September 4.

they are infected, the researchers revealed. Ten children had no symptoms. Eight showed some signs of illness but not enough for an AIDS diagnosis and the rest had the disease. Thirty six of the 42 showed no signs of illness until they were four.

(Body Positive US)

New horizon

"TREATMENTS PROLIFERATING", IS the optimistic heading in a story about new HIV/AIDS treatments in the *Washington Post*. By late next year, the *Post* reports, the number of anti-HIV drugs on the market in the US, will at least double from four to eight and possibly be as high as eleven.

The main task of researchers, in this scenario, will be to test the most effective combinations of these drugs, and the most effective sequence of treatments.

Protease Inhibitors, several of which are currently being trialed in Australia, are among the promising new treatments. They work by interrupting the reproduction of HIV. The Merck, Abbott and Roche PIs may all be licensed in the US next year.

Another treatment likely to be licensed in the US by the end of 1996 is 3TC, also being trialed here. Preliminary studies have suggested the drug is very effective in combination with AZT.

Interleukin-2 is a promising treatment that may also become available. Already licensed in the US for treating kidney cancer, some doctors have been prescribing the drug to PLWHA because it has been shown to dramatically increase CD4 cell counts — and keep them high over long periods of time. The drug can have severe side effects and not all people respond, but some report remarkable successes, like a jump from 300 to 2,000 CD4 cells.

According to the *Post*, some scientists anticipate one or two other drugs may also be licensed over the next year.

The down side is that a National Task Force on AIDS Drug Development has expressed fears that a wider range of licensed drugs may lead to a slowing of sales, prompting drug companies to back down on AIDS research. This would mean no fresh crop of drugs coming onto the market for some time.

Art therapy is often a good tool to help children deal with their mother's status.

Briefs

● Even mild stimulation of the immune system, such as a flu vaccination, appears to stimulate the growth of HIV, according to a paper released by researchers at the University of California. The researchers think such stimulation may "cause frequent small bursts of virus growth and that may lead to disease progression". They suggest, however, that most PLWHA should still get flu shots. (*Brother Sister*)

● A case controlled study of 237 people has found that people who reported smoking cocaine, crack or marijuana were twice as likely to develop pneumonia as those who did not. The use of PCP prophylaxis was similar in both groups and almost all participants were tobacco smokers. (*Positive Living Vic.*)

● A South African study of babies of 118 Positive women indicates that Vitamin A may be a useful treatment for infants with HIV. All the children who received the supplement had fewer illnesses, from rashes to respiratory infections. The study only followed the babies to age 18 months. (*The Body Positive US*)

● Animal data and anecdotal evidence have linked AZT with cardiac dysfunction and congestive heart failure. A study of 137 HIV+ children using AZT and ddI alone or in combination has found a strong association between AZT and heart dysfunction. No such association was found for ddI. (*AIDS Clinical Care*)

● London researchers who retrospectively reviewed the survival patterns of 436 PWA have suggested that while early intervention may postpone an AIDS diagnosis, it has little impact on overall survival. 339 people with prior knowledge of their HIV status (group A) had a significantly shorter average survival time after their AIDS diagnosis than the 97 people who were diagnosed HIV+ after their AIDS diagnosis (group B). Roughly half of group A (none in B) were taking antiretroviral therapy and PCP prophylaxis when diagnosed with AIDS, with a corresponding difference between the groups in the nature of their opportunistic illnesses. (*AIDS Clinical Care*)

● Pharmaceutical researchers have amassed a mind-boggling data base of 110,000 unused compounds that may be effective against HIV. In Japan, a professor at the Uni. of Tokyo has devised a computer system to search this database. He has already used his system to select 200 compounds that bind to an enzyme related to HIV. (*The Body Positive US*)

● St Vincent's Hospital Board will decide in October which services are to be axed for the sake of the hospital's budget. Fortunately, it's unlikely that the HIV/AIDS ward and outpatients clinic will be affected by the cuts.

Teacher training is needed to ensure good education for children at school.

Parents themselves need information in order to educate everyone in their child's life — parents of friends, care providers — as well as how to care for the child.

Educate children about HIV before telling them, and explain the difference between HIV and AIDS.

This forum was an ideal opportunity for women to share their experiences and realise that they were not alone in their struggle.

(ICW Workshop Reports)

Food law

PEOPLE WITH HIV/AIDS ARE NO longer banned from handling food for sale following changes to public health regulations. The changes to the Food (General) Regulation 1992 have brought NSW law into line with Federal Government recommendations dating from November 1992.

Regulation 30 of the Regulation previously provided that a person suffering from a medical condition listed under category 2, 3 or 4 of schedule 1 of the Public Health Act 1991, which included HIV and AIDS, must not handle food for sale or any receptacle, package, utensil, appliance, article or other thing used in the handling of the food.

(Chris Ward, HIV/AIDS Legal Link)

Charge dismissed

THE VICTORIAN SUPREME COURT has dismissed charges against an HIV positive man who had unprotected sex with another man [while detained in a police cell. His partner subsequently tested HIV negative.]

The man was charged under section 22 of the Crimes Act 1958 (Vic) with engaging in conduct which places another person in danger of death, and under section 23 of the Act with engaging in conduct which places another person in danger of serious injury.

At the Supreme Court in late June, evidence was given that the intercourse had been consensual. Evidence was given by a doctor specialising in HIV that there is only a one in 200 chance of HIV transmission in a single act of heterosexual or homosexual intercourse.

Justice Teague found that on the evidence there was no case to answer and directed the jury to return a verdict of not guilty on both counts.

(Tom Dalton, HIV/AIDS Legal Link)

STOP PRESS

STOP PRESS - ROCHE HAS ANNOUNCED a compassionate access scheme to their promising new protease inhibitor Invirase (Saquinavir). 50 places are available and applications close October 13 so contact your doctor quickly. If more applications are received than places are available, the drug will be assigned randomly. PLWH/A Inc. is calling for a substantial increase in the number of places, which represents less than 1% of the total available globally.

Notices

Tony Carden, AIDS activist, Clover Moore fan and Clarins Queen, died in early September. Appropriately, Tony died in St Vincent's Hospital, where he had fought so hard for AIDS beds in the early 90s. A tribute to Tony will appear in the next *Talkabout*.

Distribution hiccups — cynics will say it's been severe indigestion. Profuse apologies to those who received their September *Talkabout* late, or got fewer copies than usual. Unfortunately overseas readers will miss out this month. Increasing demand and over enthusiastic street distribution of *Talkabout* meant that we ran out of copies. If you desperately need a copy, contact the office and we just may be able to find a spare.

Open Letter



In early September PLWH/A (NSW) Inc. waved goodbye to Acting Co-ordinator Claude Fabian (now on sabbatical) and welcomed our new manager, Ryan McGlaughlin. In this letter, Ryan introduces himself.

IN INTRODUCING MYSELF I HAVE decided to enter the ongoing debate about orthodox medicine vs alternative therapies by reflecting on my own treatment regime over the last ten years. I am not doing this to say my way is the right answer, but rather to give you the basis of my philosophy. I hope also to demonstrate the importance of building your own 'truth' rather than taking other's ideals as absolute truth.

I was diagnosed HIV positive in 1985, however I believe I was infected in 1983. I never told anyone, or sought any advice or treatment. I was the only one that needed to know.

Then I became very sick, ending up in hospital falling in and out of consciousness thinking I was going to die. I became aware how vulnerable and how valuable my life was. I realised I had to be more honest with myself and consider changing my life in a big way. If I was to have the life that I wanted and believed in I had to have personal integrity. To have personal integrity I had to face my fears and prejudices.

I was on 1,000 mgs of AZT a day. I developed severe side effects and believed this was what everyone else experienced. I continued with little knowledge, but I had hope. I started to faint in the streets, home and at work.

At the same time that I started studying and practising Buddhism, I gave up AZT. I made a resolution to myself that only when my CD4 count dropped below 350 would I recommence this line of therapy. This was in 1990.

I decided to go exploring the world and accomplished some of my unfulfilled dreams. This included travelling through Scandinavia, doing risk activities such as abseil-

ing, white water rafting and tandem skydiving. On the journey I began to do workshops based on psychotherapy techniques. I continued practising Buddhism.

In Scotland I became involved with SOLAS (HIV/AIDS Resource Centre), a place that strongly supported an alternative approach to treatment. As a service user I used many alternative therapies and techniques.

Upon arriving back in Adelaide I became quite sick again. Whilst it was unrelated to HIV, I am sure having an impaired immune system was the reason why this illness manifested so severely.

I recovered and started fulfilling further dreams. However this had its own price. I no longer had the time to invest substantially into my spiritual well being.

In May this year, I found out my CD4 count had quite significantly dropped to below 350. Whilst I had made the decision to return to AZT when this occurred I was faced with a major dilemma. I had changed and now had a stronger commitment to alternatives but I knew my body was dangerously vulnerable. I was hearing what I believe were two extreme points of view. Here enters the debate between orthodox and alternative medicine. For two weeks I was in a nightmare.

Eventually I went down to Kangaroo Valley and sat on top of a mountain searching for my own answer. There I made an informed choice which I accepted as my 'higher self' deciding unconditionally. Two weeks later I had my CD4 count taken and it had risen significantly.

That choice was to take a combination of AZT and ddI and to also increase my usage of complemen-

tary medicine for six months and review the situation at the end of that period. Since making this decision I have a level of peace. I don't believe there are any secrets for long term survival but there are secrets for a better quality of life.

When I came back from overseas I really believed alternative medicine was the best and most valuable health model. My twin brother and I clashed over that. You see he is also HIV positive and a longer survivor than myself. He has been on orthodox treatment since AZT first came to Australia. We both remain reasonably well. Which one of us is right?

I believe in a balanced approach of orthodox complemented with alternative therapies which includes work on the body, mind and spirit. I believe that any extremist can lose the balance and might become obsessively health focused. That may create a high level of anxiety and stress and open you up to being sick.

My reason for wanting to share these experiences is so the community knows I strongly advocate the need for us all to have the freedom of choice over our own health regime. But to maximise the benefits of any decision we must be well informed of our options. This is the road to empowerment.



Tributes



Matthew Cook

5.2.63 - 17.7.95

For 'unn

MATTHEW WAS A MAN OF INCREDIBLE personality and diversity of experience. I only met him myself near on four years ago. He charmed me immediately and together we journeyed the last years of his life as a team, a couple, lovers.

These years were gifts, cherished and cared for by both of us, the most contented and rewarding years of our lives. During this time (which we rarely spent apart) we shared our life stories, we yarned for hours, days, weeks on end, bathed in each other's love, cared for each other and strengthened our beliefs and ideals.

The presence of the virus from the beginning of our relationship was something massive to deal with, but deal with it we did so that we could find a way of living. I have great pride in how we managed. From our struggle good things flourished, we towered. Our time together was good.

Matthew was clear on his identity. He was firstly Aboriginal, descending from the Bundjalung Nation of the far North Coast on his father's side and from the Dunggutti mob, Kempsey way, on his mother's side.

Secondly, he was gay and proud and thirdly, the hardest to place and reconcile with for both of us, was that he had been HIV positive for some years. But he got there and we shared the rewards.

Matthew, who was really Mark and every other name under the sun, was fun to live with. He was a laugh, he was wild, formidably sexy and had an incredibly giving nature. It was dangerous to let him know the things you liked, our home is brimming with china, art and garage sale nick-nacks and flooded with love.

The man that I knew had virtue, a sense of responsibility, value for man and nature, an unlimited tolerance for those he believed in and who returned that belief in him and lots of love to give. Everything he was was rooted in his upbringing, his family and his Aboriginality.

The greatest honour he gave me was to bring me to his family and for them to accept me, trusting in their son and brother, recognising his happiness and caring for me as his partner. We spent time living as a big family but taking care to find plenty of time for ourselves and this was respected. He had two homes,

here with me and with his mob. We chose not to separate the two, journeying from one to the other, together.

Kids featured heavily for us, you'd often find us dragging about someone else's child. They're fun, honest and compassionate and we'd have loved our own but as he said, neither of us had the hips for it. Consequently, I'm left with a legacy of midget fans, who are carrying their own pain for the loss of their playmate.

He was a private man, we were a private couple and he wouldn't want me to tell too much unless it was of benefit, nor would he want me to overdo his praises. If you knew him, you knew him.

We travelled a lot. Our third and last trip to Central Australia was initiated by an invitation for him to attend ANCA's National Aboriginal Sexual Health Workers Forum. We hadn't spent a night apart for about two years so he wasn't going



on his own. He had decided anyway that this was to be the last conference, he had said all that he had needed to say time and time again. People still didn't seem to be listening. They don't until they are forced to confront the virus when it hits inside their own backyard and that's not going to get us very far.

We saw friends fall away scared, knew they weren't coping, that they didn't want their lives tilted. We endured the interruptions of services and people that failed us, were thankful for the few that didn't and continued with the strength of knowing that we were each other's greatest support.

I fear that the intervention of strong medications took his life prematurely, that his indigenous

body's response was different, and call for a halt to such medical ignorance.

We found ourselves isolated, additionally, by health workers' inability to respond appropriately to Matthew's Aboriginality. A dying man's days are not the time for people to confront their inherited racism.

The biggest difference was made by people who dealt with their own fears aside from us, who crossed the line, who got to know Matthew for the unique man that he was, and those who continued to treat us as they'd always known us, visited us as they always had, came in close if we allowed it and provided acceptance. It's the strongest need for positive people and these people are always rewarded.

Matthew was a man who changed your life. He's gone now, still visits me from time to time for a cuddle and to see how I'm going and to make sure that I'm moving forward like we always were. There's plenty more to do and him getting sick meant neither of us could do it anymore. Now I can continue where he left off. I will in our own way and when I'm finished he'll come and get me and carry me home.

There is happiness to be found amongst it all, Aids doesn't have to overwhelm our lives. There is always plenty of room for joy if you make it.

Matthew is yet another Aboriginal gay man who didn't have to die yet and we must always remember these fullas.

— Tim Bishop

.....

Geoffrey Morgan
 Geoffreymorgan was kind
 Geoffreymorgan was loving
 Geoffreymorgan was caring
 Geoffreymorgan was there for me
 Geoffrey morgan attended all my parties.
 Geoffrey morgan came to all Christmas
 Geoffrey morgan was fun
 Geoffrey morgan was a party animal
 By Lauren Robinson
 Age 10

Olga's Personals

Olga is in danger of wasting away. She can only thrive and continue to provide her unique personal service with your support. Send in your personals now!

How to respond to an advertisement

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

How to place your advertisement

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

Family Support

By Vivienne Munro

In 1991 Megan Mkwanzani's National Needs Assessment of HIV Positive Women identified and documented the need for a service for families affected by HIV and AIDS. Since then, anecdotal evidence, peer support experience and research studies have confirmed the significant and growing need that is not being met in a systematic and co-ordinated way.

ADEQUATE SUPPORT FOR FAMILIES with young children has been a persistent gap in HIV/AIDS service provision. There is no system for co-ordinating substitute care for families needing respite care or alternative child care. Different government departments deal with different circumstances; situations are dealt with in an ad hoc way, usually only once a family is in crisis. This untenable situation has led to kids being admitted to hospital at the same time as their mothers, because there is no other option. Massive strains are put on existing services and families.

A list of recommendations around foster and respite care was formulated in November 1994 at the HIV and Families Conference. These recommendations endorse a collaborative approach and recognise that no single organisation can develop, provide or maintain all of the services required for the range of affected families. Rather, a strong partnership needs to be developed between government, substitute care agencies (Barnados, Centacare, Careforce, Burnside etc.), HIV/AIDS specialist services and community organisations and, in particular, families affected and infected by HIV.

In October last year a newly formed HIV Family Support Planning Committee (HFSPC) was convened by Lisa Brockwell (Women's Team ACON), Lisa Clement (Paediatric AIDS Unit, Prince of Wales Hospital — POW) and myself. This Committee is

composed of representatives from the Department of Community Services (DOCS), all the relevant substitute care agencies, HIV services (Ankali, CSN) and interested parents. The Committee has developed a model of care based on the clearly identified needs from the Family Conference recommendations and Megan's Needs



Assessment. The model proposes a partnership between substitute care agencies and HIV services, to be facilitated by one or two Family Support Liaison Officers.

The Liaison Workers' role will be to ensure that substitute care agencies and HIV agencies are communicating; to recruit and screen carers from existing networks within the HIV and families' communities; to co-ordinate and

provide specialist HIV training and support to both carers and families; in collaboration with substitute care agencies and families, match families with appropriate carers and monitor the placement of carers; handle referrals and coordination of support for families, including extended family networks.

The HIV and substitute care agencies would provide practical and administrative support, training and recruitment back up and referral networks. DOCS' role is to oversee the substitute care agencies and monitor the service.

This model was approved by the HFSPC, who have proven to be extremely co-operative and productive. Within two or three meetings we had formulated a purpose built collaborative model to provide a flexible continuum of care (from crisis to respite, fostering and adoption if necessary) that builds upon the strengths of both substitute care agencies and HIV organisations.

An application for funding has been approved and two workers will soon be appointed, one for a year and the other on a permanent basis. These workers will be placed with the ACON Women's Team. It was felt that although there could be stigma attached to being housed within an AIDS Council, the advantages outweigh the difficulties. Located with the Women's Team, the worker will be in an HIV sensitive situation in close liaison with existing networks of Positive women. They will be accountable and accessible to women and kids. This is particularly important given the fears that many women have about involving community services in caring for kids when they are ill, and the potential discrimination when care services are provided by those who are not HIV sensitive.

Frankly, DOCS and substitute care agencies have not had a good track record in the past and it's not appropriate for women to put themselves and their children in a situation where they feel there could be a loss of control, when already in a vulnerable situation. Using an HIV friendly service as a buffer to reach services will enable women to feel these services are for them.

Families affected with HIV are dispersed over a large area, (with clusters in metropolitan areas of Sydney), therefore this program is state wide in its brief so that families in relatively isolated areas will have access to appropriate care.

Priorities for the new workers will be to examine how families with HIV are currently dealt with and what changes are necessary, as well as assisting with implementing and co-ordinating the new model. They will also work closely with DOCS to develop policies that are adequate to protect families living with HIV.

A major shortcoming in existing service provision is the type of care that is available. At the moment, only respite care (every second weekend), crisis care (taking the child away from the home), or fostering and adoption are within the guidelines of substitute care agencies. DOCS has indicated that a greater emphasis on care in the home, a continuum of care and flexible arrangements will be given priority in the new policy.

This initiative is welcome at a time when, with the likelihood of vertical transmission (mother to child) being as low as between 8-20%, and with greater access to information and support, more positive women are choosing to have children. It is also a challenging period for the new service, as DOCS is in the process of restructuring and tendering out their service provision, as well as developing a new policy.

When I was diagnosed in 1985, at the same time as my husband, we didn't know where our children

would go when we died. I remember sitting in a coffee bar in Glebe with a representative from DOCS, asking her what policies were in place to protect our wishes and our children's wishes. I discovered that you can't leave children in a will like a piece of furniture and that if someone in the family didn't like our decisions they could be contested in court. The only way we could ensure our wishes would be carried out would be to have the children adopted before we died. I thought this was outrageous then and still do.

By approaching DOCS I felt that I was putting myself at risk by admitting that I couldn't cope and that my children would be taken from me immediately. The woman from DOCS told me there were no policies in place for HIV affected families and that if I wanted to start up a working party she would be interested in being on it. Well, it's taken ten years.

When my husband did eventually become ill and was dying I was fortunate to be in a position that I knew how to make the best use of the existing services. I knew the criteria for accessing them and was in a location that was accessible. I was able to co-ordinate CSN, Ankali, respite care, Homecare, child care, community nurses, doctors, specialist appointments, BGF, and the gamut of professionals that were there to assist us. I was still able to care for myself by continuing my own counselling and peer support.

Some of us are not so fortunate. This service will go a long way in providing the most accessible and flexible care to families affected and infected by HIV and AIDS.

I want to thank Lisa Brockwell for her awareness in recognising the needs of families and her persistence in following this program through to securing funding, and Lisa Clement for her support and valuable contribution to the process.

Vivienne Munro is the ACON Women's HIV Support Officer and Deputy Convenor of PLWH/A.

Poetry

Shaun

*I wish you were with me
laughing and playing,
but when I think of you all I
hear is your cries.
I look into your photo hoping to
capture the smile that is
stamped upon your lips,
but all I achieve is an ache
in my heart,
a longing that no-one but her
could understand.
He is my brother,
and she was my mother.
I used to see you every day
you both were my life,
but suddenly in a matter
of months,
what I thought was my life
was taken,
ripped away taken from within
my heart.
Looking at your photo
I try hard
to recapture my life,
to rekindle memories,
but it's no use, you're gone,
we have become almost
strangers.
I am unable to tell what your
cries mean,
unable to understand the
jumbled words that you speak,
will I ever get to know you
again?
Or will fate take you further
away from me leaving us
again as strangers.*

— Karen

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

**Talkabout, PO Box 831
Darlinghurst 2010**

NATIONAL CENTRE IN HIV SOCIAL RESEARCH

National Priority Program:

"People Living with HIV/AIDS and their Carers"

Sydney Based

Community Liaison Officer/Research Assistant

0.6 position, renewable up to 3 years

A person with existing rapport with the Sydney HIV positive communities and knowledge of the social dimensions of HIV/AIDS is required to assist in brokering between the program researchers and affected communities and with research on the above Program. Preference will be given to applicants with research interviewing skills and experience. Excellent communication, written skills and confidentiality are essential. People who are HIV positive are encouraged to apply.

Salary: Research Assistant,
\$29,539 - \$40,087 pro rata

Further enquiries to Dr Claire Parsons,
Director on (03) 418 6909.

CLOSURE DATE: 5 November, 1995



PLWHA Inc aims to empower people affected by HIV/AIDS in NSW by providing information and advice on all HIV/AIDS issues, lobbying all relevant organisations to ensure the best possible levels of care, support and treatment, and to promote a positive image of people living with and affected by HIV infection and AIDS. PLWHA/ACON is an equal opportunity employer and encourages people with HIV to apply for positions.

Treatment Advocacy Support Officer (6 month initial contract)

People Living with HIV/AIDS (NSW) Inc.

PLWHA is seeking to fill the position of Treatment Advocacy Support Officer. This position will be supporting and under the direction of the Treatments Portfolio Group. The Treatment Advocacy Support Officer will be responsible for researching treatment issues and monitoring availability of treatments, preparing minutes and reports, liaising with other community based organisations and the media, maintaining comprehensive file and data base and arranging public treatment information forums.

The successful candidate should possess a high level of commitment to working with and a sensitivity towards people living with HIV/AIDS. Demonstrated experience in research and excellent written and communication skills are essential as well as proven administrative and organisational skills.

Salary range: \$35,963 pro rata per annum

Closing date: 9th October 1995

Co-ordinator (Part time - 21 hours per week)

Positive Speakers Bureau

People Living with HIV/AIDS (NSW) Inc.

PLWHA is seeking to fill the position of Co-ordinator of the recently created Positive Speakers Bureau. The co-ordinator is responsible for the day to day operation of the PSB, allocating speakers, managing finances and human resources, planning and implementing on-going recruitment and training, developing a peer-based support structure, developing and implementing strategies to promote awareness of the PSB.

The successful candidate should possess a high level of commitment to improving community awareness of the needs of people with HIV/AIDS and to the development of the HIV+ community. A sound background in administration and a demonstrated knowledge of the current issues and needs of people with HIV/AIDS are also essential.

Under PLWHA's HIV employment policy this position is designated to be filled by a person with HIV.

Salary: \$26,168 - \$27,636 pro rata, per annum

Closing date: 9 October, 1995

Essential criteria for the above positions include a willingness to work with and a sensitivity towards people with HIV. A duty statement, terms and conditions of employment and selection criteria must be obtained before applying. Please telephone reception on (02) 206 2000 after 11am Monday-Friday. ACON is located at 9 Commonwealth Street, Surry Hills and PLWHA is located at 94 Oxford Street, Surry Hills.

No Agencies Please.

PLWHA/ACON has a policy on non-smoking in the workplace.

77193



POSITIVE RETREAT No.6

Come along to a stress free country location where you can enjoy nature, try complementary therapies, meet other positive people in a relaxed environment, learn about some of the complementary therapies on offer, do yoga, meditation, acupuncture, homeopathy, reiki and others.

The retreat will be alcohol and recreational drug free.

This retreat will be held from Wednesday 1 to Sunday 5 November 1995.

An investment of \$40 unwaged and \$100 waged is the cost of the retreat.

For more details, and to obtain an application form, call 019 98 25 25,

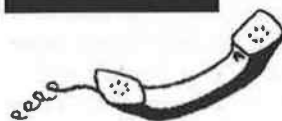
Monday to Friday, 10am to 6pm.

HIV
living

A joint initiative of HIV Living and PLWHA (NSW) Inc.



Contacts



AIDS Council of NSW (ACON)

9 Commonwealth St, Surry Hills
(near Museum Train Station)
Switchboard: 206 2000



COMMUNITY SUPPORT NETWORK (CSN)

Trained volunteers providing practical home/personal care for people with AIDS. 206 2031.

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

CSN WESTERN SYDNEY Pat Kennedy 204 2404.

FUN AND ESTEEM WORKSHOPS For gay and bisexual men under the age of 26. Groups in Parramatta, Campbelltown and city. 206 2077.

GAY & LESBIAN INJECTING DRUG USE PROJECT (GLID UP) Outreach, information & referral. 206 2096.

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

POSITIVE ASIAN MEN'S PROJECT Looks at the needs of all HIV+ Asian men. Michael Camit 206 2036 or 206 2090.

HIV living

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



ACON HOUSING PROJECT We offer help & advice about public housing, in particular: accessing priority housing; transfer; and the special rental subsidy as well as housing discrimination, harassment and homelessness

The Housing Project also has a number of houses and units available to clients who are waiting for public housing. You must be eligible for priority housing and in the process of applying

Call Arnel or Fred on 206 2043 for an appointment



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

ACON WESTERN SYDNEY 9 Charles St, Parramatta. 204 2400.

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

ACON MID-NORTH COAST 93 High St, Coffs Harbour. (066) 51 4056.

ACON NORTHERN RIVERS 147 Laurel Ave, Lismore. (066) 22 1555.

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

GENERAL

AIDS TRUST OF AUSTRALIA 221 2955.
ALBION STREET CENTRE INFORMATION LINE 332 4000.

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

AUSTRALIAN FEDERATION OF AIDS ORGANISATIONS (AFAO) 231 2111.

AUSTRALIAN NURSES IN AIDS Special interest group for nurses. John Miller 339 1111 or Maggie Tomkins 332 1090.

CIVIL REHABILITATION COMMITTEE Family Support Centre. HIV education and support to families of ex-prisoners and ex-offenders. Joanne Wing 289 2670.

GAY MEN FIGHTING AIDS A gay men's promotion project for men who live in the inner west. This volunteer driven project provides health education, advocacy and social support. Ring 519 5202 anytime. A project of Central Sydney Area Health Service.

KIDS WITH AIDS (KWAIDS) and parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772.

HANDS ON PROJECT Community based HIV/AIDS training program for youth workers 267 6387.

INNERSKILL Needle & syringe exchange, information & referral, also a range of free services for unemployed people. 810 1122.

METROPOLITAN COMMUNITY CHURCH (MCC) 638 3298. MCC Sydney 332 2457.

MULTICULTURAL HIV/AIDS EDUCATION AND SUPPORT PROJECT Workers in 15 languages who provide HIV/AIDS information. Also provides cultural information, training & consultancy. Peter Todaro 515 3098.

NATIONAL AIDS/HIV COUNSELLORS ASSOCIATION 206 2000.

NATIONAL AUDIO VISUAL ARCHIVE OF PLWA Royce 319 1887 (after 1 pm).

NATIONAL CENTRE IN HIV EPIDEMIOLOGY & CLINICAL RESEARCH 332 4648.

NATIONAL CENTRE FOR HIV SOCIAL RESEARCH (Macquarie Uni) 805 8046.

NATIONAL ASSOCIATION OF PEOPLE LIVING WITH AIDS (NAPWA) 231 2111

NSW ANTI-DISCRIMINATION BOARD Takes complaints of AIDS related discrimination. 318 5400.

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

QUILT PROJECT Memorial project for those who have died of AIDS. 360 9422.

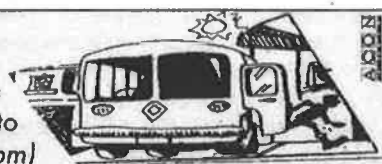
SEX WORKERS' OUTREACH PROJECT (SWOP) 319 4866.

SILK ROAD Social and support group for Asian gay and bisexual men. Meets every Friday. Workshops, discussions, social activities. Arnel 206 2000.

SOCIAL WORKERS IN AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Also acts as a lobby group for people affected by HIV/AIDS. Pina Commarano on 661 0111.

Tiffy's Transport 206 2040

Tiffy's provides transport for PLWHA to hospital or clinic appointments. The service operates early morning to early evening, Monday to Friday. For more info, or to make a booking, please call 206 2040. Ask for Monica. (Office open 8am — 3pm)



Are you an HIV Positive Woman?



Screamline
1800 630 075 (Toll Free)

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



ACON MID NORTH COAST

We offer support for PLWHA's alternative therapy subsidies; vitamin co-op; home based care & support; short-term accommodation; links to other PLWHA's; various health information

The branch also runs HIV prevention and safer sex education

93 High St, Coffs Harbour
PH: (066) 514 056



Sydney Sexual Health Centre

Sydney Hospital
Macquarie St (near
Marlin Place Station)

for an appointment
or information

223 7066

for recorded information

11646

*no medicare card required

Services provided:

- >STD test, treatment and information
- >HIV/AIDS tests and care
- >Hepatitis B tests and vaccinations
- >Counselling
- >Safe sex information
- >Free condoms, dams and lube
- >Multicultural information and interpreter services
- >Needle syringe exchange

TAYLOR SQUARE PRIVATE CLINIC

Dr Robert Finlayson • Dr Ross Price • Dr Mark Robertson
Dr Anna McNulty • Dr Neil Bodsworth • Dr Debbie Couldwell
Fellows of the Australian College of Venerologists
and Dr John Byrne

8am to 8pm Monday to Friday • 10am to 12 noon Saturday

302 Bourke St Darlinghurst

331 6151

Call for appointment • Health Care Card Holders Bulk Billed



Livingstone Road Clinic

We provide HIV/STD
testing, treatment,
counselling and

education in a friendly cottage environment.
We provide total confidentiality (medicare
cards are not required) and there is easy off
street parking.

182 Livingstone Rd, Marrickville
560 3057

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



SYDNEY PLWHA DAY CENTRE A safe space to relax among peers. Services include: delicious lunches Tue-Fri; massage; acupuncture; reiki; feldenkrais; international healing; shiatsu; yoga & meditation; child care facilities; library; sewing facilities; pool table. We also have access to a retreat throughout the year. All our services are free of charge. 20 William Lane Woolloomooloo. 357 3011.

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

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

VOLUNTARY EUTHANASIA SOCIETY OF NSW INC. 212 4782.

WORLD AIDS DAY NSW 350 2611

CLINICS & HOSPITALS

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

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

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

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

HAEMOPHILIA UNIT Royal Prince Alfred Hospital. 516 7013.

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

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

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

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

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

PRINCE OF WALES Children's Hospital (Paediatric AIDS Unit) High St Randwick. 399 2772/4. Dental Clinic, Avoca St, 399 2369.

ROYAL NORTH SHORE HIV outpatient, day treatment, medical consultations, inpatient services, counselling, support groups, sexual health clinic, testing. 438 7414/7415. Needle & syringe exchange 906 7083. Pacific Highway, St Leonards (by railway station).

ROYAL PRINCE ALFRED (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

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

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

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

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

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

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

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

EMOTIONAL SUPPORT

ACON COUNSELLING SERVICE Call 206 2000 for appointment



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

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

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

FAMILY SUPPORT City: A support group for family members of people with AIDS. Regular short term groups. Helen Golding

on 361 2213. Outer Western suburbs: Meets evenings on a regular basis. Claire Black or Kevin Goode at Wentworth Sexual Health and HIV Services on (047) 24 2598. **FRIDAY DROP-IN** for PLWHA at ACON Western Sydney. 204 2402 for confidential information.

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

PARENT'S FLAG Parents and friends of lesbians and gays. Meets 2nd Mon of the month. Heather, 899 1101, or Mollie 630 5681.

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

QUEST FOR LIFE FOUNDATION Emotional support and education for people with life threatening illnesses, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 906 3112.

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

SUPPORT OF POSITIVE YOUTH 360 2945.

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

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

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



PRACTICAL HELP

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

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

BOBBY GOLDSMITH FOUNDATION A community based, registered charity providing some financial assistance to approved clients. 360 9755.

DES KILKEARY LODGE Respite and Step-down support for PLWHA and their carers. Small day centre. Located on the Northern Beaches. Paul, 982 2310.

FUNERAL CELEBRANT General funerals, free in cases of financial hardship. Patrick Foley on (018) 61 1255.

FOOD DISTRIBUTION NETWORK Cooperative

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

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

PETS The Inner West Veterinary Hospital will never refuse urgent treatment for a pet because of lack of money. Please call 516 1466 for more information.

THE SANCTUARY Centre for complementary Therapies focussing on relation therapies. Tu-Fri 1.30-5.30pm. Gebe Neighbourhood Centre. Transport can be arranged. Bookings essential. Phone Lindy on 516 7830.

SHOPPING SERVICE FOR PLWHAs Fortnightly on Fridays, inner-city only. Bookings/& further information 360 2043.

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

OUTSIDE SYDNEY HAWKESBURY & BLUE MOUNTAINS

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

BLUE MOUNTAINS PLWA SUPPORT CENTRE Wed 11am-3pm (lunch) & Fri 6.30-10.30pm (dinner) (047) 82 2119 or Sue (047) 591611.

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

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

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

NEPEAN HIV CLINIC Nepean Hospital Mon 3-8, Thurs 9-5. (047) 24 2507 for all appointments. Counselling & Support (047) 24 2598.

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

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

CENTRAL COAST & HUNTER

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

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

COASTAL CONNECTIONS Gay & lesbian social group. (043) 65 3461. PO Box

NSW HIV/AIDS Information line Mon-Fri 9am-8pm, Sat 10am-6pm Advice and referral information for HIV/AIDS

008 451 600
Rural Project, ACON

Mon-Fri 10am-6pm

General advice and referrals on HIV/AIDS in country areas

008 802 612
Take Control Line


Mon-Fri 10am-6pm

Confidential and frank information on treatments for HIV/AIDS

008 816 518
C. L A S H

Confidential group of HIV Positive heterosexuals

1 800 812 404



People Living With HIV/AIDS (NSW) Inc.

361 6011 Fax 360 3504

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

ACCESS

PositHIV Radio

2SER FM 107.3 Tuesday 9.30pm

PO Box 473 Broadway NSW 2007
ph: 516 4772 fx: 330 3099
2SER FM 330 3000

259, Toukley 2263.

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

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

KARUMAH DAY CENTRE. First floor, 101 Scott St, opposite Newcastle Railway Station. Open Tues 6-9pm (games night), Wed 6-9pm (games night & masseur when available), Thur 11am -3pm (lunch & activities). (049) 29 6367.

KONNEXIONS DAY CENTRE 11am-3.30pm Mon for lunch & social. Lesley. (043) 23 2095.

NSW ANTI-DISCRIMINATION BOARD Newcastle. (049) 26 4300.

NEWCASTLE GAY FRIENDSHIP NETWORK Peer support, workshops and activities for gay men under 26. ACON (049) 29 3464.

POSITIVE SUPPORT NETWORK Emotional/hands on support for PLWHAs on the Central Coast. Lesley Digram (043) 23 2905. Suite 3, No6 Burns Cres, Gosford 2250, PO Box 2429 Gosford.

THE LAKES CLINIC (Tuncurry) A sexual Health Service. Bridgepoint Building 2nd flr. Manning St. Thu 10 -2pm. Free and confidential.(065) 55 6822.

WOMEN'S HIV/AIDS & SEXUAL HEALTH SUPPORT NETWORK For positive women, their partners and friends. Awareness raising. Helen (049) 524362.

NEW ENGLAND & NORTH COAST

ARMIDALE HIV EDUCATOR Melinda Spinks (067) 73 4 712.

BLIGH STREET SEXUAL HEALTH CLINIC. (Tamworth) Free & confidential STD/HIV testing & management. (067) 66 3095.

CHAPS OUT BACK (Coffs Harbour) Confidential support, advice & social activities. Hydrotherapy & gym classes Tues/Thurs. John (066) 51 2664 or Victor (066) 51 6869 or Chris (066) 52 1658.

CLARENCE VALLEY PLWHA Support Group. Peter (066) 46 2395.

CLINICAL NURSE CONSULTANT Karin Fisher Providing service to barwon, Lower North Coast, New England & North West (067) 66 9870, page 016 020 x 61 1476.

CLUB 2430 (Taree) Manning Area Gay and Lesbian Support Group. Social functions, newsletter, monthly meetings. Lloyd (065) 52 7154 or Liz (065) 51 1409.

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

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

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

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

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

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

LISMORE SEXUAL HEALTH/AIDS SERVICE A free, confidential service for all STD and HIV testing and treatment. (066) 20 2980.

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

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

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

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

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

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

TROPICAL FRUITS Gay & lesbian social

group. Regular events. (066) 22 4353.

WOLLUMBIN CARES (North Coast) Community AIDS Resources, Education and Support. Gerry or Keven (066) 79 5191.

ILLAWARRA

CSN WOLLONGONG (042) 26 1163.

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

PORT KEMBLA SEXUAL HEALTH CLINIC Confidential and free support for PLWHAs. Fairfax Rd, Warrawong. (042) 76 2399.

POSITIVE SPACE ILLAWARRA A confidential meeting place to chat, listen and share with other positive people. Don't hesitate to call (042) 26 1238 to chat with or meet others. Wednesdays and Fridays 12pm-5pm.

THE CLUB Social & Support group. Contact Frank Velozzi (042) 26 1163.

SOUTH WEST/EAST

ALBURY AIDS SERVICES Community Health Centre 665 Dean St (060) 23 0206. Needle & Syringe Exchange, Judy Davis.

ALBURY/WODONGA HIV/AIDS BORDER SUPPORT GROUP (060) 23 0340.

BEGA & EUROBODALLA SHIRES-HIV/AIDS WORKER Jenni Somers, 018 604 180 for free, confidential info, counselling & support from Bateman's Bay to the Vic. border.

BEGAY Bega area gay & lesbian social group 018 60 4180.

COOMA/SNOWY MOUNTAINS HIV/AIDS VOLUNTEER SUPPORTER GROUP Emotional support for PLWHA, their family and friends living in this area. Lorraine on (018) 48 4834 or (064) 52 1324.

GRIFFITH HIV EDUCATOR/SUPPORT WORKER Laurane Pierce. (069) 62 3900.

NOWRA SEXUAL HEALTH CLINIC Confidential and free support for PLWHAs. Nowra Hospital, (044) 23 9353.

QUEANBEYAN HIV/AIDS/STD WORKER Yantene Heyligers (06) 29 89236.

SOUTHERN HIGHLANDS HIV/AIDS/STD WORKER David Williams 018 48 3345.

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

WAGGA WAGGA HIV & SEXUAL HEALTH SERVICES Paula Denham (069) 38 6411. AIDS Task Force (069) 25 3055 or (069) 38 6411.

YOUNG HIV/AIDS VOLUNTEER SUPPORTER GROUP Valerie, (063) 82 1522.

WEST

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

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

Regional Health Service HIV/AIDS Coordinators

CENTRAL COAST

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

CENTRAL SYDNEY

Lesley Painter
Ph: 550 5366

CENTRAL WEST

Vacant
Ph: (063) 32 8576/8538/8571

EASTERN SYDNEY

Marlene Velecky
Ph: 399 4832

HUNTER

Tony Butler
Ph: (049) 29 1292

ILLAWARRA

Vivienne Cunningham Smith
Ph: (042) 75 5823/76 2399

NEW ENGLAND

Christine Robertson
Ph: (067) 66 2288

NORTH COAST

Wendi Evans
Ph: (066) 20 2145

NORTHERN SYDNEY

Graham Stone
Ph: 438 8237

SOUTH EAST

Greg Ussher
Ph: (048) 27 3148

SOUTHERN SYDNEY

Colin Clews
Ph: 350 2959

SOUTH WEST REGION

Dalton Dupuy
Ph: (060) 23 0350

SOUTH WEST SYDNEY

Mark McPherson
Ph: 827 8033

WENTWORTH

Elizabeth O'Neil
Ph: (047) 22 2255

WESTERN SYDNEY

Chris O'Reilly
Ph: 843 3118

WESTERN NSW

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

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

ORANGE COMMUNITY AIDS TASK FORCE Shirley-Ann Bailey. Central West HIV Support worker, Luke Austin. Community Health Centre. (063) 62 6422.

Please let us know if you want to update your listing or add a new one!

Reviews



Books for Young People

Uncle Paul has AIDS

by Phil Nott

illustrated by Sally Heinrich

Little Gem Publications

Reviewed by Mark Reid

This stunning book, aimed specifically at six to ten year olds, offers a poignant and sensitive look at the reality of death from HIV/AIDS related illness. It has been lovingly and sensitively written by Phil Nott and the illustrations by Sally Heinrich are both joyful and beautifully drawn.

Uncle Paul has AIDS sets out in language that any child in this age range would understand, the issues about losing someone we love to AIDS. It is simple and straightforward, doesn't beat around the bush.

The day after we received our copies at the PLWHA centre we sat down after lunch and one person decided to read it out to some of the others that were here that day. All that listened to the story were moved by it and found it refreshingly honest and also well written. It touched all of us in different ways, but we all agreed that it was a superb book.

You can purchase "Discussion Notes" to accompany the book that are invaluable for any teacher or parent using the book with children.

Phil Nott says in his statement at the beginning of the discussion notes that "I discovered that there were not many books in Australia specifically aimed at young children about death and dying. I found books about someone's favourite

labrador, cat or fish dying, but very few publications which dealt with the death of a person."

"There were no publications dealing with death from an AIDS related illness."



This is a very emotional book and on the day that I read it I spent some time during and after having a good cry. It is a good idea before you read it to the children, that you spend some time reading it and getting your own reactions to it sorted out.

Uncle Paul deals openly and honestly with the illness of AIDS, the death, the funeral, the process of grieving and the memories we have after a person has died. These are portrayed in a manner both emotive and frank. I can certainly recommend it.

This review originally appeared in Positive Living, the newsletter of PLWH/A (WA).

Pink Balloons

by Beverley McGregor

Ashton Scholastic, \$9.95

Reviewed by Larna Burgess
age 13

Anyone who reads *Pink Balloons* will think it a very moving and emotional story of Skye Bussenschutt, a young girl who lived and died with AIDS.

It is also the story of a girl who touched the lives of anyone who made her acquaintance — teachers, nurses and friends as well as family. She had a very strong loving nature and strong will to live, but she was not afraid to die. Beverly McGregor portrays Skye's story of life, death and what she chose to put in the middle, very well.

I would recommend this book to any age. It's very short and easy to read but it will leave a big indent on your life, as it did in mine. A very good read!

Part of the royalties from this book is donated by the publisher to Kids With AIDS.



The next edition of
Talkabout will take a
look at Positive pregnancy.
Send your contributions to:
PO Box 831
Darlinghurst 2010
before October 17.

A KID CALLED TROY

With Skye Bussenschutt and Eve van Grafhorst, Troy Lovegrove was one of the public faces of children with AIDS in Australia. His story has been told in an ABC TV documentary and a book, written by his father Vince Lovegrove, both called A Kid Called Troy. Following is an extract from the book.

WE RETURNED TO SYDNEY [FROM Oenpelli, NT] on April 21 and I immediately admitted Troy into hospital. His appetite had diminished, his weight had gone down, his entire system had begun to crumble.

He was set up in a room in Ward CB at the Prince of Wales and it quickly became obvious that he was dying. He wasn't eating and eventually had to be drip-fed liquid through a tube inserted into his nose. He wasn't very happy about it and I think it was then that he also realised the end was near.

We had many things planned for his eighth birthday on June 25, including a visit to Disneyland, viewing a rocket launch from NASA, and a visit to Michael Jackson's Neverland and although we never gave up hope, those fun plans were raised less and less.

His day-by-day survival took precedence over anything else.

We were swamped with well-wishers, his schoolmates, his teachers, my friends. As each visitor saw him and gauged his weight, they left to spread the word. Troy wasn't going to recover this time. After his third week in hospital, I realised I was going to have to tell him that it didn't look like he was going to make it.

"Matey, we're going to try and beat this bug no matter what, and we'll fight it until the very end, but I think you know that we're losing the battle right now."

"I knew it," he angrily told me. "I knew as soon as I had this drip that I was dying. That's what happened to Blake and Skye before they died. They couldn't eat, either

and as soon as they went on the drip, they died."

Blake and Skye were approximately Troy's age. Both had contracted AIDS from blood transfusions. Both had died in 1992.

"Well," said Troy, "I don't want the drip any more and I'm not going to take any drugs anymore. I want to go home."



The doctors didn't think it a good idea for Troy to take out the drip, cease his drugs and go home. They felt his quality of life would have been better at the hospital. Troy felt differently, so I asked him if he still wanted to go home, and stop his drug intake. Yes, he did.

"Well, Dad, the drugs didn't work, the drip didn't work, let's go home and try and fight it ourselves."



I asked the doctors to give me a prognosis. One of them told me, "He might live for a few months, even until the end of the year, but I don't think he'll be here this time next year."

It was clear to me, and to everyone who knew Troy, that he would be lucky to last another month.

On Friday, May 21 we arrived home minus the nasal drip and minus Troy's drugs, but well stocked with a month's worth of 'get well' cards, games, flowers.

It was the first time Troy had been drug free since he was six months old.

I was completely humbled by Troy's last two weeks of life. Here was a little boy, home from hospital to die, and he knew it. He spoke about it, he lovingly shared it. No bitterness, just resolution and hope.

He and I decided that no matter what happened, he was going to finally conquer the AIDS virus. Having decided that seven and a half years of drugs, whilst possibly helping to maintain his life, hadn't killed the virus, Troy felt that he had a two to one chance of killing it if he went home to fight it.

His first chance was if he ate the right foods, he would recover himself, heal himself and the virus would die.

His second chance would be if he died, the virus would die with his body. This would be a bonus method, he thought, because this way he would also finally meet his mother, whose spirit would be waiting for him, with Jesus's spirit by her side.

"Because I was only two when I last saw her, Dad, so I really want to get to know her."

*Twinkle, twinkle, little star,
How I wonder what you are.
Up above the world so high,
Like a diamond in the sky.*

Once upon a time Troy had believed that the first star at night was his mother and that when we died our spirit was drawn up to the vast heavens and we became a star, forever more.

As the years passed the nursery rhyme was replaced and Troy developed other theories on life, death and the stars. From about age six, Troy began to believe in Jesus the man. Jesus died on the cross, according to Troy, at the same age as his mother. Jesus was a great man who died bravely, proudly. He believed that when we die and go to

heaven, Jesus will be the first person we see.

His thoughts and beliefs on God were a little different. He could not quite come to grips with the question that if God created everything, then who created God?

At times I think he taught me about the realities of afterlife and philosophical beliefs. Who am I to question them?

Troy died at home early on June 3, 1993, just a few weeks before his eighth birthday. Reprinted with permission from A Kid Called Troy, by Vincent Lovegrove, ABC Books.

Part of the profits from this book go to the Troy Lovegrove Foundation. The TLF has been established to assist children living with HIV/AIDS have a better quality of life. The TLF provides emotional and financial help to families; raises funds for Camp Goodtime and paediatric HIV/AIDS research and helps to organise outings and support groups for children infected/affected by HIV/AIDS.

For more information call 018 290 889. If you would like to make a tax deductible donation please send it to:

The Troy Lovegrove Foundation, PO Box 624, Double Bay 2028.

TALKING WITH KIDS

When you're ready to discuss a child's diagnosis with your infected and uninfected children, be honest. Lack of information can cause children to develop their own conclusions about what is wrong, and those conclusions can be more frightening than reality. Virg Parks offers some ideas.

- Remind your infected child that you and the doctor are doing everything you can to help him or her feel better.
- Remind your uninfected children that they are in no way responsible for their sibling's illness and that although their brother or sister will require extra care and attention, you still love them just as much.
- Try to create special or quality time with the uninfected children. Also try to involve them as much as possible in the experiences their siblings go through. A sibling can be a vital support and ally for the sick child (like holding their hand when they get blood drawn or infusions).
- Encourage all of your children to be as 'normal' as possible. Just because a child has HIV doesn't mean they stop playing or fighting with siblings.
- Instead of singling out the infected child, encourage all of your children to practice basic hygiene: washing hands frequently, using lotion to avoid dry skin, brushing teeth at least twice a day, keeping cuts and scratches



clean and covered, etc. This will also help prevent transmission of germs or bacteria to the immune-compromised child.

- Keep explanations as simple as possible using concepts they can relate to. For example, telling a child that icky-tasting medicine will help them be able to play more or run faster will probably get you further than telling them that the medicine will make them well.
- As your child learns more about his or her disease, she or he will probably ask you about death. If this is a question you can't deal with yet, it is certainly alright to say "I don't know, but we're doing all we can to keep that from happening (which is true) . . . and when I learn more about AIDS, I'll tell you everything I know" (which you should). Eventually, you will need to provide a more complete answer. When that time comes, remember that children often understand and accept a lot more than adults give them credit for.

This article originally appeared in full in WORLD.

BEING THERE



Big needles, strange people, weird machines, confusing procedures — hospital can be a scary place. But it doesn't have to be. You can make being in hospital feel much safer for your kids. It's a difficult time for everyone, but the key, Jill Sergeant suggests, is in preparation, honesty and support.

Preparation

If possible, before he or she goes into hospital, prepare your child for what it will be like. Read books about it, play hospitals, talk about it, explain why they have to go, explain what's going to happen to them. Be honest and matter of fact. Kids are likely to be more scared and anxious if their illness is mystified or they feel that they're not being told the whole story. If they don't have all the facts, they might imagine something much worse.

You could treat going to hospital as a special thing. Robyn and Paul told their toddler Lavinya that she was going to have her own special bed that no-one else could use while she was in hospital. "We made a big thing about it, we tried to make it fun and make it seem like she's special to be there", says Robyn.

At the Prince of Wales Children's hospital (POW), all children are taken on a tour of the hospital as soon as they are admitted. If they're going to have an operation, this includes being taken to the operation waiting room and recovery area. They're introduced to the staff who will be caring for them. If you're at your local hospital, ask for such a tour, it helps reassure the child.

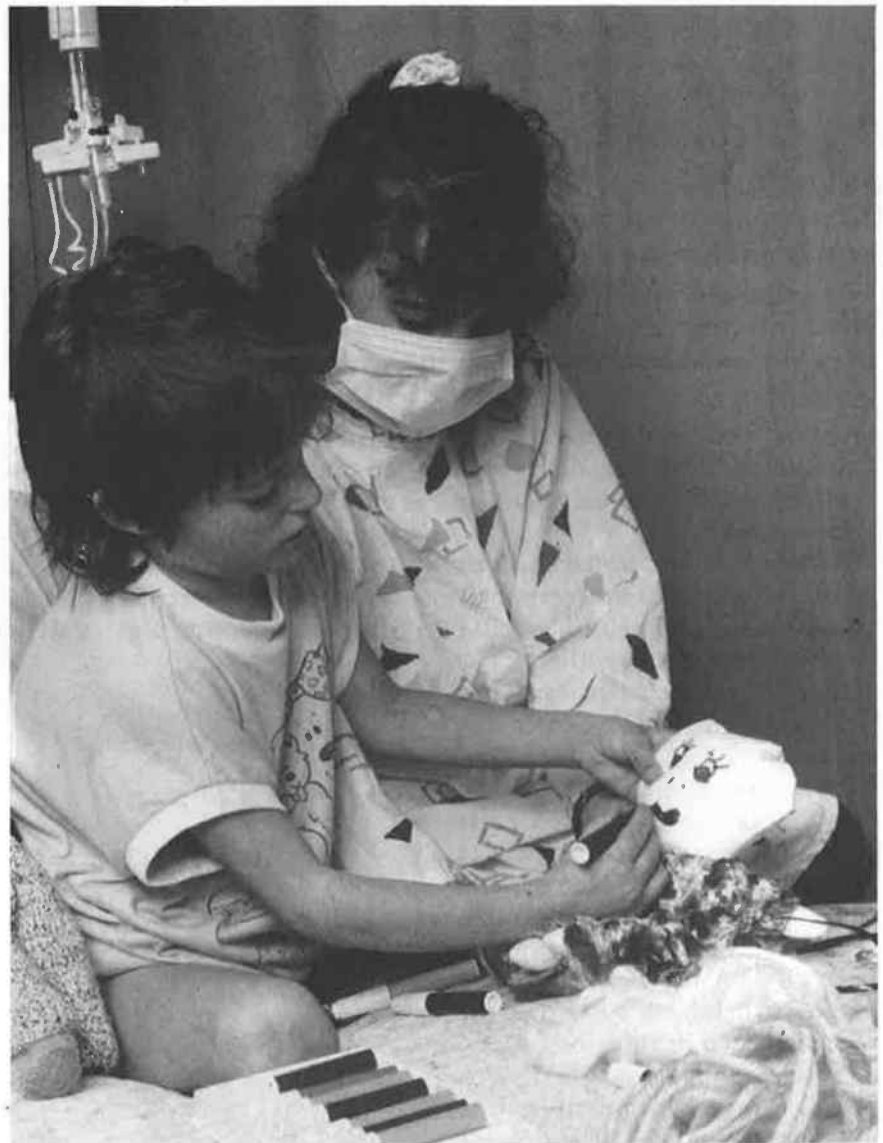
Prepare your child for specific procedures they'll have to undergo. This applies to everything from the smallest of pin prick blood tests, to needles, to operations. "Things that go inside them or stay inside them (like naso-gastric tubes) need the most explanation," says Paediatric AIDS Unit (PAU) Social Worker

Lisa Clement. "And things that hurt. Needles are a big fear".

At children's hospitals a play therapist can prepare your child, but it helps if you're there. If there's

no play therapist, (and even when there is) you can do it yourself.

Play therapists use dolls and medical equipment to familiarise the environment and procedures — for example by giving a doll a needle, or using syringes to paint with. Drawing, doll play and play dough can all be used to enable children to express their feelings about what's happening to them, both before and after procedures and



*Skye paints and dresses a rag doll
(The mask is part of the play).*

hospitalisation. For children who are in hospital frequently, play that's similar to what they'd be doing at home also reduces stress and normalises the experience.

"When Vinya was wearing her hospital gown, she looked like an angel", says Robyn. "So we were playing with that, saying she was an angel, a princess. We were singing and playing counting games during procedures. We had her favourite toy, Big Bird, hiding in a bag and after she had a needle Big Bird would come out to play. With PJ, when he was on the ventilin we called him Puff the magic dragon".

You can show your child what's going to happen either through play — being given a 'pretend' operation — or by having the procedure yourself so that they can see what happens, and see that you can handle it. If you're calm and confident about the procedures, children are much more likely to feel that they can handle it too.

Play therapists also provide support to parents by involving you in the play and giving tips on parenting skills and behaviour management techniques.

"Play helps children a lot", says POW Play Therapist Vanessa

Smith. "For example, one child could only have certain procedures done when he was sedated, but having done a lot of play therapy, he can now have them without sedation".

The problem with many procedures, apart from the pain, is that the child must remain still. If they're not calm enough to remain still, they may have to be sedated or worse, held down. That's where techniques like play, meditation and relaxation are particularly valuable. They allow the child to find their own way of coping with pain and powerlessness.

Children in hospital have very little power over what has to be done to them and finding their own coping mechanisms enables them to feel they have more control over what's going on. For the same reason, try to allow the child to decide when, where and how a procedure is performed.

Support

As parents or guardians, you are the most important people in your child's life. This is a time when you really must *be there* for them. It's important and enormously comforting for them to have you around. Stay with them for procedures, go with them right to the doors of the operating theatre. You can stay with them while they have anaesthesia. Be there when they wake up after the operation.

Lots of cuddles and physical contact will help reduce their fear. Hold them, on your lap if you can, while procedures are performed. You know the tricks that will best distract them from pain or boredom. Singing, playing favourite games, just plain old loving will all help them to cope.

Bring in familiar toys, photo albums, treats. You may be able to take the child out of hospital for short outings. Make sure your child always knows what's going on. If you're going out, say good bye and tell them when you'll be back.

The Paediatric AIDS Unit

IN NSW, MOST CHILDREN WITH HIV or AIDS are likely to go to the Prince of Wales Children's Hospital in Randwick (POW). The hospital has a Paediatric AIDS Unit (PAU) which either directly case manages, or is involved in some way with, all the infected children in this state.

The PAU team consists of Clinical Nurse Consultant Michele Goode (currently acting for Marilyn Cruickshank) and Social Worker Lisa Clement, who work with POW medical staff, play therapists and health care and community workers in children's local communities, as well as services such as CSN and Ankali. Their role is to support families both at home and when a child is in hospital. They run family support groups, Camp Goodtime and workshops for health professionals, and co-ordinate care and support for children at home.

If your child is HIV positive, or you have a baby whose HIV status is still unknown, you're likely to meet them for the first time through POW outpatients. If you live in the country, Lisa and Michele may be closely involved with your family, or may be advising and supporting the

local doctors and community workers who are helping care for your child.

There is no AIDS ward at PAU, children are admitted to whatever ward is available and appropriate for them (where they won't catch anything off the other kids). If it's a long stay, the family can stay at Ronald MacDonald house, siblings can go to the POW Place child care centre or the hospital school. If a child is coming into hospital regularly, they will try and place them in the same ward each time so that staff are familiar.

If you live in the country, it's important that there's at least one person in the area such as a community nurse, whom you like and trust, who knows your needs and can refer you to the appropriate agencies when necessary.

Most hospital admissions are planned but if you do have an emergency and have to turn up to a strange hospital, you will need to disclose your child's HIV status if their condition is AIDS related. Tell someone you feel you can trust and refer them to your child's GP or the PAU. You can call the PAU on 399 2772/2774.

Continued over page

From previous page

It's important that they know they're not alone.

Be honest about your own feelings — don't be afraid to cry in front of your children, but explain why. Tell them if you're scared. They need to know how you're feeling and will feel a lot safer if it's out in the open. If you try to hold everything in, they'll sense it anyway and just be anxious. On the other hand, you can't fall to pieces in front of them. "If you completely lose it and get angry in front of the child, the child senses a loss of control and gets scared by that", says PAU Clinical Nurse Consultant Michele Goode. You might be feeling pretty angry about what's happening, but try not to express this in front of the child.

It is Health Department Policy that some form of accommodation must be provided for parents of children in hospital. In children's hospitals you can generally sleep either beside your child's bed or in a room attached to the ward, for short stays. For longer visits, parents can stay at Ronald MacDonald House at POW. Ronald MacDonald House will also be available at the Camperdown Children's Hospital after it's relocated to Westmead.

Don't allow yourself to be intimidated by the hospital environment into expecting 'good behaviour' from your children. "It's a problem when parents are tense. Don't sit there quietly because it's a hospital, don't try and make them be quiet", advises Robyn. "They're kids. I found when we were in hospital that our kids being relaxed made everyone else in the ward relaxed too. One of our goals is to have fun with our kids. I want our kids to *be* kids. Why should Vinya be told to sit down and behave? People don't get better if they're being quiet and not enjoying themselves. When we're sick we laugh, because you feel better."

Allow family and close friends to become involved. They can be a

great source of support for you and your child.

Don't feel you have to leave younger siblings at home — they can feel excluded, and the one in hospital will miss them. It helps make the hospital experience more normal for everyone if siblings come to visit.

You need to be in control of the situation. If you feel it's not appropriate, or is disruptive for your child to have visitors at any particular time, say so. Don't feel bad if you decide to limit visiting, for example, if the child has to undergo a procedure, you're waiting on important test results or your child is worn out by too many visitors.

"Deprived of play the child is a prisoner, shut off from all that makes life real and meaningful. Play is not merely a means of learning the skills of daily living. The impulse to create and achieve, working through play, allows the child to grow in body and mind . . . Play is one of the ways in which a child may develop a capacity to deal with the stresses and strains of life as they press upon him. It acts, too, as a safety valve, allowing him to relive and often come to terms with fears and anxieties which have become overwhelming."

— World Organisation for Early Childhood Education, *Play in Hospital*, 1966

Remember that crises and stress can trigger conflict — if your child is very ill and you're tired and stressed, you might all be better off without having to deal with visitors.

You need emotional support yourself. You need time out, especially if your child is chronically ill or dying. Try and develop a good relationship with hospital staff. They can support you, and if your child gets on well with them and trusts them, it'll make things easier for you. You don't have to be there 24 hours a day if there's a nurse or

social worker they really like and trust.

The Paediatric AIDS Unit runs a regular support group for families which you can join. Consider having a regular counsellor.

What's going on?

Ask a nurse or social worker to help explain test results and medical jargon. Specialists sometimes just don't talk plain English and if you're going to explain things to your child, you need a clear idea yourself, of what it all means. It's particularly important to have someone with you at difficult times. If a specialist tells you bad news, you might just blank out and need someone else to do your talking or listening. Also, nursing staff can help put your fears in perspective.

You are probably just as scared about the whole hospital scenario as your child. It's an institution, you and your precious child are in the hands of experts. You're probably worried about your child's illness. You might feel vulnerable and pressured to make decisions. There may be a sense of urgency in hospital, but usually you do have time to think things over.

If you have to make a difficult decision about treatments or procedures, take time to make sure you understand the situation and explore all your options. You don't have to rush into decisions. You have a right to second opinions. Get away from the hospital environment and talk it over with your family and close friends. See what your child thinks. Don't be afraid to say what you want, even if you think medical staff might not like it — deciding to discontinue treatment, for example.

It is your child — you have a right to be in control of decision making about all aspects of their treatment; to accurate and honest information about their condition; and to emotional and practical support for your whole family. And remember — it's a tough time when your child is ill, but you don't have to go it alone. ♦

Tears fell everywhere

*Some people have lived with HIV/AIDS for almost as long as they can remember — children. *Karen's Mum found out she had AIDS after giving birth to Karen's younger brother, Shaun, when Karen was about six. Karen, now 15 years old, tells their story.*



I'LL START FROM WHEN I WAS BORN. For as far as I know the first three years of my life I lived with Mum and Dad — it was the three of us. Things went wrong, and their young, foolish marriage ended. I remained with Mum and until recently grew up without my Dad. The first place I remember living was in Forster with my Nan and Pop. But before that the three of us lived near Laurieton.

We were constantly on the move. Fairlight was where I remember living next. I was five or six and had started Primary School. Mum had John, her long time boyfriend. I remember my teacher and my best friend. And nothing much more except for Mum and John's engagement party.

Next was Port Macquarie, where Mum fell pregnant with my brother. Nine months later he arrived. Mum had numerous tests and to her greatest shock she had contracted AIDS from sharing needles. Both Shaun and Mum were Positive, which meant a short lived life for both of them.

John was not a user — as far as I know — and he left, frustrated, as Mum could not stop using drugs. He kept vaguely in touch.

Mum eventually told Nan and Pop. They were very shocked and scared.

I have memories of sleepless nights, many loud parties, a group of bikies who were mean, naked bodies, many drugs, a prostitute who lived with us who was seventeen and baby Shaun.

At school one day I remember crying to my teacher Mrs Smith, I don't remember why, something to do with home. John returned some-

times for long periods. I told him that I had seen a man taking drugs using a needle. The man's face will never look the same. About a year passed. John decided enough was enough, we needed out.

We travelled on.

Mum never once stopped using, but I was a little girl — I trusted



my Mum. I didn't realise things were wrong. I didn't think anyone should know. It was my life — I was happy and felt loved.

We stayed with my aunty and her family. This is where the doctor told Mum she and Shaun had less than a year to live. Mum was really scared and tried to take her life and that of her six months old son by cutting their wrists — but she failed.

My aunty knew most things and apart from hitting Mum a few times, she could do nothing to stop it. Nan and Pop knew barely anything, they continued to love us all.

The doctor was very wrong.

John and Mum went their separate ways, again. We stayed with a

drug dealer, his mum, his sister and stepdad. He was a drunk and I remember nothing except for a walking fish. The sleepless nights continued and so did the drugs.

Her boyfriends came and went. A few years passed. At eight years old I remember moving to Sydney. I stayed here three years. This is where we were living when Mum told me she had AIDS. I was in year 2 at Primary School.

My Aunty said if Mum didn't tell me, she would. This didn't leave Mum any choice but to tell me. I cried because Mum was dying, but I didn't really understand.

I guess I took it all because we were all so happy and healthy. We went to the beach and had fun like a 'normal' family would. It was hard to realise that Mum was ever going to die, she was in her twenties, young, fit and beautiful.

I just couldn't bring myself to see her dying or even sick. You always expect your parents to be around forever — or at least until you can look after yourself.

I guess sometimes we as children take our parents for granted. We see them as parents — people who have to take care of us. But sometimes we don't see them as people that have needs of their own.

John was still a small part of our lives. But there were other boyfriends, during the times in which they were separated.

I remember one boyfriend, Tom, who my mum fell pregnant to. I often woke to their early morning parties, where they drank too much and both ended up with black eyes and bruises. I used to cry myself to sleep. I don't remember Shaun waking up, Thank God. I had a friend

Continued over page

From previous page

who knew nothing, but she was my friend and she and her family made me feel normal.

Most kids my age said they didn't enjoy school, but I loved it. It was where I got away from it all. I didn't have to think about home. My friend and I spent nights at each others houses. We were very close. A teacher and I became friends. I told her Mum went to gaol, I never knew the exact reason. I only knew it was a fight with Tom.

Mum lost her baby. At a party one night my uncle and Mum had a fight and he kicked her in the stomach. She miscarried. What a blessing in disguise.

We went to church sometimes on Saturdays. Mum became close to the minister and his wife. It helped her a lot.

I was in year six at Dee Why Primary School. I thought things were good, but as I look back they were bad. I saw my real Dad sometimes in the holidays. Mum had told me things about him. I didn't like him very much.

Suddenly, Mum had more trips to the hospital. Sometimes she stayed there and when she came out she was better. That gave us hope. I never thought she was really going to die. I thought one day everything would be okay.

Through the hospital Mum met two of the most beautiful people I've ever met. They took care of Shaun when Mum was sick. Over a period of twenty five years, they have fostered and adopted over one hundred kids. Shaun was happy and willing to go with them on weekends. They loved him, and gave him all the attention he needed. It was

decided that when Mum died Shaun would live with them.

Within months, trips to the hospital came faster, and more often. Shaun was with them. More often John was at work. More often I seemed to be at school or other places. And more often Mum was in hospital. Mum and I spent time together. I didn't realise this would be the last month of her life.

Mum came to Forster to be with her Mum and Dad. She prepared for death, while getting sicker and skinnier. Tears roll down my cheek, as I remember.

For three long weeks mum survived — barely — on biscuits and intravenous tubes. John, Nan and Pop cared for her, while I stayed with friends and Shaun stayed with his foster parents. In her last three weeks many of our family members visited her to say goodbye.

I visited her when she was 25 kilos, too skinny to walk, sit, eat, drink, too weak to talk. We cried, as we both were unable to look at each other. The end was drawing near.

For the first time I knew she was going to die. I was scared, but still held hope. For one long week, she ate nothing. For the first time the drugs were given to her, instead of her taking them, to ease her pain. John had tests, but still showed up negative.

I was in Sydney, at my aunty's. I was in the shower, when I heard the phone ring. Suddenly, I knew. My aunty knocked on the door. As I opened it, I saw her white face. And I knew the battle was over. I picked up the phone to hear Nan's voice telling me mum had slipped away to heaven.

Tears fell everywhere. She was gone. On the 29th February 1992.

Later that year John was tested once more and it came up positive. The battle was not yet fought. Many lives still were to be shortlived. Grief was all around.

But she was free. Free of her pain. Free of her suffering.

— *The names in this story have been changed.*

Hospital Help . . .

THE AUSTRALIAN ASSOCIATION for the Welfare of Child Health is a national community organisation funded in this State by the NSW Department of Health. AWCH aims to educate and raise awareness about the non-medical needs of children, adolescents and their families in the health care system.

AWCH advocates a holistic family orientated approach to the care of children. The organisation provides a range of services, including a telephone advisory service, a volunteer 'grandparent' scheme, a variety of publications and a library with a unique collection of printed and audio-visual material.

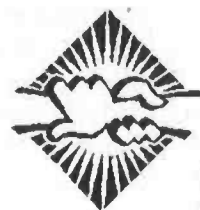
Useful free pamphlets include "Your Child in Hospital", "What are the effects of hospitalisation on a child?" and "Anaesthesia and your child". Hospital theme activity books are available for \$1.50. Videos and films can be borrowed from the library.

For more information call the AWCH library on 685 9317 or the National Office on 633 1988.

Bobby Goldsmith Foundation

BGF provides assistance to people with advanced HIV/AIDS to enable them to maintain a reasonable standard of living by helping to alleviate some of the financial stresses during an extremely difficult time in their lives. For more information about BGF guidelines for assistance, or to make an application for assistance, please contact the BGF Office.

BGF, L4, 376 Victoria St PO Box 97 Darlinghurst NSW 2010
Tel 360 9755 Fax 360 9334





A lemon a day



This month, Gloria takes a look at food as medicine. Now for those of you lunching on lattes this might be a new concept — but what you eat/drink can be not only nourishing but actually therapeutic. This rather surprising lemon drink is being quaffed in Canada and the US by people who'd like to gain weight.

Lemon weight gain drink

Cut up one lemon very finely. Be sure to wash and scrub it well first, because commercial lemons may have waxed skins. Put into a blender (seeds, skin and all) with 1 and 1/2 cups of water and half a teaspoon of honey. Some recipes for this drink use orange juice concentrate, but this makes it far too acidic. (Lemon juice, unlike other citrus, creates alkalinity in the body, even though the fruit is acid).

Blend together 1/3 part extra virgin olive oil, 1/3 part Melrose Linseed oil and 1/3 part Melrose wheatgerm oil. (Make sure it's Melrose brand because these oils go rancid easily and this brand is the freshest.) Olive oil alone is fine.

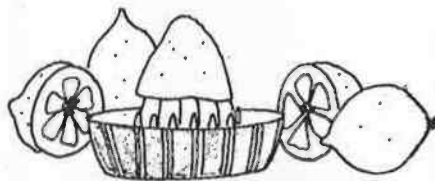
Add one tablespoon of the oil blend to the lemon mixture and blend until extremely fine. Strain through a metal sieve and use a spatula or wooden spoon to press as much juice as possible from the pulp. Discard the pulp.

Divide the drink into three or four portions. Drink one portion with each meal. If you have problems sleeping, drink the last portion just before you go to bed. It will help you get a good night's sleep.

How it works

The therapeutic value of this drink comes from the whole lemon and the oils. The honey is a sweetener. As you gain weight you can reduce the amount that you take each day.

Lemon juice and olive oil flush toxins from the liver. During HIV progression, fat and essential fatty



acids are not well absorbed. Fats and oils raise saliva pH (a measure of acidity/alkalinity). In people with HIV and AIDS the body becomes too acidic, particularly as their condition deteriorates and this seems to increase a breakdown of body mass. By bringing the body back to a more normal pH (a normal acid/alkaline balance) you're able to put on weight more easily.

Essential fatty acids are needed by the body for the production of

various hormones. Pectin from citrus rinds and apple sauce (not the juice) helps in the assimilation of fats and oils.

When oil is added to water, it will not mix. However, you will notice that the olive oil is totally dispersed throughout the whole lemon drink. This dispersion of the oil is caused by the pectin in the lemon rind. The proof of absorption of the oil could come from a blood test, but is also indicated by the return of saliva pH to normal 6.4.

In addition, the lemon juice acts on proteins to break them into a free form, which is more easily assimilated. Also, the lemon juice helps to dissolve minerals in the food for better assimilation. This drink should be used with all dietary supplements to improve their assimilation.

A tablespoon of lecithin granules added to the lemon drink each day can help painful neuropathy.

Naturopath Peter de Ruyter cautions that this drink, which he says tastes rather nice, is a medicine and should be treated as such. Don't over do it, stick to the prescription above.

This article by Mark Konlee originally appeared in the Canadian newsletter BCPWA News. It has been adapted by Peter de Ruyter.



Beyond Prognosis



The body talks . . .

. . . So listen!

says Reinhold Bergmoser.

That's what he's learned after living with HIV since 1983.

I remember the day when I sero-converted. Having flu like symptoms was so unlike me. In fact I almost never got sick back in those days, not with something as minuscule as the common influenza. Of course back then I did not understand what was happening. The real cause of my 'influenza' was something a bit more life threatening.

Now, almost half my life I have been a person living with HIV. I still sometimes wonder what could have been. What should have been? The first years were easy, you simply ignored it and it was supposed to go away. Half expecting that I eventually could claim to be a *non* progressor.

In 1989 my T-cell count had dropped to below 200. With the help of my partner, who gave me a much needed kick in the pants, I started to educate myself about this thing. I knew the basics, but nothing that came close to understanding the specifics of HIV and disease progression.

It was a major step for me to acknowledge for myself the clinical state of being a person with AIDS. We knew that in the USA they statistically classified any person with a T-cell count of 200 or less as a person with AIDS. It took courage to get myself into that mental state. I would not allow myself to be com-

placent any longer. Progression was happening undeniably, at a fast rate with constantly deteriorating T-cell count. What a dread it was, listening to my latest monthly blood results at Albion Street Centre.

What a relief when I lost my last T cell and my report came back as zero in 1991. Finally I could relax. No more T-cells to lose but still relatively healthy and alive. Possibly the doctors had been wrong, maybe I could go on living with HIV? A new mental frame! You see the AIDS industry had conditioned me to believe that no T cells means almost instant death.



Nevertheless, I did not die, mainly because I did not accept my (ex) GP's prognosis that my life expectancy was only six months. I had friends who died, only for the fact of self-fulfilling prophesies shortly after reaching the expiry date their GPs predicted. Indeed, I took every prognosis and diagnosis of my doctors with a grain of salt. These professionals were supposed to be

the experts who had to know better . . . and yet got it wrong so often.

I changed doctors twice, settling finally with a specialist at Albion Street and one at Woden Valley Hospital. They restored my confidence in a medical system that is often incompetent and misleading. I still see a GP to get the necessary scripts. Routinely, I go in with a list of needed medications and have him fill out what I require.

Do not believe that the standard medical education of a GP will suffice to treat a person with AIDS. If you believe that, you might as well order your lot at the local cemetery. For example, ask your GP how he would stop AIDS related night sweats. The most likely answer will be resignation and "nothing can be done". Yet I know of people using the homeopathic "Reckenweg" clearing up night sweats within three days. Find a GP who will support you using alternative treatments and remedies. Having found such a person I now realise that I had been missing out for years.

We used to order the latest information newsletter from Los Angeles to keep informed about the latest drugs, trials and updates. These days we have an excellent Australian newsletter called *AIDSX*.

Often I suggested the latest 'flavour of the month treatment' to my doctor and got involved in a series of trials and new treatments, mostly on compassionate access. Once I imported an experimental medica-

tion myself, only to get an urgent message from the product company urging everyone to stop using it immediately. Apparently this treatment killed more people than AIDS.

My T-cell count stayed mostly at zero except once two years ago when it jumped to a sudden 40. I could not believe my 'good fortune' until I understood why there was increasing immune system activity. I had picked up cryptococcal meningitis and within three days found myself at the hospital fighting for my life. Never in my life did I expect that much pain. It took three weeks of intravenous Amphotericin (with all the accompanying side effects), to lower the amount of this fungus in my brain membrane.

Of course it would have never hit me so completely unprepared had I known what set of symptoms suggest what sort of infection. This is where education comes in. Know your stuff and survive.

For me, getting involved with the local Positive Support Network was imperative. More importantly,

I became an active member of my community, putting in place a network of helpers and friends to support me when needed. I became the expert about my disease. I took a job with PLWHA (ACT) and started to support others.

The survivors' mentality can clearly be learned although it can't be taught. Understand that it was more important to listen to my body than to listen to my doctors. My specialist at the hospital told me that we have to stop relying on the blood results and rather listen to how I feel.

Bringing alternative treatments into my health maintenance was one of the best things I did and long overdue. Before then I had relied on the power of all available prophylactic and anti virus treatments without taking responsibility for my own healing. I started to cut back on the constant bombardment of various synthetic drugs, using naturopathic remedies instead.

Finally I stopped the usual blanket antibiotics prescribed for my recurring sinus infections (that did

not improve my condition) and started taking Sinoplex (a homeopathic treatment). My sinuses cleared within three days. Every case needs individual attention, all this stuff might be completely wrong for you. But if you do not know . . . who do you think will? That is the big lesson to learn. Take the responsibility for your healing or die.

My lover happens to be a chiropractor and it was amazing to watch the improvement of various conditions achieved simply by being adjusted. I got a good Naturopath and I am also a Reiki student. Of course, once a week, the usual massage. My community nurse gives me a shot of vitamin B12 when needed. The point is, I am in control! These services are free or at a tiny \$5.00 charge. Do you know what services your local Aids Council and PLWH/A provide? If you do not have those services readily available, perhaps it is a good time to start demanding.

Pessimism is a luxury I cannot afford. Negativity feeds on itself just as the positive attitude and mind will manifest itself in the body. So I condition myself. Mind you, this is bloody hard work. I need to constantly reinforce myself with positive messages. Often this is achieved by driving myself to fill unmet goals and I have plenty of those.

Frequently I am drooping with fatigue. Consistently resting for a good while helps me to regain my strength.

All my family and friends support me in making my health a priority and the choices we must make depend on what my needs are. Utterly unfair to my lover's needs, who often has to come second. I am very fortunate having a partner that will stand by me. How often have I changed plans in the last minute simply because I did not feel well?

Here is to the body speaking! Learn to listen to what your body says or it will speak up in a louder voice until you understand. ♦

HIV Prevention Services

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Herbert St, St Leonards

Ph (02) 9906 7083

Mobile: 018 978 596

Vending Machine - 24 hrs

NORTHERN BEACHES

14 Pittwater Rd Manly

Ph: (02) 9977 2666

Mobile: 018 440 296

DELIVERY SERVICE

For hours of service please contact

018 440 296 or 018 262 751.

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contact ADIS:

(02) 331 2111

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51-53 Blaxland Rd, Ryde

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Mobile: 018 262 751

SERVICES PROVIDED:

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Further enquiries to Dr Claire Parsons,
 Director on (03) 418 6909.

CLOSURE DATE: 5 November, 1995

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WHERE WE SPEAK FOR OURSELVES

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Philip McGloth

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

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☐ **Yes!** I want to apply for membership of PLWH/A (NSW) Inc. \$2 per year (Membership is only available to NSW residents)

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PO Box 831, Darlinghurst NSW 2010. **Thank you!**





HIV living information weekends

HIV living information weekend workshops for people with HIV/AIDS and partner, carer or friend.

These workshops are free and confidential.

The topics presented cover a comprehensive range of information from HIV treatment options, complementary therapies, recreational drug use, social security entitlements, housing, international travel, legal issues, positive sexuality and many more. The number of participants is limited so to book a place or find out more call stephen 206-2011

orientations

have you recently become HIV positive?

'you are not alone'

Orientations are weekend workshops covering issues specifically for gay men who have recently become HIV positive (in the last 2 years.)

These workshops are free and confidential.

Orientations workshops are run every few months, there's one starting soon. There are a limited number of spaces in each workshop, so to book a place call stephen on 206-2011

(please note that these sessions are for people with HIV only)

HIV living support groups

Support groups give you the chance to meet others with HIV, talk about feelings, exchange ideas, make friends. You may be surprised to find how your own experience can help others. Groups meet for around two hours a week, and run for eight to ten weeks. There are about ten people in each group including two trained facilitators who also have HIV. What's talked about in group is entirely up to it's members, everything said is confidential. If you'd like to join a group, or just find out more about them, give us a call. New groups are starting all the time. call scott tues, weds, thurs 206-2014

long term survivor groups

A chance to meet others who have been living long term with HIV/AIDS, to make friends, talk about our feelings and exchange ideas. These groups are run in the same way as our HIV living support groups. The HIV living project does not define what makes a long term survivor. The emphasis is on our emotional issues about living long term with HIV or AIDS. The group is open to anyone living with an HIV/AIDS diagnosis for 5 years or more regardless of health status or T-cell count. New groups are starting all the time. call scott tues, weds, thurs 206-2014.

ks support groups

ks groups provide a space to meet others with ks, to talk about the way we feel about living with ks, exchange ideas and make new friends. These groups are run in the same way as our other groups, but they are only open to people living with ks. New groups are starting all the time, call scott tues, weds, thurs 206-2014

