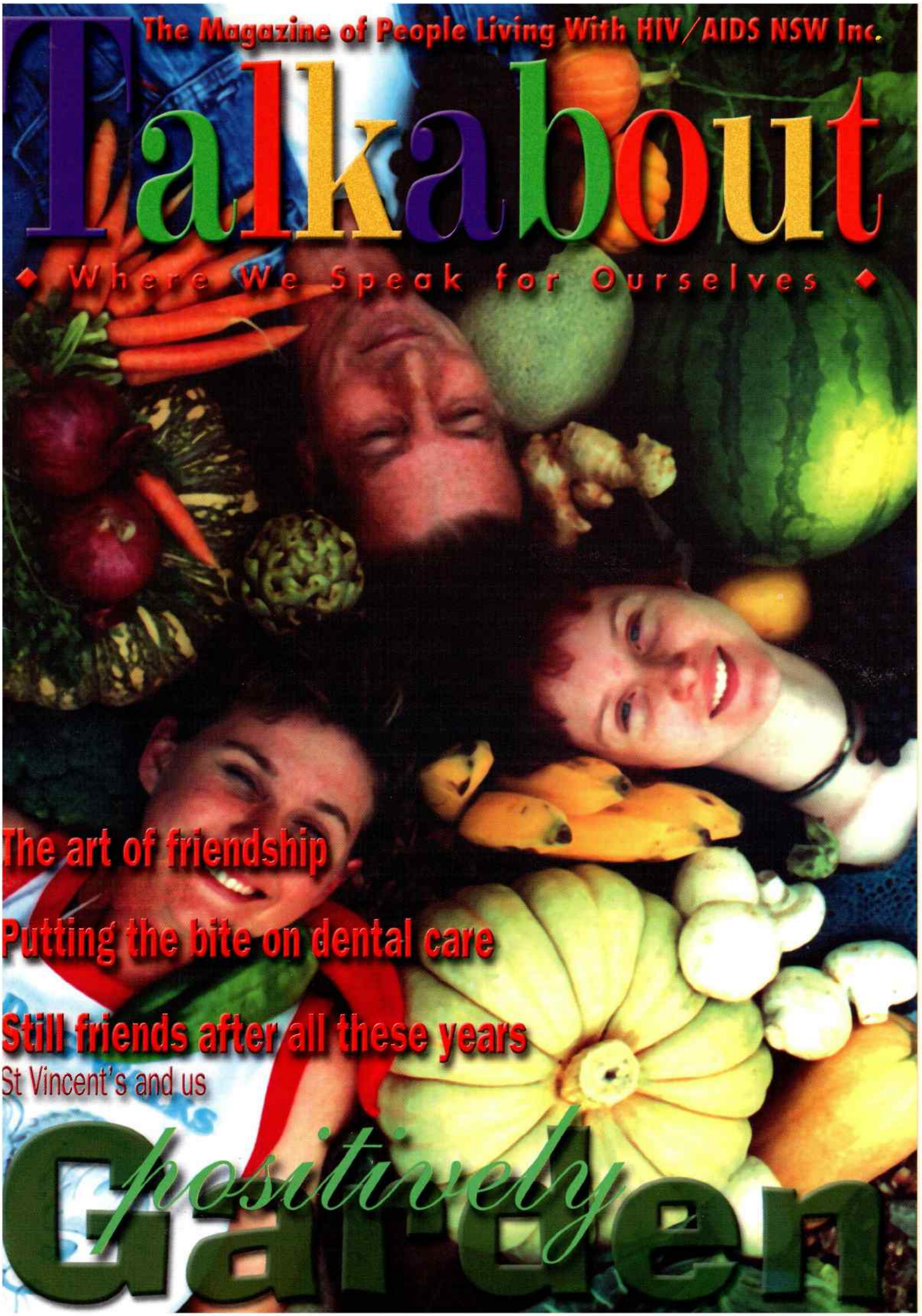
The Magazine of People Living With HIV/AIDS NSW Inc.

Talkabout

Where We Speak for Ourselves



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Putting the bite on dental care

Still friends after all these years
St Vincent's and us

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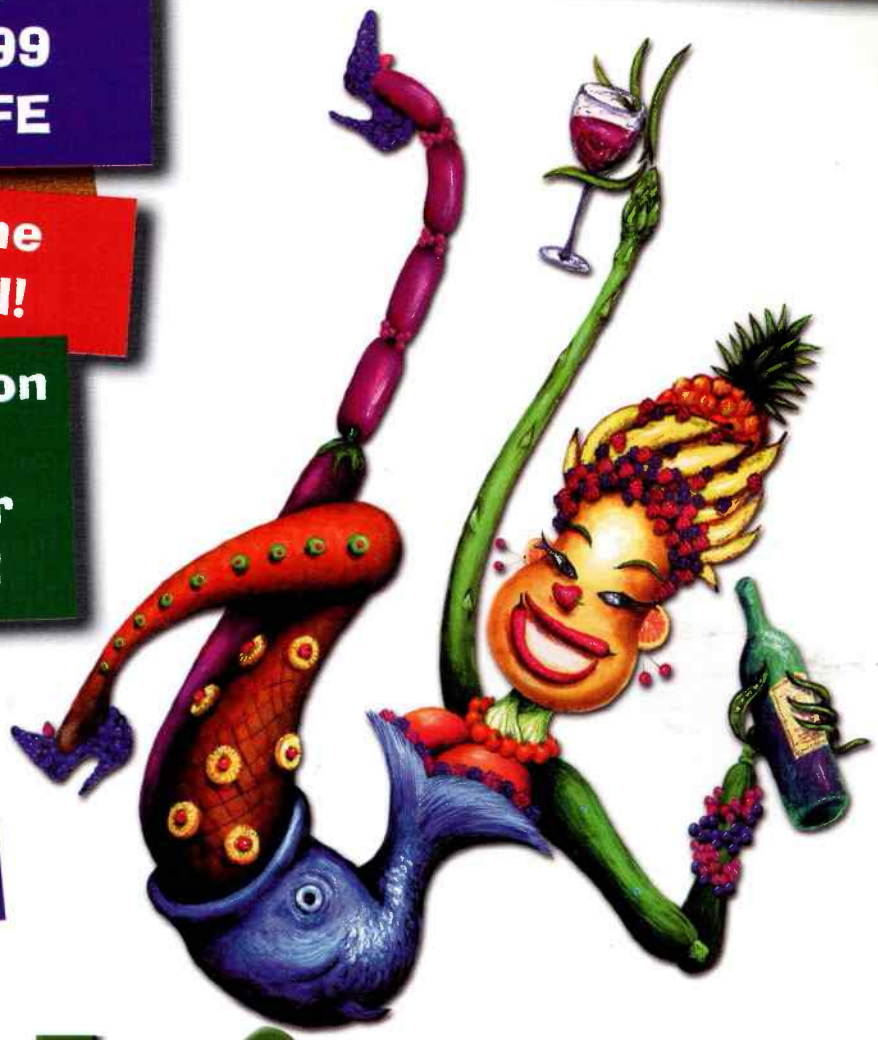

Cooking Combo's

ACON
AIDS Council of New South Wales Inc.

AFRO

South Eastern Sydney
Area Health Service

CSAHS
Central Sydney
Area Health Service

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FROM THE PUBLICATIONS WORKING GROUP

I joined the Publications Working Group twelve months ago. Since that time I have taken part in two Planning Days and have been on the Sub-Committee, responsible for the implementation of the Publications Review conducted earlier this year. From that vantage point, I am proud to be able to say that I have played some small role in the continuing emergence of a quality magazine. I have also watched, with respect and admiration, the committment and the long hours of work invested in *Talkabout* by the editor, feona studdert. She maintains the fine traditions of her predecesors.

When I informed her of my recent decision to resign from the Working Group, feona said she would miss my optimism. On reflection, I realise I am optimistic: I am doing post-graduate study for a new career, such is my belief in my future. The demands of this work and my representative duties for PLWHA (NSW) Inc. called for this resignation.

I am optimistic about the future of *Talkabout*, a publication respected throughout Australia and internationally. So long as it remains the magazine "where we speak for ourselves", it will serve well its many readers.

Moreover, I am most optimistic about the future of PLWHA (NSW) Inc. Through the efforts of committed and professional staff and volunteers, this Association continues to evolve as an effective voice for the positive community throughout this society. It is with pride and confidence that I look to the year 2000.

Douglas Barry
Resigned October 1999

PLWH/A(NSW)
People Living With HIV/AIDS

PositiveAction with Ryan McGlaughlin

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Talkabout
is published by People Living With HIV/AIDS (NSW) Inc.
 Talkabout is made possible by subscriptions, advertising revenue, donations and a grant under the State/Commonwealth AIDS Program. *Talkabout* thanks the many volunteers without whom its publication would not be possible.
email editorial material to feonas@plwha.org.au

Printed on recycled paper by Breakout Printing
Phone 9281 5100.
ISSN 1034 0866

Candlelight, spotlight ... and travel-light

'tis the season ...

This is the season of annual general meetings. In the past month the AIDS Council of New South Wales and the Bobby Goldsmith Foundation have both had elections. David Stone for ACON and Levinia Crooks for BGF have both been returned for second terms as President. We congratulate them and look forward to working with them closely. The PLWHA (NSW) AGM was held on 26 October and I'll update you on the outcomes in the December issue. Ray Hansen has retired from the committee to focus his energies as a Governor of the AIDS Trust of Australia. He became involved with PLWHA (NSW) during the 1998 Mardi Gras and has taken our fundraising endeavours to new heights including the Wockpool Benefit, and the Celebrity Shoe Auction. We wish him well.

New Directions

We are contributing to drafts of the implementation strategy for the State HIV/AIDS Strategic Directions. Our representatives are on the teams drafting the Treatment, Care and Support, Health Promotions and Education Plans. Provision is being made for feedback about the Strategic Directions.

Privacy on trial

We have been involved in a proposal for the trial of an antenatal resource in three areas of the state. Together with ACON we have been lobbying the NSW Ministerial Advisory Committee on AIDS Strategy to begin a trial of community pharmacies to access s100 Drugs. In conjunction with ACON, talks have begun with the South East Sydney Area Health Service regarding a proposal to upgrade state wide pharmacy computer systems and the consequent issues regarding the privacy of PLWHA treatment records.

Retreat evaluation

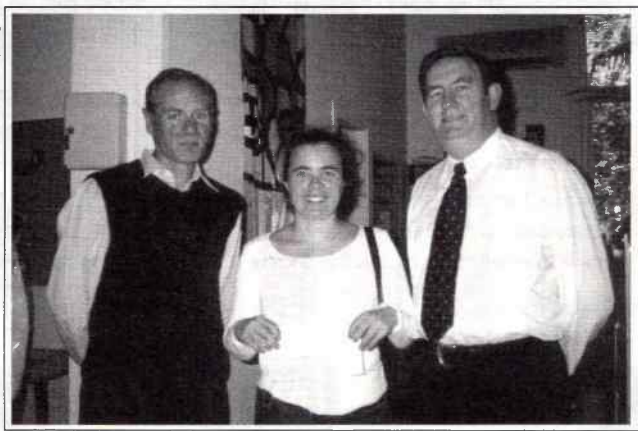
Activist Paul van Reyk and Amanda Nickson, a board member of the Sydney Gay and Lesbian Mardi Gras, have been appointed to evaluate the Positive Retreat Project. The report and recommendations will be completed by December. ■

PLWHA (NSW) Major Fundraising Event

Ready for take-off?

For the third year in a row KLM Royal Dutch Airlines has generously supported us by donating a return economy class trip to Western Europe. This year we will run a raffle over summer. We are seeking volunteers to sell raffle tickets up and down Oxford Street, at special events and to friends and family. **If you would like to help, contact Antony Nicholas on 9361 6011.**

Photo Tony Creighton



The Positive Speakers Bureau (PSB) received an AIDS Trust of Australia community grant for $22,000 from Levi Strauss to produce a video based on the lives of it's three speakers and speaking engagements they conducted in NSW metropolitan high schools. The video is being produced specifically for rural high schools and tertiary institutions where travel costs prohibit the services of the PSB getting to these areas. Pictured (left to right) are Paul Maudlin (Positive Speakers Bureau), Alex Chrysiliou (Levi Strauss) and Terrence Trethowan (AIDS Trust of Australia).

Briefs

Improved supply of ritonavir

Drug manufacturer Abbott has announced that hospital pharmacies should now have sufficient supplies of the new ritonavir capsules. When the new capsules – that replaced the nasty-tasting liquid form of ritonavir – became available last month they were in short supply. To ensure equitable access some hospital pharmacies only provided a one-month's supply to patients. PLWHA should now be able to get three-month's supply of the new capsules.

Efavirenz launch

At last month's launch of the new non-nucleoside drug, efavirenz, a panel of Sydney HIV doctors and Jo Watson, National Coordinator of NAPWA and the AIDS Treatment Project Australia (ATPA) said they were generally in favour of starting treatments with a protease-sparing regimen containing efavirenz, particularly when the person had liver problems caused by hepatitis C. At the launch, results of a clinical trial were presented which showed a combination containing efavirenz to be superior for initial therapy to a combination containing the protease inhibitor, indinavir. However, Professor Bruce Brew, an HIV neurologist, said a person with a previous history of depression might be more likely to experience the neurological side effects of efavirenz.

Promising new drug

Research presented in September at the Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAC) in San Francisco suggests that tenofovir, a nucleotide analogue reverse transcriptase inhibitor, reduces viral load ten fold. Nucleotide analogues differ from nucleoside analogues such as AZT, because they don't need enzymes within body cells to become active. Tenofovir does not cause kidney damage, unlike its relative adefovir, and is active against virus that has developed resistance to all nucleoside analogues. Interestingly, when resistance to tenofovir develops it tends to be reversed by 3TC or abacavir, suggesting that it should work well with these drugs. Not yet available in Australia, tenofovir is still being evaluated in clinical trials. *Medscape*

Tell it like it is is your opportunity to get a straight answer to questions about health, treatments and side effects. Send your questions to Tell it like it is, *Talkabout*, PO Box 831 Darlinghurst 1300 or fax 02 9360 3504 or email feonas@plwha.org.au

Q I started combination therapy including protease inhibitors, about six months ago. I am planning to take some 'party drugs' this weekend. Should I be worried about possible interactions?

Andrew, Mount Druitt

A *HIV drugs can cause the levels of 'party drugs' to increase in the blood stream and this can be a problem leading to unwanted side effects and in extreme cases, death. However, the most common troublesome interaction is that 'party drugs' may lead you to forget to take your HIV drugs. This can be serious in terms of losing control of viral suppression and the development of drug resistance. You should follow a few simple rules: take smaller amounts of your 'party drug' and only take more after one or two hours if you don't experience the desired effects; tell your friends what you've taken and when you've taken it (including your HIV drugs); keep well hydrated; seek medical help at the first sign of physical abnormality; and take special measures to assist you to remember to take your HIV drugs. These include alarms; signs around the house; drugs at your friend's house; pillboxes etc.*

Q I have noticed some facial wasting over the past three months. I wanted to stop my protease inhibitors but my doctor stopped d4T. Has she gone mad?

Max, Double Bay

A *Probably not. The first thing to say is that there are no right or wrong answers regarding this topic at the moment. Once upon a time we thought that only protease inhibitors caused the fat redistribution we have all observed in patients taking HIV drugs. Now we are not so sure. Nucleoside analogues, including d4T, have now been accused of causing some fat redistribution as well. Some say that the fat wasting of the face and limbs (as opposed to the fat gain in the abdomen) is more related to nucleoside analogues. For this reason, if fat loss or 'lipoatrophy'[1] is the predominant problem some suggest stopping the offending nucleoside analogue. While there have been a few word-of-mouth reports that this approach works the jury is still out.*

Q My doctor was quizzing me about my family history of heart disease. What relevance does this have to my HIV disease?

David, Surry Hills

A *The link is hyperlipidemia – increased fat or lipid (cholesterol and triglycerides) levels in the blood. Some HIV drugs cause hyperlipidemia. We know that, in the general population, hyperlipidemia is a risk factor for the development of blocked arteries around the heart or ischaemic heart disease (IHD). People with higher levels of lipids in the blood are at increased risk of developing IHD such as angina and heart attacks. Other risk factors include smoking, diabetes, high blood pressure, obesity, reduced exercise and a family history of IHD. At the moment we do not know if HIV drug induced hyperlipidemia increases the risk of IHD. While the jury is still out, many doctors advise their patients, especially those with multiple risk factors, to modify their lifestyle to reduce their risk of developing IHD. While you can't do much about your family history, you can stop smoking; lose weight; exercise regularly and control your diabetes and blood pressure.* ■

The most common troublesome interaction is that 'party drugs' may lead you to forget to take your HIV drugs. This can be serious in terms of losing control of viral suppression and the development of drug resistance.

Answers provided by Dr Virginia Furner and Dr Mark Kelly of the Albion St Clinic. Decisions about treatments should be made in conjunction with your GP.

[1] Lipoatrophy refers to wasting or loss of fat deposits from the body and lipodystrophy refers to any change in fat deposits in the body including loss, gain and redistribution.

For further insight into the relevance of heart disease for PLWHA, see Barrie Harrison's 'HAART to Heart' on page 25).

Briefs

Puplick appointed for second term

Canberra The Federal Government last month re-appointed Mr Chris Puplick as chairman of the Australian National Council on AIDS, hepatitis C and Related Diseases (ANCAHRD). The Federal Minister for Health and Aged Care, Dr Michael Wooldridge announced the appointment. "The Council has made considerable progress in developing nationally focused policies and programs for hepatitis C education and research, without diminishing the importance of HIV and AIDS," Dr Wooldridge said. Mr Puplick will be at the helm as Australia embarks on its fourth National HIV/AIDS Strategy and first National hepatitis C Strategy. Mr Puplick is also President of the NSW Anti-Discrimination Board, Chairman of the AIDS Trust of Australia and Chair of the Central Sydney Area Health Service. Mr Puplick's new term will run for three years.

One million PLWHA in W. Pacific

Manila The World Health Organisation (WHO) estimates about 1 million people in the Western Pacific now have HIV/AIDS and says figures are rising rapidly, reports Associated Press. Last year's estimates gave about 700,000 people living with HIV in the region and 40,000 with AIDS. Officials predict the number of people living with HIV/AIDS could exceed 1.5 million in 2000 if left unchecked. Addressing a workshop on AIDS and sexually transmissible infections, WHO Regional director Shigeru Omi warned against complacency. WHO said the use of condoms should be a priority in preventing the spread of HIV and other sexually transmissible infections, and recommended mechanisms to guarantee the safety of blood supplies. WHO defines the Western Pacific as 37 countries and areas in East Asia and the Pacific.
Sydney Star Observer

US 'disability to work' bill

Washington The United States House of Representatives has approved a bill that may encourage some of the nation's nine million people with disabilities, including people with HIV/AIDS, to enter the work force without worrying about losing their government-funded health coverage.
The House voted 412–9 to pass the legislation that over the next ten years would also more than quadruple, to 550,000, the number of people with disabilities receiving rehabilitation and training services. Fear of losing Medicare and Medicaid benefits is one of the major disincentives for the nation's disabled to seek employment. The House bill would extend Medicare coverage for up to ten years for Social Security Disability Insurance beneficiaries who return to work, six years beyond the current law. Currently less than 1 percent of people who enter government disability rolls ever leave. *Associated Press*

Shop Talk

PLWHA (NSW) staff and committee members are active in many projects, consultations and meetings that affect the interests of PLWHA. **Antony Nicholas** – our Community Development Project Worker – profiles what's happening in NSW this month.

Time Out

Sleaze Volunteers and staff of PLWHA (NSW) ran the Time Out Room at Sleaze Ball. This year we invited PLWHA to drop off their prescription medications for those who did not want to carry them around. Several people used the service. (New gel cap medications are not so easy to shove down your shoe.) There was some confusion around the time out room finishing at 6am but everyone picked up their pills in the end! Thankyou to the Sydney Gay and Lesbian Mardi Gras for providing the tent. We are hoping to use one of the rooms in the Horden Pavilion at Mardi Gras so PLWHA can feel more included in the party.

Brush up on your advocacy skills

Mid North Coast Area Health Service in cooperation with PLWHA (NSW) will be running an Advocacy and Campaigning Course for positive people, HIV workers and volunteers. The course will be on 13 November, on the coast and will cover areas such as government processes, laws, campaigning skills and techniques, media skills and utilising positive representation on committees and boards. The course is free, but numbers are limited. Call Robert Baldwin on (02) 6588 2750 during business hours.

Switched on

Switched On Living is a initiative of St Vincent's Hospital to provide support, encouragement and guidance to PLWHA, their partners and carers, family and friends who want to live a healthier lifestyle. Seven sessions cover topics like stress management, muscle relaxation, nutrition, skin care, meditation, employment training, and exercise and budgeting. Enquires and referrals can be directed to Belinda Hocking on 9361 2213 or Belinda Moyan on 9361 7361.

Knocking down walls at the PLC

Refurbishment has well and truly begun with many of the internal walls knocked down. If all goes well, they plan to open for business on World AIDS Day. Keep an eye out for information on progress.

Help!

Community Support Network (CSN) is desperate for new volunteer carers, if you are interested please contact CSN. CSN have people on their waiting list in need of a carer. Full certified training is provided and there is continuing support for carers. Call Lisa on 9206 2025 or Tess on 9206 2031.

Anglicare Care Force

Anglicare Care Force offers emergency relief. To use the service you must ring for an appointment, bring proof of identity, income, rent receipts and unpaid bills. Anglicare can offer assistance with food, chemist prescriptions, unpaid bills, assistance with removals and rent arrears. Conditions apply but there is no need to disclose your status if desired. Anglicare is located at St Michaels, 196 Albion Street, Surry Hills. Drop in is available between 9am and 4pm or you can contact them on 9331 3482. ■

Waratah Clinic, the centre of the HIV outpatient services at St George Hospital in Kogarah was opened in 1989. The unit now cares for close to 70 patients and is staffed by two staff specialists, HIV social worker, HIV Clinical Nurse Specialist and an HIV Registrar. The team at St George HIV/AIDS Unit, Kogarah– pictured (left to right) – are Helen Colinet (CNC), Terry White (CNS), Dr Pam Konechny, Dr Richard Lawrence – sitting (Staff Specialist in Infectious Diseases), Amanda Fossey (HIV Social Worker) and Professor Steven Krilis (Immunology).

Briefs

5400 in vaccine trial

United States Drug company, VaxGen, Inc. has announced that it has completed enrolment in the United States portion of the North American trial of AIDSVax, a vaccine designed to prevent infection by HIV. The inoculation of more than 5,000 volunteers in the study, the first ever Phase III clinical trial of a preventive HIV vaccine, took place at 56 US clinics. and at one clinic each in Puerto Rico and the Netherlands. Canadian enrolments will bring the number to 5,400 volunteers. The company is also conducting a Phase III trial in Thailand of a separate formulation of AIDSVax. To date, no vaccine to prevent HIV infection, other than AIDSVax, has received approval from the Federal Drug Authority for testing in Phase III clinical trials. *VaxGen*

Women's study

United States Details on a new clinical trial to determine gender differences in the treatment of HIV were released at a National Conference on Women and HIV/AIDS held last month. The new trial, sponsored by Bristol-Meyers Squibb Co. and Merck & Co, will compare a group of 100 women and 100 men for whom current drug regimens have failed. A gap in survival rates between men and women with AIDS still exists. In Los Angeles County, women are 18 percent less likely to survive than men, even with the advent of new medications, according to advocacy group Women Alive.

The 48-week trial will compare sex differences for viral load suppression, diabetes, abnormal distribution of body fat and elevated cholesterol levels. The study will assess the regimen of two nucleoside reverse transcriptor inhibitors with two protease inhibitors. *Reuters*

Future bright for Victorian CCU Unit

Victorian community groups expect the long awaited continuing Care Unit to be finished by July 2000 after the fate of the Victorian government was settled late last month. Community groups have written to the new Victorian Health Minister, John Thwaites, seeking a meeting with the hope of securing his commitment to the project, and to ensuring that the current schedule for construction is adhered to. Interim arrangements for respite care are still to be confirmed. It is expected that the Alfred will make available Commonwealth funded Carer Respite Centres throughout Melbourne for the interim respite needs of HIV/AIDS patients who do not want to use the sub-standard Wards 3A and 7 at the Alfred Hospital.

Welfare squeeze: Newman gets tough

The National Association of People with HIV/AIDS has slammed plans by the Federal Government to get tough on welfare payments.

In a speech to the Federal Press Club on 29 September, Senator Jocelyn Newman announced a toughening of the Federal Governments approach to welfare payments arguing that the economic and social future of this country relied on changing a "destructive, self-indulgent welfare mentality".

Care and Support Spokesperson for NAPWA, David Menadue, said in a statement that the government would be better advised to pay more attention to the training needs of PLWHA. "Increased awareness among staff in employment agencies and Centrelink to the specific return to work issues for HIV positive people would be a useful initiative," he said.

"Dealing with potential discrimination in the workplace, confidentiality and arrangements for dealing with the medical requirements of having HIV can all be helped by these staff, better enabling people to make the transition into the workforce," said Menadue.

Newman said that with the ageing population, a lower birth rate, a decline in low skilled jobs, increasing costs of health and pharmaceuticals and increased demand on the education system, the nation "cannot afford to leave unchecked the waste, economic, and social isolation that is the cost of welfare dependency".

While acknowledging that there will be a section of the population who cannot work and who will require support, the government wants to see a change in community perceptions towards a greater self-reliance with social security regarded as a stop-gap and a "spring board" to returning to the workforce, where possible, rather than relying on it as a "passive safety net". Newman suggested a further development of the concept of mutual obligation for people on pensions, involving a greater focusing on case management, return to work plans and incentives to train and rehabilitate.

The implications for people with HIV on the disability support pension are not clear yet. The Senator has set up a reference group headed by an academic with health bureaucrats and people from the business and community sector represented, to prepare a Green Paper on welfare reform for the Parliament early next year.

"The devil will be in the details," said Menadue. "We want to see exactly what is meant by the concept of 'mutual obligation'. If this is about forcing relatively ill people, including PLWHA to submit to more rigorous case management or increased meetings with Centrelink that will be an added burden on PLWHA.

"NAPWA plan to put a submission to the government's reference group pointing out the particular difficulties we see for tightening up the Disability Support Pension arrangements for people with HIV/AIDS." ■

David Menandue of NAPWA says 'the devil will be in the detail' of Newman's proposed Green Paper on welfare reform

Reconstruction takes off

The much awaited Reconstruction Project has set up house at the offices of PLWHA (NSW). Project Manager, Pene Manolas (pictured), previously the Coordinator of the Colàa Project, told Talkabout *that the four-month pilot project would run a series of educational forums. "The aim is to address the practical and emotional concerns of PLWHA who have experienced renewed health". The Project has been adapted to Australian standards from the original Reconstruction Project developed by AID Atlanta in the United States. (Watch out for our Community Feature in the February issue of* Talkabout.)

Briefs

Activist banned from auction

British Columbia A Canadian person with AIDS who tried to auction the rights to his corpse on the Internet after he dies has been prevented from doing so. The man, who lives in British Columbia, put his corpse on the block through US Internet auction house, eBay, with the heading "For Sale: A Dying Human Body For Life." But eBay pulled the item within 24 hours because it violated a company policy against offering bodies or body parts for auction. eBay spokesman Kevin Pursglove said British Columbia resident Richard Hollingsworth planned the move as a publicity stunt to raise awareness of the fight against AIDS. "We wish him every bit of success, but you just can't sell body parts under federal law." Pursglove said. *Reuters*

Boy loses karate court battle

United States A Virginia boy with AIDS who wanted to take 'hardstyle' karate lessons with his friends has lost his US Supreme Court appeal. The justices, without comment, left intact rulings that said Michael Montalvo's participation in a rough and tumble karate school would pose too much of a threat to the health and safety of other students. Michael's father, Luciano, had sued the karate school, saying its refusal to let his son participate in group classes violated the *Americans with Disabilities Act*. After learning that Michael had AIDS, the school refused to let him participate in group classes. The offer to give the boy private lessons was rejected. A federal judge threw out the Montalvo lawsuit last year, ruling that Michael's infectious HIV posed a direct threat to other students and that the school had reasonably tried to accommodate his disability.

Associated Press

HACC Shake up

The NSW Ageing and Disability Department has commissioned consultants to undertake a project to improve access for people living with HIV/AIDS to Home and Community Care (HACC) Services. Consultation has identified potential projects that may be undertaken to improve access. PLWHA identified a range of constraints that limit access to HACC services. The consultants have selected four projects that aim to develop networks between HACC and HIV services and raise awareness of PLWHA and HIV services about HACC services.

Step forward for Medical Cannabis campaign

The move to legalise cannabis for medicinal use took a step forward in October with the announcement that the State Government would establish a working party to examine the controversial issue.

Community groups welcomed the announcement, calling it a step forward for common sense. Spokesperson for the Australian Committee for Medical Cannabis, Timothy Moore, said in a statement that the committee was confident the working party, informed with the latest research, would support the call to have cannabis available for medical purposes.

"It is difficult for people with life threatening or chronic illness to come out publicly", he said. The ACMC supports the rights of patients who use cannabis as medicine, including people with cancer and HIV/AIDS.

Last month's announcement follows calls by the Australian Committee for Medical Cannabis, the Australian Medical Association and the Australian Association for People with Cancer and AIDS to allow the prescription of cannabis for pain relief and to facilitate research.

In his announcement the Premier cautioned that the proposal would have to be carefully examined as it raised complex issues like those of possible dependence and creating legal supplies.

"This is not a proposal to legalise cannabis, I have already ruled that out", Mr Carr said.

Recently, a Surry Hills HIV positive man was found guilty in the Downing Centre Court for possession of nine grams of marijuana. The man, who represented himself, submitted a letter from his doctor to the judge that stated that the marijuana was used to control side effects from the man's HIV drugs, including diarrhoea, nausea, and loss of appetite. The man was released without the conviction being recorded and without costs or fines being awarded.

In his announcement the Premier acknowledged a recent House of Lords Select Committee on Science and Technology that concluded that cannabis could serve a therapeutic function.

Robert Griew, Executive Director of ACON, welcomed the introduction of any measure that could help control pain or nausea for PLWHA.

"There is a lot of work to be done fine tuning legal and medical issues surrounding this move. However, we are very keen to make medical cannabis available for PLWHA as quickly as possible," Griew said.

Currently there are 11,000 people in NSW registered as HIV positive. Approximately seventy seven percent of these are using antiviral drugs. According to the most recent *HIV Futures* report by the Australian Research Centre in Sex, Health and Society. Three-quarters (73%) of the people using antiviral drugs experience side effects from these drugs.

The campaign to have cannabis legalised for medicinal use progresses slowly

Of these, diarrhoea (experienced by 32% of PLWHA using antiviral drugs), nausea (31%), and gastric reflux/indigestion (10%) were among the most common.

Representatives from community organisations, including ACON, the NSW Cancer Council and the Law Society of NSW, will be invited to join the working party. The Working Party will report to the Cabinet by July next year.

ACON will be gathering anonymous testimonials from PLWHA who are now using cannabis to relieve symptoms and/or the side effects of treatments. Call 9206 2000. ■

Photo Mozz Images

Work hard for the money

Over 200 people turned up to make red ribbons for the AIDS Trust last month. Volunteers spent the day making nearly 60,000 ribbons from 14,000 metres of ribbon. The ribbons will be sold on World AIDS Day to raise funds for the Trust, Australia's largest philanthropic HIV/AIDS fund.

HotBox

Write to **HotBox** at PO Box 831 Darlinghurst NSW 1300 or **Fax** 02 9360 3504 or **Email** feonas@plwha.org.au

Should the Royal Prince Alfred Hospital amalgamate its HIV ward with the plastic surgery ward and lose specialised nursing and medical staff in the process?

I believe it shows a great lack of sensitivity to house positive people in a ward with people recovering from plastic surgery.

HIV worker

It removes the specialised care for HIV positive patients in the ward and leads to a reduction in the skills base of the staff and quality of care offered to patients. Staff are far more likely to be generalised medical staff rather than HIV specialised. However it makes it damn easy to get those needed beauty touch ups.

LuLu, Pos male

I think the major concern is the loss of specialised nursing staff. I realise there may be beds being vacant periodically, however there is a risk of losing specialised care. Plastics is probably not a ward to mix with positive people.

Brian, pos male late 30s

It could have been worse, plastic surgery is an odd mix, but it is hard to justify maintaining six empty beds. Gastro wards would be a far worse choice.

Jaded Old Queen
(positive Welfare Worker)

Letters

As a long term survivor and some one that has worked in the HIV/AIDS sector for eight years I feel equipped to make some comments about what I observed at the recent HIV Service Provider's Forum 2 in September.

The following are my impressions and I do not expect everyone to agree with them. On the day I felt the large group discussion was quite destructive and because of all of the varied opinions that were given I needed time to reflect on what had been said. It is good that the community is having the debate but it would be more rewarding if individual, political and historical agendas are loosened and greater respect is given to the many diverse views that make up this sector. Listening to the arguments at the forum I found it hard not to validate most of them. The views expressed were representative of the diversity of how positive people and service providers are now experiencing the epidemic. Many circumstances are demanding us to change, but this needs to be done in context of diversity not through a homogeneous approach. It appears to me there are some individuals and organisations that need to look outside of their own experience and consider this diversity and find a 'middle road' and hopefully more common ground to best serve the interest of our communities.

At a community meeting at ACON in 1996 I said it was time we as a community map the services we provide and identify the gaps, duplication and also what is no longer appropriate.

I still believe this is required and have not resolved the reasons for resistance whenever others and myself suggest a mapping exercise.

Having said all this, whether because of the forums or coincidental I believe the sector is striving to work more cooperatively than it has done in the past. This is obviously a sign of encouragement.

Ryan McGlaughlin
Potts Point

Diary

Events

Outings

Next Outings event will be a day in Darling Harbour on 5 November. Lunch will be provided with tickets to the Maritime Museum, Sega World and the Sydney Aquarium available. For transport call Jan on 9319 4439

Candlelight Memorial – Lismore

A candlelight memorial will be held on Sunday 21 November 1999 at ACON, 27 Uralba St Lismore at 5.30pm. Light refreshments will follow the memorial. If you would like to contribute a poem or participate in the memorial please contact Ron. If you have a name that you would like to be read out at the memorial please let Sue know. (02) 6622 1555

Candlelight Memorial – Sydney

The annual Candlelight AIDS Memorial will be held on Sunday 21 November. Participants should assemble at Green Park, Darlinghurst at 7pm. The procession will leave Green Park at 8.15pm for Hyde Park North. There will be performances and the Reading of Names ceremony. The Candlelight Memorial is a joint event that has always relied on sponsorship and donations. This year that support has dwindled, in the weeks before Candlelight, you will notice collection tins in venues, so please give any loose change to assist this community event.

Art from the Heart

The 5th Annual Art from the Heart in association with The AIDS Trust of Australia for AIDS Awareness Week '99 is calling for artists to contribute their artworks to this annual event. Art From The Heart as an exhibition, does more than just educate people about HIV/AIDS but also allows the public to express themselves through art for AIDS Awareness Week. Artists from all over Australia are invited. Paintings, sculpture, poetry or performance works. If you would like to submit your art to the exhibition contact Grant on 02 9974 5560.

Support

Shopping spree

The Newtown Neighbourhood Centre runs a shopping service six times a week to Marrickville Metro and Market Town, Leichhardt. They'll pick you up from home, give you two hours to shop, then drop you off again. $4.00. Available to residents in Dulwich Hill, St Peters, Tempe, Newtown, Enmore, Marrickville, Camperdown, Stanmore, Petersham, Erskineville or Darlington. Call Diana on 9516 4755.

Living with loss

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

HOPE – HIV drop-in group.

Open to all HIV positive people, their partners/carers. Drug and alcohol free. Every third Tuesday at the Tree of Hope, cnr Riley and Devonshire Streets Surry Hills. Info call Ray 9360 3008 or Kath 9660 1325

Significant Others of People with HIV/AIDS Dementia

We are a newly established support group formed and run by significant others for significant others who have a loved one with HIV/AIDS Dementia. We meet at 6.30pm on the last Wednesday of every month at the Tree of Hope, cnr Riley and Devonshire Sts, Surry Hills. For more information call Carole Knox (02) 9580 5718 or Angela Kelly (02) 9829 4242.

Counsellor / Therapist

Kim Gotlieb free service is available to PLWHA on Tuesday afternoons at the Positive Living Centre. Bookings are essential. Bookings 9699 8756. Call 9310 0931.

Learn

Free Courses

Wesley Mission is conducting free courses in film and video, plants and gardens, hospitality, and sales and marketing. Call Vicki or Anna on (02) 9261 4855.

Learn computers

An introduction to computers and other courses at TAFE. At Sydney Institute of Technology. Phone Jenny at Outreach (02) 9339 8657.

ACON Northern Rivers HIV Training course

HIV training course for volunteers and interested community members 12 – 14 November 1999. Contact Glenn or Sue for more information and registrations. Applications close 8 November. Telephone: (02) 6622 1555

Your Community Gym Fit X Gym

Fit X Gym is at the Community Pride Centre, Hutchinson St, Surry hills. "Positive Access Project" offer qualified instructors, free assessments, free nutritional advice, free individual programs and free session to try out gym. $2 a session = $18 – 10 visit pass. Contact Ingrid on (02) 9517 9118 leave a message and your call will be returned. Fit X Gym (02) 9361 3311 4pm – 7pm Monday to Friday.

Send details of your event or service to Talkabout *Diary, PO Box 831 Darlinghurst NSW 1300 or Fax 02 9360 3504 or Email feonas@plwha.org.au*

Personals

Hetero guy 38 HIV+, employed, easy going, positive attitude with sense of humour needs a mate, HIV+ or - to share life with. Eventually would like to have HIV- children. Nobody knows I'm HIV+ so discretion a must. ***Reply 02 10 99***

Gay Guy, 50s, lives in NSW country, seeks any other HIV + person to share my house and quiet times. All I ask is for someone honest, reliable. Please include phone number. ***Reply 011199***

30 yrs old, positive, little bear cub. Try anything once. Looking for gym and swim partner as well as a mate to have some close times with from 18 to 30 years. I work heaps and love life. I hope you love life too. ***Reply 031199***

Active sailor seeks HIV+ or friendly girl to 35ish for friendship and sailing comfortable 35' cruising yacht. No need for sailing experience, my aim is for friendship and maybe a relationship. Might even take the boat (and you!) to the Whitsundays. ***Reply 041199***

36 hetero male, new to Sydney, healthy, very good shape, successful professional, discreet about status, seeks female who likes to laugh for friendship/relationship. ***Reply 021199***

How to respond to an advertisement

• Write your response letter and seal it in an envelope with a 45c stamp on it • Write the reply number in pencil on the outside • Place this envelope in a separate envelope and send it to: Olga's Personals, PO Box 831, Darlinghurst 2010

How to place your advertisement

• Write an ad of up to 40 words • Claims of HIV negativity cannot be made. However, claims of HIV positivity are welcomed and encouraged • Any letter that refers to illegal activity or is racist or sexist will not be published • Send the ad to Olga, including your name and address for replies. Personal details strictly confidentially

What works when you are living with HIV/AIDS?

Practicality was the formula for a day packed with difference and choice at the annual PozHet workshop held last month. PozHet Coordinator, **David Barton** reports.

Over forty people attended the ever-popular Pozhet workshop at the Tree of Hope. This year we tackled this issue of Practical Stuff. Thirteen group leaders ran sessions on topics reflecting the range of mind and bodywork positive people and their partners do on a daily basis to keep themselves afloat.

To get focussed on what matters we kicked off with practical tips from a panel. Doing something every day that was enjoyable and meaningful was the number one advice. Next up one group shared ways of beating depression while another highly interactive session got into 'What's Cooking?' with the how-to-do of good nutrition and much swapping of healthy recipe ideas. Two popular sessions focussed on the secret business of men's and women's work, with men reviewing those parts of themselves not usually mentioned by twenty four blokes together, while the women explored greater sexual intimacy and their needs to improve communication in sexual relationships.

Three choices in treatment groups met the needs of a highly diverse group of Pozhet men and women. I discovered that 72 percent of us at Practical Stuff took HIV/AIDS treatments and over one third of us had received their diagnosis since 1996. Nearly half of us on current treatments were experiencing side effects So groups – one for the recently diagnosed, another for those embarking on treatments and yet another for those others experiencing side effects – were well received.

Homeopathy also managed to tap into the fact that nearly every second person at Practical Stuff used complementary therapy combinations to manage the virus. Eleven therapies were commonly used, the three most popular being vitamin supplementation, massage and aromatherapy.

Half of us were seeing a counsellor or social worker to support HIV/AIDS in our daily lives so we ended the day enjoying some practical mind work with guided imagery that lifted energy and developed a sense of relaxation. The finale to Practical Stuff was a chorus of forty voices singing and expressing themselves to the Beatles song 'Let it be'. And everybody was in tune!

This was the best annual workshop Pozhet has ever run. So it's heartfelt thanks to our group leaders – Marie Lavis (Pozhetwest), Bill Robertson (Foley House), Mark Tietjen (BGF), Angelo Morelli (ADHAPS), Monique Rennie (HIV/AIDS Community team CSAHS), Greg Millan (Australasian College of Sexual health Physicians), Miranda Shaw (Family Planning Australia), Denise Cummins (RPA Hospital), Jo Watson (ATPA), Patricia Austin (Sacred Heart), Matra Robertson (Circles of Light), Francesca Murdoch (Homoeopath), Diane McCombe (voice and sound teacher) and not least Margaret Mines, Gina Svolos and Wa'el Sabri our tireless helpers for the day. ■

Practical Stuff was the 4th annual Living Heterosexually with HIV/AIDS Workshop.

Practical Stuff Group Leader Miranda Shaw from Family Planning NSW's Women and AIDS Project

Got a story to tell?

Talkabout *welcomes stories and letters from PLWHA.*

In our last issue for 1999 – December/January – **Talkabout** reflects on the last fifteen years including personal stories, a look at treatment and social activism ... plus exercise, the Women's Retreat and the Asian Women's Project!

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

Talkabout welcomes your feedback on future directions for the magazine – so get involved ... it's your magazine.

Deadline for the December/January issue is **10 November, 1999**.

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

PLWH/A(NSW)
People Living With HIV/AIDS

the bite on dental care

Stopping the rot

Tim Alderman is a long-term survivor of HIV/AIDS. He told *Talkabout* that his experiences with HIV dental services in Sydney have ranged from barbaric to as good as could be expected.

I was originally on the HIV Periodontal Study at UDH (United Dental Hospital) until I got ill in 1996, when I let the regular checkups slip. I had to have a loose tooth removed urgently about 20 months ago, and knowing I would have a full days run around at UDH, not having been there for a couple of years, I opted for the Outpatient Dental Clinic at St Vincent's.

Boy, what a mistake! The tooth was pulled before the anaesthesia had even taken full effect, and I was then told to go through the booking process to have the rest of my teeth removed. I was told this would be done in early 1998. Fortunately for me, I have heard no more about it. Recent dental problems sent me back to UDH, where I am now back on a regular basis of care.

Despite being massively overworked, I have always found UDH staff polite and helpful. They have even fitted dentures for me where I did not think they could be fitted. I have lost a lot of the bone in my jaw due to chronic Candida in the early days of HIV, so cleaning and maintenance requires special care, which I find they always give. They have also informed me that I will get quite a few more years out of my teeth yet, contrary to what St Vincent's told me. I know UDH can be a pain, particularly on your first visit, with a whole day taken up seeing all the people you have to see. But once you get into a regular round of appointments, you find they are very prompt, and you are in and out in no time. ■

by **Lindsay Varcoe**

Dental services for people living with HIV/AIDS are inequitable, poorly resourced and fighting a constant battle to secure ongoing funds. That's the contention of HIV/AIDS advocates in virtually every state and territory of Australia, but what are governments and health professionals at every level doing about it?

Australian Dental Association executive director Dr Rob Butler said he believed that for extremely low-income earners who qualified for a health care card, access to dental services was "reasonably good". However, he said, there were a very significant number of people living with HIV/AIDS who were "by no means wealthy" but did not qualify for a health care card.

"It's these 'middle-of-the-road' patients who don't qualify for a health care card but can't afford the dental services they really require that have the biggest problem," Dr Butler said.

So should dentists in private practice adopt a policy of reducing their fees for patients who have HIV/AIDS?

It's worth noting that in the 1997–98 financial year, the Australian dental services industry recorded an operating profit margin of 26.9 percent according to recent figures from the Australian Bureau of Statistics. Total income generated by the industry was almost $1.7billion with an average return per dental practitioner in the form of wages or profit of $87,000.

The bottom line

On average, general practitioner dentists performed 54 consultations a week and made $76,600 wages or profit per year while specialists such as dental surgeons saw 86 patients per week and grossed over $165,000 a year in income or profit. On face value the figures suggest private dentists could squeeze in a couple more low or no-cost consultations without doing too much damage to their bottom line, but Dr Butler urges caution.

"These figures have to be put in context," he said. "You must remember that we're talking about self-employed people who receive no workers' compensation insurance, have to fund their own superannuation, get no paid leave or leave loading or anything else that most income earners take for granted. It doesn't shape up as all that fabulous an income."

Dr Butler said the ADA made no recommendations to private dentists about how much money they should charge for their services, nor does it have any policy on reducing or waiving those costs to patients in genuine need or hardship. Such issues are left up to individual member dentists to decide for themselves.

"To some extent private dentists are picking up part of the bill for public health services that the Federal Government is refusing to pay." Dr Butler said

It's patients who don't qualify for a health care card but can't afford the dental services they really require that have the biggest problem

Fees paid to the ADA by dentists around the country fund a number of activities including the association's efforts to lobby the Federal Government for funding. So in one sense, Dr Butler said, all dentists were contributing something towards the battle for better public dental services.

In 1994 the Federal Government established the Commonwealth Dental Health Program (CDHP) to provide a comprehensive free dental service to health care card-holders. The current Government axed the CDHP in January 1997, and instead provided reduced funds direct to state and territory governments to supply public dental services. Since that time it's been an ongoing battle to preserve

dedicated funding for dental services for HIV/AIDS patients and resist co-payment arrangements in the face of diminishing resources.

The NSW Health Department acknowledges that there are now gaps in the provision of dental services in NSW.

In a statement, NSW Health told *Talkabout* that in the last 33 months, the loss of the Federal Government's program had resulted in the accumulated shortfall of over $95 million in funding for oral health services in NSW. The Department nominated waiting times, oral health in rural and regional NSW, and dental information technology systems as areas to be addressed.

Deafening silence

But perhaps the most frustrating aspect to emerge since the axing of the Commonwealth Dental Health Program in 1997 is the Federal Government's deafening silence on dental health issues in general.

In February 1998, Care and Support Spokesperson for the National Association of PLWHA, David Menadue, put a submission on dental services to the Senate Community Affairs Reference Committee. The submission identified key problems facing PLWHA including unacceptably long waiting lists, lack of services in suburban and rural areas, discrimination against patients seeking treatment and the unwillingness of publicly-funded services to offer anything other than very basic dental services. It described how a destructive combination of financial pressures was forcing many people living with HIV/AIDS into poverty traps. New drug treatments, although effective, were becoming increasingly costly. Special dental needs, already more than twice those of the rest of the population, were made more acute by drug side effects, especially dry-mouth problems. Then there was the problem of reduced earning capacity due to illness and personal presentation/self-esteem issues. People living with HIV/AIDS were living longer, but they were also living poorer.

"In the past people did not think they had a future," Menadue said. "That's now changing but the health services are yet to catch up with this concept to some extent. The number one problem facing PLWHA in dental care is still access to affordable, 'HIV-experienced' dentists".

But what was the Senate Committee's response to the paper? "That's a good question," said Menadue. "We don't know. We never received a response on any issue raised. Sadly very little, if anything, has changed since that submission was made."

What you get

In NSW the two main providers of dental services for PLWHA are the St Vincent's Hospital dental clinic and the United Dental Hospital (UDH). UDH director Dr Sue Buchanan said the HIV/AIDS patients with health care cards were given priority for 'normal' treatment, enabling them to bypass waiting lists, and were guaranteed treatment for pain relief within 24 hours.

A similar system has recently been introduced in the Northern Rivers Area Health region, which extends to the Queensland border in the north, Urbenville in the west and Grafton in the south.

It was acknowledged by a range of sources that work classified as 'cosmetic', including crowns and bridges, was virtually non-existent in the public system.

St Vincent's Hospital's consulting dentist Dr Peter Foltyn *(pictured below)* is regarded as an expert in the field. He has been treating patients with HIV/AIDS for many years, through the hospital and in his private practice. Dr Foltyn said there was a chronic shortage of publicly funded dental services throughout NSW. He lays the blame for this squarely at the feet of the Federal Government.

"The problem is that Medicare treats the mouth differently to other parts of the body when it comes to public health funding," he said.

Dr Foltyn said awareness of HIV/AIDS-specific treatment issues among dentists in private practice was now much greater than it was only a few years ago, but it was also the case that the majority of people living with HIV/AIDS were still seeking treatment through the public system.

The focus of treatment has most commonly been on treating quite advanced periodontal disease, which has often meant removal of most of, or all, the patient's teeth and the fitting of dentures. While greater patient life expectancy and new drug treatment side effects have shifted the treatment focus somewhat toward preventative and so-called 'cosmetic' work, the fact remains that for many patients in the public system their only option, both medically and financially, is dentures. Douglas Barry's experience in the past was typical of many.

"I first attended St Vincent's Outpatient Dental Clinic several years ago," he said. "My teeth were in terrible shape and I was aware I would need a major intervention."

Once Barry had made his decision to have the 'remains' of his teeth removed and dentures fitted, the arrangements were made quickly and the operation went ahead with what Barry felt was consideration for his comfort.

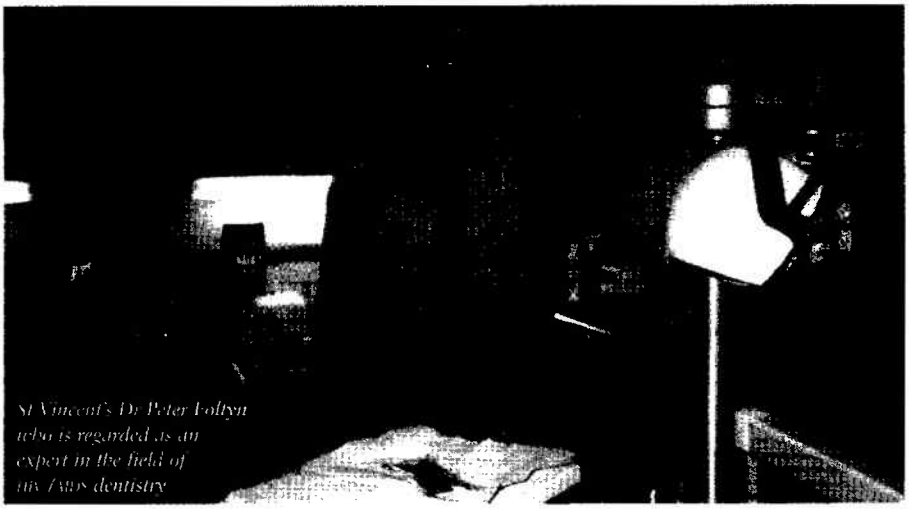
Barry learned of Dr Foltyn's seminars for dentists around the State and expressed his interest in contributing to the work. Since then he has spoken to groups of dentists in Gosford and Wollongong, adding an 'in the flesh' patient element to the theory being taught.

Demand for such seminars peaked in 1995, and according to Dr Foltyn they were now quite rare occurrences. "This is a positive thing really, as it means the level of knowledge and understanding of the issues has risen dramatically," he said.

Dr Foltyn still lectures to final year dental students about HIV/AIDS issues, and he is confident the 'average practitioner' has the necessary level of expertise in the area to deal with most problems, as well as the confidence to refer patients to a specialist if required.

continued on page 19

The problem is that Medicare treats the mouth differently to other parts of the body when it comes to public health funding



St Vincent's Dr Peter Foltyn who is regarded as an expert in the field of HIV/AIDS dentistry

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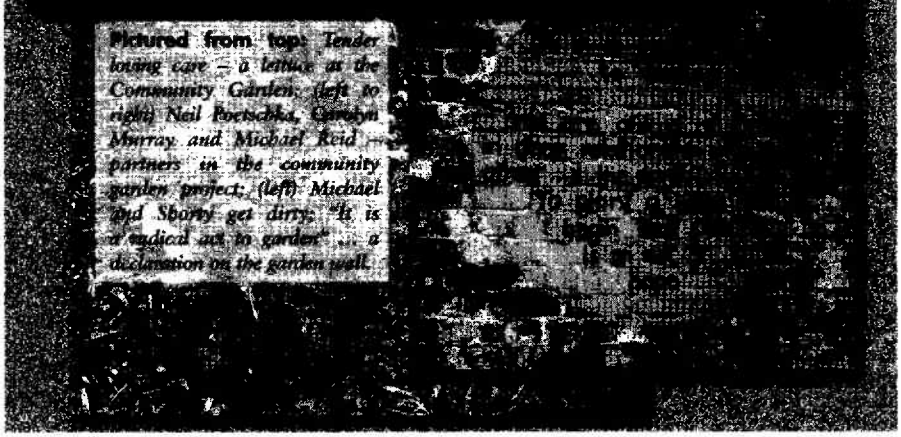


Pictured from top: *Tender loving care – a lettuce at the Community Garden; (left to right) Neil Roetsckha, Carolyn Murray and Michael Reid – partners in the community garden project; (left) Michael and Sbarny get dirty; "It is radical out to garden" – a declaration on the garden wall.*

The Positive Community Garden Project is a joint partnership between South Sydney Council, Central Sydney Area Health, South Eastern Sydney Area Health, the Sanctuary Holistic Centre and the AIDS Council of NSW. Phase One of the project is taking shape in a small community garden in Raglan Street, Waterloo. Paul Anderson is one of the project's early recruits ***(see our story on page 14)*** **and his success in the small garden can already be seen as he potters about in the sun, surrounded by bales of hay, compost bins and the rich smell of earth.**

The Positive Community Garden Project aims to provide garden areas for positive people to work together. Michael Reid of ACON is one of the project partners. He told *Talkabout* that the project aims to relieve food-related poverty by enabling poz people to grow their own food. "It's also just as important that we increase the opportunities for PLWHA to improve their physical and mental wellbeing, decrease social isolation, interact with the local and wider communities, and address issues of environmental landcare, landfill reduction and recycling."

"They can work at whatever is their capacity and grow some of their own food outside the framework of a very individualistic consumer society. It can free people from the usual reliance on supermarkets. Also, this kind of community activity breaks down the social isolation that a lot of positive men and women face."

ng rty

Wanna get dirty, hang out in your favourite shorts, get sweaty, feel the sun on your back, and heave butch tools about? **Bill Phillips** thinks a new project for positive people may be just what you're looking for this summer.

For Carolyn Murray from SouthEast Sydney Area Health Service working together is part of the project.

"Depending on a person's level of health and interest, their participation can vary from very light to deep involvement in practical work, planning or design. All levels of skills are welcome, from the most proficient gardeners to complete novices who've never raised a seedling or planted a vegie in their lives. People can share their skills, learning from each other or taking advantage of the free training workshops we're planning as part of the project's ongoing activities."

A second much larger garden will be established as the project evolves. Smaller gardens are also planned throughout inner Sydney. The gardens will eventually form a network of positive gardens that will all be designed according to permaculture principles *(see box right)*.

"Permaculture is known as the 'no dig' system," Michael points out. "It's a design that yields the maximum result from the least effort. It's self-sustaining, very low maintenance and as applicable to a courtyard or balcony garden of pot plants as it is to a 50 hectare property."

According to Neil Poetschka from the Central Sydney Area Sexual Health Promotion Unit this will be the first community garden project for positive people that he is aware of.

"Other garden projects in Australia and elsewhere have been of the memorial variety. Groves of trees or rose gardens in memory of those who've died. This project is about lively interaction, growing your own food, working together, environmental responsibility and improving the quality of life."

The project partners have reservations about defining 'the positive community', and claim that to identify a single group ignores the vast diversity of people with HIV.

"Community gardening refers to community in the widest sense," said Michael. "Positive people, whether gay or straight, young or old exist in a multitude of communities. A lot of feelings of disenfranchisement and disempowerment arise out of creating myopic notions of what our 'community' is."

Although the garden project is primarily for positive people, it would be a lunacy to make it exclusive. It has to involve local communities to be relevant. All the gardens will be open to whoever wants to participate. It's about developing community, and that 'community' will define itself in relation to the garden, not by a working group drawing boundaries about who can and can't access the project."

Carolyn is keen for people to get involved in the garden. "We hope that a lot of people will get involved in the project. This is an opportunity for positive people to re-engage with life, to improve their health, their social options, and their diet and general wellbeing.

"It doesn't matter if you have two green thumbs or you can't keep a spider plant alive, come and spend some of those hot summer days getting dirt under your fingernails, raising a tomato or two, learning some new skills and hanging out with new friends."

To get involved or find out more about the project, contact Robert Ball on 9690 1222 or Carolyn on 9382 8374. ■

Bill Phillips is a freelance writer and a member of the Publications Working Group at PLWHA (NSW)

What is Permaculture?

Permaculture (permanent agriculture) is the conscious design and maintenance of agriculturally productive ecosystems, which have the diversity, stability, and resilience of natural ecosystems. It is the harmonious integration of landscape and people providing their food, energy, shelter, and other material and non-material needs in a sustainable way.

The philosophy behind permaculture is one of working with, rather than against, nature; of protracted and thoughtful observation rather than protracted and thoughtless action; of looking at systems in all their functions, rather than asking only one yield of them; and of allowing systems to demonstrate their own evolutions.

Permaculture means thinking carefully about our environment, our use of resources and how we supply our needs. In this way, permaculture is as relevant to a balcony in inner city Sydney, as it is to a farm in South Africa. ■

Adapted from Bill Mollison's (the founder of Permaculture) **Permaculture: A Designer's Manual**

Permaculture Workshops

The Positive Community Gardens Project will be running a series of workshops on permaculture gardening, focusing on gaining the highest possible yield with minimal space and time. If you live in an apartment, don't despair: there will even be a workshop on how to gain a harvest from the smallest balcony. The workshops will be practical utilising the garden at Waterloo.

Training opportunities in permaculture design will also be available, with the view of developing the skill base among garden members to design and manage large-scale gardens, in preparation for any additional community gardening space that may become available to the project.

Workshops will begin by the end of the year, so if you are interested contact either Carolyn Murray (02) 9382 8374, or Robert Ball (02) 9690 1222, to register your interest. ■

community feature

a whole new lease of life

You don't need a horticulture degree to get something from the Community Garden Project. New recruit Paul Anderson, tells **Bill Phillips** that the project has given him a new lease of life.

Paul Anderson is a positive man who lives in Alexandria just a short walk from the Positive Community Garden Project's pilot garden in Raglan Street, Waterloo. He's brown and fit, comfortable in some spectacularly daggy shorts and an old t-shirt, and looks absolutely at home among the garden beds, piles of hay and assorted garden tools.

Standing surveying the young tomatoes he has just staked, Paul glows with a real sense of pride.

"The garden has given me a whole new lease of life," he says of his two-month involvement in the community garden.

"My physical and mental health have improved no end. It's gotten me out of the house, helped me to deal with the sense of loss from losing so many friends to the epidemic and given me a lot of alternative outlets for the energy I have."

Paul had no background in gardening – "apart from mucking around in Grandad's garden at home" – and has found his dream of retiring to a country retreat coming true in deepest Waterloo. "This just suits me down to the ground. I can work at my own pace. Sometimes, I just come here and sit in the sun, enjoying the sight of the garden around me. It makes me feel so useful."

Having been a recipient of parcels from the Food Distribution Network and other agencies, Paul knows positive people living on the pension often need to accept help.

"I'd like to think the garden project will soon be able to supply local positive people with fresh food, grown organically by other positive people. This really has given me a chance to feel I'm making a contribution, giving something back after having received so much."

Bill Phillips is a freelance writer and a member of the Publications Working Group at PLWHA (NSW)

This just suits me down to the ground. I can work at my own pace. Sometimes, I just come here and sit in the sun, enjoying the sight of the garden around me.

Photo Keora Studdert

Community Support Network

SERVICES PROVIDED

Home based practical and physical care
❤
Shopping
❤
Cooking meals
❤
House cleaning
❤
Visiting
❤
Pet care
❤
Social support
❤
Vitamin supplements
❤
Information and referrals

now has carers available in

Coffs Harbour
Port Macquarie
& Taree areas

For more information about receiving care or becoming a carer, call 1300 658 878 or 6584 0943

ACON
AIDS Council of New South Wales Inc.

Complementary Therapies Treatment Working Group

Expressions of Interest

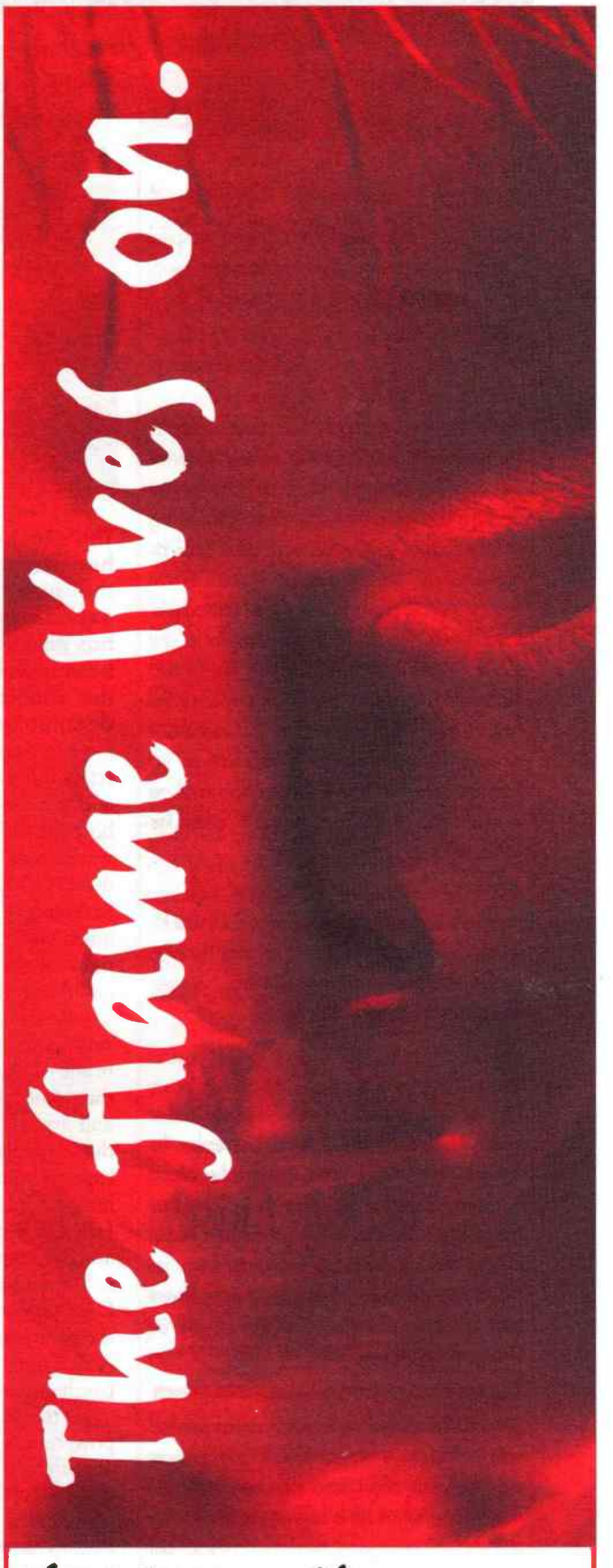
PLWHA (NSW) are seeking expressions of interest for an exciting new HIV/AIDS complementary therapies project. This project will focus on widening the options for information on complementary therapies for PLWHA in NSW.

We are looking for individuals with the following qualities:

- Broad knowledge of complementary therapies and their use in HIV/AIDS treatment
- Research skills
- Baseline understanding of HIV
- Good communication skills
- Community awareness
- Ability to build referral networks

The Complementary Therapies Treatment Working Group would like to encourage expressions of interest from PLWHA, practitioners and all other interested parties.

PLEASE CONTACT
Claude Fabian – Convenor CTTWG
Telephone (02) 9300 8933 **Facsimile** (02) 9300 8923
Email claudef@rainbow.net.au



Sunday 21 Nov 1999

Procession and Rally: Gather at Green Park cnr Burton St and Darlinghurst Rd from 7pm, Procession starts at 8:15pm

Candlelight AIDS Memorial
A celebration of lives lost

Daniel's Story

Have you always used St Vincent's?

No. I have used the United Dental Hospital (UDH) but I've never had any real problems with my teeth so there wasn't a great need to see a dentist regularly.

Why did you go to St Vincent's Dental service?

I heard that they had a service for positive people. For me going to the dentist is an ordeal; I'm one of the 'white knuckles' with the chair. Not when I'm having a clean or something simple but if I'm having an extraction or some major work done it can be excruciatingly difficult because I don't breath through my nose properly. I did not feel comfortable. It was the first time that I'd used the hospital for any services related to HIV. The only time that I would have gone in there other than to visit someone in the hospital and I was appalled at the treatment I received. He had no right to comment on my treatment or my health care. He was there to tell me whether I had good or bad teeth or I needed this treatment for my gums or whatever.

Have you been back to St Vincent's?

Yes. I've been back to the dental service. I'll wait for an appointment to come up with the other dentist to avoid having to see the dentist I had seen. I've never had a problem with the other dentist.

Why is it that you access the services at St Vincent's?

One reason is financial but also I've used the other service (UDH) and wasn't satisfied. I remember the first time I went in there. There was a real emphasis on gloves and masks. They were masked if I walked into the room. This was 1987. I remember I was in hospital and I had bad bleeding gums. It was an ordeal because I was treated like a leper. I went back a couple of times but it was always an uncomfortable experience.

Do you use other services at St Vincent's

I've used the counselling service and was satisfied with that. I have visited friends and patients over the years and I have seen horrific things. People extremely ill left in hallways and not being attended to or saying they've registered but haven't seen anyone for six hours. But my bad experience has been with the dentist.

Is there anything good about St Vincent's that sticks in your mind?

I've met some amazing staff and they're so dedicated. Some of those individual people who work or have worked over the years in the wards or in the treatment room. Some of those people are dedicated above and beyond the call. But there's always a bad apple somewhere. ■

The journey undertaken by the staff and management of St Vincent's Hospital and the PLWHA community has been long and sometimes bumpy with far-reaching impact on the quality of Australia's medical response to HIV/AIDS. **Jo Watson** reports.

Our Amazing Journey

The Australian AIDS epidemic has had many constants running through the past 15 years. People have experienced loss and death. There has also been an amazing response, both individually and collectively, to the challenges and demands of a decimating disease.

One of these constants is the relationships built between our community and the hospitals which serve us, those hospitals which have housed the HIV/AIDS wards and given us a legion of nurses, doctors and other health care professionals. St Vincent's Hospital (SVH), deep in the inner city of Sydney, has probably seen more of the manifestations of HIV disease and death than most could claim.

Based squarely in the centre of the very community which has borne the brunt of the Australian epidemic SVH is the prime HIV/AIDS treatment site in NSW, and arguably Australia. On either side of the hospital are two of the institutions that support the role and expertise of the hospital services, – the National Centre in HIV Epidemiology and Clinical Research, and the Sacred Heart Hospice. In the latter is housed the Immunology B Ambulatory Care section of the Hospital – including the treatment room and consulting rooms. A five minute walk away is the specialist psychiatric service – Caritas.

These services add up to a powerhouse of expert staff and resources and a significant commitment to HIV/AIDS clinical care and management. Over the past several years SVH has experienced major changes and major restructure. The interface between community and hospital management has shifted, and indeed there have been several crisis points in this time where community representatives have met with hospital management to negotiate around a range of concerns, including staff levels, bed numbers, cuts in hospital services, and future redevelopment plans. Since 1998 there has been a formal HIV Consultative Committee which acts as the forum for communication between SVH, and representatives from PLWHA (NSW) and ACON.

The meetings have been regular and from the initial frustration that brought us to the table with a degree of hostility and suspicion, we have moved into a more reasonable and constructive phase of the relationship.

Currently SVH is in the process of major building works and the establishment of a huge new building for the complex. The size of the hole in the ground directly outside the main entrance to the hospital has to be seen to be believed. The noise and disruption of the ongoing work is regrettable, and tests the tolerance levels of those staff and patients caught in the areas closest to all this activity.

Chronic nursing shortages are apparent across the state, and in the specialised areas of infectious diseases, especially HIV/AIDS, there is an acute problem for all the major hospitals. Staff recruitment is not filling the vacancies, and this has led to hospital management facing serious choices about the level of patient numbers that can safely and expertly be maintained.

Consequently the available bed numbers in the Cahill 17 ward are at a low point, and this is creating a busy and demanding time for the nursing staff. The numbers of patients being admitted since January has kept the ward consistently occupied at 95 percent capacity. The situation is exacerbated by the intensity of cases. The added complexity of treatments, and their related toxicity, means nursing staff and doctors are regularly dealing with more involved clinical management. Gone are the days when nurses and doctors had time to stay and have that long conversation with a patient. Many of the people who remember the different pace of the wards have noticed the change. It is also worth mentioning that the PLWHA patient population is probably one of the most experienced with matters of hospital care and service delivery, and changes to staff and procedures are noticed with acute focus. The nursing shortage is a significant

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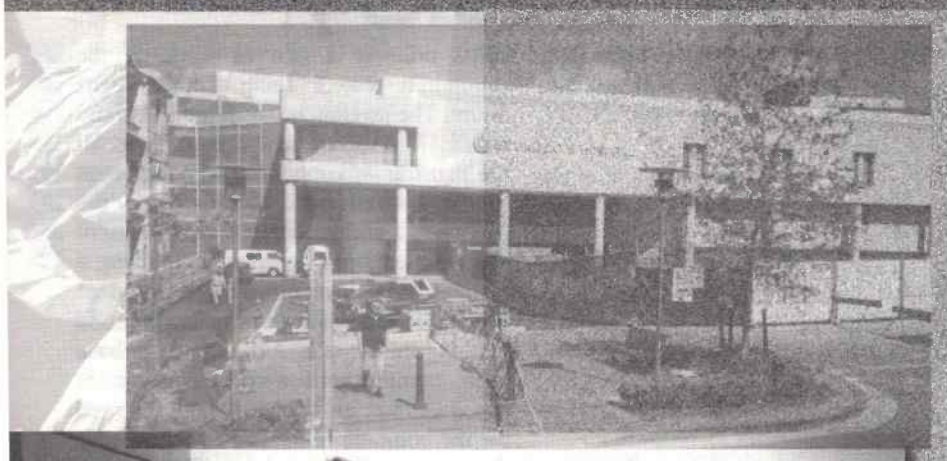
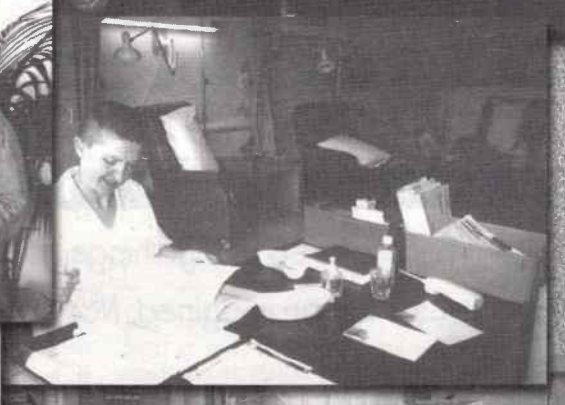




Pictured clockwise from top *St Vincent's HIV/AIDS Services (left to right) Kathryn Joyce, Dr Andrew Corr, Sedi Dawson, Professor David Cooper, Phillip Beil, Robert Fielder, Associate Professor Bruce Brew, Debbie Hunt, John McAllister and Bronwyn McGuire; Registered Nurse, Sedi Dawson, at work in the Treatment Room; Clinical Nurse Educator Kathryn Joyce and Clinical Nurse Consultant John McAllister; Director of Immunology and Infectious Disease Professor David Cooper; Registrar Dr Sarah Pett and Dietician Danay Brown*

Mike's Story

My first experience with St Vincent's was January last year when I was taken into hospital seriously ill. I had amocillous influenza endocarditis which resulted in open heart surgery and putting a mechanical valve into my heart. I was HIV positive at the time, which threw up other issues. I wasn't in the HIV ward, I was in the cardiac ward and it was great. The only thing I would say I lacked was information about my conditions. I was frightened of having the open heart surgery, as you would be.

When I was in for my heart surgery one of the staff came in and said to me: "We need to put these gloves on Mike because of your HIV status." I was in a room with other people so I was outed. I said, "No you're putting the gloves on because it's universal practice." We're talking about individuals rather than the system. I think you have to have a degree of self-esteem to be able to deal with that.

My HIV stuff was put on hold. My next experience was later when the amocillous had gone into my lungs. I was having lung trouble and I was in Ward 17. I haven't had any problems in that ward except, I guess, I was classified as a 'junkie'.

You told the staff that you were an intravenous drug user?

It was that 'he's a junkie' mentality. Well, my attitude is "I'm here, I'm ill, I can lie if you want me to but what's the point. I'm coming here for treatment and if I'm not up front and honest then how can you treat me?" There were a few apologies over that. Once I got over all of that it was fine.

My treatment has been excellent. I went back in with the virus in my brain, and I was in there for a while but they got on to it pretty quick. The doctors that I see I trust. If I have questions they answer honestly and openly.

You've spent a lot of time at St Vincent's?

I see the nutritionist, the heart specialist, the neurologist, the neuropsychologist, psychiatrist the drug and alcohol people, physio. All of the departments seem to work well. I go to the dentist and the eye clinic. I've seen every one of them and they're good and they all coordinate because of my heart medications.

It's been a heavy two years and at one stage I was going to the hospital every day for blood tests and I can't complain about any of that. I feel I'm well looked after. I'm comfortable with the hospital. There are all those 'God things' around the place which are irrelevant, and being an ex-catholic they are more irrelevant, but I have good experiences and I trust the people that I'm working with. ■

issue that needs to be addressed as an urgent public health care priority by the NSW area health services and the state and national nursing associations.

The Committee and hospital personnel have met recently to clarify the access procedures for the two designated beds in the ADC Acute Stabilisation Unit. Again staffing these beds is an issue because the appropriate numbers of HIV specialised nursing staff is not available. The procedure in place for admission to these beds is now clarified and reflects the short management needs for those patients who have limited or non existent options with other existing support services, or who are awaiting admission to Caritas or an AIDS Dementia Complex and HIV Psychiatry Service placement.

The Sacred Heart Hospice (SHH) is in the process of formulating a development plan for the integration of rehabilitation services, in consultation with South Eastern Area Health Service (SEAHS). The Consultative Committee has had general discussions about these plans, including coordination of community care provision and its services, recruitment into community palliative care team positions and standardisation of models of care. There is still no final document available to date, as SHH is awaiting confirmation on the issue from SEAHS. In terms of the admission criteria to SHH beds, this remains available for those patients who require respite care, symptom control, and/or terminal care.

This year we saw the renaming of the Immunology B Ambulatory Care Unit (IBAC) – with many of us moaning at the new acronym – and a move into the third floor of SHH. The IBAC team is experiencing the busy demands of HIV clinical management as well, and has reviewed the hours of operation for the treatment room to better utilise staff resources. The unit also began a patient satisfaction survey in August, and the staff are keen to get feedback from patients about their service and care (remember the good as well as the critical). The unit has dealt with a lot of changes over the past twelve months, and emerged with renewed vigour. The recent lipodystrophy seminar produced by the SVH team, through the IBAC unit, is a sign of some of the community projects being planned in the future. The juggling between the IBAC and Cahill 17 is also evidenced by the pace of the registrar – Sarah Pett, who has been running between both clinical areas for the past year. The intensity and complexity of HIV treatments and therapies has challenged many PLWHA this year, and the need to respond to this has raised challenges for all working in the area. Although there have been communication problems at St Vincent's Hospital this year, there is a need for the community sector to acknowledge the commitment and focus that medical and nursing staff within the campus bring to PLWHA patients. It is also important for us to monitor the external pressures that impact on hospitals around the state, within the current health care environment.

Although there have been communication problems this year, there is a need for the community sector to acknowledge the commitment and focus that medical and nursing staff bring to PLWHA patients

From my conversations with hospital management, I believe there is now a thorough understanding around the key issues for PLWHA. This will support both the community and SVH as we move into the new phase of collaboration for high standards of care and support in HIV/AIDS medicine for PLWHA. ■

Jo Watson is the National Coordinator of the ATPA and National Association of People With HIV/AIDS. She sits on the HIV Consultative Committee as a representative of PLWHA (NSW).

P L W H A (N S W)

PozTalk

There are so many things to say about our lives, real or imagined. Now is your chance.

C O M P E T I T I O N

PozTalk is open to all people affected by HIV/AIDS.

◗ One entry per person and category and your entry must be unpublished. Posthumous writings will be accepted. ◗ Categories are fiction; non-fiction; and there's a special kids section (to 16 years – words or pictures). ◗ Two prizes[†] will be awarded for each category. ◗ The word limit for all categories is 800 words and an A4 page for pictures ◗ Deadline for entries is 1 February, 2000 ◗ Winners will be announced in April 2000 and published in *Talkabout*. ◗ Attach the entry form below to each entry *and check below for the conditions that apply.*

[†] We are in the process of gathering the prizes – but we can tell you they'll be gorgeous!

PozTalk Competition Entry Form

If entering multiple categories, please attach one form per entry

Name

Age *(only required if eligible for children's category)*

Address

Daytime phone or e-mail

Category

Title of entry

Word count *(limit 800 words)*

Conditions of entry

Entry is open to all people affected by HIV/AIDS except PLWHA (NSW) Inc. staff, family members and members of the Publications Working Group. **Entries close February 1, 2000.** The PLWHA (NSW) Publications Working Group will judge entries. The judge's decision will be final and no correspondence will be entered into.

What is far less easy to address is the issue of discrimination in treatment. Still somewhat of a taboo in medical circles, it is an unreliable assumption that all health care professionals are free from fear and prejudice. While few if any cases have been brought against medical professionals for discrimination based on a patient's HIV status, it is also clear that many living with HIV/AIDS are not taking any chances.

Dental tourists

The South Australian experience with special dental services for HIV/AIDS patients is a good example, and, many would suggest, typical of trends in other states. In SA the Adelaide Dental Hospital provides a dedicated HIV/AIDS dental clinic funded by both State and Federal governments through various combined HIV/Hepatitis C programs and staffed by Dr Liz Coates and Dr Richard Long.

Dr Coates said the service caters for more than 300 patients from all over the State. She said they travel enormous distances to attend the clinic, partly because of the lack of comparable services in rural and suburban areas but also out of fear of discrimination if they seek treatment in the areas in which they actually live.

"People travel into town to get their prescriptions filled and have their teeth checked away from the eyes and ears of the communities in which they live," she said. "It's very understandable, but also very sad in a way."

Co-payments are also a factor in the SA system. All public patients pay a $20 fee per denture, not to offset costs in any significant way but to encourage patients to value and maintain their dentures. Basic dental and emergency dental work is free, but a procedure such as a crown that might cost $600 to $1,000 in normal circumstances is classed as 'cosmetic' and attracts a co-payment of around $180.

Waiting lists are not an issue in SA due to the State's small population and relatively well established services. Anecdotal evidence suggests that some patients from eastern states, tired of languishing on waiting lists, travel to SA and register with the service under a local address just to get basic work done.

These so-called 'dental tourists' can presently be accommodated, but for how long is a significant question, particularly if waiting lists continue to grow in other states.

Provision of public dental services in Victoria is a political battlefield, with HIV/AIDS advocates constantly fighting for funds and against co-payments. Public dental services are offered for health care card holders at the Alfred Hospital, and there are some special needs clinics as well, but again the issue is one of access. Waiting lists for some procedures are over two years and many patients, even card holders, regularly spend up to $2000 a year on dental services from private dentists. PLWHA Victoria has been pushing for some time for special exemptions from public dental waiting lists such as those that apply in other States for HIV/AIDS patients, but to date the requests have fallen on deaf ears. Menadue said private dentists who were prepared to do work on HIV/AIDS patients for a reasonable fee were often swamped by requests through word-of-mouth referrals.

The unique dental health needs of people with HIV/AIDS and the poverty traps associated with the disease should be ringing alarm bells around the country, but even the most recent policy advances have failed to tackle the issue head-on in any coordinated, national way. *Talkabout* understands that even the latest draft of the Fourth National AIDS Strategy contains no reference to dental services. Until such time as there is a comprehensive national commitment to providing acceptable minimum standards of dental services to people with HIV/AIDS it seems the inequities and shortcomings of the present patchy arrangements will continue. ■

Lindsay Varcoe is a freelance writer

Talkabout understands that even the latest draft of the Fourth National AIDS Strategy contains no reference to dental services

Compelling Sadness

Bill Phillips reviews Tony Ayres' screen adaptation of William Yang's ground-breaking monologue for the theatre *Sadness*.

Written and directed by Tony Ayres, based on the original work *Sadness* a monologue by William Yang. A Film Australia National Interest Program.
Screens on SBS television, Sunday 14 November 1999

Williams Yang projects a slide of his friend Alkan, whose story forms part of Williams' [illegible] performance in "Sadn

As a piece of theatre, first performed in 1992, William Yang's *Sadness* was a moving exploration of his Chinese background and his 25-year career as a social photographer in Sydney. Translated to the small screen by filmmaker Tony Ayres, *Sadness* has lost none of its emotional power. This is a moving documentary about ethnicity, racism, HIV/AIDS, family, sex, friendship and death.

Yang's two worlds of fourth-generation Chinese Australian life and the chronicle of gay life in Sydney since the seventies are bound by a common grief. His family story of assimilation, alienation, and murder are woven with images of the friends, lovers and companions lost to the HIV epidemic. The result is ineffably sad, and reminds us of the monumental scale of the loss individuals have faced over the last two decades.

The personal and particular become universal. The journey into a family's past in far North Queensland is told in images of landscape, domestic memories and Rashomon[1]-like recreations of a brutal racist murder. The parallel journey through fifteen years of the epidemic is filled with images that have become rarer in the late 90s: the beautiful and talented reduced to living corpses lying stark against hospital sheets, dying eyes filled with something beyond words.

Both journeys resonate intimately. Anyone with family, anyone who has survived thus far will recognise part of their own history. William Yang tells us the origin of the work was in his need to recover his past as a Chinese Australian, to integrate his past and present. Equally, as a gay man who has seen so many of his friends die, he felt "compelled to tell and unburden myself of the things I have seen".

In words and photographs, Yang captures the extraordinary within the seemingly ordinary. The apparently mundane is transformed. *Sadness* provides each viewer with the opportunity to integrate another's narrative and make sense of our own experience.

Director Tony Ayres has done a fine job of adapting live theatre to the screen. Having worked in both media, he understands the demands of each form and has created a seamless flow of image and idea. Using a different medium, he has brought Yang's work to a wider audience without lessening – perhaps increasing – the power of the original.

As a gay man living with HIV, I've buried too many friends. My mother died recently. Yet I can agree with William Yang: the experience has shown me there is great kindness everywhere, and through it, I have seen a better side of human nature. ■

[1] **Rashomon** *is a film by the Japanese director, Akira Kurosawa, who made a lot of fabulous films in the 1960s.* **Rashomon** *tells the story of a criminal event from the differing perspectives of seven witnesses. The film explores questions around 'the nature of truth'.*

Bill Phillips is a freelance writer and a member of the Publications Working Group for PLWHA (NSW).

Chrissy's story

On World AIDS Day this year SBS will broadcast *Chrissy*, a documentary by filmmaker Jacqui North, based on the final years of Chrissy Napier's life. **Vivienne Munro** previews the film.

Chrissy and film maker and best friend Jacqui North

Chrissy's story has many paths that run and merge together, my story, like the other HIV positive women who knew her, was a very different one from the story her family knew, and later as she was ill and dying, those of her carers.

I first met Chrissy in 1992, at the first meeting of the steering committee that was to organise the 2nd National Positive Woman's Conference. She had been elected from Queensland, as the state representative, and her youth and enthusiasm impressed me. Even in 1992, she seemed protective of herself, unwell, yet full of energy. Over that year she worked hard on the conference but I wasn't to meet up with her again until she moved to Sydney some years later. I learnt she had continued her volunteer and paid work in HIV and had completed courses.

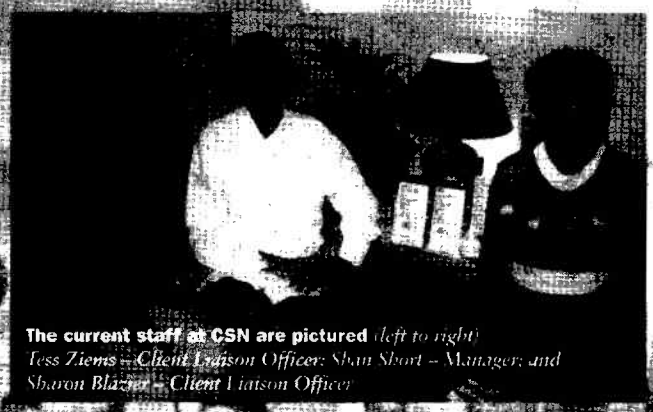
Chrissy's youth and unassuming nature made her especially vulnerable, but what came through was her determination and belief in herself that ensured she achieved equity of services in her community. Her bravery and strength led her to share a most intimate and personal time of her life. For one year Jacqui North, a good friend of Chrissy, and her production team filmed Chrissy and her family coming to terms with her illness and death.

Chrissy lived in a block of flats run by the Bobby Goldsmith Foundation, with easy access to the women's support groups, retreats, medical attention, and social services. She lived at the heart of all that is available to a person living with HIV and then AIDS. Yet the story of Chrissy that Jacqui unfolds is one of little faith in treatments, isolation and aloneness. Throughout the film I am conscious of Chrissy's struggle for independence and normalcy, "Sometimes I just stay in bed, it's very lonely, I wish I just lived in a normal place". Chrissy's resourcefulness ensures she was well looked after, but as she says "Lots of my friends have died of HIV, I like to have negative friends because there is more chance of them being around."

The video depicts a childhood, captured by endearing home movies, of a close knit family, Chrissy and her three sisters performing for the camera. The destruction that followed Chrissy's rape alienated her from the family, who couldn't deal with her differences. It wasn't until eight years after being diagnosed HIV positive that Chrissy found the courage to tell her family. That honesty became the catalyst for her re-acceptance and they share Chrissy's story, and her journey. Her sister initially believes HIV is self inflicted, happening only to gay men, but as the years pass, ignorance becomes understanding. Chrissy's story is as much about her family's acceptance, love and support as it is about Chrissy's final year. As Chrissy's life and vitality withdraws the family changes and draws on her strength. ■

Chrissy *screens on SBS on Wednesday December 1 at 7.30pm.*

Vivienne Munro is the convenor of the Publications Working Group for PLWHA (NSW)



The current staff at CSN are pictured *(left to right) Tess Ziems – Client Liaison Officer; Shan Short – Manager; and Sharon Blazier – Client Liaison Officer*

Core services are:
- Personal care
- 24 hour palliative care,
- Shopping, cooking, cleaning, laundry
- Transport (to and from approved medical and HIV related destinations)

Other services may include, depending on branch/local need:
- Hospital visits
- Emotional/social support
- Pet-care
- Gardening

CSN fifteen years

The Community Support Network (CSN) is a remarkable organisation that has provided voluntary home-based care for fifteen years. Over fifteen years, the development of new treatments, new side effects and the long term effects of living with HIV/AIDS has meant that although much has changed the need for CSN remains strong. ***Talkabout*** asked a range of people to reflect on what CSN means to them and where the service might be headed.

1984 A network of carers – known as CSN – is formed when gay men in Sydney take care of their ill friends and lovers, because hospitals and health services are discriminating against people dying from AIDS.

Trish, Thelma and Louise – three middle-aged, heterosexual women start CSN Illawarra from the 'boot of their car'.

CSN conducts formal training sessions

First full-time paid volunteer trainer employed

CSN incorporated

CSN/ACON management agreement developed

1989 CSN working out of Sophia Street in Surry Hills

Services established in Hunter branch of ACON, volunteers begin running training programs

CSN services at ACON Western Sydney and a volunteer worker runs the roster service

First promotional posters produced

1993 First external review of CSN

1994 First review of CSN training

1995 CSN and ACON move to Commonwealth St, Surry Hills, Home-care, Housing and Transport services are amalgamated into one unit

1996 World AIDS Day service award
Second review of CSN training

1998 World AIDS Day outstanding achievement award

CSN Sydney integrates with the Care and Support division of ACON and begins to renegotiate its management agreement with ACON

CSN Sydney and Western Sydney receive CHASP accreditation meeting highest level of achievement in the process

CSN initiates a review of carer recruitment

CSN is managed by ACON and the relationship between the two organisations – both incorporated associations – is defined by a management agreement. A Carers Representative Committee represents carers.

Shan Short is the Manager of CSN and she welcomes the 15th birthday as a time of celebration and acknowledgment.

For this birthday, I'd like the staff and carers to have a bloody good time celebrating an enormous achievement – and see that carers get the public recognition and acknowledgment for the work they do and that they continue a tradition of being a strong carer based culture.

The ACON vision for CSN?

CSN is a service that has evolved out of the community. It should remain there as a choice for people. We don't know if we are going to get a vaccine in the next five years and that could impact quite radically on where all HIV services go.

But as long as the need is there, a form of CSN service will continue to operate. One of the things that I've been very involved in since I became manager, is working to develop better partnerships with mainstream services like HAAC to build capacity and support those services so they are better able to work with PLWHA.

What is driving that vision?

There's always been recognition that we need to develop partnerships. I think that earlier we were dealing with managing a

crisis and it wasn't a top priority. The priority was to get services that were sensitive and competent. Now the opportunities and timing are better. There is also the reality of funding and client choice. We always advocate client choice and I think it is opportune that we develop partnerships now so people can have choice.

Is recruitment keeping pace with changing community attitudes?

We are revising recruitment strategies to look at how to recruit better because we are having difficulties in recruiting the same volume of carers that we have in the past. CSN is a volunteer-based service and people have given enormously of their time and support to do the work so there is a level of burnout. We will consult with long-term carers, people from the community, and staff. Once we bring people in, the mechanisms like training and support are phenomenally good.

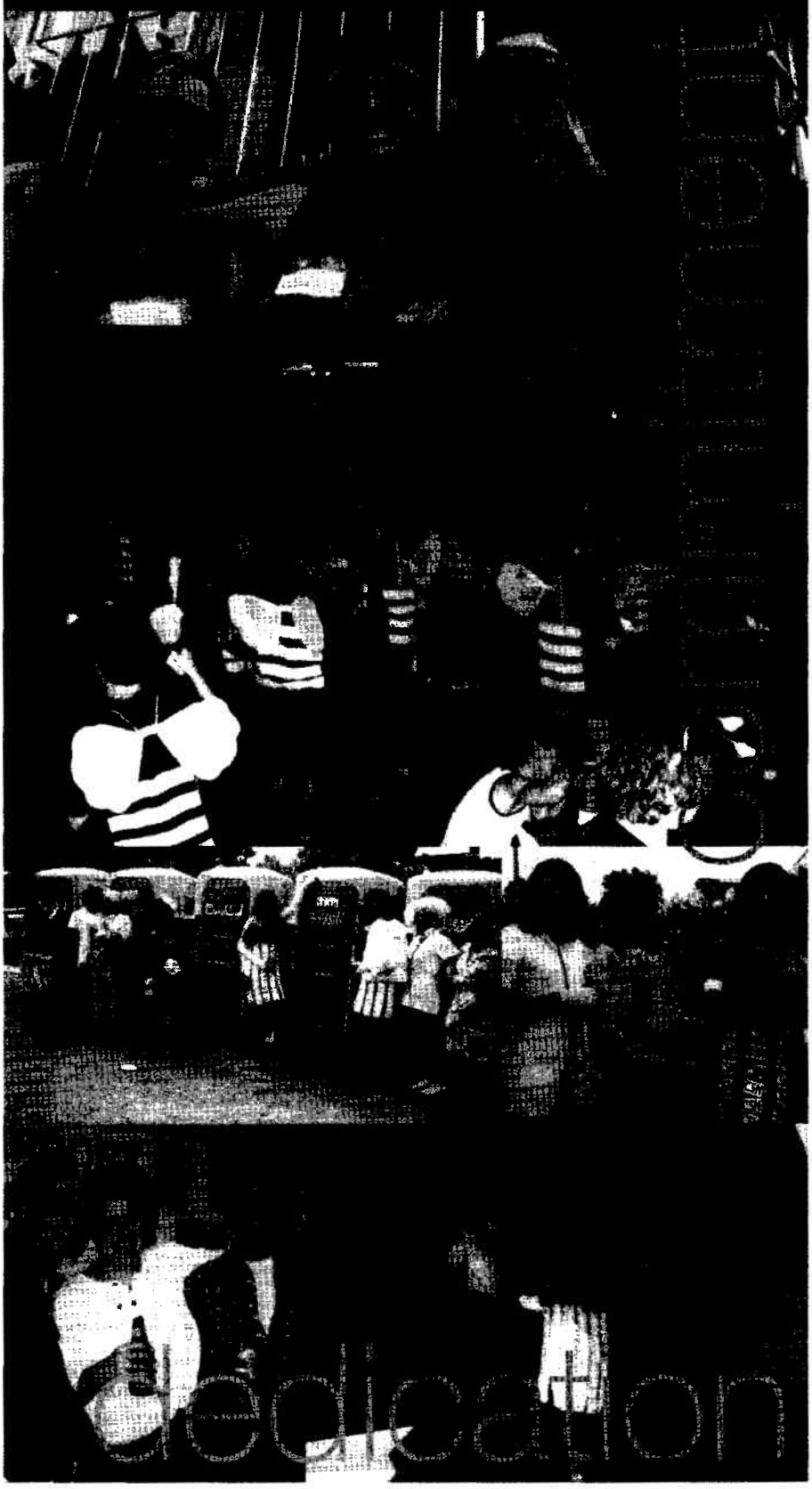
What was the rationale for the reduction of client liaison officers?

The intensity of the work has changed. We are rostering far fewer people to 24-hour palliative care shifts. We roster people onto shifts that may only be a month or two because the client has changed combination therapies and is experiencing side effects, or they need care at that moment but won't in two months. We don't need four or five care liaison officers but individual clients may experience an impact. We've created dialogue with clients and carers so people broadly understand how services have shifted.

How would you describe the relationship between ACON and the Carers Representative Committee during this time of change?

Dynamic. It's a complex relationship. We've had a management agreement since 1988 and it was in recognition that CSN was a community-based service and needed infrastructure. It made absolute sense given that both services were closely related with the same target group and values. We are currently renegotiating the management agreement. Accountability between the two bodies is a part of the management agreement. I write a blurb in *Network News*, the carers' newsletter so people get to know me and find out what we're doing. I invite feedback and input from carers and I attend the Carer Representative Committee meetings on a monthly basis. Currently, the chairperson of the committee is also on the ACON Board so you can't get much more transparent than that.

Since 1984 CSN and its Branches have trained approximately 1,800 volunteer carers from 153 training courses. Current membership of CSN (carers are full members of CSN) is 620 and current active carers approximately 250. CSN carers have cared for approximately 2,500 clients and currently provides between 17,500–26,000 hours of direct care per year.
***Talkabout* have prepared this pictorial tribute (with more pictures on page 24) to the work, dedication and service of everyone at CSN.**



John Kell joined the CSN Committee as Treasurer in 1998 after being a carer for six years.

CSN has achieved a great deal. I'd like to think the service could continue to make a great contribution but at the moment it's as though we are treading water.

How has the service changed over the years you've been involved?

In the early days I did palliative care for people with AIDS or respite care for their primary carer. After 1994, the nature of care became more practical although people were still very sick. The guy I care for now is probably able to do the things I do for him but it's a quality of life issue. The change in the nature of the epidemic has meant we don't ask as much of our carers as we used to. Four hours used to be the average shift; my impression is that now the average shift is more like two hours.

There is a heightened need for open discussion now that the nature of the epidemic has changed

Do you have a vision for CSN in five years time

It's the social and economic problems facing CSN clients, especially poverty and loneliness, which present a challenge to the CSN Committee and ACON management. There's a real question about how CSN should best serve the community in the present circumstances.

I don't think the CSN Committee has a lot of vision at the moment. There is a turf war going on between ACON and the Committee. I don't know what role ACON has in mind for CSN either. I think ACON views CSN as an important source of funding and credibility but this year I have gained the impression that ACON would be quite happy to do away with the Carers Committee and integrate CSN carers as ACON volunteers. I don't think there is enough open discussion between the CSN committee and ACON management as a whole. There is a heightened need for open discussion now that the nature of the epidemic has changed. The committee's response must also change.

Is recruitment of carers the major issue facing the service

Voluntary organisations are in trouble generally. Voluntary causes go through phases of being fashionable and HIV/AIDS seems to be out of fashion. Our traditional source of carers has been the gay community but we need to look outside the traditional base.

There is a shortfall of carers and current recruitment strategies are not filling that gap. In those circumstances the recent reassessment of clients is a very good idea.

For David McGuigan knowing that he can stay at home is part of the joy of having a service like CSN.

I have AIDS and have used a carer off and on since I was last in hospital a year ago. I prefer to remain as independent as possible and live at home with my two dogs. My carer, Graham, comes once a week on a Thursday to vacuum, sweep and do the other heavy chores, like washing the dogs.

I am a long-term survivor and it's getting more difficult to do the day-to-day things. Combination therapy has prolonged my life but I am hovering around 20 T cells and a viral load of 70,000. I am less able to work as my need to rest increases.

Graham is very non-judgemental and doesn't make me feel guilty about needing care. Whatever the training is, I approve of it. I think the transport service is fantastic. I suffer from chronic diarrhoea, and have bad hips and feet so I walk with a stick. I live in Newtown and getting public transport to doctors and appointments is very difficult. It's embarrassing to have to stop along the way and ask shopkeepers if I can use the toilet. Having the transport service has changed that and I wish I'd used it earlier.

Graham Bakewell has cared for three clients since 1995. He currently does the heavy housework once a week for David. He describes his experience of caring as satisfying.

The training was fantastic – the best three or four days I've spent, I learnt so much. CSN may be heading in the direction of Ankali because although palliative care is still done there is a lot of social support and cleaning and not much in between. I never know what I'm getting until I start with a client, but it gets easier as you get to know them.

My work as a carer is in a very separate place to the rest of my life but I wouldn't be doing it if I didn't still get something back. I think it's a reality check – caring brings me back to earth. In the past I've done a lot of single shifts filling in for people who can't make it that day so I meet interesting people in a lot of different situations. ■

HAART and heart disease

Protease inhibitors have been a lifesaver for **Barrie Harrison**, but not without a few ups and downs.

When I first started taking a protease inhibitor combination in 1996, my T cells were under 50 and my viral load was in six figures. Now my viral load is undetectable and my T cell numbers have increased dramatically. A success story? Well, yes and no Unfortunately, while taking my drugs, I have developed lipodystrophy and earlier this year I was diagnosed with coronary artery disease.

Lipodystrophy is known to be associated with protease inhibitor use but is there also a link between protease inhibitors and coronary artery disease? What is coronary artery disease? How can it be dealt with? What effect is it going to have on my HIV treatments in the future? These are some of the questions that have run through my mind over the last six months.

Towards the end of last year, I noticed chest pains when I walked the short distance from home to the station to catch the train for work. I would have to stop and rest until the pain went away. My doctor thought it could be a heart problem and tests proved him right. Three of the main arteries (coronary arteries) that supply blood to my heart muscle were almost completely blocked by fatty deposits. I would need bypass surgery. Without surgery there was a good chance that before long I would have a heart attack or stroke. It was a shock.

Having lived with HIV for so many years, it never occurred to me that heart disease, rather than HIV, could finish me off. Bypass surgery involves taking arteries or veins from an arm or a leg and grafting them to the coronary arteries of the heart so as to bypass blockages in the blood vessels. This restores the blood flow to heart muscle. It also offers the opportunity to live a normal life again.

Bypass surgery is still considered major surgery but the risks of serious complications or death following surgery are now quite small (about 3 per cent). I agreed to the operation, which involved a stay of just five days in hospital. As soon as I was out of intensive care, the physios pounced on me to do coughing exercises. It was agony but they assured me coughing helps the lungs to re-inflate and prevents fluid accumulation that can lead to pneumonia. Reluctantly I did as I was told and, even with my ravaged immune system, I did not develop any complications. My wounds healed amazingly quickly.

What about my HIV medications during this period? After discussions with my doctor, I decided to stop them altogether while I was in hospital. I could not be sure of keeping to my normal dosing schedule. It is less likely that resistance to HIV medications will develop when all the drugs in a combination are stopped at once rather than delay or miss doses. I stopped taking my HIV treatments on the evening of surgery and restarted them when I felt able again to keep to my usual routine. This turned out to be just three days after surgery. I had a viral load test about a month after I came out of hospital and I am happy to say that my viral load remains undetectable.

I am now swimming regularly and I can walk long distances without getting chest pains. I feel fit and healthier now than I have done for a very long time. The surgery was a great success. But will the problem come back? Have my HIV drugs contributed towards coronary artery disease? Should I switch to a combination that does not contain a protease inhibitor? Research has not yet provided the answers to these questions. So I am maintaining my protease regimen and doing all I can to reduce my 'risk factors' for heart disease. I monitor regularly the levels of cholesterol and triglycerides in my blood.

I've cut out butter, cream and fatty foods from my diet as much as possible and I have added a cholesterol-lowering drug to my regimen. Within six months, my cholesterol and triglyceride levels have fallen considerably and are now well within the normal range. Changing my diet was not the problem that I thought it would be. Not being too strict with myself has helped. I occasionally eat no-nos like lamb and cheese but now I find that I don't seem to enjoy them as much as I did. They seem too rich and sickly. I'm also doing regular exercise (and enjoying it) and trying to reduce stress as much as possible. My HAART (highly active antiretroviral therapy) is working and so is my heart. I hope that they both continue to do so. ■

What is coronary artery disease? How can it be dealt with? What effect is it going to have on my HIV treatments in the future? These are some of the questions that have run through my mind over the last six months.

talkabout money

If you owe money and the payments are in arrears, naturally the creditor has the right to contact you to find out the situation and arrange repayment. But you do have rights, says **Maree Crosbie**, and the creditor does not have the right to harass you.

Who's the knocking?

The Australian Competition and Consumer Commission (ACCC) has recently conducted research on harassment. They have released a paper, *ACCC Research Project on Section 60 Undue Harassment and Coercion – An ACCC Research Project.*[1] It states that "Section 60 prohibits the use of physical force or undue harassment or coercion in connection with the supply or possible supply of goods or services, or for payment for goods or services".

According to the ACCC's interpretation of Section 60 is: "Harassment is conduct that causes distress, agitation, anxiety, or worry to the recipient, interferes with the recipients peace and quiet, and/or amounts to pestering or plaguing with repeated requests or demands."

Harassment can include various forms of unreasonable contact, including:

- Telephone communications between 9.00pm and 8.00am (without prior agreement with the client)
- Visits between 8.00pm and 9.00am (without prior agreement with the client)
- Repeated communications during 'reasonable' hours
- Telephone calls or visits at a person's workplace when the trader has been asked not to contact the person at work
- Communications at times or places when the trader has been advised that these are not acceptable or convenient
- Use or threat of violence to person or property (this could include physical force)
- Misrepresentation about the consequences of non-payment, or of the debt recovery process
- Misrepresentation about the amount, character or legal status of a debt
- Disclosure of information, or threat of disclosure, to a third party who does not have a clear and legitimate interest in the information (for example, employer, neighbour, welfare agency, government agency)
- Threatening to publish, post or cause to be published, or post, any list of consumers commonly known as a 'default list' for the purpose of forcing or attempting to force payment
- Contacting the consumer when asked to deal directly through an adviser (solicitor, financial counsellor etc)
- Contacting a consumer after being advised that the consumer wishes the trader to cease communication
- Use of abusive, threatening, offensive or obscene language
- Misrepresentation that documents are court documents or official documents and
- Misrepresentation that the trader is a solicitor or is employed by a solicitor, is an independent debt collector, or is a bailiff or police officer.

If you feel that your have been caused undue distress or harassment, you should draw the callers attention to Section 60 of the *Trade Practices Act 1974*, under which a creditor is prohibited from using undue harassment in connection with the payment for goods or services. ■

If you feel that your have been caused undue distress or harassment, you should draw the callers attention to Section 60 of the Trade Practices Act 1974

[1] Find the paper at www.accc.gov.au/docs/sect60

Maree Crosbie is a Financial Counsellor at The Bobby Goldsmith Foundation.

Further help may be sought from a Financial Counsellor, Community Legal Centre or by ringing Credit Helpline on 1800 808 488.

Glossary

Adherence Often shorthand for 'strict adherence to therapy', meaning pills are taken exactly as prescribed – on time, every time, and observing any specific dietary requirements. Also referred to as 'compliance'; less frequently, as 'concordance'

AIDS 'acquired immunodeficiency syndrome'.

Antiretroviral a scientific term for antiviral drugs.

Blood-brain barrier A barrier between the blood vessels and the tissue of the brain, which is part of the brain's specific defence system. Many drugs cannot pass through this barrier.

CD4 cells *(also called T cells or T helper cells)* A type of blood cell involved in protecting the body against viral, fungal and protozoan infections. CD4 cells are part of the human immune response. The CD4+ test is a measure of how your immune system is coping.

Combination therapy Treating HIV with a combination of two or more antiviral drugs at once to suppress viral replication and minimise the opportunities for the virus to become drug resistant.

Complementary therapies A term used to describe therapies that follow holistic, traditional, or culturally diverse philosophies and practices of healing, which can be used alongside medical treatment. The term 'alternative therapies' is related, but refers to practices and philosophies that are used instead of (not in addition to) medical treatment. Naturopathy, acupuncture, massage and herbalism are examples of complementary therapies that people with hiv have described as being useful.

compliance *see adherence*

cross-resistance Virus that is resistant to several or all of the drugs within a particular class of drugs (eg. to several or all protease inhibitors)

Drugs that directly treat HIV *(antiviral drugs)*
There are three different classes of drugs currently in use, which block HIV replication at different points in the life cycle of the virus.

Nucleoside reverse transcriptase inhibitors
Abacavir (Ziagen) also known as 1592
AZT (Retrovir) – full chemical name zidovudine
combivir – full name zidovudine/lamivudine
ddI (Videx) – full name didanosine
ddC (HIVID) – full name zalcitabine
3TC (Epivir) – full name lamivudine
d4T (Zerit) – full name stavudine

Non-nucleoside reverse transcriptase inhibitors
nevirapine (Viramune)
delavirdine (Rescriptor)
efavirenz (Sustiva or Stoctrin)

Protease Inhibitors
Nelfinavir (Viracept)
Indinavir (Crixivan)
Ritonavir (Norvir)
Saquinavir (Invirase)

HAART Highly active antiviral therapy. Usually means a combination of at least three HIV antivirals from at least two of the three classes of anti-HIV drugs available.

hepatitis C Viral disease caused by the hepatitis C virus. Can cause liver disease in the long term. Principally transmitted by exchange of blood via transfusion or intravenous drug use.

HIV Stands for 'human immunodeficiency virus', the virus that causes AIDS.

Homeopathy is diametrically opposed to Western medicine. Homeopathics treats 'like with like' by finding substances that cause the symptoms to be treated and administer them to the patient in a diluted form. The approach is intended to stimulate the body's own immune response. An approach to healing sometimes used by positive people because it is non-toxic.

Hyperlipidaemia Elevated concentrations of any or all of the fats found in the blood.

Lipodystrophy A clinical condition involving body fat redistribution and high levels of glucose, cholesterol and triglyceride levels. Men commonly experience increased fat around the stomach and upper back and women can experience a narrowing of the hips and breast enlargement. Thought by many to be associated with the use of protease inhibitors.

NNRTIs *see Drugs – Non-nucleoside Reverse Transcriptase Inhibitors*

Opportunistic infections *(OI)* HIV damages parts of the immune system. Once the damage reaches a certain level (roughly indicated by your CD4 count), some of the infections your body could normally deal with may establish themselves.

PBS *Pharmaceutical Benefits Scheme* which has a list of the different drugs listed by the Federal Government. These drugs are subsidised for people prescribed those drugs.

Peripheral Neuropathy *(PN)* Nerve damage, usually involving the hands, arms, fingers, legs and feet. It can cause numbness, tingling or burning sensations, pain and muscle weakness. It is a side effect associated with some HIV antiviral, particularly ddC, d4T and ddI.

PCP *(see opportunistic infection)* Pneumocystis carinii pneumonia. Life-threatening inflammation of the lungs caused by a protozoa (parasite-like particle). Common in immune suppressed people unless preventative measures are taken, and the disease is fatal in 15 to 30 percent of people. Bactrim is the commonly used and effective prevention measure.

PEP post-exposure prophylaxis. This term is used in HIV medicine to refer to individuals taking a course of anti-viral drugs after they have come into contact with HIV in such a fashion that infection may occur. The aim of the treatment is to make infection with HIV less likely. Some clinicians prefer the term 'post-exposure treatment (PET)' because they argue that it is about treating HIV infection before it affects the body.

Resistance test A test which looks at the genetic structure of HIV, to determine if any mutations in the virus would make it likely to be resistant to particular antiviral drugs. Sometimes referred to as resistance assays.

s100 drugs licensed under section 100 of the *National Health Act*, and mainly but not exclusively, antiviral drugs.

Special Access Scheme A scheme that allows access to experimental drugs prior to being licensed in Australia.

tenofovir New drug in the nucleotide analogue reverse transcriptase inhibitor class currently under trial.

toxicity The capacity to cause a poisonous or unwanted reaction.

Vaccine *(therapeutic)* An agent introduced into the body that is designed to stimulate an immune response to a virus or infection that is already in the body.

Viral load The quantity of virus measurable in blood serum or other fluid or tissue. This test is used to show how active the virus is at any particular time. The test is also used to show whether the treatments you are on are having any effect.

Sources

Terms taken from, but not exclusive to, the following:

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Taking Care of Yourself, AFAO NAPWA, July 1999

HIV Drug Book, AFAO, 1998

Living With HIV/AIDS, Peter de Ruyter, Allen & Unwin, 1996

Positive Living, various, AFAO 1999

hyper active

with **Tim Alderman**

The Bungalow
http://members.xoom.com/_XOOM/thebungalow/homepage.html

Rating A fascinating site, and an interesting insight into the beliefs of an Indian tribe doing HIV prevention using a cultural perspective.

The Index page lists South Dakota Resources; HIV/AIDS in the New; Ask A Question; HIV Chat Room; Message Board; Instructor AIDS; Death and Dying; Two Spirit Issues; Lakota Education; HIV/AIDS 101; Editorials; Links, and contains their Mission Statement.

The death and dying link has some interesting insights into the beliefs of the Lakota people, including Self Image; SUNDANCE and the universal precautions they use in their ceremonies to protect against spreading HIV, how they view disease and trauma.

Hint Clicking the 'Lakota' button at the bottom of the page takes you to the 'Lakota Wawokiye' perspective on HIV prevention and education, and a section on a form of spirituality called 'Two Spirit' with a link to an archive Two Spirit belief in other cultures.

National Centre in HIV Epidemiology and Clinical Research
http://www.med.unsw.au/nchecr

Rating Primarily for medical and research people.

Index page includes: About the Centre; Annual and Quarterly Surveillance Reports; A History of Peer and Non-peer Reviewed Publications from 1986–1999, Antiretroviral Guidelines, and their Annual Report. Personal Links lists people associated with the research project.

Hint Acrobat Reader required for PDF documents.

Australian Society for HIV medicine
http://www.unsw.edu/clients/ashm/ashm.html

Rating Mainly for medicos.

Contains a notice of their Annual Scientific Meeting, CTTAC Guidelines, and all their publications. Also includes position papers on PEP, and Vaccine Guidelines. Other sections are Who We Are; What We Do; Aims and Objectives; and Membership and Members.

OZPOZ
http://www.cia.com.au/hol/ozpoz

This is about as functional as a site gets (in the most positive sense). The objective is to join a mailing list for discussion between HIV positive people. Index page includes About OzPoz; Subscribe; FAQ; and Links. That's it!

HIVPOSITIVE.COM
http://www.hivpositive.com

As it states on its Index Page "Learn Something New Everyday" – an interesting, innovative site.

The Main Menu uses frames, with the indexes running down the right of the screen. A very comprehensive site with an index that includes HIV and You; HIV and Nutrition; HIV Can Be Treated; Pain and HIV; Opportunistic Infections; Testing for HIV; Women and Children with HIV; Those Wonderful Caregivers; Occupational Exposure; Resources and Assistance; Drug Advice; Money Matters; Newsline; Special Focus; Find a Doctor (US) and Search. The Special Focus section covers updates like Vaccine studies, funding for twelve centres for HIV research, success in implementing Public Service Guidelines, new findings to help explain 'Rebound' in HIV patients etc. Though probably useful for Researchers, most of the items were from 1997/98. As much as the site is regularly updated, this section doesn't seem to be.

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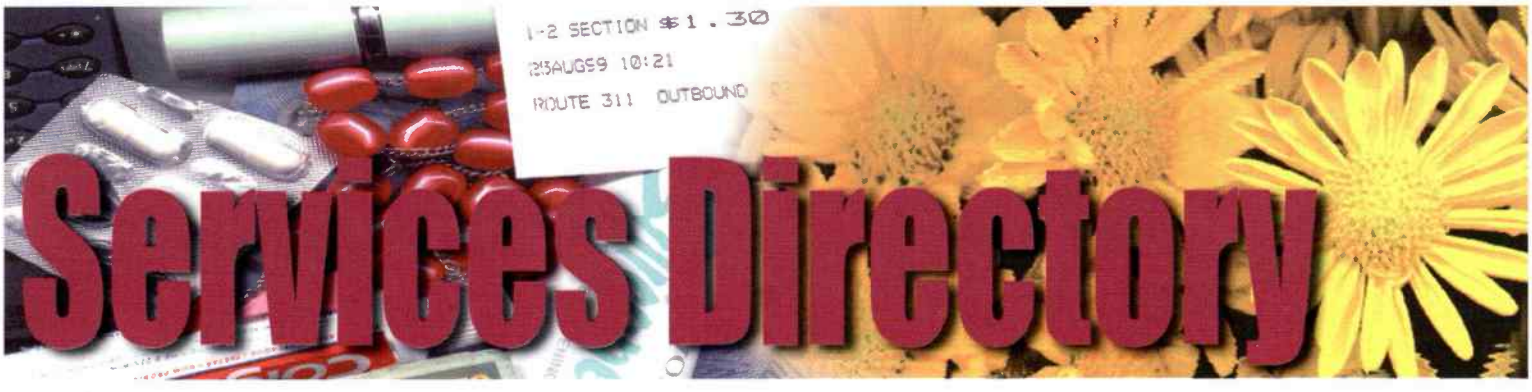

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events

- **CANDLELIGHT MEMORIAL RALLY - SUNDAY 21ST NOVEMBER**
  The Candlelight Memorial Rally from Green Park, Darlinghurst to Hyde Park celebrating and remembering lives lost.
  For more information contact ACON on 9206 2000.

- **QUILT DISPLAYS - 21ST NOVEMBER - 1ST DECEMBER**
  Australian AIDS Memorial Quilt State Tour.
  The Quilt will be displayed throughout the state during AIDS Awareness Week.
  For details of where it can be seen in your area contact your local Area Health Service.

- **AWARDS NIGHT - SUNDAY 28TH NOVEMBER**
  World AIDS Day Awards Night at Customs House, Circular Quay. Invitation only event to honour the outstanding work of those in advocacy, care, education and support of HIV/AIDS in NSW.
  For more information contact World AIDS Day Project on 02 9360 7669.

- **BBQ - WEDNESDAY 1ST DECEMBER**
  World AIDS Day BBQ and entertainment in Green Park, Darlinghurst.
  For details contact SESAHS World AIDS Day Co-ordinator on 9360 3169.

For details of the 200 plus regional events in NSW contact your local area Health Service World AIDS Day Co-ordinator or the NSW World AIDS Day Project Office on 02 9360 7669.

with ... Complements

The official newsletter of the HIV Complementary Therapies Collective
Vol. 9, No. 4 July / August 1999

Herbs for HIV

by Leslie Hanna
BETA April 1998, San Francisco AIDS Foundation.

In the U.S. today, the mention of herbal medicine is likely to conjure images of Chinese herbalist shops, Mexican tiendas naturalistas or hippie alternative natural food stores. Yet more and more North Americans report use of herbs to treat some form of illness or interest in learning more about herbal medicine. In fact, herbal medicine has been practiced responsibly for thousands of years in different cultures around the world. People with HIV living in the U.S. today may seek qualified health care from legitimate herbalists ranging from the naturopathic to the Chinese medicine disciplines. In addition, the number of medical doctors who also have received some training in holistic medicine - and thus may be well informed about herbal medicine - is increasing.

This article was largely based on an interview with Carlo Calabrese, ND (Doctor of Naturopathy), MPH, co-director of the AIDS Research Center at Bastyr University in Bothell, WA, who, along with a team of dedicated researchers, conducting groundbreaking research into alternative medicine and HIV disease. Here, the basics of herbal medicine in the context of HIV disease will be outlined. For an article that discusses complementary and alternative medicine (CAM) in general, see the January 1998 issue of BETA <http://www.sfaf.org/treatment/beta/b35/b35cam.html>

What is Herbal Medicine?

No widely accepted or standardised definition of herbal medicine has yet been established. Simply put, herbal medicine uses herbs as the active agent to treat disease. It is one type of CAM that may be used beneficially by HIV positive people, but that also may involve risks. Botanical medicine is an alternative term for herbal medicine. Various conventional medicines in widespread use in the West today derive from plants. For example, digitalis is extracted from foxglove, and aspirin is derived from the willow tree. The prescription of specific herbal treatments is an individualised process, since herbalism takes into account not only a person's illness or condition, but also lifestyle factors such as diet and exercise.

Botanical or herbal medicine refers to a spectrum of healing philosophies and treatments. Often, the choice of word reflects the type of practice. At one end of the spectrum is herbalism, which refers to what some consider the hippie tradition of herbal use - *an ad hoc*, do-it-yourself approach. On the other, more scientific, end is phytopharmaceuticals ("phyto" means plant), which approaches plants as drugs, with specific biologic action(s), that are given in standardised, established doses in order to achieve an intended effect.

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With plants, as with synthetic drugs, people have individual variable responses and sensitivities.

What passes for herbal medicine in daily life is usually less scientific. The following is an example of what may be classified by the non-practitioner as "herbal medicine." A man with HIV brews a bitter melon tea using a teabag that has been sitting on a shelf in his kitchen for 2 years. Before the man purchased the tea, the teabag was stored at a supplier's warehouse for a year and a half; the supplier in turn purchased the tea from a collector in south east Asia, where the tea was acquired. Whether or not there is any activity left in the dried formula when the tea is brewed is far from clear, which is one reason consumers are advised to purchase products that include expiration or "best used by" dates on their labels.

One beneficial consequence of this sort of use may be the placebo effect, an important medical term and concept. The placebo effect refers to benefits that a person experiences while taking some

continued on page 2 ➢

Herbs for HIV

continued from front page

treatment, such as a reduction in symptoms, that are attributable to the treatment process, rather than to the therapeutic value of the agent or therapies used. The placebo effect is not specific to herbs, but may occur with any type of therapy, whether orthodox Western treatment (drugs, procedures) or complementary and alternative therapy (herbs, yoga, acupuncture, etc.) Most likely, the placebo effect is directly related to the expectations of the patient. The simple act on the part of the patient of seeking medical assistance and making decisions about how to better one's health may have extremely powerful health benefits. Although the benefits thus may be seen as psychologically based, they are nonetheless real. "Personally, I feel that this sort of use still may be beneficial, as long as there is no harm. Often when people use something because they believe that it may help them, then it will, via the placebo effect," says Calabrese.

Calabrese cites another, related consequence of herbal use of the type just described. "In real life, people tend to use several approaches simultaneously. In this way, they may hit on something good for them." Yet the obvious risk inherent in the sort of scenario described above is that an individual may also "hit on" something that is not good for them. For example, kombucha "mushroom" tea was all the alternative rage for a short time in the mid 1990s, particularly on the West Coast, until reports began to surface from within the HIV positive community of adverse reactions, at which point enthusiasm declined sharply. (Kombucha is actually a gelatinous, globular fungus, not a true mushroom.) Several persons in Los Angeles reported nausea, vomiting and severe yeast infection. Aspergillus, the fungus that causes the life-threatening infection aspergillosis in people with AIDS, was identified in some Kombucha "mushrooms."

Although some herbal studies have been conducted, few have been rigorous clinical trials. Fewer still have been conducted in the context of HIV/AIDS. As with many forms of CAM, there are few data available from strictly conducted, Western-style scientific studies. Still, documented medicinal use of plants and herbs to treat illness or to promote health dates back at least to the time of the ancient Egyptians. Documentation dated around 1500 BC describes 700 plant-derived medicines. Other documentation exists from Greece and from Western Europe, from 400 BC through the Medieval period and into the present. The history of herbalism in Europe and China is similarly lengthy and continuous. The historic use of herbs has led many contemporary proponents of herbal medicine to opine that herbs have, in effect, been evaluated extensively.

However, since safety data in humans may not exist, it is important for anyone considering herbal medicine to consult as many sources and to collect as much information as possible before trying an herbal treatment.

Some Herbal Medicine Applications are Better than Others

Most authorities on the medicinal use of herbs, like Calabrese, consider botanical medicine to be most appropriate for treating chronic, incurable diseases including HIV, hypertension and cardiovascular disease (including heart failure) and arthritis.

Calabrese offered arthritis as an example. "First-line conventional treatment is nonsteroidal anti-inflammatory drugs [NSAID]. If relief is not achieved with the first dose level of an NSAID, then the next step typically is to take more of the NSAID. If that does not work, some patients have been instructed to take still more; some people have reported the side effect of the sensation of ringing in the ears. At this point the patient may be given steroids, and then possibly methotrexate, which can have significant adverse effects."

"On the other hand," Calabrese says, "up to 60% of people with arthritis who have tried glucosamine sulphate, a nutritional supplement derived from plants and available in many health food stores, report symptomatic relief without side effects." Yet conventional doctors do not typically recommend the substance.

In the context of HIV disease, there are better and worse applications for herbal medicine. In general, herbal medicine is better used for chronic, non-urgent HIV-related complaints. For instance, herbs might be used to boost the immune system, but probably would not be used to treat cryptococcal meningitis. The goal of herbal medicine in the context of HIV disease is to restore overall immune balance, strength and health, rather than to isolate and cure symptomatic illnesses.

Depending on the individual's health status, herbal treatment may emphasise elimination and detoxification, nourishment or health maintenance. Herbs that have been used in HIV disease management include tea tree oil (for fungal infections), garlic (an extract called allicin for cryptosporidiosis), sage (for night sweats), slippery elm (for diarrhoea) and echinacea (for HIV infection). Incidentally, echinacea is an immune stimulant that is used cautiously by herbalists, who consider it possibly too strong for people with fewer than 200 CD4 cells/mm3. Certain plant polysaccharides (sugar chains) are being evaluated for immune stimulation in the U.S., Switzerland and Japan.

Herbs for HIV

In the context of HIV infection, there are 4 aspects to or purposes for using herbal medicine:

1. To attack the virus (the anti-HIV ability of plants).
2. To support the immune system and/or to correct HIV-related immune deficits.
3. To treat or prevent specific opportunistic infections or neoplasms.
4. To relieve side effects from conventional antiviral medications.

The Examination in the Western Herbal Tradition

Other articles have discussed the traditional Chinese medicine approach to diagnosis. This section describes evaluation in the Western tradition of herbal or botanical medicine, which in the U.S. goes by the term naturopathy.

Persons trained in naturopathy receive the ND degree, which stands for Doctor of Naturopathy. The degree is awarded after 4 years of postgraduate work and clinical training that resembles medical school. The first 2 years consist primarily of course work in the basic sciences, and the last 2 years focus on treatment. There are 5 modalities that NDs work with: physical medicine, nutrition, botanical or herbal medicine, homoeopathy, and counselling or psychotherapy. In North America there currently are 5 accredited schools of naturopathy. NDs are licensed to practice in about 12 states. Prospective patients should always inquire about an ND's training and licensure, especially in states where NDs are not officially licensed and where fraud may be easier to perpetrate. The American Association of Naturopathic Physicians may provide some information about members, as well as about the field.

The practice of herbal medicine does have parallels to other forms of alternative medicine, all of which are in at least partial contrast to conventional or orthodox Western medicine. Practitioners report that the heavy emphasis on individualisation that is part of the process, from evaluation to diagnosis to treatment and follow-up, is an attraction and possibly a benefit in and of itself. In herbal medicine as in, for example, Chinese medicine, the typical amount of time the practitioner spends with the patient is much greater than the typical amount of time the Western style physician spends with the patient. Practitioners do not attempt to prescribe any treatment without first trying to synthesise a great deal of information gathered about the individual patient as a "whole person," a term often used to describe the approach taken by alternative medicine practitioners. The type of information gathered about the individual often differs with an alternative practitioner, compared to a Western doctor; for example, the herbalist may ask more about diet or emotions. When a patient meets with an ND, the ND takes an extensive history, does a physical exam and comes up with an evaluation, which is more or less the same thing as a diagnosis. Treatments can vary widely from individual to individual, which is why the word "evaluation" is more appropriate than "diagnosis."

How Can Herbs Be Used to Treat Disease?

In botanical medicine, plant extracts are used for treatments the way synthetic drugs or pharmaceuticals are used in orthodox Western medicine. An advantage of plants over drugs is that plants often have several helpful ingredients. Today, the science of creating plant extracts is becoming more precise. While assuring the amount of active ingredient in an herbal medicine through precise manufacturing and quality control is a desirable goal, a less fortunate consequence is the loss of efficacy. Some compounds in development became increasingly less effective as they were purified. In other words, other active agents were removed during purification. So, although the recent tendency has been to purify extracts until they have become a single identifiable chemical molecule (often with the intention of then synthesising the molecule in order to create an industrial material for mass manufacturing), drawbacks have become apparent.

Another drawback to the purification of plant extracts is that, in effect, the traditional use of the herb becomes less and less clinically relevant. Although Western scientific data are lacking for many plants, there is, in some cases, a tradition of use for many plants dating back thousands of years. In this traditional manner of use, multiple chemicals in a plant may work together to produce the desired effect; a single, isolated chemical may be less effective. Oral and sometimes written records have been dated far back in the Chinese and Ayurvedic traditions. Naturopaths, who practice the traditional European use of plants, still consider one of the most influential and important sources to be the Culpepper records, created in 1650. Thus, while indications for the use of specific plants may have changed through the generations, their original use dates back to Avocenia and Galen from the late Roman times. (Today, some pharmaceutical companies in Europe have a Galenical department, named after Galen.)

The centuries old traditional use primarily relied upon crude extracts or whole plants. Even though crude extracts or whole plants involve possible toxicities - like drugs, plants can have deleterious effects - they are probably generally safer than synthetic compounds for human use. One reason for this is that humans have coevolved with plants; human livers are more accustomed to dealing with plants and adverse reactions to them than with synthetic chemicals that did not exist until fairly recently. Since plants generally have multiple ingredients, usually the first adverse reaction to occur is nausea and vomiting, an

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effective way of purging the problematic substance. With drugs, on the other hand, people may develop neurologic or kidney-related reactions before the body recognises a problem and purges itself. For example, too much Tylenol (acetaminophen/paracetamol - Ed.) may cause liver damage, along with vomiting. A study by the New York Academy of Sciences found that 9% of hospital admissions were related to adverse effects of conventional medicine. Another study found that 16,000 deaths during a 1-year period in New York state were attributable to iatrogenic causes - not necessarily the individually prescribed treatment or drug, but indirectly through the receipt or delivery of treatment or health care. In other words, conventional medical treatments are not free of the possibility of harm to the patient.

The best way to address these concerns may be to establish a healthcare system that takes advantage of the strengths of both orthodox and alternative medical approaches.

Some Words of Caution

Herbs should be regarded as drugs. Although herbal treatments often may work well as a complement to standard Western medical treatment, herbs may be very potent and toxic. They also may interact with standard medicines. The Chinese herb ma huang (*Ephedra sinica*), sometimes used in tea marketed as a dieting aid, has caused serious health problems; the U.S. Centers for Disease Control and Prevention (CDC) has reported deaths associated with ma huang in herbal teas or other formulations. At the July 1996 XI International Conference on AIDS, Sherwood Gorbach, MD, reported near-fatal reactions in people with HIV that were linked to the following herbs: chaparral, germander, comfrey, mistletoe, skullcap, margosa oil, Gordolobo yerba tea, Kombucha tea, pennyroyal (squawmint oil) and some types of Mate teas. Because of the potency and potential toxicity associated with some herbs, pregnant women should be especially cautious about their use. Certain herbs, like certain medicines, have been linked to birth defects. Some herbs are contraindicated with homoeopathy as well as with certain Chinese medical treatments.

Since herbal books are widely available in bookstores and natural food stores, herbalism lends itself to self-treatment. The "materia medica" is the list of herbal remedies and dosages found in herbal books. However, people with HIV are advised to seek the assistance of professional healthcare providers before beginning any herbal (or other CAM) regimen. But beware - people presenting or advertising themselves simply as "herbalists" are not required to have specific training. On the other hand, certified practitioners of traditional Chinese medicine who often prescribe herbal remedies have undergone extensive training. Likewise, medical doctors who are also trained in holistic medicine or those who have received an ND degree have undergone training that has specific standards and licensing requirements.

Other caveats remain. Herbal products available in stores contain variable amounts of the herb in question, which, when self-medicating, can lead to adverse reactions including undesirable interactions with other medications. They may also contain compounds other than the pharmacologically active ingredient that may be toxic. In herbal formulas, "other" compounds include coumarins, which cause the blood to thin, and allergens, which may provoke severe reactions in people who are allergic to ragweed (e.g., chamomile and yarrow formulas). Finally, not all herbal products are labelled with expiration dates; look for those that bear both the plant's Latin name and the product's expiration date.

Patients should discuss both symptoms and CAM therapies with their primary care provider. Sometimes harm results inadvertently from people using herbal medicine or some other form of CAM; people sometimes delay seeking professional care, due to an attempt to self-diagnose and self-treat. On the other hand, people have been harmed in the course of dutifully employing conventional treatments as well. Open and regular communication between patients and providers is essential.

Why People with HIV are Interested in Herbalism

Use of herbal and other alternative forms of medicine by people with HIV is widespread. Data gathered in a comprehensive survey of 1,689 people with HIV/AIDS conducted by Bastyr University researchers is currently being analysed. Among the first 500 people surveyed, there were reports of 500 different treatments, including substances (echinacea, SPV 30), modalities (bitter melon enemas, the orgone box) or practices (yoga, aerobic exercise), that survey respondents used and considered alternative medicine. In a parallel study with Johns Hopkins University and the Multicenter AIDS Cohort Study (MACS), participants at 2 of the regular 6-month evaluations received questionnaires asking about alternative medicine. Of the MACS participants, 86% considered themselves to be using some form of alternative medicine.

Although there are few data, there are different levels of evidence for the effects of herbal medicine in treating HIV. None of the evidence is definitive. "There is no such thing as proof, only evidence," says Calabrese. "Given that we do not have a cure for HIV/AIDS, even if some herbal treatments confer benefits through a placebo effect alone,

these are worthwhile." Persons with HIV who are interested in herbal medicine can consult buyers' clubs, which often have much information.

Plans are underway at Bastyr University to screen combination herbal agents for antiviral use. Part of the rationale is that both HIV research and clinical practice clearly suggest the preferability of a multipronged antiviral attack. Traditional herbalism uses herbs in combination, since each person seeking treatment presents with a unique combination of symptoms.

First, researchers will scan the literature and look for botanicals and nutrients that have been clearly shown in laboratory studies to attack HIV. Next, they will evaluate the traditional use of the herbs to see if it lends itself to possible use in HIV disease. Another goal is to determine whether or not the traditional dose would reach therapeutic levels *in vivo* (in the body) as well as in the *in vitro* (laboratory) studies.

Key questions to be addressed by this screening study of combination botanicals include: Is there any *in vitro* evidence of action against HIV? Is there a history of safe use? Is there any clinical evidence of benefit? Can a sufficient concentration be achieved *in vivo* that would correspond to *in vitro* levels without causing toxicity? Combinations that appear promising would be tested to evaluate their *in vivo* longevity and to determine the half-life of the herb in the bloodstream. Possible formulations would then be considered. Is the herb palatable? Can it be eaten? Is it available, i.e., can it be grown in many locales? Is it affordable? People who cannot tolerate or who do not benefit from conventional antiviral cocktails, as well as people who cannot afford them, might benefit from herbal cocktails.

Although there is little clinical evidence of anti-HIV efficacy, herbs that have already aroused interest in researchers for that potential application include curcumin, glycerrhizin (licorice), hyssop (Hyssopus officinalis, being developed in Japan) and lentinan (shitake mushroom). Other, less familiar herbs are also of interest, including *Prunella vulgaris*, commonly known as "heal all" and long used by herbalists in both the Eastern and Western traditions. Another interesting example involves rosemary compounds, or *Rosemary officinalis*, which appear in vitro to have anti-HIV potency. Studies conducted in France indicated that rosemary compounds suppressed HIV replication without damaging cells studied in the laboratory.

Does this mean that people with HIV who like to cook with Provencal herbs might be receiving some additional, antiviral benefit? Obviously, it is impossible to answer this question definitively, at least for the time being. However, Calabrese points out that garlic, which may be useful for treating oral candidiasis, may be consumed raw, boiled or baked, and that some beneficial properties remain after being heated.

A key question with regard to using herbal medicine to support the immune system is what are the targets and desired effects. As with any treatment that stimulates the immune system, herbs that stimulate the cells and cellular machinery to fight HIV may also stimulate the virus.

Published HIV-Related Herbal Medicine Research

A literature search revealed 10-15 articles that have been published in peer-reviewed journals that report HIV-related herbal studies. Several were from Asian publications not widely available in the U.S. Others were surveys that gauge the opinions and preferences of people with HIV, serving as a first step in beginning to design relevant clinical research.

Over the years, community-based publications have reported on various plant-based therapies, ranging from the now debunked Kombucha "mushroom" to SPV-30, which has active proponents today, to curcumin (studied at New England CRIA), to garlic (allicin, studied at Search Alliance in Los Angeles). While some small community-based efforts produced data, none progressed to a larger clinical trial.

Summaries of Published Studies

Canadian researchers studied CAM use by people with HIV, and evaluated the associations between CAM use and personal (sociodemographic, clinical) characteristics. A survey, completed between September 1995 and June 1996, questioned people's reasons for use. CAM was defined to include alternative medicinal, dietary, tactile (e.g., massage) and relaxation (e.g., meditation) therapies. Of 657 participants, 39% reported ever using some sort of CAM. Of these 256 people, 141 (22%) used herbal or other medicinal therapies, 195 (30%) used dietary supplements, 145 (22%) used tactile therapies and 128 (20%) used some sort of relaxation technique. CAM use was associated with being young, having an annual income greater than $7,300, being college educated and experiencing greater physical pain. Thus researchers concluded that use of herbal medicine or other CAM was associated with being young, highly educated and experiencing symptoms associated with HIV disease.

Researchers from the University of Alabama at Birmingham surveyed 20 area health food stores, asking employees what they might recommend for people with AIDS. Store employees recommended many herbal products to customers with HIV/AIDS. The authors concluded that physicians with HIV/AIDS patients should be aware of this alternative herbal use among their patients and of the possible side effects of such use.

On behalf of the Australian Federation of AIDS Organisations in Sydney, Australia, I. McKnight and M. Scott described the frequent use of CAM by people with HIV and their lack of disclosure of such use to their primary care physicians. They suggested that doctors learn more about what sorts of CAM are being used by people with HIV and be willing to discuss

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CAM use.

An agent called Sho-saiko-to (SST), used in the Japanese Kampo tradition, was studied at Kagoshima University and found, in vitro, to enhance the anti-HIV efficacy of 3TC (Epivir). SST has been studied elsewhere, and is known to have anti-HIV potential. The conclusion of the study was that combination SST/3TC might be a powerful antiviral regimen for use by people with HIV.

From Aichi Medical University in Japan, researchers report the in vitro anti-HIV activity of rooibos tea (*Aspalathus linearis*). Active substances were derived from the leaves of rooibos tea leaves, Du Zhong and Japanese tea leaves, and were studied in the laboratory. In short, researchers found that alkaline extracts of the rooibos and Du Zhong tea leaves were safe and able to suppress the ability of HIV to kill human cells in vitro.

A review article published in the Journal of Traditional Chinese Medicine looked at studies of single herbs and herbal combinations used, both in China and elsewhere, in the Chinese medicine tradition to treat HIV, apparently with some promise.

A couple of African studies have examined how traditional use of herbs may contribute to increased risk of HIV transmission. In one behavioural study, 75 HIV positive and 76 HIV negative women were interviewed in-depth. A majority reported using an average of 4 different types of herbs intravaginally over the 5 previous years to enhance sexual pleasure, yet a significant number of women experienced post-coital adverse symptoms including vaginal and abdominal pain, vaginal lacerations and increased secretions. Twice as many HIV positive as HIV negative women reported using intravaginal substances. In another, similar study in Zimbabwe, researchers concluded that this "dry sex" custom may adversely impact HIV prevention strategies primarily because of the way it affects condom use or effectiveness. Basically, some women reported not using condoms when they used drying herbs because they felt condoms would prevent the intended magical effects; others reported that they used both condoms and drying herbs, but that condoms frequently broke when used with herbs. This custom has clear implications for locally implemented AIDS prevention practices and technologies.

M.J. Balick from the Institute of Economic Botany in New York described the increasing number of ethnobotanical studies that are trying to identify new products. Recently there have been initiatives on the part of government and the private sector to sponsor interdisciplinary efforts that involve experts in the areas of anthropology, botany, medicine, pharmacology and chemistry. In particular, the Belize Ethnobotany Project has brought in scientists on behalf of pharmaceutical companies to become acquainted with traditional medical systems. (Terra Nova Rainforest Reserve is an ethno-biomedical reserve in Belize that received legal status in June 1993.)

In another study, a flavonoid compound called *baicalin* that was purified from Chinese herbal medications was tested for its anti-HIV potency. The compound was purified from the plant *Scutellaria baicalensis* georgi, which has been used as a traditional Chinese herbal medicine, and studied *in vitro*. It appeared to inhibit HIV-1 replication.

A study from Japan looked at the effect of a Chinese herbal medicine, called BG-104, in 2 HIV positive hemophiliacs. Both persons, who had been losing CD4 cells, took BG-104 daily and were able to maintain stable CD4 cell counts for 3 years. Disease progression halted as well.

A study conducted in Hong Kong devised a way to screen multiple compounds used in Chinese medicine as antivirals to evaluate their anti-HIV potential. The 19 agents were evaluated in a laboratory. Six of the herbal extracts were found to inhibit the interaction between HIV-1 and CD4 cell receptors, 2 extracts appeared to be potent reverse transcriptase inhibitors and 14 inhibited another enzyme involved in cell infection (glycohydrolase).

Another study evaluated anti-HIV drug leads garnered from Kallawaya herbalists in Bolivia. Studying extracts of over 60 species of herbs used in the Kallawaya medical tradition, and using a "therapeutic index," researchers found that aqueous formulations appeared more promising than alcoholic extracts, and that plants traditionally used to treat lung and liver disease had the most anti-HIV activity.

A report from Brigham Young University evaluated the ethnopharmacological tradition in Samoa. Tests of plants used in traditional Samoan medicine indicated pharmacological activity in over 86%. Some appeared very promising as anti-inflammatory agents. However, both the practice of traditional Samoan

medicine and the sites where the plants are grown - the rain forest - are threatened. Currently people are trying to set up rainforest reserves.

Conclusion

According to Calabrese, more than 75% of higher plants would likely possess anti-HIV potential, were they to be tested. The primary problem is that many plants and their extracts are toxic to humans. The bottom line today is that there are no large, controlled Western-style studies that can be consulted for insight into the various herbal remedies in use.

However, many promising herbal approaches are available for evaluation. Persons with HIV - the consumers - are advised to carefully consider any potential treatment and to follow the guidelines for making decisions about any type of CAM. Close and open communication with primary healthcare providers is essential.

For herbal medicine, as for most forms of CAM, studies and data are lacking at this time. There is widespread agreement that more research is needed, to understand what agents work, and how. Today's lack of understanding of how herbal medicine works, from a conventional scientific perspective, clearly does not mean that it does not work. That is, absence of evidence that herbal medicine works is not the same as evidence that herbal medicine does not work. Public awareness and educational programs must expand as well. In any case, both conventional and CAM practitioners need to be aware of whatever a patient is using, for optimal safety and health. This is especially true for persons with chronic conditions, including people with HIV.

Leslie Hanna is Associate Editor of BETA

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Organizations: AIDS Clinical Trials Information: Phone 800-874-2572. ***AIDS, Medicine and Miracles****: P.O. Box 20650, Boulder, CO 80308-3650 USA. Phone 303-447-8777, 800-875-8770; email: <amm@inspirational.org>* ***AIDS Project Los Angeles*** *- Greenburg Alternative Treatment Library, 1313 North Vine St. Los Angeles, CA 90028; Phone 213-993-1529.* ***American Association of Naturopathic Physicians*** *(AANP), 601 Valley Street, Suite 105 Seattle, WA 98109. Phone 206-298-0125.* ***Center for Natural and Traditional Medicines*** *PO Box 21735 Washington, DC 20009; Phone 202-234-9632.* ***DAAIR (Direct AIDS Alternative Information Resources)*** *31 East 30th St., Suite #2A New York, NY 10016 Phone 212-725-6994 or 1-888-951-LIFE.* ***Healing Alternatives Foundation*** *1748 Market St., Suite 204 San Francisco, CA 94102; Phone 415-626-4053.* ***Health Education AIDS Liaison (HEAL)*** *937 Fulton St. Brooklyn, NY 11238; Phone 718-398-9478.* ***International Foundation for Alternative Research in AIDS****: Phone 954-630-8002.* ***National Commission for the Certification of Acupuncturists****: Phone 202-232-1404.* ***Positive Images and Wellness Inc.*** *13100 New Hampshire Ave. Silver Springs, MD 20904; Phone 301-236-4614.* ***Project Inform*** *205 13th St. #2001 San Francisco, CA 94103; Phone 800-822-7422.*

Internet Resources: AIDS Treatment Data Network: *<www.aidsnyc.org/network>* ***AIDS Treatment News Directory:*** *<www.aidsnews.org>* ***Bastyr University Home Page:*** *<www.bastyr.edu/index.html>* ***CDC National AIDS Clearinghouse:*** *<www.cdcnac.org> Provides access to HIV-related news and resources through the AIDS Daily Summary, communication through electronic mail, access to AIDS-related articles in the Morbidity and Mortality Weekly Report, and databases of AIDS organizations and resources.* ***Critical Path AIDS Project:*** *<www.critpath.org/critpath.htm>* ***Project Inform:*** *<www.projinf.org>* ***The Body:*** *<www.thebody.com> A world wide web site dedicated entirely to AIDS. Patients and others can obtain information, talk with others, and organise politically.* ***Quackwatch, Inc.:*** *<www.quackwatch.com> A nonprofit corporation whose stated purpose is to combat health-related frauds, myths, fads and fallacies.*

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Distant Healing and HIV/AIDS

by Jim Arachne

"Psychic healing" for people with AIDS works as well as some drug treatments? Prayer reduces illness and hospital admissions among those with HIV? "Spiritual healing" results in fewer AIDS defining illnesses? Perhaps people from some "weird New Age cult" or fervent Christians might believe this but surely no serious medical researcher or scientist would lend credence to such ideas? However, that is exactly what has happened!

Researchers from the University of California, the California Pacific Medical Centre, the Geraldine Brush Cancer Research Institute and the Sausalito Consciousness Research laboratory have completed a 6 month collaborative study which gives scientific support to the idea that "distant healing" can bring about significant improvements in health for people with AIDS.

Study Design

A) The Patients

The study enrolled 40 people with AIDS. They all had T4 counts of less than 200, all were taking, at least, preventative medicine for *Pneumocystis carinii* pneumonia and had also had at least 1 AIDS defining illness. People were grouped into pairs based on similar ages, T4 counts and the number of AIDS defining illness they'd experienced. Blood tests and psychological scores were done and then people in the pairs were randomly assigned to either receive "distant healing" or to a control group. None of the people in the study knew which group they were in. They were told "there's a 50:50 chance you'll be in the healing or control group". Throughout the study people continued to receive standard medical care and more than 90% were on protease inhibitors.

B) The Healers

The 40 healers who participated in the study were recruited from professional healing associations and healing schools. To be included they had to have, as a minimum, 5 years of continuous healing practice, previous experience in healing at a distance with 10 of more patients and done previous healing work with people with AIDS. The healers used a variety of techniques and came from very different backgrounds - some were Buddhist or Christian while other were Native Americans, Jewish or shamans. Some came from "non-religious" healing schools of bioenergetic or meditative healing.

Methods Used

The study was done using "healing at a distance". That is, the healer was not with their patient when they were conducting healing sessions. Indeed, study participants never met any of the healers, and did not know where they lived or when healing was being performed.

Healers were randomly assigned to treat individual people in the healing group and then were rotated to a new person every week. People in the healing group received an hour of "healing" every day. The technique used was left up to the individual healer - they were asked to "direct an intention for health and well-being" to the person they were treating.

After 6 months an independent doctor who had not previously taken part in the trial was called in to tabulate changes, if any, in the health of all study participants and then the study was "unblinded" - that is, people found out who had been in the healing or control group.

Results

On 6 scores people who had received healing were better off than those who had not. Compared to those in the control group people in the healing group had significantly fewer outpatient visits, less days in hospital, fewer new AIDS defining illness and fewer illnesses overall and, if when they did get sick their illness was less severe. Those receiving healing also had more improvements in their psychological health. By the end of the study they were less depressed and confused and had less tension and fatigue. More details are in the table below:

Health Related Events Over 6 Months Trial P value3	Healing Group Number = 20	Control Group Number = 20	
Outpatient visits	185	185	0.01
Hospitalisations	3	3	0.04
Days in hospital	10	10	0.04
Severity of illness	16	16	0.03
New ADD1 illnesses	2	2	0.04
Change in POM2 score	-25.7	-25.7	0.02

1. ADD means "AIDS Defining Illness." 2. POM stands for "Profile of Mood" - one of the psychological tests used. 3. The P value is a statistical measure of significance. Briefly, any score less than 0.05 is considered significant and unlikely to be due to chance. That is, all these results were seen to be "significant" and not due to chance.

Unfortunately, viral load was not measured. T4 counts increased a little for both groups but there was no significant difference between them.

Other Studies

Although these results may seem surprising many other studies have shown similar benefits.

One of the more publicised experiments involved patients in the coronary care unit at San Francisco General Hospital being prayed for by prayer groups. 192 patients received prayer versus 201 who did not. Neither patients, doctors or nurses knew who was in which group. Statistically significant results are shown below:

	Prayed For no.= 192	No Prayers no.= 201
Needed antibiotics	3	16
Developed fluids in the lungs	6	18
Needed mechanical help for breathing	0	12

Results of prayer for patients in coronary care ward at San Francisco General Hospital published in Southern Medical Journal 81: July 1988: pp 826-29

Other studies have been more remarkable in that "distant healing" was demonstrated to affect animals or cell cultures which shouldn't be susceptible to placebo effects. In one such study (J Amer Soc for Psych Res, 84, no 1, Jan '90: pp1-24) researchers placed fresh blood cells in test tubes of water. Normally the cells would then begin to swell and eventually burst. However, when 32 people in a distant room in the same building tried to "mentally protect" the red blood cells the cells remained whole for a statistically longer period.

Conclusions

Enough research has been done in this area to begin to establish some basic principles.

It doesn't seem to matter which deity is "prayed to" or if any deity's help is invoked at all. So far, no specific healing discipline has been shown to be more effective than any other - although further research may identify differences.

General, non-specific intentions may work better than very specific, directed intentions. That is, a general intent for a person "to have the best outcome", "let everything be for the best" or, if praying to a deity, "let thy will be done" might be more effective than trying for a focussed outcome such as "to fix my broken leg" or "raise my T cell count" - although both methods have been shown to be of use. This area needs more research. The healer benefits from their healing intentions as much as the person healed

Clearly much can be gained from further investigations of healing. The researchers who designed and conducted the original AIDS trial at the Univ. of California wrote: "The finding of reduced medical utilisation and improved medical course in the Distant Healing group is both exciting and surprising, but it remains crucial for this work to be replicated to be more confident that the effect is real."

Similar reservations were noted by the editor of the journal which published the results (*Western Journal of Medicine* 1998; 169:356-63). Dr Clever noted: "We note that the study was relatively short and analysed rather few patients. [However], this paper has been reviewed, revised, and re-reviewed by nationally known experts..... We have chosen to publish [it] to stimulate other studies of distant healing and other complementary practices and agents..... Now is the time for scientists to be courageous, as well as careful and precise, to help separate truth from hope and fact from myth..... It is time for more light, less dark....."

If you'd like to follow up other scientific trials of distant healing, a good reference book is *Healing Words* by Dr Larry Dossey, Harper Collins, 1993..

Jim Arachne is a Medical Herbalist and Complementary Therapy Educator with a specific interest in HIV and Hepatitis C. He has been conducting seminars for people with HIV throughout Australia since 1986. He is currently the Complementary Therapy Information Officer with the Victorian AIDS Council and is available for individual information consultations at the Positive Living Centre in Melbourne on Fridays between 11am to 1pm. For an appointment ring (03) 9525 4455. Victorian country people can have a free phone consultation on the freecall number 1800 134 840.

News Cont...

◆ Antioxidants may play a role in treating HIV

by Ed Susman, 3rd International Conference on HIV Infection and Nutrition, Cannes, France

In a study evaluating possible use of vitamin supplementation in people living with AIDS, Dr. Johane Allard of the Toronto Hospital said the antioxidants may play a role in treating the disease.

She presented in vitro, epidemiological and clinical data showing a decrease in liquid peroxidation - a marker of antioxidant activity - with vitamin C and vitamin E supplementation. In one study which recruited 29 HIV patients, she said, "There was also a small decrease in viral load among patients taking vitamins E and C, while viral loads rose in those on placebo."

Source: pi-treat Digest #160 - Monday, April 26, 1999 from the 3rd International Conference on HIV Infection and Nutrition. Conference highlights by Thomas N. Kakuda, Pharm.D. <kakud001@tc.umn.edu> Day 3: April 24, 1999

Access to Complementary Therapies by PLWHA's

by Claude Fabian

From the beginnings of the AIDS epidemic people living with HIV/AIDS (PLWHA's) have been using complementary therapies both to holt the progress of the virus and to improve quality of life.

Upwards of 80% of PLWHA's regularly use complementary therapies such as massage, counselling, acupuncture, Traditional Chinese Medicine (TCM), vitamins, homoeopathy, naturopathy, herbs, meditation, to name just a few.

In today's environment of combination therapies most people tend to include complementary therapies in an effort to manage the many debilitating side effects of the cocktails of medications used to combat HIV.

PLWHA's face a number of issues in accessing complementary therapies including a lack of accurate information and practitioners with an appropriate level of knowledge. It may be difficult to find information that is not tainted by conflicts of interest such as the desire to promote a particular product. Knowing how to choose or shop around for a practitioner that would be suitable to their needs can be difficult and confusing.

It is also important to find complementary practitioners, GP's and specialists that are willing to work together, which is not always easy. There's nothing more frustrating than your GP and specialist belittling the efforts you and your complementary practitioner/s are making or the other way around. Whilst this is unfortunate, it often happens, leaving the consumers in a fog of confusion.

These issues are usually much harder to overcome if you are living in rural or remote areas, where you have fewer choices and more often than not much travelling to do to access a practitioner.

Whilst the challenges mentioned can be overcome using some of the established networks of PLWHA organisations, the singular most difficult hurdle can be being able to pay for the chosen therapies.

Our public health system does not currently assist people in accessing any of the complementary therapies mentioned. There are some general practitioners who have undertaken studies in the above fields and choose to use this knowledge in their overall practice, and may therefore be able to bulk bill. There are very few of these GP's around and in some cases they may not have as much knowledge as say a herbalist or acupuncturist who has devoted anywhere from three to six years of study in their chosen field.

Private health funds provide for various types of refunds with respect to some complementary therapies. Unfortunately many PLWHA's do not have the financial means to access private health care due to living with limited incomes from a Disability Support Pension (DSP).

A number of submissions have been made to the Federal Government over the years in an effort to make some complementary therapies accessible through Medicare. To my knowledge all of these submissions have been either ignored or rejected by the Health Department. Some of the reasons given for rejection are that there is not enough scientific verification that these therapies are useful to there being no regulatory bodies to oversee the accreditation of therapists or that the ones that are in place are somehow not sufficient.

Underlying these rejections are issues of cost and the consistent opposition of the medical establishment to acknowledge that some complementary therapies are in fact very useful and merit inclusion in our Medicare system.

It is unfortunate that the preventative qualities of complementary therapies are not taken into account when considering their costs by our elected representatives and bureaucrats.

Unlike pharmaceutical companies who have millions of dollars at their disposal to lobby our government to include new therapies in our health system, complementary therapies lack this valuable resource, mainly due to their inability to be patented. Most complementary therapies have been around and have being useful for many years. For example Traditional Chinese Medicine has been utilised for thousands of years.

What can be done to remedy these situations by us as consumers?

One of the first things we can do is to inform ourselves. As the old idiom tells us "Knowledge equals Power". Publications that are independent or consumer orientated such as *Talkabout and with Complements* are preferable. Instead of publications that rely on advertisements, some of these publications are little more than advertorials for whatever product is the flavour of the month.

The Internet is a valuable source of information. View any article that hails the many wonderful and miracle cures that a particular product may be said to cure or alleviate, with a bit of caution. Again look for sites that are maintained by consumer based organisations whose purpose in producing and sharing the information is to empower their members to make informed choices.

Sharing information with other people facing similar situations continues to be one the most useful methods of augmenting what knowledge you may already have and finding new topics to investigate.

PLWHA/NSW Inc. has produced a resource that will go some way to improve access to complementary practitioners with it's 'NSW Complementary Therapies Directory'. Apart from providing a list of complementary practitioners who treat PLWHA's it also has some tips of how to go about choosing a practitioner.

The issue of how to pay for your complementary therapies once you choose what might work for you is a more difficult one to resolve in the short term. It will require continued lobbying by consumer organisations and a more orchestrated approach. It is hoped that the CHF 'Choosing your medicines workshop' in November '98 was a part of this process.

Ultimately what will work best for the consumer is a holistic approach to medicine that is, one that embraces western and complementary therapies.

Claude Fabian is Convenor of the Complementary Therapies Treatments Working Group, People Living With HIV/AIDS NSW Inc

News *Cont...*

◆ Sublingual Vitamin B12 as effective as injection

March 11, 1999. Peter Masebu, PANA Correspondent Dakar, Senegal (PANA)

Kathryn Slayter of the Queen Elizabeth II Health Sciences Centre at Dalhousie University presented the results of a comparative study of sublingual vitamin B12 supplementation versus vitamin B12 injection. Low levels of vitamin B12 have been associated with anaemia in eight to twelve per cent of HIV-infected people. After screening patients at an HIV clinic for decreased vitamin B12 levels, six subjects were enrolled in the study. All subjects had vitamin B12 levels below 156 pmol/L. The subjects were randomised to receive supplementary vitamin B12 either sublingually (under the tongue) or by injection.

After one month of therapy, vitamin B12 levels had returned to normal in all subjects. As a result, the researchers conclude that sublingual vitamin B12 offers a safe and effective alternative to vitamin B12 injection, in addition to being less invasive and more convenient to take. In addition, sublingual vitamin B12 is associated with no risk of accidental exposure to HIV for health-care professionals administering vitamin B12 injections.

It should be noted that this study was extremely small and makes no specific reference to the effect of sublingual vitamin B12 on patients with varying degrees of immune suppression. These factors may affect the results seen in the general HIV population.

Source: CATIE-News. Alain Boutilier, Translator/Editor. Wed May 5 1999. Copyright by the Community AIDS Treatment Information Exchange. For more information visit CATIE's Information Network at <http://www.catie.ca>

with Complements Website

After over 3 years of work from inception, *with Complements* is finally on the Internet. The site is at *<http://withcomplements.rainbow.net.au>*

There is still work to be done on the site but it is very useable now. The site works best with the latest version of your browser. The site includes every back issue of the newsletter from the first edition in November, 1991 in the "Archive". Readers can obtain copies of past issues or articles. The latest issues of the newsletter, currently not available, will be on the site real soon. There is a search engine on the site which allows you to find specific information on a subject from any and all of the published issues. As well there is information about *with Complements* and its history. There is also a "Links" section.

Other features will be added in time. You can email *with Complements* at *<withcomps@pia.org.au>* *with Complements* hopes you find the site rewarding and interesting.

Pets reduce depression in AIDS patients

New York, May 10 (Reuters Health) - Owning a dog or cat appears to significantly lower the risk of depression among male AIDS patients, according to researchers at the University of California, Los Angeles, School of Public Health.

Dr. Judith Siegel, a professor of public health and lead author of the report, told Reuters Health that the results of the study, one of the largest ever undertaken on pet ownership and depression, show "there really is something psychologically beneficial about owning and caring for a pet."

"I wouldn't necessarily advise someone to go out and buy a pet for someone who has AIDS, unless the person really wants a pet. But I would suggest that pet owners make special efforts to find housing where pets are allowed, rather than give a pet away if they have to move," she said.

In the survey of more than 1,800 homosexual and bisexual men, Siegel and her team found that men with AIDS who had pets were about 50% more likely to report symptoms of depression than men without AIDS. But men with AIDS who did not own a pet were about three times more likely to report symptoms of depression than men who did not have AIDS.

Dogs and cats offered similar benefits to the AIDS patients studied, the authors report. There were not enough participants with fish, birds, or other pets to determine whether or not they offered benefits.

"More important than the type of pet was the strength of the bond between the animal and the owner," explained Siegel. "The benefit is especially pronounced when people are strongly attached to their pets and have few close confidants."

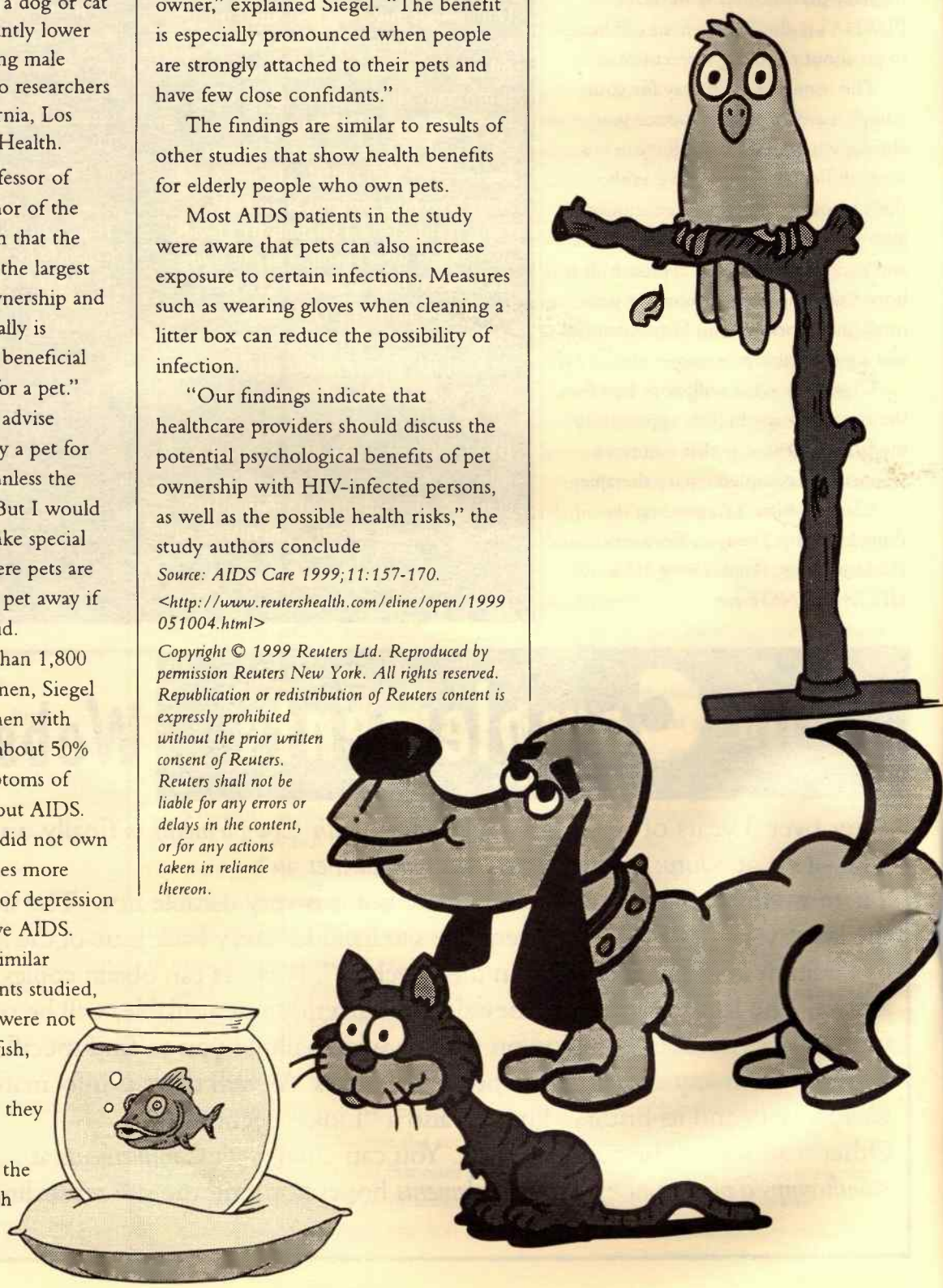
The findings are similar to results of other studies that show health benefits for elderly people who own pets.

Most AIDS patients in the study were aware that pets can also increase exposure to certain infections. Measures such as wearing gloves when cleaning a litter box can reduce the possibility of infection.

"Our findings indicate that healthcare providers should discuss the potential psychological benefits of pet ownership with HIV-infected persons, as well as the possible health risks," the study authors conclude

Source: AIDS Care 1999;11:157-170.

<http://www.reutershealth.com/eline/open/1999051004.html>



The use of traditional Chinese medicine to treat HIV disease in China

Antiretroviral drugs have not been officially approved to sell in China, so traditional Chinese medicine has been used for years in care of HIV disease, in conjunction with antibiotics and antifungal treatments and other routine care such as nutritional support.

At a presentation from Workshop on AIDS Diagnosis and Treatment held in 1996 in Beijing, by Professor Wei-bo, a researcher in Institute of Chinese Medicine, at least 12 preparations made of Chinese herbal medicines had been used by that time in treatment of HIV disease or AIDS in China or in other countries such as Tanzania.

Clinical observations on these medications showed that patients had experienced weight gain, decrease in symptoms such as fatigue, fever, diarrhoea, and improvement in some immunological indicators. However, few of these clinical observation had measured viral load.

Di Tan Hospital is one of two infectious Hospitals in Beijing where some HIV infected or AIDS patients have been treated (the other is You An hospital). Dr. Li Xing-wang, director of Department Three of the hospital, said that they had used two herbal preparations and herbal decoction to treat more than 30 HIV infected persons or AIDS patients. But they only observed symptomatic relief and CD4-cell count because the hospital's laboratory could not test viral load before. Even the clinical observation for these medications was not easy since only a handful of HIV/AIDS patients were identified and sought medical treatment in Beijing.

So the samples of patients in these observations were very small. It is hard to say the results were conclusive. Moreover, the pharmaceutical companies which provided Chinese herbal preparations were usually not affluent enough to support a systematic clinical trial.

Now the hospital has been appointed as one of the centers for clinical trials of AIDS-related drugs by National Bureau of Medical Drugs. They are planning to collaborate with some researchers and conduct clinical trial on some Chinese herbal preparations.

They are enthusiastic to share information with people in other countries. If someone needs further information, please contact Dr. Xing-wang Li (Director of Department Three) or Dr. Fu-jie Zhang (Director of Department One) at Di Tan Hospital.

Di Tan Hospital, #13 Di Tan Park, East District, Beijing 100011, China. Fax: 86-10-64281540. Dr. Xing-wang Li can also be reached by email: <xingwangl@263.net> Su-Su Liao, Beijing. Email: <susuliao@mx.cei.gov.cn> Web site: <http://www.icaap99.org.my> A posting from SEA-AIDS <sea-aids@hivnet.ch>

News *Cont...*

◆ Study results provoke increased scientific interest in NAC

N-acetylcysteine (NAC) is a supplement which many people with HIV take to increase their blood levels of a substance called glutathione. An antioxidant, glutathione helps rid the body of toxic substances called free radicals. As well, glutathione plays a role in supporting the activity of blood cells important to the battle against disease. In people with HIV, levels of glutathione tend to become deficient, a fact which may contribute to a higher incidence of disease and death. Researchers in Texas have now reported the results of a study designed to evaluate the role of NAC supplementation on glutathione production. For their study, researchers at Houston's Baylor College of Medicine evaluated rates of glutathione synthesis in five symptom-free AIDS patients and five healthy subjects. At the start of the investigation, those patients with AIDS had lower levels of glutathione than the healthy control group. As well, the rate at which glutathione was being produced in the group with AIDS was significantly slower.

After one week of NAC supplementation, significant increases in both glutathione production and concentration were observed. In fact, both the rate at glutathione was being synthesised and the overall level of glutathione in the blood returned to almost normal. The researchers therefore conclude that NAC supplementation may improve patients' ability to cope with HIV infection.

According to Dr. Farook Jahoor, further studies involving NAC supplementation are planned to help determine the optimal dose patients should be taking, as well as the effect of NAC supplements on patients at different stages of HIV infection.

American Journal of Physiology 1999:276:E1-E7.

News

- **Congress On Traditional Medicine** *March 11, 1999. Peter Masebu, PANA Correspondent Dakar, Senegal (PANA)*

The first international congress on traditional medicine and HIV/AIDS opened in Dakar Thursday amid complaints bypractitioners in that field that they were ignored in the fight against the pandemic. This was the view of a woman traditional healer from Nigeria, Elizabeth Kafaru, who was sceptical about calls by two leading Senegalese doctors, Ibra Ndoye and Souleyman Mboup, for an affective union between the two types of medicine to combat the unrelenting pandemic. She said that traditional healers, including those who had managed to reverse HIV symptoms like diarrhoea, found it difficult to consult their colleagues because they discouraged patients from consulting them.

"The best solution would be to conduct laboratory tests to establish the viral load of patients before and after taking traditional medicine to see the difference," she said during a panel at which the view points on traditional medicine were exchanged.

A delegate from Mauritania, where 90 percent of the population consults raditional or health healers, called for caution among African medicine practitioners before coming up with claims for curing AIDS.

Ibra Ndoye, had called for enhanced partnership between the two types of medicine, religious leaders and NGOs to at least prevent the spread of HIV, which now afflicts over 30 million people, 21 million of whom are located in Africa, with no cure in sight.

The panel's moderator, Dr Gilbert Parks, from the Black American psychiatrics Association in the US, had highlighted the importance of African traditional medicine, which had "kept alive the the knowledge of our ancestors."

He said it will probably be on the basis of this old knowledge that mankind might find a solution to the AIDS menace. "I am a trained doctor, but it was only after I came to Senegal that I learned what real healing means," he told the panel. A Belgian pyschiatrist said that although he was a trained doctor, he has always learned a lot from African traditional medicine every time he visits the continent. He urged Africans not to ignore that important sector of medicine.

Opening the congress on behalf of president Abdou Diouf, the Senegalese minister of scientific research, Balla Moussa Daffe, said that African traditional doctors should impart their knowledge to others before dying. Traditional healers need to train others so as to perpetuate what has been left behind by our forefathers," the minister said.

The convenor of the congress, Dr Eric Gbodossou, chairman of the Association for the Promotion of Traditional Medicine, said that he expected the current congress would create "a bridge" between the two medicines in the fight against HIV/AIDS. He urged African decision makers to base their health policies and HIV/AIDS control policies strategies on traditional medicine, which is "concrete, available, efficient and accessible."

"We do recognise that the means that have been used so far are in general unsuitable, far expensive or simply out of reach of our population," he added. The congress has brought together over 350 people from Africa, Europe and the US.

- **Chinese Herbal Medicine and Acupuncture**

Chinese herbal medicine and acupuncture have been studied for HIV/AIDS for a number of years in the US. We have been doing research with Chinese herbal medicine and acupuncture for HIV/AIDS since 1985 in San Francisco at the Quan Yin Healing Arts Center, and integrated East/West center primarily working with people with HIV/AIDS. Currently, I have completed three herbal studies with Dr. Donald Abrams for HIV-related symptoms at the UCSF Community Consortium and the SFGH AIDS Program , and an acupuncture study for co-infection of HIV and hepatitis (reported at the XIIth International AIDS Symposium Geneva), and an herbal study with physicians at the University Hospital in ZFGH. We are currently working to study a complete Chinese medicine approach to co-infection with HIV/HCV. The first double-blind, placebo-controlled of Chinese herbal medicine for HIV/AIDS symptoms is reported in J AIDS, August 1996, Burack, et al.

For those of you who would like to be on our HIV/AIDS and Chinese Medicine mailing list, please e-mail TCMPaths@aol.com. All newcomers are welcome. For more details, you can email <TCMPaths@aol.com> Misha Cohen, OMD, L.Ac.,Author, The HIV Wellness Sourcebook: An East/East Guide to Living Well with HIV/AIDS and Related Condition. Web: <www.docmisha.com> Email: <TCMPaths@aol.com>

◆ Stress Speeds Passage From HIV To AIDS, Support Retards It

Bangkok, Feb 23 (Reuters)

In a 5.5-year study of HIV-infected men, researchers have found that the men's passage to AIDS status was greatly accelerated by stressful events and by low levels of social support.

The probability of progressing to AIDS during the 5.5-year period was two to three times higher for HIV-infected men with more than average stress or with less than average support than for those below the median on stress and above the median on social support, the study published in the June issue of Psychosomatic Medicine reports.

"We showed that for every increase in cumulative average stressful life events - equivalent to one severe stressor or two moderate stressors - the risk of AIDS was doubled," said Jane Leserman, Ph.D., of the University of North Carolina School of Medicine, who headed the group of eight scientists conducting the study.

Leserman said that the finding with regard to the cumulative effects of stressful life events "is perhaps among the most compelling evidence to date linking psychosocial variables with HIV disease progression."

They started with 82 asymptomatic HIV-infected gay men and tested the participants every six months for disease status (AIDS was determined by CD-4 lymphocyte count below 200 and/or having an AIDS indicator condition), depression, stressful life events, and social support. Thirty-three percent of the men progressed to AIDS, in an

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average time of 2.8 years. Eight men died of HIV-related causes.

Major depressive episodes were not significantly related to AIDS progression in the study itself, and few men were depressed at testing times. But there was a trend for men who developed AIDS to be twice as likely to have had one or more major depressions before the onset of AIDS than those who did not develop AIDS.

She added, "Now we need to determine whether interventions that have been shown to reduce distress and improve social support can alter the course of HIV infection."

The study was supported by grants from the National Institute of Mental Health and the National Institutes of Health. AEGiS From: <PoWeRTX@aol.com> Date: Tue, 25 May 1999. Psychosomatic Medicine is the official peer-reviewed journal of the American Psychosomatic Society, published bimonthly. For information about the journal, contact Joel E. Dimsdale, M.D., editor-in-chief, at 619-543-5468.

◆ Most Frequently Used Alternative and Complementary Therapies and Activities by Participants in the AMCOA Study

Journal of the Association of Nurses in AIDS Care (05/99-06/99) Vol. 10, No. 3, P. 60; Greene, Kari B.; Berger, Jose; Reeves, Cherie; et al.

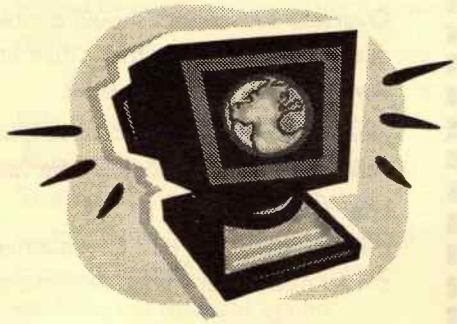
Investigators from Bastyr University AIDS Research Center looked at the most popular complementary or alternative medicine (CAM) that AIDS/HIV patients practice using data derived from peer-reviewed journals indexed in MedLine reported by 1,016 participants in the Alternative Medical Care Outcomes in AIDS (AMCOA) study. The most popular CAM activities were aerobic exercise (64 percent), followed by prayer (56 percent), massage (54 percent), needle acupuncture (48 percent), and meditation (46 percent). The list was rounded out support groups (42 percent), visualisation and imagery (34 percent), breathing exercises (33 percent), spiritual activities (33 percent) and other exercises (33 percent). In most cases CAM was found to be of benefit to the mental health of the patient; however, some also yielded enhanced physiological well-being, including exercise and aerobics.

Source: CDC HIV/STD/TB Prevention News Update. Monday, May 17, 1999.

◆ New email list for Australian heterosexual people with HIV

A new email list, based in Cairns, for Australian heterosexual people with HIV is now on line. The moderator of the list, who is HIV positive, says one of the aims of her list is to "exchange health regime information, particularly on complementary therapies." The list will also offer peer support and discussion. The list is not exclusively HIV positive and heterosexual, but is intended to have predominantly an Australian heterosexual focus. The web site is <http://www.hetx org> and email is <hetro@hetx.org>

Source: Direct communication.



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with Complements **is made possible by funding from the NSW Department of Health.** ***with Complements*** **is also grateful to People Living with HIV/AIDS (NSW) Inc. for assistance with resources, ACON for funding administration and particularly to our readers for their ongoing support.**

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