

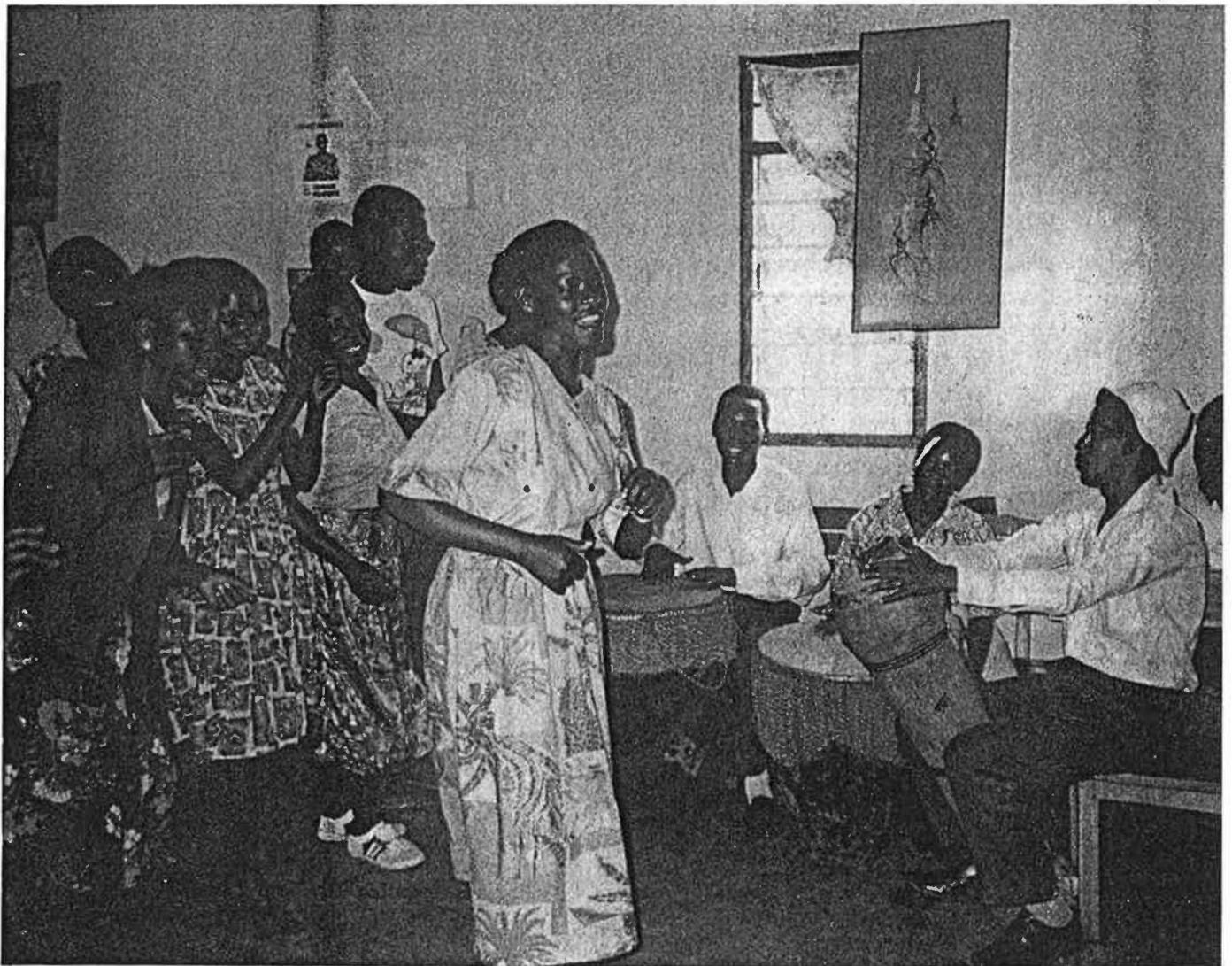
Vol. III No. VII October 1992

Talkabout

The Newsletter of People Living With HIV/AIDS Inc NSW

◆ Where We Speak for Ourselves ◆

AFRICA



a not-so-dark continent

En attendant acyclovir

AS *TALKABOUT* GOES TO PRESS, Wellcome Australia claims to be in negotiations with its parent company over the issue of providing high-dose acyclovir for people with HIV.

Wellcome Australia has been under pressure from an extraordinarily wide range of people, including activists, doctors, researchers and even government bodies, to make high-dose acyclovir available.

In December, a Wellcome-sponsored trial showed that certain people with HIV (those with less than 150 CD4 cells and who also test positive for the virus CMV) could live longer if they took 3200 mg of acyclovir a day. Most people in that trial were on AZT as well.

While acyclovir has been approved in Australia, the approval only covers its use as a herpes drug. Its use as an HIV drug cannot be approved until Wellcome submits an application to do this, which Wellcome says it will do in November. In the meantime, the funding bodies which usually pay for acyclovir will only pay when it is used as a herpes drug.

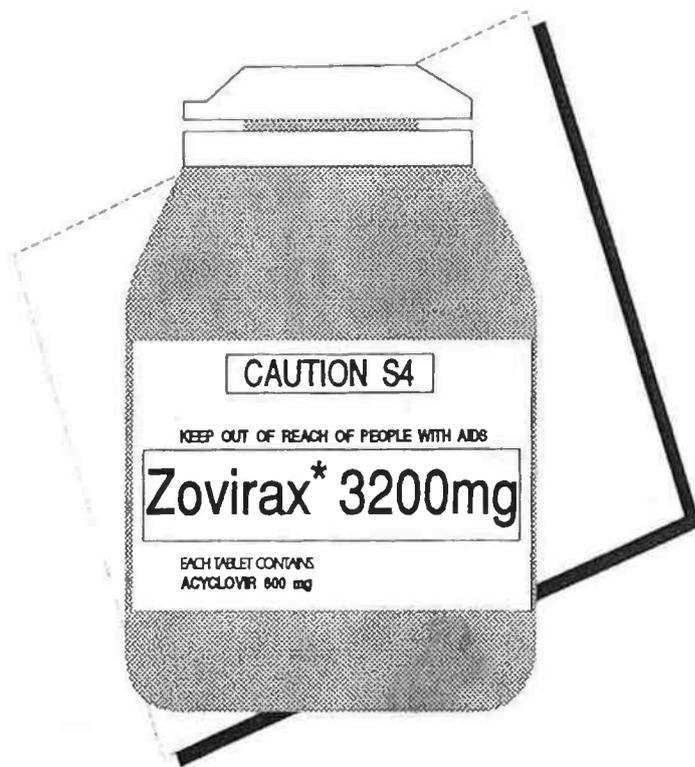
Theoretically it is possible for a person to purchase acyclovir with a doctor's prescription. However, its high cost prohibits this. At the dose used in the trial acyclovir would cost about \$10,000 a year.

In recent months the Commonwealth Clinical Trials and Treatments Advisory Committee, the Australian National Council on AIDS (ANCA), the National Centre in HIV Epidemiology and Clinical Research and the AIDS Council of NSW have all requested that Wellcome make high-dose acyclovir available. ACTUP has placed advertisements in gay community newspapers urging for a boycott of Wellcome products until this is done.

Wellcome is expected to announce by the first week of October any arrangements it will make to provide high-dose acyclovir.

— Lyle Chan

(See also page 4).



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This Month's Cover

The Music and Drama Group of The AIDS Support Organisation in Uganda (TASO) rehearse a show. The group does outreach education in schools, churches and villages. (See page 10).

Photo: Jill Sergeant.

Update: anti discrimination

NSW Anti-Discrimination Board Inquiry Report into HIV and AIDS Related Discrimination.

NSW ATTORNEY GENERAL JOHN HANNAFORD has established an Advisory Committee to monitor and evaluate the implementation of this Report's recommendations by government departments and other organisations.

The Committee is chaired by former Senator Chris Puplick. Members are Peter Grogan (ACON President), Guenter Plum (PLWHA NSW), David Lowe (Director, AIDS Bureau), Clover Moore, MP, Phillip Chown (Gay & Lesbian Lawyers Association), and Sr Margaret Mines (St Vincent's Pastoral Care). Following a request by a meeting of community organisations (both HIV/AIDS focussed and gay and lesbian) that a PLWA be appointed to the Committee, representations were made to the AG, who appointed Neil McGowan from a list of people nominated. Neil is a doctor (no longer practicing), open about his status, and keen to help redress the discrimination experienced by people with HIV and AIDS, their friends, carers etc.

The Committee will produce several interim reports for the Attorney General and a final (public) report by the end of June. Its intention is to have the Report's recommendations implemented by then, although that will necessarily be a partial implementation as many recommendations require phasing in or have lead times of up to twelve months to prepare or introduce changes. An energetic start has been made on what is a mammoth task, with four meetings scheduled in its first six weeks.

Right now we are all waiting for the promised statement to Parliament by Premier John Fahey, announcing the Government's

"endorsement" of the ADB Report. Hopefully he will also announce the Government's intention to resolve the qualifications ("further consideration required", etc.) which currently mark its response to many of the recommendations. Stay tuned.

National HIV/AIDS Anti-Discrimination Education Media Campaign.

TWO WEEKS BEFORE THE PLANNED launch this TV and newspaper campaign, which was developed with the co-operation of PLWHAs, has been deferred until early in the new year. There are many reasons, the most important being that more research needs to be put into some aspects of the campaign to make sure that it will reach most Australians and that they will act on the message of the ads.

A lot of people will be working very hard over the next few months to ensure that the campaign will not be put into the too-hard basket.

— Guenter Plum

Drug access extended

ACCESS TO SUPPLIES OF AZT AND acyclovir — which were about to run out — have been extended for people who took part in two now-concluded trials. The supplies have been extended by another six months by the drug company Wellcome Australia.

One trial, which was placebo-controlled, proved that very early intervention AZT among people with more than 400 T4 cells was worthwhile. The second showed that high-dose acyclovir, a drug usually used to combat herpes, extended life in people with advanced HIV disease.

Both trials were concluded earlier this year when researchers found significant benefit. The AZT trial was the first in the world to

reach these conclusions.

Part of the deal by which people were recruited for these trials was that, if benefit was demonstrated, people taking part would be offered active treatment when the trial concluded.

But earlier this year Wellcome offered only six months supply. For the participants of both trials, the six months is now up. Many patients and their doctors were worrying whether the supply was about to run out.

Following pressure from researchers, Wellcome announced that the supply would not be cut off after all, at least not yet.

Wellcome is still preparing submissions to the Australian Drug Evaluation Committee for approval to market these drugs for these important new uses. It is unlikely that these will be ready before the new year.

The chief investigator of both trials, Associate Professor David Cooper, said he believed Wellcome would actively push ahead with the approval process.

But the good news on access applies only to people who took part in the clinical trials. Meanwhile, Wellcome is resisting angry pressure from ACT UP and other community organisations to make free supplies of acyclovir available to all who need it.

Wellcome relies on its two big-selling antivirals, AZT and acyclovir, for much of its international profit. A third of the company's British operation recently changed hands on the London Stock Exchange for \$A10 billion.

— Martyn Goddard

Community trials

A DIRECTOR HAS, AT LAST, BEEN appointed to the Community HIV/AIDS Trials Network. He is Dr Don Smith, whose last job was researching PCP prevention and

treatment at St Stephen's Hospital in London.

CHATN was set up about three years ago to extend trials and trial drugs to people without ready access to major teaching hospitals. The idea was to recruit a network of GPs whose patients would not need to go to hospitals to be able to take trial drugs. It would also make recruitment for some large scale trials easier. But funding to appoint a director was received only this year.

The trend towards community-based HIV medicine was necessary because, characteristically, people with HIV remained well for so long. It was therefore appropriate for early intervention treatment to take place in the community setting, rather than in a hospital.

"It was one of many changes being forced onto the medical system by the realities of the epidemic," Dr Smith said.

Dr Smith agreed early intervention treatment appeared increasingly to be the way of the future.

"I've always been of the belief that HIV disease is not, and never has been, an infection where someone picks up a virus which remains latent until all of a sudden they become unwell. It requires a lot of damage before people notice any effects. . . the sooner you can interrupt the virus, the longer people are going to remain in good health.

"Really, if you have a safe, effective antiviral, you should give it to a person as soon as you know they are infected.

"What I would really like to see CHATN doing is to use some of these newer agents at a much earlier phase."

Dr Smith is based in Sydney at the National Centre in HIV Epidemiology and Clinical Research, which runs most of Australia's clinical trials. He is in the process of setting up a national network of GPs and will visit

Melbourne and other state capitals shortly — and, he says, frequently. — M.G.

Positive women

THE RESOURCE PACKAGE "POSITIVE Women", consisting of a documentary style 20 minute video and a booklet of up to 40 women's stories was launched in Melbourne on June 22.

This package, auspiced by the Victorian AIDS Council and funded by CAPE, has been distributed nationally to HIV positive women seeking support. It has also been given to their immediate health care workers to sensitise them to the various needs of HIV positive women.

The video created an opportunity for positive women to speak for themselves to other women about personal coping strategies, overcoming isolation through sharing experiences with each other and gaining confidence through knowledge.

The booklet continues this theme with anecdotal and factual information on legal issues, telling others, diagnosis and many other issues faced by women living with HIV or AIDS.

The ACON Women and AIDS Project and HIV Support Project undertook the task of evaluation and orientation of this product in NSW. Two sessions were held for 20 - 30 health care workers and researchers. S  n n   Chrochuir and I took this opportunity to emphasise that this valuable resource has been made primarily by and for positive women, particularly women in isolation and newly diagnosed women.

The consensus of the evaluation was that although much of the information and insights in this package is not readily available, this resource is primarily for *positive women* and using the package as a training aid would

undermine the confidentiality of the women who have openly and honestly shared their experiences.

ACON can distribute "Positive Women" to HIV positive women and their direct health care providers. If you fit this description and have not yet received this unique package, please contact the Women and AIDS Project, (02)283 3222.

— Vivienne Munro

HIV at work

THE COMMONWEALTH DEPARTMENT of Health, Housing and Community Services is funding Worksafe Australia to develop a *National Code of Practice for Health Care Workers and Other People at Risk of the Transmission of HIV and Hepatitis B in the Workplace*.

The draft of this National Code of Practice was released for public comment on October 5. Public comment closes December 31, 1992. Your comments will be taken into consideration prior to the issue of the final version of the Code. For a free copy, call the Publication and Sales Section of Worksafe Australia on (02)565 9555, or write to this Section at PO Box 58, Sydney NSW 2001.

PLWHA Committee

Co-Convenors

Alan Brotherton, Wayne Holt.

Treasurer

Gerald Lawrence.

Secretary

Robert Van Maanen.

Claude Fabian, Peter Hornby,

Michelle Morrison, Kosta

Matsoukas

Three positions are vacant.

Correction

In the September *Talkabout* it was stated that guidelines on confidentiality had been issued by the Health Department (page 2). This was incorrect. The AIDS Bureau has advised us that the guidelines will probably be issued by the end of October.

Talkabout

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Talkabout is also grateful for the assistance of the AIDS Council of NSW.

DEADLINE FOR THE NEXT ISSUE

October 19

Send contributions to PO Box 1359 Darlinghurst, NSW, 2010. Call Jill for the date and time of the next Newsletter Working Group meeting.

How to Contact People Living With HIV/AIDS Inc (NSW)

Talkabout Co-ordinator
Jill Sergeant
Level 2, AIDS Resource Centre,
188 Goulburn Street,
Darlinghurst NSW 2010
Ph: (02) 283-3220
TTY Only (for deaf and hearing
impaired) (02) 283-2088
Fax: (02) 283-2199

Committee News

Alms for the poor

PLWHA IS AWAITING THE OUTCOME of funding submissions to the AIDS Bureau of the NSW Health Department. We are requesting an administrative support officer to handle the ever growing number of telephone and information requests and enough money to maintain *Talkabout* at its current size and quality.

The PLWHA submission has been supported by the AIDS Council of NSW, the Australian Federation of AIDS Organisations and the Central, Eastern and South Western Area Health Services. We hope to pass on good news soon.

Housing

THE HOUSING SITUATION IN Sydney continues to provide little comfort for PLWHAs requiring public housing. The Department of Housing has made real progress in sensitivity training and in their efforts to maximise current housing stock. However, the virtual ceasing of any building projects in inner Sydney means that people in need of public housing face a crisis. This is a problem that will not be quickly resolved and will require the input of many people. PLWHA is discussing tactics with ACON and the Gay and Lesbian Rights Lobby.

AFAO Conference

I ATTENDED AN AFAO MANAGEMENT Conference in Canberra on September 14 - 16. This was a unique opportunity to peer into the dark recesses of the federal AIDS bureaucracy. There are more committees and working

parties in Canberra than I've had hot dinners. Most of them do good work.

The Conference was a chance to meet the people in charge of the AIDS Councils in each state. Most do a wonderful job under trying conditions. Some don't. I believe that PLWHAs get a mixed reception from their respective AIDS Councils, which vary widely from state to state.

Conferences like this inevitably cause me to think about my own back yard. I would like to put the view that ACON, while it is still a difficult organisation to deal with, scrubs up very well in comparison with some other states. ACON has room to improve, but problems are at least recognised. Some states cannot claim any great success with the involvement of PLWHAs in decision making structures.

The Conference also gave me the opportunity to meet PLWHAs from other states, hopefully the basis of a strengthened network.

ACON Committee of Council

ON SEPTEMBER 14 THE ACON returning officer, Robert French, declared the following positions elected unopposed:

President: Peter Grogan;
Secretary: Wayne Holt; Vice President: Robert Walmsley;
Treasurer: David Harbourne.

Several openly positive candidates stood for Committee member positions, and of these, two PLWHA committee members, Peter Hornby and Gerald Lawrence, were elected.

The Shift comes through again!

PLWHA RECEIVED A CHEQUE FOR \$2,500 from the management of the Midnight Shift recently. The money was sorely needed and will resource a number of activities for people living with HIV and AIDS. A large vote of thanks goes to Terry Paterson and the staff of the Shift.

Speak out when bureaucrats bite

THE PRIVACY COMMISSION IS interested in hearing about the problems experienced by PLWHAs who have had their confidentiality breached by federal government departments. (This includes Taxation, Social Security, CES and Immigration).

One of the ways in which we can protect our rights is to report incidents as they happen. The Commissioner is keen to act on complaints.

Write to:

Privacy Branch
Human Rights and Equal
Opportunity Commission
(HR & EOC)

GPO Box 5218, Sydney 2001

Or just speak out!

ADVOCACY AND REPRESENTATION continues to take a large part of the Committee's time. Over the past month, members have been telling their individual stories at many forums, such as medical conferences, the Public Interest Law Conference, schools, trade unions, churches and so on. PLWHA would like to encourage many more people to come forward and tell how it is.

North coast AGM

PLWHA MEMBER MICHAEL STAIFF attended the Annual General Meeting of ACON's North Coast Branch. He also met with members of the branch and the Positive



Position Vacant PLWHA Co-ordinator

PLWHA Inc. (NSW) aims to empower people affected by HIV/AIDS in NSW by providing information and advice on all HIV/AIDS issues; lobbying all relevant organisations to ensure the best possible levels of care, support and treatment; and promoting a positive image of people affected by HIV infection and AIDS.

We are looking for a dynamic and dedicated person who primarily understands the needs of people with HIV infection and AIDS. The person would be responsible for managing the day to day running of the office, administrative/financial duties, supporting the work of the PLWHA committee, co-ordinating volunteers and providing information and referral services to members.

The successful applicant must have experience in managing a small office or community based organisation. We are seeking applicants with time management skills, computer skills and the ability to work with volunteers. The person must have sensitivity to people living with or affected by HIV/AIDS.

Selection criteria:

Essential: 1. Demonstrated experience in managing a small office or a community based organisation; 2. Demonstrated ability to manage time effectively and work to tight deadlines; 3. Sensitivity to the needs of people living with or affected by HIV/AIDS; 4. Demonstrated ability to work with people at all levels, in particular the ability to work with and encourage volunteers; 5. Demonstrated understanding of HIV/AIDS issues; 6. Experience in wordprocessing and maintaining a computerised database. **Desirable:** 1. Skills/experience in servicing the needs of a community based organisation; 2. Skills/experience in making presentations; 3. Skills/experience in making referrals.

Affirmative Action Policy

PLWHA Inc. (NSW) is an equal opportunity employer.

PLWHA has an affirmative action policy in respect of people living with HIV. Thus, if two or more applicants for a position are equally qualified, favour will be given to those applicants who are HIV infected.

Salary \$33,548 per annum

A duty statement, terms and conditions of employment and selection criteria must be obtained before applying. Please call Wayne Holt on (02) 793 0722.

Closing date: October 26 1992

Time group. Hopefully there will be more opportunities to hold meetings with regional groups across NSW.

PLWHA may be able to offer some financial support to regional groups for activities that aim to overcome the isolation of PLWHAs, to assist people in accessing services and in reporting discrimination.

Conference notes

THE FIFTH NATIONAL CONFERENCE on HIV/AIDS will be held in Sydney from November 23 to 25. On the Sunday night (November 22) prior to this another Anti-body party will be held upstairs at the Midnight Shift by ACON's HIV Support Unit and PLWHA

Inc (NSW). This dance party offers a fabulous chance to socialise and have fun before the hard yakka of the conference.

The PLWHA Committee seeks to establish much stronger links with any PLWHAs from country NSW who are in the big smoke for the Conference. Committee members will be reasonably conspicuous during the conference itself, but in addition We intend to hold a social gathering for all PLWHAs from country NSW on Tuesday November 24 from 5pm to 7pm at Gilligan's bar (1st floor, Oxford Hotel, Taylor Square). Please join us for a drink and a chat.

— Wayne Holt,
Co-Convenor

Talkback



Prison opinions

I MUST COMMENT ON THE HIV AND Prisons article in the September issue of *Talkabout*. Jo Weston is entitled to his opinions on the current situation within the New South Wales Correctional Centre System in regards to HIV and AIDS, however the comments on the incident involving the infection of a prison officer were unwarranted, malicious and not deserving of printing.

I would have expected better from *Talkabout*, particularly as the officer was named (it appears confidentiality is not only an issue for the Department of Corrective Services) and the mode of transmission questioned (does this make him an innocent or guilty victim now?).

In response to the relevant issues raised by the article I would like to let your readers know that the Prison Medical Service is currently reviewing all of its services with the assistance of the Department of Corrective Services, Health Department and community agencies. In particular all HIV/AIDS services are being reviewed by a working group consisting of staff from the Prison AIDS Project, Prison Medical Service, ACON, the AIDS Bureau and Prince Henry Hospital.

Whilst it is acknowledged that there are problems in the correctional centre system the efforts of the Prison AIDS project and the Prison Medical Service to provide a level of HIV/AIDS education, service and treatment equal to that in the community should not go unmentioned.

The Department of Corrective Services recognises the potential HIV epidemic for inmates and has a number of initiatives to counter this. As Jo Weston states "the prison system may have some faults but HIV/AIDS ignorance is not one of them". Perhaps an article on what services and programs are available would also be beneficial for your readers.

I wish to reiterate that Jo Weston is entitled to his say, however *Talkabout* surely has a responsibility to present a researched and balanced article without prejudice to any organisation or in particular any individual.

Gino Vumbaca
Manager, Prison AIDS Project
Department of Corrective Services

Share a home defended

THIS LETTER IS IN RESPONSE TO Peter of Newtown's letter published in last month's *Talkabout* under "Housing discrimination".

When ACON had a Share Accommodation service for HIV positive people and others, the only other alternative was an agency that charged a fee to all concerned, and, as we know, having HIV can sometimes have quite an effect financially.

The homes ACON had all came from people who approached ACON to help them find a flatmate. In other words, people who were aware of HIV, wanted a flatmate, wanted to help and didn't mind having someone in their home who might be HIV positive.

This side of ACON's

accommodation service was wound up because Share a Home was started to help everyone find a home no matter what their financial, health or emotional situation, and also because it is free to homeseekers (people looking for a home to share).

Peter is fortunate that he has the lease on the home he lives in. If someone moved in who didn't wish to live with an HIV positive person and a situation arose where Peter got sick, his flatmate would more than likely move out. Peter would then have to find himself a new flatmate. On the other hand, if Peter moved into someone else's house, and that person didn't want to live with, or couldn't cope with the emotions involved in helping to care for someone who has HIV and is ill, Peter could find himself looking for a new home.

There are many situations that have arisen at this agency where:

- a flatmate has been found to be HIV positive and was then thrown out onto the street because the person they were living with couldn't cope with the situation;
- a flatmate has moved out because they couldn't cope with the situation.

The reason I ask "if you mind living with someone who has HIV" is to make this less likely. As we all know, if you get sick you need all the help and support you can get, without the added drama of finding a new home to live in because the person you're sharing with can't cope.

Peter decided he didn't mind seeing people who didn't want to live with anyone who is HIV positive, as he would take that

risk. So the question was unnecessary in Peter's case. But a lot of other people who contact this service do want to know that the house I am sending them to is HIV friendly.

He also neglected to tell you I did find him a flatmate who didn't care about his HIV status.

I don't agree with Peter that HIV shouldn't be an issue. If you are HIV positive and a flatmate moves into your home, or you move into someone else's home, wouldn't you like to know that it wouldn't be a problem with them, so you could possibly get some support from them if the need arises?

Regarding Peter's comment that I said a person "sounded like a bit of a dickhead anyway, really dumb": the word dickhead is not a word I would use. I would have said "He must be a bit ignorant about HIV, if he thinks he can avoid being involved with it, within our community".

It is unfortunate that discrimination exists throughout this country, we would all like to cut it out totally. But in the case of share accommodation you should be able to select and decide what type of person you want to share with, as you have to live with them and put up with their quirks etc. If it was illegal to discriminate in share accommodation there would be less properties available on the market. Because why would you live with anyone that you could not be comfortable with? As an example, I have people using this service who wouldn't live with: girls, guys, transvestites, smokers, animals, vegetarians, the unemployed, party animals. These are all discriminatory requests people have regarding who they want to live with.

Of those who wouldn't live with someone who is HIV positive (only 5% of my clients) the most common reason they give is that a friend has died of HIV, and they

couldn't go through the emotional roller coaster again.

Stephen Haire
Proprietor, *Share A Home*

Share - a - gripe

WELL THANK YOU PETER FOR YOUR last letter to this paper. I have also had the same problem. Got in touch with the same share accommodation, stated I was HIV positive but cannot find anyone I can share with. I was HIV positive, is that a dirty word? No-one wants to know you.

I ended up in a rooming house paying \$100 per week. What has happened to "we are one, we fight together"? I have not seen any of it. It seems gays are *not* coming together as one.

Name withheld by request

Mum's request

THANK YOU FOR YOUR MAGAZINE, I find it very informative on all aspects of the gay scene. If it's possible could you please print this letter from a mother who has a gay son. He has disappeared and doesn't want anything more to do with his family. I hope he is safe and well.

I am not very good at writing in flash words but is it possible to

print a parent's view of having a gay son?

Son, I know you are hurting, we are hurting too, but is being gay a reason to disown your family? We love you, we love you for being you, you have the right to your life as we do. But that is no reason to throw us aside. Please accept yourself, love yourself and hold your head high.

It hurts more not knowing where you are, and that you don't want to be in the family, than it does that you're gay. As your mother I have had to come to grips with all the issues of you being gay and the gay scene. You said I needed educating, that I have, but doesn't it go both ways? If we are to understand you, so do you need to understand where we are coming from. But it all boils down to: it doesn't matter, big deal, so what, you're gay. Maybe you have a name for me but I just call myself your mother. You are my son, I love you. I'll even let you have all my jewellery. Please son, just ring to say hello.

Maureen Martin.

We welcome your letters.
Send them to:
**Talkabout, PO Box 1359
Darlinghurst, NSW, 2010**

DDI

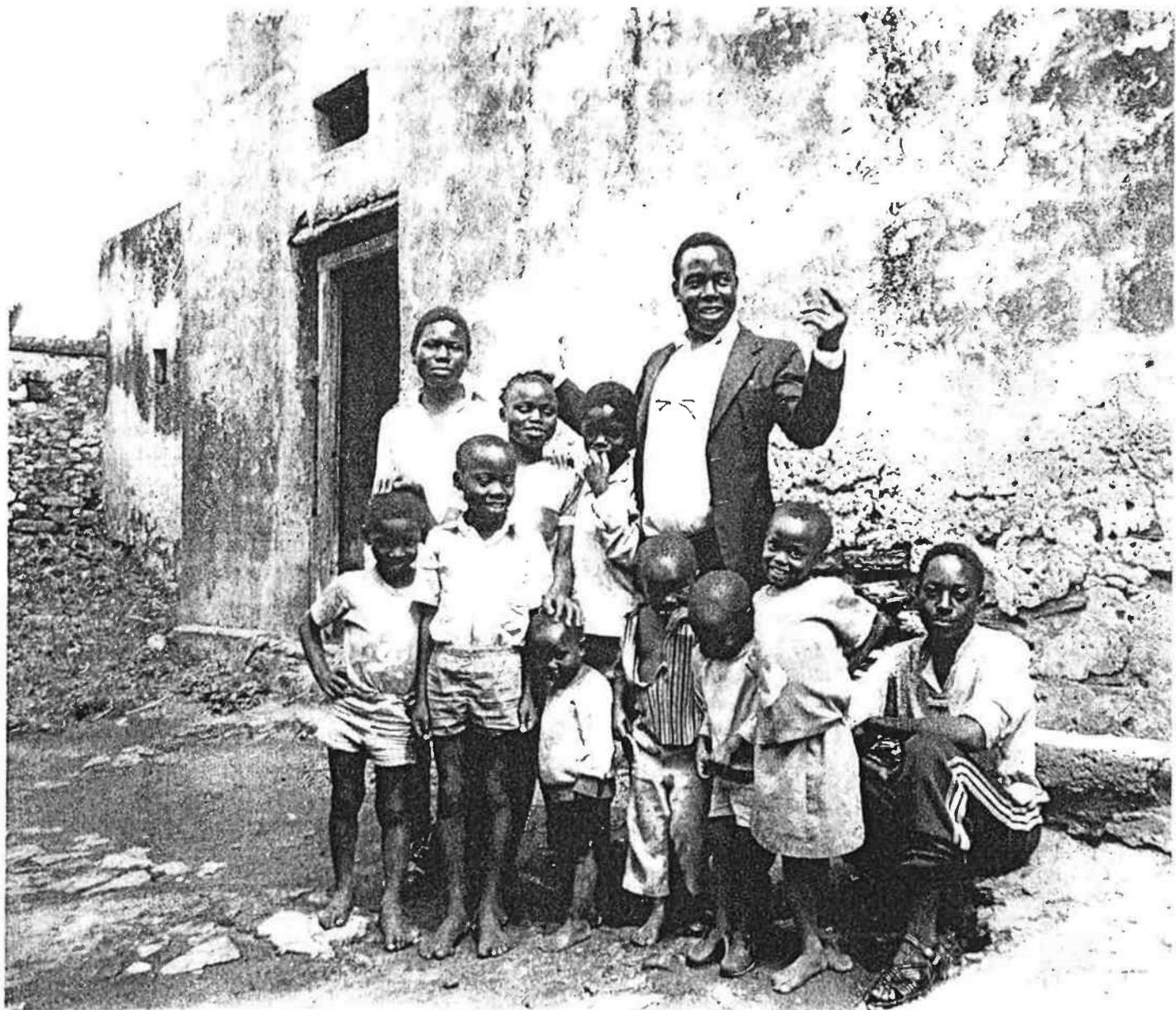
(An ode for the 90s)

DDI is a horse tablet; two in fact:
A calcified peppermint LifeSaver (without the hole),
Worthy of the dentist's glass with its dribbling
stainless-steel swan's neck.
A last resort: a security blanket.

And HIV is a horse tablet too; in fact.
You must learn to cope with *it* and *them* . . .
The rubbery bars of your shaky cell
(As they easily admit the uncaring souls)
Allow you the freedom to dream and to live.

So reflect on this as you crush that pill:
Your soul is your own — *your* liberty still.

— Allan



Long term Subscriber Januarius Rodgers, (centre) with some of his young neighbours in Fort Portal, Uganda.

Light in the dark continent

For the last two months Jill Sergeant, Talkabout Co-ordinator, has been playing foreign correspondent. This is her report on visiting HIV and AIDS organisations in East Africa.

THERE'S A POIGNANT SONG WHICH begins: "I'm hearing only bad news from Radio Africa", and proceeds to catalogue the continent's woes — war, famine, AIDS. I don't think it's sung by an African band, which perhaps is why it's only about the bad news.

Listening to African music, and having African friends in Sydney, I've long been convinced that grief isn't the only thing to come out of Africa. That's one of the main reasons I decided to go there and visit grass roots HIV/AIDS organisations. There had to be some good news.

So in mid-July I hopped on a flight to Amsterdam, my first port of call en route to East Africa. I was full of hope that it would be an exciting trip, and terrible fears that it would be a total disaster and I might never return, victim of some exotic tropical fever in the swamps of Uganda.

My itinerary was structured around the fact that *Talkabout* has two Long Term Subscribers in East Africa. One, Januarius Rodgers, in a place with the unlikely name of Fort Portal in South West Uganda; the other, Rowlands Gombe Lenya, in Nairobi, Kenya. It was reassuring that Fort Portal was listed in my *Africa on a Shoestring*. I decided I would concentrate on Uganda (for all of two weeks) with a quick whip around Nairobi AIDS organisations and then check out either Zimbabwe or South Africa or both.

At the International Conference on HIV/AIDS in Amsterdam I met David Scheinman, a gregarious American; his project was working with traditional healers at a place called Tanga on the coast of

Tanzania — why didn't I come and visit? I was going to be visiting game parks in Tanzania, the project sounded promising, so Tanga herbs elbowed Southern Africa off my agenda. I planned to spend seven weeks in Africa, three of which were to be a holiday. In July, it seemed a huge amount of time. Once I'd arrived, it was all too short.

*It doesn't really matter
how many people are
infected right now.
Whether it's 6% or 60%
of the population,
fighting AIDS is an
uphill battle.*

MY SAFARI BEGAN IN NAIROBI, A dingy city of dusty bougainvilleas and musical bus horns. I got off to a bad start, my bag was snatched the day I arrived. Farewell to *Africa on a Shoestring* (perhaps not such a bad thing), and, worse, to my diary, camera and sunglasses. Fortunately, my absolutely vital address list (kept in duplicate) was not lost and I was able to contact Joe Muriuki, Director of Kenya's Know AIDS Society (KAS).

On my third day in Africa, I was driven to KAS in a grand black Austin taxi past some of the slums and shanty towns of Nairobi. I felt numb by the time I arrived. Looking back, this was my first indicator of what AIDS means for Africa. In the developed world, we're obsessed by statistics. In Africa, the poverty in which so many people live is the biggest problem. It doesn't really matter how many people are infected right now, whether it's 6% or 60% of the population, fighting AIDS is an uphill battle. Accurate statistics, in any case, are hard to find, and outside of Africa it's always the worst figures that get the most

publicity. When you're in Africa, you don't need the numbers to know how bad it is.

The Know AIDS Society was formed in 1989 and the KAS Centre was opened, with assistance from the World Health Organisation and the Ford Foundation, in January this year. Like many such organisations, KAS was started as an informal mutual support group by eight HIV positive people who somehow found one another in this country where Joe Muriuki estimates only about five people are completely open about their HIV status. The Centre now runs a Hotline, provides counselling, an informal support group and educational outreach. It is open every day to PLWHAs who can come in for company, a meal and some activities. Many who use the Centre are unemployed. KAS counsellors are also giving pre and post test counselling at six clinics around Nairobi.

Joe's wife, Jane, is working on setting up a positive women's group and a program to assist orphans, is a consultant for the organisation of the International Conference in Berlin in 1993, and hopes to organise a positive youth group in the near future. KAS depends almost entirely on overseas funding.

On a later visit to Nairobi I finally caught up with Rowlands Gombe Lenya. He's a busy man; I'd tried to contact him on previous visits but never managed to actually meet him until the day before I left Kenya.

I'm glad I did. Like so many of the people I met in Africa, Rowlands is a generous man, rich in compassion and ideas for change. He is a founder of The Association for People With AIDS in Kenya (TAPWAK), a sister organisation to KAS which does not yet have quite the same level of resources. TAPWAK has about ten active members who do



no-person's land. But Uganda is not the burnt out, savage place you might imagine. As soon as you cross the border from Kenya the effects of war are very visible — half demolished buildings with weeds growing through them, almost non-existent roads and energetic rebuilding projects. But in Kampala, the capital, the atmosphere is calm, the streets are clean (though seriously potholed) and you can see that a once beautiful city is slowly reclaiming its former style.

I got lost, of course, within about fifteen minutes of arriving and asked directions from two women. They offered me a lift to my hotel and after we'd chatted for a few minutes one of them casually asked: "and what is the AIDS situation like in Australia?" She didn't know what my job is, or why I was in Uganda. I can't imagine this happening anywhere else, and it wasn't the last time. Ugandans impressed me as being very well informed and open to discussion about AIDS. Those two women knew more about HIV and AIDS than the average Australian. That's fine tribute to a country that only got its head above the mire of civil war in 1986.

I think it's because of the past that Ugandans are determined to get the better of AIDS, just as they are determined to improve their economy, stabilise their political system and solve the enormous range of problems that are a legacy of war. HIV/AIDS workers I spoke to admired President Yoweri Museveni for his openness about HIV and AIDS — alone among African Presidents. Museveni has declared that AIDS is a national crisis and because it affects all areas of life, all ministries must have an HIV/AIDS policy and programs. The government of this impoverished country has no money to invest in AIDS care or prevention — all organisation rely on overseas aid agencies —

outreach education and support, with some assistance from the National Council of Churches of Kenya. They are also concerned with doing something for orphans and are planning to establish a women's wing of TAPWAK.

AFTER MY INITIAL FLYING VISIT TO Nairobi I headed for the Ugandan border. This journey took me through some spectacular country which became increasingly tropical. Nairobi is situated on a dry and chilly plateau above the Rift Valley. The further west I travelled, the greener it became, with glimpses of the vast Lake Victoria, tea plantations carpeting the hills and everything from oranges to coffins for sale at the sides of the road.

The border crossing was all you might expect from a third world

country: barbed wire scrawled across a dirt road, surly guards, touts urging me to change my money on the black market and an immigration official who was so amused by my military surname that he forgot to stamp my passport (as I discovered when I tried to get out of Uganda two weeks later). My little stash of condoms and a fitpack remained undiscovered.

After this intimidating reception, however, I fell in love with Uganda. Many muzungu (white) travellers I met later in other parts of Africa regarded me with a mixture of horror and respect when I told them I'd been to Uganda. The country's reputation hasn't yet recovered from Idi Amin and twenty years of war. More recently, AIDS has pushed it further into the realm of

but its political will and motivation may be unequalled in Africa.

THE MAJOR AIDS ORGANISATION in Uganda is TASO: The AIDS Support Organisation, which is based in Kampala. Like KAS, it was founded (in 1987) by a small group of PLWHAs who initially met for support and later decided to seek funding. There are seven regional branches. Unfortunately, I wasn't able to meet the director, Noerine Kaleeba, who was one of the founding members. Our schedules never seemed to coincide, but I did spend quite a bit of time interviewing staff and chatting to clients at the Kampala TASO office and Day Centre.*

The TASO Day Centre, based at the Mulago Hospital, is like Maitraya, Albion Street Centre and ACON all rolled into one. It provides counselling, a regular clinic, daily meals, education, some food supplements and medications. A music and drama group of TASO clients do educational outreach.

TASO lunches are cooked in massive pots over a charcoal fire in the building's central courtyard. The idea behind providing a meal to clients was, originally, to demonstrate nutritious cooking, which is seen here as an important part of 'positive living'. The food was tasty and filling — *matoke*, the national staple food, is cooked, mashed green bananas, eaten with greens and a meat or fish stew. Being so close to Lake Victoria, fresh fish is abundant. Many of the clients, who can't work, rely on the meal — it may be the only one they have all day.

At lunch (in a counselling room about the size of a telephone box), I was discussing the Amsterdam Conference with Peter Kasule, a TASO counsellor, when he turned to a colleague and said, in a tone of mixed amusement and incredulity: "In Amsterdam, people eat *all the time!*" I'm not surprised it made

such a big impact on him. Few people in Africa can afford to treat eating as a recreational activity.

AFTER I'D CIRCULATED AROUND TASO all morning, Peter Kasule took charge of me for the afternoon. I was whisked away on the back of his small motorbike to visit another organisation he's involved in, AIDS Widow, Orphan, Family Support (AWOFS), based at the Nsambya Catholic Hospital in another part of Kampala.

"You have to tell people what our problems are. In five years we're going to have five million orphans here in Uganda."

AWOFS has been running for about a year and it aims to help people with AIDS become self supporting and encourage them to save money for their children. It particularly targets widows because traditionally in Uganda women don't work outside the home and when their husband becomes sick or dies they may be without any income. AWOFS runs training programs and helps set people up in small businesses such as poultry farming, tailoring or baking.

I met a woman called Joyce Rose, who has been helped to establish a small dressmaking business. She also teaches sewing to people in the local community. Some are also HIV positive, and AWOFS pays their fees; others are not and pay their own way. Her students know she has HIV. She told me that before this project started she was very sick and depressed, but now — and I could see this for myself — she had no health problems and was happy and "living positive". She had been able to pay off both the treadle sewing machines that AWOFS had bought for her, and her first class

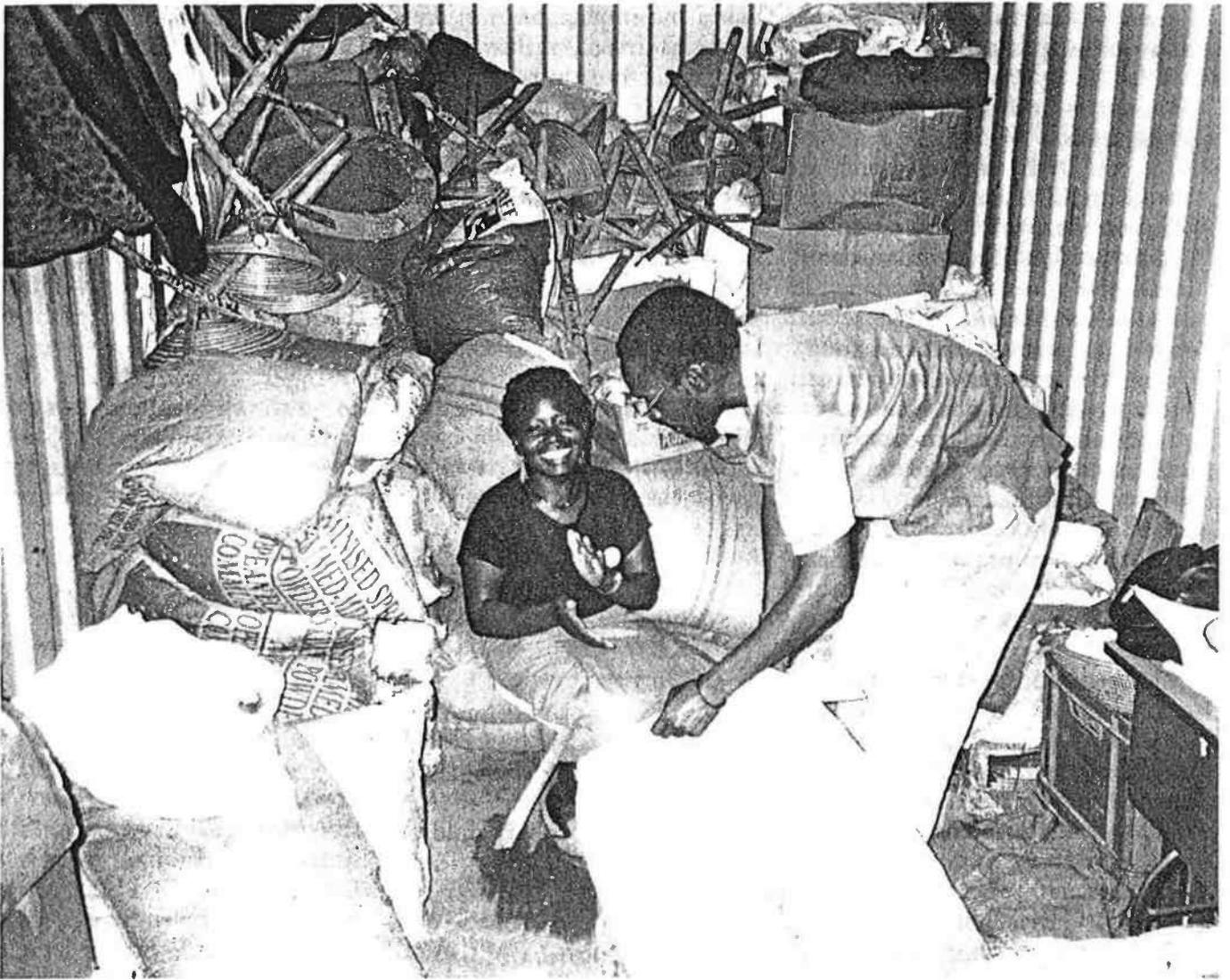
of students was about to graduate. I left Joyce Rose's house feeling more optimistic about AIDS in Africa than I ever expected to feel.

Orphans are becoming a big issue in Africa. I first realised this at the Conference in Amsterdam, and while I was meeting AWOFS staff, a grey haired muzungu priest involved in the project swept into the office to get something, noticed me and said "Ah, this is the journalist from Australia who's going to tell them our story and raise lots of money. You know they have lots of sheep in Australia, that's how they've become a rich country." He turned to me and said: "You have to tell people what our problems are. In five years we're going to have five million orphans here in Uganda." (An orphan in Uganda is defined as a person under 18 who has lost one or both parents.)

IT WAS CHARACTERISTIC OF MY TRIP to Africa that I never had enough time for everything. After I left Uganda, tourists I met always wanted to know what the gorillas were like, or the famous mountains of the moon, the Ruwenzoris.

Well I didn't have time to find out. All I could tell them about was Uganda's AIDS programs (which was usually their next question anyway, in hushed tones: "Don't they have a terrible AIDS problem there?"). I was due to join a safari in Tanzania in mid August, so after a day with TASO and AWOFS, and promising to come back before I left Uganda, I had to speed off towards the south west of the country — towards the Ruwenzoris and the gorillas, in fact — in search of the person who originally inspired this mad idea to go and find out about AIDS in Africa: Long Term Subscriber Januarius Rodgers. Who, it turned out, had absolutely no idea that I was coming.

Januarius — known as 'Rodgers' to the locals, which



Getting ready to distribute food supplements at TASO. Seated: Margaret Nalumansi.

explains my difficulties in finding him — gave me the warmest welcome I could have wished for, introduced me to more of his relations than I'd ever imagined one person could have, and proceeded to thoroughly confuse me about the local HIV and AIDS projects.

Actually, that's not quite true. I was confused before I'd even arrived there, and it took me a while to realise that far from being an obscure one horse town, Fort Portal is a major centre which serves a region of more than one million people: the Kabarole/Bundibugyo District. It has several hospitals, a Regional AIDS Control Program, (Government

run, funded by a German Agency) some home care for PWAs, an AIDS Information Centre and is one of the regions of Uganda which is hardest hit by AIDS. The other, apparently infamous district, which even tourists outside the country have heard of, is Rakai, closer to Kampala.

Januarius' project, which he started after his own diagnosis a few years ago, is called the Good Samaritan Project and aims to provide counselling and some material support in the form of food supplements — when available — and money for transport and medications. All the counsellors work on a voluntary basis. At the moment the local

Catholic church provides an office and some support, but the project has no regular funding. At the time I visited Januarius was working on submissions to European Funding agencies.

A comedy highlight of my visit to Fort Portal was my demonstration of how to use lube with a condom, (on my fingers) in Januarius' lounge room one morning when two local HIV/AIDS workers had come for breakfast. I gave my supply of ACON Safe Paks to Resty Agaba, the Director of the AIDS Information Centre. When I arrived at the Centre a couple of hours later, a lot of people were sitting around with very smug

grins — the condoms had gone out already. I gave another pep-talk on how to use lube — condoms in Africa are all pre-lubricated.

I felt quite ambivalent about what I was doing. The people I spoke to were keen for new information, but dubious about using the lube. It was explained to me that in their culture, women are not supposed to see a man's penis, so it might be too difficult to use it in the dark. One of the men was rather scathing about this taboo, however, so I don't know how widespread it really is. The Centre does get free condoms for distribution, but not as often or as many as they'd like. They are expensive to buy.

I FOUND IT DIFFICULT TO GET ANY statistics on HIV/AIDS in the district, or even Uganda as a whole. Before I arrived in the country people I met were telling me "80% of the hospital wards", "60% of the prison population"; figures which usually got inflated to represent the whole population. The worst statistic I heard that sounded fairly representative because it was randomised, was from Dr Paul Kabwa, Director of the Regional AIDS Control Program at Fort Portal. Up to 26% of pregnant women had tested positive at antenatal clinics in urban areas. The figure was as low as 3% for some rural areas.

The *National AIDS Surveillance Report* gives a total of 33,971 AIDS cases, 2,781 of which are children under the age of eleven. The population is about the size of ours in Australia. There were no figures for HIV. But it was in Fort Portal that I decided to stop chasing figures. I could see the scale of the problem.

Januarius took me to visit his village, about 17 kilometres out of the town, and meet his mother. On the way he told me that four of his adult relatives are HIV positive,

and that his village had buried six people from AIDS in the past two weeks. When we arrived, I commented on the peace and quiet. His mother responded that a few years ago, the air would have been filled with the sound of people's voices, but now, all you could hear were birds.

As we walked around, Januarius kept pointing at houses and saying things like "The man who lived there died last week"; or "Someone is very sick in that house". We visited three women who were sick in their homes — mud brick houses with dirt floors, no running water or electricity, hens and goats wandering through. Two of them had small children who also appeared to have AIDS. I have rarely felt so powerless. Januarius gave them all some money.

Margaret has worked as an educator, but seemed disillusioned with that role; she said that often people don't believe she is HIV positive, because she doesn't look sick.

Most of the houses were only accessible along walking tracks from the main road. As we left, we met one of Januarius' step sisters, who had just arrived back from hospital in Kampala and was on her way to her mother's house. Basically, I was told, she had been sent home to die. Someone at TASO later explained this to me even more bluntly: it is cheaper to transport live bodies than dead ones.

It is, if you speed, about a five hour drive from Kampala to Fort Portal. The faster you go, the less comfortable your ride, and believe me, it's not comfortable to start with. The 15 seater minibus that I travelled in carried 18 adults, six children and a lot of baggage. Usually there are hens as well. For

about half the distance the road is more like a four wheel drive track.

Januarius' step sister had come in the back of a pickup truck. Because the truck could only drop her at the main road, she had to complete the last few kilometres of her journey on the back of a bicycle, being slowly and carefully wheeled along by two teenage boys. There's no other transport in the village.

AFTER DOING THE ROUNDS OF the Fort Portal HIV/AIDS infrastructure I headed back to Kampala, where I hung around at the TASO Day Centre for a few days just to see what they were doing.

I spent one morning interviewing Margaret Nalumansi, who supervises the distribution of material assistance to clients. Margaret was also teaching yoga and meditation, until they ran out of space to hold the sessions. She is very interested in aromatherapy and massage, but there is no space for that either. Margaret has worked as an educator, but seemed disillusioned with that role; she said that often people don't believe she is HIV positive, because she doesn't look sick. I heard this from other people too, they said that many Africans are sceptical, and think they're in AIDS work just for money and fame.

Towards the end of our conversation, we had to move because we were sitting in a big storage container to talk and were in the way of people who'd come to get the bags of food supplements which they were about to distribute — oil, milk powder, rice. Space is a bit of a problem at TASO, and the building was congested that morning as it was also a clinic day, and everyone was waiting to see the doctor. In between the powdery corner of food distribution, the cooking corner and the queue for the clinic, you could hardly move.

I wedged myself onto a bench to watch, and started chatting to a friendly woman who was waiting, with her sister's small daughter, for lunch to be served. She had left her job so that she could care for them both. The sister's husband had already died. I was surprised to find that her sister had been using AZT — one of the very few Africans who could afford it. She stopped it because the side effects were too severe and was now quite ill.

For most Africans, AZT and other drugs used for HIV or opportunistic infections are beyond even dreaming about. Many have access to only the most basic of medications.

In Fort Portal I went with Januarius to visit a sick relative. Panadol was the precious medication he handed to her, a few pills wrapped in a twist of paper. I later visited a very sick woman in Tanzania whose only medications were paracetamol for pain and fever, milk of magnesium for her digestive problems and, but only because she was in a trial, a herbal medicine.

The almost constant monitoring that is a regular part of the lives of most Australian PLWHAs is almost unheard of here, unless a person is very wealthy.

CHRISTIANITY IS A DRIVING FORCE behind many organisations. Religious faith, Muslim or Christian, is taken so completely for granted in Africa that people were often shocked when I told them I had no religion.

I saw some pretty ghastly church literature on HIV and AIDS, which portrayed people with AIDS as individuals who had probably sinned terribly, but nevertheless should be shown compassion. Such pamphlets also showed sex workers as evil tempters. I was relieved to find, whenever I visited AIDS organisations, that this judge-

mental attitude was not the prevailing one. "Prostitutes!" snorted Marble Magezi, Public Relations Officer for TASO, "I don't know why people are so worried about prostitutes! It's not prostitution that's causing AIDS to spread so fast."

The almost constant monitoring that is a regular part of the lives of most Australian PLWHAs is almost unheard of in Africa, unless a person is very wealthy.

Marble was the first of many people to tell me that "unofficial" polygamy was the main problem in HIV transmission, mainly because men won't admit that they have more than one girlfriend at a time. Men are often reluctant to use condoms because their wife/girlfriend will become suspicious.

In Fort Portal I met a young woman whose experience illustrated what Marble had told me. Helen** is 24, she is HIV positive, and so is at least one other woman who was her husband's 'unofficial' wife. Both of Helen's children died early this year, one from measles, one from AIDS. Her husband left her after she was diagnosed and, as far as she knows, has never tested, because he denies that he could have AIDS. She believes he has other girlfriends now. She said she doesn't want to have any more relationships. What for?

I SAID AT THE BEGINNING OF THIS article that I was convinced that grief is not the only thing to come out of Africa. Now that I've been there, I'm even more convinced. What I have seen of AIDS in East Africa is just as frightening and distressing as everyone told me it would be, but I haven't returned

full of grief and depression.

I met some wonderful people doing grass roots HIV and AIDS work. I was overwhelmed by the depth of their compassion, tolerance, support, humour and creativity in the face of this terrible epidemic.

The only thing they don't have enough of is money and what it can buy: medications, good roads, piped water... the list goes on. My anger about global economic injustice intensified while I was in Africa.

I don't want to downplay the scale of the problem, Africans do face an enormous challenge and they need all the support that wealthier countries can give. They can't go it alone. But I never felt that I was among people floundering in the face of something too big for them, which is how Africans are frequently portrayed in the western media. Africans living with HIV and AIDS are not tragic victims. They are working very hard to be survivors. Some of the people I met said to me: "You in the developed world can learn from us too." I think they are right.

Thank you to everyone I visited and spoke to in Africa for your hospitality, friendship and sharing of wisdom.

In the next *Talkabout* you can read about my visit to a project with traditional healers in Tanzania.

*Noerine Kaleeba has published a book on the history and philosophy of TASO, called *We Miss You All*, which is in the ACON library.

** Not her real name.

Some HIV+ women in Africa would like to write to positive women in Australia. If you're interested, please contact Jill at PLWHA.

CHAPTER 14

by Ms. Ada O.

The story so far: Disturbed by his musical neighbour's post-piano distress, Nigel comforts Leonard with a cup of condoms. Brad recovers consciousness to a vision of a giant martini — his mother. Robbie and Wayne's vigil at Nancy's bedside is interrupted by the arrival of Robbie and Nancy's parents. Nancy's mother is distracted by the on-off switch on her life support system... Everyone is asking: will Nancy recover from being smashed by a piano three episodes ago? For the answer to this, and other pressing questions, read on...

The Funeral Chapel of the Musty Odour

"I JUST THINK IT'S IN PREPOSTERIBLY poor taste", Beryl spat into Brad's ear. Brad adjusted his pillbox hat, thinking his mother was about to try and get him to take it off again, and listened as the piano played a plaintive refrain of Kum-Ba-Yah.

"The poor girl was killed by one", Beryl continued. "The least they could do was not play one at her funeral".

Robbie squirmed in his pew. "That tune again", he thought. On his left sat Wayne; on his right sat his parents. He could hear Beryl prattling on to Brad behind him.

The piano music eased into silence and the meditations of the bereaved were interrupted by a booming knock upon the door of the chapel.

Everyone turned as a large Nun



opened the large oaken door. A young man resplendent in a black cape over an embroidered peasant shirt stood before a coffin borne by three similarly attired monks.

"We, the Little Brothers of Positive Joy, request entry to this place, in the name of Universal and Positive Joy!" rang the tones of the young monk's voice.

"We admit you gladly," responded the large Nun.

The Little Brothers of Positive Joy paraded the coffin, solemnly, yet strangely joyously, through

the congregation of the bereaved. They reached the bier at the front of the chapel, gently placed the coffin upon it, and took their places flanking three Nuns who stood motionless before the congregation. Their heads were bowed and the middle one stood behind a lectern. The middle Sister looked up and gave them all a beatific smile.

"Welcome to Nancy's funeral", Sister Sarah Monial began. "She may be dead, but that girl sure ain't forgotten." There was a pause then as everyone thought a bit.

"I'm not going to bore you all with anecdotes about her life", Sister continued. "Because frankly, I didn't know her from a bar of soap." Another pause.

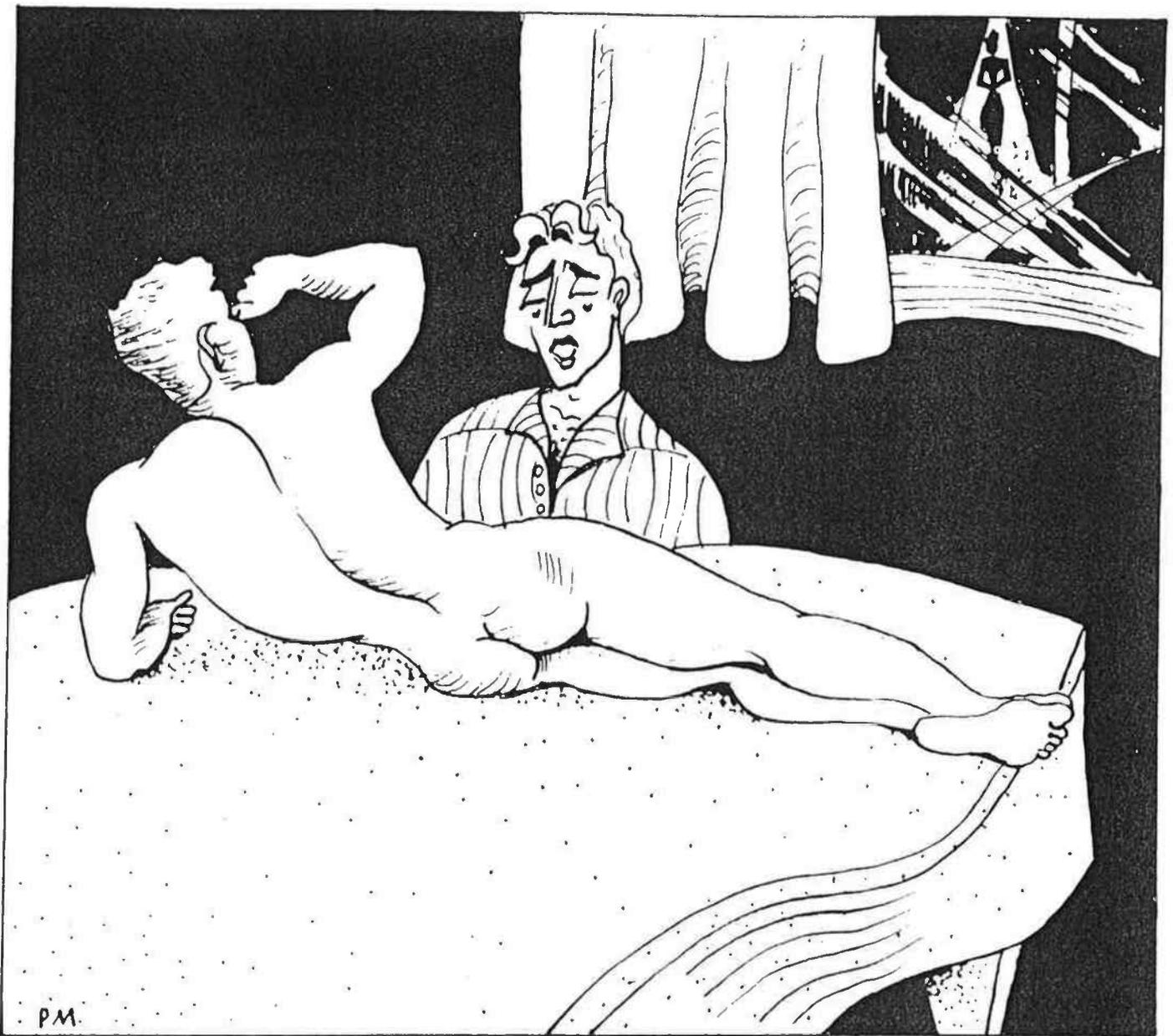
"All I'm going to say is she had AIDS but died from being squashed by a piano. I think there's something in that for all of us, don't you?" There was another longer pause. "Now let's all go and have a drink. The Manhattans are on us."

With that the three Sisters walked down the aisle and the piano started playing cocktail bar music.

"Well, that was *very* Nancy", Nigel said to Leonard as they stood up to leave. "Short and blunt."

"I thought I was going to cry", Robbie confessed to Wayne, relieved. "Those Nuns sure know how to run a painless funeral."

His parents looked a little dumbstruck as they stepped into sunlight, but sighed when they took in the spectacular view of the ocean. The King Elvis Hospital and Sacred Hard-On-Sea Hospice rose above them to their right, and



to their left, grassy slopes seemed to roll on forever.

"Over here!", came a cry from a small marquee pitched on the grass by the edge of the cliff. The small group meandered over to the Nuns in the marquee, and to the Mannhattans and the bracing sea air.

The denial stage

"YOU HAVE TO EAT SOMETHING Max," a weeping Mrs Kelly said.

A stoned face Mr Kelly sat puffing his pipe.

"I'm not touching a bloody plate or cup in this place Mary. I'll go

out and get something later."

Mrs Kelly cried even louder. She picked up a tea cup, which rattled loudly in her shaking hand.

"It's those queer bloody friends of Nancy's that did it Mary," Mr Kelly continued. "They gave our only daughter that dreadful disease and now they've made my son — my only son — a bloody poof! He might as well be lying in that grave next to Nancy."

"Where did we go wrong Max? Where did we go wrong?"

"It's all my fault Mary. I should have played footy more often with Robbie when he asked. I've failed as a father."

"No, no. It's my fault Max. I

should never have let him have access to my *Weeklies*."

There were several minutes of near silence as Mrs Kelly continued to mourn and Mr Kelly continued to puff.

"Oh well, at least we won't have to tell people what Nancy had now," Mrs Kelly said eventually. "We can safely say she died respectably."

"Yes, well that's one thing," Mr Kelly murmured as he rose and walked to the window. "The sooner we get out of this wicked city, the better." He stared down into the street, watching a woman standing under a lightpost on the opposite side. "The place is

crawling with queers. Look at that one across the street. Probably a lemon. Pervert!"

Mother is always right

"I'M SURE THAT WOMAN IS LOOKING up at me! Knit one pearl one." Beryl exclaimed for the third time. A very agitated Brad continued to read his Elizabeth Kubler-Ross book. Beryl turned around and looked at him sternly.

"Bradley, you're not listening!"

"You're imagining things mother. She's probably just a hooker waiting for some trade. Now leave the poor thing alone and get away from the window," Brad hissed through gritted teeth without looking up.

"Bradley!" the shocked woman cried, "how can you speak like that to your own mother? Knit two, pearl one."

"I try my hardest," her son mumbled to himself.

"Now Bradley, don't go telling me that curiosity kills chefs. I know when I'm being watched."

Brad threw his book on the coffee table and jumped out of his seat. "For god's sake mother! Cats! Curiosity kills cats. Chefs spoil broths. Now for crying out loud *get away from the window!*" And with that he stormed off into his room, leaving Beryl staring after him, stunned. After collecting herself she turned back to the window, positive that the woman under the lamp post was watching her.

Parental guidance

"TAKE BIRDSWORTH TO SOLITARY Miss Bennett!"

"Oh fair go, Mrs Davidson. What about me weak ticka?"

Robbie grabbed the remote control and turned the video off. Wayne protested.

"I'm just not in the mood for re-runs of *Prisoner* tonight Wayne, alright?"

"Yeah, okay baby." He reached over and patted Robbie affectionately on the back. "I never thought I'd hear you say you're over Erica Davidson."

Robbie turned and tried to smile. He apologised for his bad temper, saying he wasn't feeling very happy about the situation with his parents.

"I guessed as much. You're lucky Nigel said you could use his apartment while they're here."

Robbie leaned back and rested on Wayne's chest, tears welling up in his eyes. "It's so frustrating!" he said. "I just don't need my parents' not talking to me right now, not with Nancy just dying."

"I know babe," Wayne replied. "They just need some time to adjust. It's a bit of a double whammy, what with their only daughter being killed by a low flying piano and their only son having a torrid love affair with another man — an older one at that. God, think of how they would react if they knew I was positive. They'll need some guidance, but you might have to prepare yourself for some rough times with them."

Neither talked as Robbie had a good cry. Eventually Wayne rose, held his hand out to Robbie and suggested they go to bed. As he was leading Robbie into the bedroom he glanced out the window. The street was empty except for a lone figure standing under a light post, looking up into the Bohemia apartments.

Sex in D major

NIGEL TRIED HARD TO CONCENTRATE on the crossword before him, but Leonard's tinkling was driving him insane. He rose and moved towards the new baby grand at which Leonard was sitting. He wrapped his arms around the musician.

"Come on Len, haven't you had enough practice for tonight?" he suggested in the nicest way he could, considering his present mood.

"Don't call me that. Just a few more minutes," was the distant response.

Nigel growled. Then he had an idea. He released Leonard and moved around to the lid, grabbed the stand and pulled it roughly. The lid slammed shut.

"What on earth do you think you're doing!" Leonard protested in a loud, panicky screech. "Don't you realise how much this thing cost me?!"

Ignoring the complaint, Nigel began to undress, throwing his clothes in all directions.

"Now what are you up to?"

"I'm sick of that plink plink plink. Besides I've got a better idea for breaking in your new toy."

Leonard asked what he meant. Without saying a word, Nigel, now totally naked, removed Leonard's glasses. He jumped on top of the Steinway and spread himself seductively across the smooth surface.

"Oh," Leonard said meekly. "I see." He wasn't too sure this was a good idea.

"Go and close the curtains, big boy."

Speechless, the musician obeyed.

Over and out

DOWN IN THE STREET, THE MYSTERIOUS figure watched the curtains close at Leonard's apartment window. She pulled out a little note pad and scribbled some notes. She had seen enough. Tomorrow she would act. Turning, the mysterious figure walked off into the darkness of the night.

TO BE CONTINUED

Fair Treatment



We're on line

THE NATIONAL TREATMENTS Project has joined a computerised information search service called BRS. This program has access to 170 different data bases, including Medline, Mbase, and AIDSline.

In effect we now have access to the majority of the clinical data associated with the treatment of HIV/AIDS and the associated opportunistic illnesses.

The principal benefit is that we will be able to perform information searches on the requests that we receive from our clients. We are developing a request guide and a search application form.

Fluconazole: new trial

IT HAS BEEN ESTABLISHED THAT HIV infection can adversely affect the absorption of ketoconazole, an antifungal drug. HIV infection can also alter the way in which the body gets rid of the drug. No such studies have been conducted with another important antifungal agent, fluconazole, and it has been proposed that a study be commenced through the National Centre.

The trial will enrol 20 men who will be asked to attend St. Vincents Hospital four times over a seven or eight week period. A dose of fluconazole will be given and participants will be asked to remain at the hospital centre for a period of eight hours for blood tests. All participants will be reimbursed \$50 per study day attended.

If you would like to participate in this study call me at the National

Treatments Project on (02) 283 3222 or Dr Susan Tett on 361 2368 or Ms Diane Carey on 361 2124.

SO 221 . . . Press misleads

A NUMBER OF THE DAILY PAPERS around Australia recently reported that there was a "promising" new antiviral drug about to become available. The drug SO 221 was reported to have good results as an anti-HIV agent. Of course this has prompted a number of enquiries to this office.

SO 221 was developed at Southampton University in England and, as the number indicates, is the 220th agent that they have screened.

At this time there is only evidence that the agent has anti-HIV activity in the 'test tube'. As yet it has not been introduced into animals, let alone into humans. At the very least it will be two to three years before anything further will be known about the activity of SO 221, so it can hardly be called a promising new drug at this stage.

A further delay in the development process is that the drug is shortly going to be auctioned off to a pharmaceutical company. This indicates that there are no immediate funds to develop the drug further. When and if the drug is sold there will be some lead time before it moves into more work.

The newspaper reports were not only premature, but also misleading, as the drug is not really even a therapeutic substance yet.

A lot of work needs to be done before it can be called an antiviral drug.

ddl: better than we thought?

A RECENTLY PUBLISHED STUDY that compared AZT (zidovudine) and ddI (didanosine) indicated that there were significantly fewer new AIDS defining events and deaths among the group that were taking ddI at a dose of 500mg/day compared to the group that continued to receive AZT. All participants had tolerated AZT for at least 16 weeks prior to the study. The efficacy of ddI was not related to the time that the people had been taking AZT previously.

In the subjects with ARC, and those who were asymptomatic, the treatment with ddI significantly delayed the first new AIDS defining event or death. However, this was not seen in people who entered the study with AIDS and was not confirmed in the group who were taking the higher dose of ddI (700mg/day). (This may have been because there was a substantially higher rate of withdrawals from the treatment within this group.)

The numbers of reported side effects did increase with the higher dose of ddI. In contrast, the levels of anaemia were higher in the group taking AZT than in those on ddI. The rates of peripheral neuropathy did not differ between any of the treatment groups.

The ddI treated groups were both able to demonstrate

significant improvements in CD4 counts and P 24 antigen levels.

The study indicates that there is an advantage in changing from one effective nucleoside to another, rather than continuing with a single drug even if it has been well tolerated. However the question still remains as to when is the best time to make this change, and more work is still needed in this area.

The results also indicate that ddI will be helpful to people who have a low CD4 count or who have ARC.

d4T — soon to be in Oz?

AMONG THE MOUNTAIN OF information presented in Amsterdam, there was the quiet news about a nucleoside analogue antiviral called d4T (Stavudine).

This drug is manufactured by Bristol Myers Squibb, the company that produces ddI (Hivid). The drug has been around for some time and has had a mixed career with respect to the amount of support behind it.

Much of the controversy has surrounded the fact that there is a very fine line between the point where it does the job that it is designed to (i.e. inhibit HIV replication) and the point where serious and intolerable side effects begin.

The report in Amsterdam looked at a study which showed significant and sustained increases in CD4 levels at doses greater than 2.0 mg per kilogram per day. There were also significant falls in P24 antigen. The maximum tolerated dose is probably around 4.0 mg/kg/day. Above this level the toxicities are generally intolerable. The dose which will be used when and if the drug is approved remains unclear, but it is my feeling that it will be around 1.0 mg/kg/day.

The report claims that the drug is well tolerated, but some of the



results in this area are a little worrying. Some 29% of the participants had some form of problem with the treatment and 16% discontinued the study within the the first six months of commencing treatment. As expected the side effects did appear to occur at the higher doses and included peripheral neuropathy. These problems did resolve on withdrawal of the drug and some tolerated the drug well.

One of the problems, in my mind, is the use of d4T in combination therapy. Because d4T, ddI and ddC all have peripheral neuropathy as a side effect, combining any of them would place the patient at a far higher risk of developing neuropathy. It may be possible to overcome this in the case of ddI through using much lower dosages.

The drug cannot be used in combination with AZT, as both drugs work at the same site of

action. This means the drugs compete with each other and may cancel each other out. Some strains of HIV with AZT resistance may also be resistant to d4T.

While d4T does not appear at this stage to be a strong contender in the nucleoside stakes it may be effective in certain circumstances. It may be very useful when side effects such as anaemia are observed. d4T has also been demonstrated to be absorbed into the blood stream very well, and hence does not need buffers etc. as does ddI. Given that the profile of d4T is very like AZT it may well be useful in an alternating therapy scenario.

The next stage of the development plan is to start a wider access program and compare d4T with AZT. We have heard that a large study along these lines is well under way in the USA and Europe with over 400 participants already enrolled. We have also heard that the Australian subsidiary of Bristol Myers Squibb are interested in doing work here in the near future.

Prof. David Cooper feels that d4T has a very limited place for treatment of HIV. He suggests that conducting formal trials would be a waste of valuable trial resources. He suggests that the drug should be made available on the Special Access Scheme until the reports from the US studies come to hand.

— Ian McKnight

Support group for parents of (adult) HIV+ people

Meeting every 3rd Friday in the month at Ankali House
335 Crown St
7- 9pm

Confidentiality assured.
Julie Fuad, herself the mother of an HIV+ daughter, is the trained facilitator.

Call 569 2579
for further details

Home Front



"Very common with HIV"

ALTHOUGH I'VE GENERALLY BEEN healthier since my HIV infection than before, there are times when something goes berserk. My first preference is always for a close-to-nature treatment, but I've found that for some infections those wonderful (but very expensive!) chemist shops have the answer. If it works, I use it.

Here's *my learning* about dealing with minor infections, from eight years of sharing my life with my virus.

Rashes

WE ALL SEEM TO GET THEM: NO specific cause, and doctors purse their lips and say "Very common with HIV". Then they reach for their pads and write out prescriptions for hydrocortisone creams: symptomatic relief which bashes your immune response over the head. On a fairly intuitive basis, I use one or more of the following:

- Chickweed gel (that's gel, not cream). Especially for rashes that are itchy or irritable, this is one of the world's best soothers.

- Aloe Vera gel. Ditto.

- Tea Tree Oil. For anything that looks fungal, or that looks like it needs drying up, the 100% stuff. For dry or flaky skin, one of the Tea Tree Oil skin conditioners.

- Scarless Healer. Once the skin's closed over, this one seems to help healing back to the 'baby smooth' look. Well, almost.



White tongue

I'VE BEEN LUCKY, I SEEM TO HAVE avoided candida thus far. But I do get a white-coated tongue that comes and goes. Apart from scrupulous oral hygiene (lots of flossing etc.), two things that work for me are:

- Vicco Vajradanti toothpaste. This one has more herbs than you can poke a stick at, and something

in it does a power of good. I use a method given to me by a naturopath: brushing my teeth with Vicco in the shower, then holding the foam in my mouth until the end of the shower. A bit stinging, but it works.

- Tea Tree Oil rinses. Yep, Tea Tree again — six drops in a tiny amount of water and swooshed around your mouth, gargle a bit and spit it out. Three times a day — in my experience this gets rid of any coating.

Mouth ulcers and fissures in the tongue

I used to nearly always have one tiny, viciously painful mouth ulcer on the go at any time — and this was before I was HIV positive. A lover recommended the Vicco toothpaste and they've pretty much stopped. The two treatments above I find good for any breaks in your mouth.

Feet

I'VE TRIED THEM ALL AND I NOW use a standard pharmaceutical preparation for fungal things on my feet: Daktarin powder. It costs the earth but it works.

Molluscum

MANY OF US COP A FRIENDLY little skin virus called *molluscum contagiosum* — which gives rise to pimply-looking things that are

hard and have a "characteristic dimple" on top.

Medical options are burning them off (usually with liquid nitrogen), cutting them off or jolting your immune system into shoving them off with a solution called Podopholin. I've not found any complementary therapy to rival Podopholin — if anyone knows one, I'd be grateful. (Podopholin is no the most beautiful substance in the world).

Respiratory stuff

I'M PRONE TO RESPIRATORY infections and I've always found bowel-tolerance Vitamin C to be effective, especially if used early when you "feel something coming on".

I won't go into the very sound naturopathic theory that backs up bowel-tolerance Vitamin C here, but the regimen involves one gram of Vitamin C every hour (okay, skip overnight) until you feel

diarrhoeash, then back off to a dose that lets you feel comfortable and keep it up for 48 hours. Drink lots of clean water. Don't do it if you already have diarrhoea or kidney problems.

(Some doctors don't like you doing bowel-tolerance Vitamin C if you're on medical drugs, since it does tend to 'flush' your system, lowering the circulating amount of the drug.)

Ear infections

TEA TREE SOMETIMES HELPS, AS does an antibiotic solution called Kenacomb.

Insomnia

IT'S OFFICIAL — WE DO HAVE MORE disrupted sleep. A US study showed that PLWHAs wake more often, but also spend more time in deep, or delta, sleep, possibly dealing with our virus.

For nights when I absolutely

have to get a good night's sleep, I use one of the combinations of the sedative herbs that have been used safely for thousands of years: valerian, skullcap, hops, passion flower etc. Eco-herbs do a great one called *Sleep Easy*, which give me eight uninterrupted hours, and even more important, no woozy 'hangover' feeling. Again, bloody expensive.

— John Westlund

Queensland Positive People's Workshop Tapes available now

Tape recordings of this unique event are available at \$10.75 (inc. postage). All proceeds will go to establish a facility for people who need 24 hour care. For a list of tapes available, write to QUAC, PO Box 1191 Maroochydore Qld 4158.

Bill Spear Seminars

Prominent New York Counsellor & Educator who has worked closely with many community HIV groups



Here in Sydney from Nov 6 - 15

For programme details contact:
the Australian School of Macrobiotics
on (02) 660 1878

The following are people & groups who encourage & highly recommend you to participate in Bill's lectures & seminars while in Sydney

Anthony Muto

A survivor since 1982 - featured in the book *A Way of Hope* by Tom Monte

Dr. Marsha Woolf (New World Medical Centre N.Y.)

Dr. Woolf directs a medical centre serving many HIV+ patients by incorporating Oriental & conventional medicine

Richard Pierce (Manhattan Centre for Living)

MCLC is fast becoming the leading resource for the HIV+/PWA community in N.Y. Directed by Marianne Williamson who wrote *The Course in Miracles*.

ICARE (London AIDS Council/HIV+ group)

ICARE is a community resource in London.

Community Health Foundation London

This centre works closely with numerous HIV+ groups.

Kay Drais (AIDS Salt Lake City)

Dr. Martha Cottrell (Director of Health Services NY)

Co-director of the PWA support group in NY & co-author of a book on AIDS.

Dr. Christopher H. Hassell (Toronto area HIV+ physician)

Doctor, Doctor



AS PLWHAS WE ARE ALL automatically involved in a very important (one could say life determining) relationship: that with our doctor(s) and/or other health care providers including those who offer complementary and alternative therapies.

Nurturing and encouraging an upfront interaction with those whose task it is to help us encourages a positive participation in the treatments that effect our lives. Accepting that we are *major* partners in the maintenance and strengthening of our lives goes, I believe, a long way in helping ourselves in the fight.

It is easy to let ourselves be cared for and looked after by those who we expect or demand will know a lot more than we do, but taking an active interest in a treatment and a continuing responsibility for our well-being requires not just informed, but a change in attitude — I know it does for me.

Changing your attitude is not easy, but working at changing it is a very good starting point. It often depends on how you view a given situation. For instance I can look upon being infected with HIV as a sexually transmitted, terminal condition, but taking another perspective I can say "Life is a sexually transmitted, terminal condition." (Thanks Bernie Siegel). What's your way of looking at "IT"?

This month we start a new series: *Doctor, Patient and HIV: Building a Co-operative Relationship*, Project Inform Discussion Paper #3. (Reprinted by permission). This article is particularly interesting for the

approach it takes towards alternative, complementary and unapproved therapies when used in conjunction with standard medical approaches.

Project Inform is a major HIV/AIDS advocacy group based in San Francisco. Part of PI's mission is to provide "outreach on early diagnosis, immune health monitoring and treatment access". One of its services is a treatment information hotline which can be contacted on 1-800-822742.

Building a co-operative relationship

A POSITIVE ANTIBODY TEST, LIKE A diagnosis of AIDS or ARC, sets off many changes in a person's life. Few aspects shift more profoundly than the doctor/patient relationship.

Many people develop a more assertive attitude about what is happening and what to do about it. This shift in attitude can make for a bumpy ride unless both patient and physician learn to work together. Typically, both are striving to learn what works from a variety of available treatments. Just as there is no single intervention which is universally acclaimed by patients, there exists no single approach among doctors which might be called the accepted medical position.

Two factors demand new consideration of the doctor/patient relationship. First, this late in the epidemic, growing numbers of people are no longer willing to 'wait and see' and instead insist upon an aggressive treatment strategy, even if it means self treatment.

Secondly, there is an

acknowledged uncertainty among many physicians about how to respond to requests for monitoring and/or assistance in using complementary and alternative treatments. While perhaps only a minority are unwaveringly opposed to such medications, few will recommend or initiate such approaches. Even those who are sympathetic search for the right way to deal with this complex issue.

The following general guidelines are suggested for discussion. Our intention is to help both parties establish reasonable expectations of each other and set up a climate of co-operation and joint responsibility for healing. They should be viewed as starting points in a challenging situation, not as hard positions or demands.

1. Begin the education process at home. Education can begin at home about the implications of a positive antibody test or having an AIDS or ARC condition. Likewise, it is fairly easy to learn about basic treatment strategies and options. Overtaxed physicians today seldom have the time to instruct patients in the fundamentals, and most welcome working with patients who learn as much as possible on their own.

2. Choose a relationship style. People have different styles of relating to physicians, and those styles may vary at different times or for different illnesses. For example, some prefer that doctors take a directive, authoritative stand because it makes them feel secure. Others may see the physician as a specialist called in to advise on a particular problem. Still others seek a collaborative relationship

in which a physician and patient together weigh the pros and cons of a treatment strategy before the decisions are made. If a person seeks a certain relationship style, he or she must let the doctor know.

3. Prepare for appointments.

It takes only a few minutes to write down key questions ahead of time. The limited time in the doctor's office should be used to focus on the most critical issues, rather than conversing about every thing that comes to mind. Both patient and physician benefit when a visit is well-planned.

Preparation might include bringing along treatment literature that will be discussed in the visit. This allows the doctor to know a patient's sources and how to evaluate them.

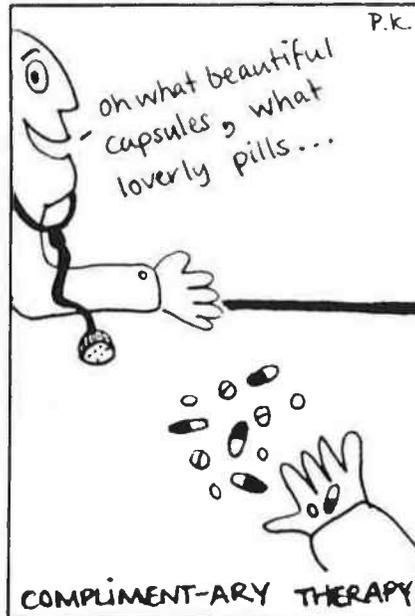
4. Communicate treatments requests in a spirit of mutual respect.

For a variety of reasons, most physicians feel they can't recommend unapproved treatments — even if they see possible value and know they are non-toxic. Some take a conservative view and don't see any point in using unproven remedies. Some are concerned with legal questions, and others simply feel uncomfortable dealing with uncertainty. Yet this doesn't mean the doctor is or has to be opposed to such interventions.

When unapproved treatments are discussed, some aspects of the usual patient/physician role may be reversed. Patients often have to take the more active role in reviewing and selecting treatments. The use of unapproved medicines needs to be discussed, avoiding confronting approaches. This calls for a well-planned visit in which adequate time for conversation is allowed. It makes no sense to just demand a treatment, no questions asked, in a brief visit. Only discord and frustration can result.

When the time and place are right, the patient should discuss what's known about a treatment

and why he or she has decided to use it, all the while welcoming the physician's input. When requesting prescriptions for existing medications which show some promise, a friendly and firm request is likely to work best.



If the doctor is opposed, the patient is entitled to know why, in clear terms. The doctor's concerns and knowledge are due respect — whether or not the patient agrees. Remember, both parties may be new at this kind of dialogue.

Some doctors have worked through their concerns with these issues and actively support their patients' efforts to use unapproved

treatments wisely. Their courage has taken them a long way from the traditional medical model and risks possible criticism from other doctors. These doctors are exceptional people and deserve to hear our appreciation expressed.

Whether or not agreement is reached on the use of a treatment, cooperation in the form of proper monitoring through examinations and lab tests should be secured. The patient, in turn, should agree to pay heed to reasonable warnings suggested by the monitoring process.

5. Be prepared for the emotional content of the visit.

Most physicians treating HIV infection are sensitive, caring people who respond emotionally to their patients. They have seen an enormous amount of suffering. When fear is written all over a patient's face, no one should fault the doctor for using 'kid gloves' gentle treatment, perhaps even shielding the patients temporarily from the harshest implications.

Having looked at the patient's side of the relationship next month we will continue this discussion paper from the doctors vantage point.

Till then, as usual

Ciao for now

— Peter Hornby

Just a reminder about the

Youth HIV Project

featured in August *Talkabout* (on page 8)

We are interested in talking to more people who are HIV positive, under the age of 25 and who were diagnosed before the age of 21. (Please see August *Talkabout* for details about the study.)

If interested, please call Guy or Kay on 361 2100 (or if calling from interstate please ask the operator to reverse charges and call (02) 399 2966).

We pay young people \$30 for an interview.

Living with HIV on ANCA

**We're pleased to invite . . .
or: what the f* is a nice boy (???)
like you doing here?**

BY ROSS DUFFIN

THE AUSTRALIAN NATIONAL Council on AIDS (ANCA) is the peak advisory body to the Federal Minister for Health, Housing and Community Services, Mr Brian Howe. Its membership is revised every two years.

Until recently I just knew it as this high and mighty body that was somehow important in the Australian response to AIDS. Then I heard I was to be asked to be on it. Two meetings later I know a bit more — and I've flown 'business class' for the first time in my life.

This is not an attempt to have an in depth or serious look at ANCA and its role. That will be done by others far more qualified than me and unfortunately I'll probably not be alive to read them.

Since I've been involved in AIDS, ANCA, or its predecessor, NACAIDS, have been criticised — lack of leadership, too power hungry, abducted by the gay lobby, not effective, not enough profile, a debating club . . . And every time a 'new ANCA' gets appointed there is hope that something different will occur — that it will be somehow better. Precisely how is a bit vague. It's too early to judge this ANCA.

I am not on this august body as an 'expert'. I am there because I am a person with HIV. Although ANCA is not a representative body, I believe my role is to 'represent' my constituent community — people with HIV and AIDS — and to legitimise our voice as one of the voices in the oft talked about partnership involved in the Australian response to AIDS.

The papers for the meetings arrive and are the size of a large novel — but that's what business class is for — quick reading time. AIDS has been described as a tree destruction business before and the so-called fourth wave of the epidemic — that of meetings and conferences — is alive and well.

Enough of the cynic. There are in fact good reasons for a lot of that paper. ANCA can and does play a very important role in the

response to AIDS. It has considered all sorts of matters in the two meetings I've been at and some of them are very important to people with HIV and AIDS, including the proposed anti-discrimination campaign, acyclovir access, monitoring the Baume report, priorities for research etc.

Having a voice is one thing — using it well is another. I guess I'm there to be used. So use me.



Living with HIV The Next Decade 23 - 25 November 1992

As we draw to the end of the period covered by the National HIV/AIDS Strategy and look at the results of the National Evaluation, this Conference will provide an opportunity to examine our experiences to date and to develop and expand our capabilities to ensure that our future responses are as successful as our past efforts.

Major foci for the Conference are economics and health policy, science, treatment and care issues, and education, intervention and research. Plenary and forum sessions will cover such issues as HIV in Asia and the Pacific; Epidemiology; Living with HIV — Issues Now; and Prospects for the Next Decade.

The main emphasis of the Conference will be to encourage discussion and interaction from a cross section of people involved in HIV/AIDS.

Keynote speakers include Dr. Lew Katoff and Dr. David Ho. Lew Katoff is director of the Fellowship Program at New York's Gay Men's Health Crisis. He is currently involved in research on the coping skills of long term survivors.

David Ho is the Director of the Aaron Diamond AIDS Research Centre for the City of New York. He has made major contributions to HIV and AIDS clinical and laboratory science over the past decade.

The steering committee recognises that the Conference will greatly benefit from the presence and participation of people with HIV. A special retreat room and access to emergency medical care will be provided.

Venue:

The Sydney Convention and Exhibition Centre, Darling Harbour.

Registration: \$270.

Call (06) 289 6860 for a registration form.

What's Goin' On



Newtown HIV group

What is it like for you living with HIV?
How do you deal with your concerns surrounding HIV?
Do others understand what it is like having symptoms
of HIV infection?

An HIV group enables you to:

- meet, support and learn from others in the same situation;
- learn more about current treatments;
- know what you are entitled to;
- know how to access services;
- explore your thoughts and feelings on a range of HIV issues
— in a safe, confidential and secure environment.

Newtown Neighbourhood Centre,
cnr. King & Australia St. Newtown
Wednesday nights from 7-9pm,

Commencing October 14 (for 8-10 weeks)

This is a closed group and numbers are limited. If you are
interested in attending, call the facilitator, Mark Cashman on
516 6437 by October 7

Community Transport is available.

Brighton Street Clinic Western Suburbs Sexual Health Clinic

- Medical checks
- Information on all STDs
- HIV/AIDS testing
- Pregnancy and pap tests
- Needle and syringe outlet
- Condoms and lube
- Information and education
- Counselling and referral

Monday 5pm - 8pm

Wednesday 9.30am - 12.30pm

Thursday 2.30pm - 5.30pm

For appointment call 744 7043
8 Brighton St Croydon

**This service is free
and confidential
No Medicare card is required**



Blue Mountains Women's Health Centre

Positive Women

We are interested in
creating a supportive
meeting environment for
HIV positive women in the
mountains.

If you are an HIV+ woman,
or affected by these issues
and would like to meet with
others, please phone and
talk to Vera.

Confidentiality is assured.
(047) 82 5133

SERVICING THE WESTERN SUBURBS *The Kendall Centre*

**AIDS information and
support services**
Needle exchange

- Condoms •
- Education • Counselling
- Referral • Outreach •
- Support groups •

A unit of the Western Sydney Area
Health Service

26 Kendall St Harris Park 2150

Tel. 893 9522 Mobile 018 251

888 Fax. 891 2087

**Are you
a gay man
who is currently
participating, or has
participated in an HIV
clinical trial?**

If so, we'd be interested in
talking to you about your ex-
periences. It takes about 30
minutes and confidentiality
is assured.

The study is concerned with
the effects of trial anti-HIV
agents on an individual's
quality of life.

If you are interested in
participating in this study,
call Lorna Ryan, 332 1090
ext 290 (Monday -Friday
10am - 6pm) for further
details.

**National Centre for
HIV Social Research**

HANDS ON

- Massage and Reiki for PLWHAs
- Training of volunteer masseurs

Call Richard
660 6392

Join ACON's Meditation group

ground floor
AIDS Council of NSW
188 Goulburn st, Darlinghurst

ALL WELCOME

Open to all people living with HIV/AIDS, their friends, supporters, carers, health workers etc.

Meditation can be useful as a means to reduce stress, energise the body and increase clear thinking
Instruction and assistance in how to meditate is available to newcomers

Tuesday mornings 9am - 10pm

Thursday evenings 6pm - 7pm

Just turn up, or ring David (02)358 1318

S I L K R O A D

A social and support group for Asian gay and bisexual men which meets every Friday.

Activities include workshops, discussions, social activities, etc.

More information available from
Arnel on (02) 283 3222

RED CROSS

Cosmetic Care Specialist Service

A service that trains people with Kaposi's Sarcoma (KS) to apply covering makeup is available at *Ankali Cottage*. A trained consultant assists the individual to choose the correct skin tone, and in correct application and removal of the makeup.

Use of makeup can assist individuals in raising their self-esteem.

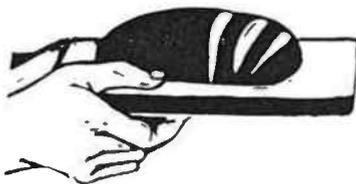
The service is free.

APPOINTMENTS
are necessary.

Telephone (02) 332 1090
- ask for *Ankali Cottage*.

Enquiries can be made by calling the **Cosmetic Care Coordinator** at the **Red Cross** on (02) 229 4296.

LET'S DO LUNCH



The *Talkabout* editorial group meets twice a month for lunch. While we're at it, we talk about — *Talkabout*.

The editorial group discusses what should go into *Talkabout* each month. Some of us write articles or interview people, some of us contribute ideas and opinions. You don't have to be a brilliant writer or A grade journalist to get involved.

The next meetings will be:

Thursday, October 23 and

Thursday, November 6.

Meet at the PLWHA office at 12.45, 2nd floor, 188 Goulburn St Darlinghurst. Call Jill on 283 3220 if you have any questions.

ACON west

Contact List



GENERAL

AIDS Coalition to Unleash Power (ACT UP) A diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis.

Phone the Info Line 281 0362. PO Box A1242, Sydney South 2000.

AIDS Council of NSW (ACON) Provides services in education, welfare, support and advocacy in relation to HIV/AIDS to the gay and general community. AIDS Resource Centre, 188 Goulburn St, Darlinghurst 2010. 283 3222, fax 283 2199.

ACON Hunter PO Box 1081, Newcastle 2300. (049) 29 3464.

ACON Illawarra PO Box 1073, Wollongong 2902. (042) ~~76 2399~~

ACON Mid-North Coast PO Box 990, Coffs Harbour 2450. (066) 514 056.

ACON North Coast PO Box 63, Sth Lismore 2480. (066) 22 1555.

ACON's Rural Project Telephone service for men who have sex with men. Info on HIV health services, gay networks/advocacy. Encourages the adoption & maintenance of safe sex practices in country NSW. Call Nik or John 008 80 2612 (free call). PO Box 350 Darlinghurst 2010.

AIDS Trust of Australia A non-government national fundraising body which raises money for research, care and education related to HIV/AIDS. PO Box 1272, Darlinghurst 2010. 211 2044.

Australian Federation of AIDS Organisations (AFAO) Umbrella organisation for Australian state and territory AIDS Councils. (06) ~~247 3411~~

Central Coast Services Sexual health service, support groups, positive support network. For info call Peter (043) 23 7115 or Paul (043) 20 3399.

Deaf Community AIDS Project Call Colin Allen at ACON 283 3222 or (TTY only) 283 2088.

Euthanasia Voluntary Euthanasia

Society of NSW Inc. PO Box 25 Broadway, 2007. 212 4782.

Fun and Esteem Workshops and drop-in groups for gay or bisexual men under the age of 26. Meets in Darlinghurst and Parramatta. The groups are a chance to talk about everything from safe sex to coming out. Social and fun. For more information call Aldo or Brent 283 2599.

Kids With AIDS (KWAIDS) and Parents of KWAIDS. Inquiries c/- Paediatric AIDS Unit, Prince of Wales Hospital, 39 2772. Donations c/- AIDS Trust, 211 2044.

Metropolitan Community Church (MCC) International gay church. 638 3298.

National Centre in HIV Epidemiology & Clinical Research Federal research centre conducting trials for AIDS treatments and other AIDS related research. 332 4648.

National People Living With AIDS Coalition (NPLWAC) GPO Box 164, Canberra ACT 2601. Call (06) 257 4985.

New-England Needle Exchange Program Fits, swabs, water, condoms, lube, information and education. For locations of outlets and outreach services call (067)66 2626 message, (018)66 8382 mobile.

NSW Anti-Discrimination Board Takes complaints of AIDS related discrimination and attempts to resolve them by a confidential process of reconciliation. Currently employs a full time AIDS Project officer. Sydney 318 5400. Newcastle (049) 26 4300. Wollongong (042) 26 8190.

NSW Users and AIDS Association (NUAA) Community/peer based organisation providing advocacy, support and referral for injecting drug users and their friends. Needle exchange services also available. Free forums/information nights 3rd Monday each month at 6pm. 369 3455.

Quilt Project Memorial project for those who have died of AIDS, consisting of fabric panels completed by friends, lovers & family of those to be remembered. 283 3222.

Sex Workers Outreach Project (SWOP) 391 Riley St, Surry Hills. 212 2600.

Social Workers in AIDS (SWAIDS) A special interest group for social workers working with people with HIV/AIDS. Contact the secretary, Lib Edmonds, C/- Kirkeaton Road Centre, PO Box 22 Kings Cross, 2011 or the chairperson, Grahame Colditz, C/- Prince Henry Hospital, 694 5721.

South East Region HIV/AIDS Unit HIV/AIDS support, needle and syringe exchange and HIV education. For more information contact (048) 21 8111.

Sydney South West Needle Exchange For access and locations call 601 2333 or Mobile 018 25 1920.

DAY CENTRES

Blue Mountains PLWA Support Centre Wednesdays 11am - 3pm (lunch). Fridays 6.30 - 10.30pm (dinner). For further information call the Centre on (047) 82 2119 or Dennis (047)88 1110.

Central Coast (Konnexions) HIV+ Drop-In Centre, 11am-3pm Mondays at the old stone building, Anglican grounds 3 Mann St Gosford. Inquiries Patrick (043) 20 2241.

Newcastle (Karumah) Upstairs, 101 Scott St Newcastle, opposite Newcastle Railway Station. Every Thursday from 11am. Contact John (049) 62 1140 or ACON Hunter branch (049) 29 3464.

Sydney (Maitraya) Daytime recreation/relaxation centre for people with AIDS. Lunch Tues, Wed, Fri. (free or donation). Massage also available. Some group meetings. 396 Bourke St Surry Hills. Inquiries (incl. membership) 361 0893. Client's phone 360 9896.

CLINICS & HOSPITALS

Albion Street AIDS Centre (Sydney hospital AIDS Centre). Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. 332 1090.

Central Coast Sexual Health Providing HIV clinic and support services.

69 Holden St Gosford. (043) 20 2114
Haemophilia Unit Royal Prince Alfred Hospital, 516 8902.

John Hunter Hospital (Clinical Immunology Ward) Lookout Rd, New Lambton, Newcastle. (049) 21 4766.

Kirketon Road Centre Community based primary health care facility of Sydney Hospital. Nursing, medical services, counselling, 9am - 8pm, Mon-Fri. Social welfare service, needle & syringe exchange 9am - midnight Mon - Fri. Cnr William St & Kirketon Rd, Kings Cross. 360 2766.

Lismore Sexual Health/AIDS Service A free, confidential service for all STD and AIDS testing and treatment. For further information or appointment (066) 23 1495.

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

Prince of Wales (Paediatric AIDS Unit) High St Randwick. 399 0111.

Royal North Shore Pacific Highway, St Leonards. 438 7414/7415.

Royal Prince Alfred (AIDS Ward) Missenden Rd, Camperdown. 516 6437.

Sacred Heart Hospice A palliative care facility. 170 Darlinghurst Rd, Darlinghurst. 361 9444.

St George Hospital HIV/AIDS Services (Inpatient, Outpatient and Day Treatment Centre): South St, Kogarah. Call 350 2960

Sexual Health Clinic: Belgrave St, Kogarah. Call 350 2742.

St Vincent's (17th Floor South AIDS Ward) Victoria St, Darlinghurst. 361 2337.

Sydney Sexual Health Centre Sydney Hospital, Macquarie St, Sydney. Appointments 223 7066.

Transfusion related AIDS (TRAIDS) Unit: For people with medically acquired

HIV/AIDS. Crisis/long term counselling and welfare support to clients and their families throughout NSW. TRAIDS is based at Parramatta Hospital. Contact Pam or Claire 843 3111 ext.343. **Red Cross BTS:** Contact Jenny 262 1764.

Westmead Centre (Westmead and Parramatta Hospitals). Westmead 633 6333. Parramatta 843 3111.

EMOTIONAL SUPPORT

Ankali Emotional support to PLWAs, their partners, family and friends. Volunteers are trained to provide one-to-one non-judgemental and confidential support. Ankali is an Aboriginal word for friend. 332 1090.

Bathurst AIDS Support Group Meets Tuesdays 7-9pm at the Women's Health Centre, 20 William St. Call Vi (063) 31 4133.

Bega Valley HIV/AIDS Volunteer Carer Group Emotional and practical support to PLWAs, their family & friends living in the Bega Valley area. Call Ann Young (064) 92 9120 or Victor Tawil (048) 21 8111.

Civil Rehabilitation Committee Family Support Centre. HIV education and support to families of ex-prisoners and offenders. Call Pam Simpson 902)289 2670.

Club 2430 (Taree) Manning Area Gay and Lesbian Support Group. Social functions, newsletter, monthly meetings. Contact Bill or Barry (065) 537502 or Liz (065) 511315. PO Box 934, Taree 2430.

Friends & Partners of People With AIDS A peer support group for friends and partners of PLWAs. 7pm, 1st and 3rd Mondays in the month at Maitraya Day Centre, 396 Bourke St Surry Hills. Inquiries Gary 369 2731.

HIV Living Support Groups For HIV+ people. Call HIV support officers 283 3222/2453.

Hunter Area HIV Support/Action group 6:30pm, 4th Wednesday every month at ACON, level 1, Bolton St Newcastle. Inquiries call ACON (049)29 3464.

Karuna Blue Mountains Emotional support for people with HIV/AIDS, their partners, family and friends. Call Ann (047)82 2120.

Newcastle Gay Friendship Network Peer support, workshops and activities for gay

men under 26. Call ACON Hunter branch, (049) 29 3464.

North Coast Positive Time Group A support and social group for PLWAs in the North Coast region. Contact ACON North coast (066) 22 1555.

Parent's FLAG Parents and friends of lesbians and gays. Meets monthly at the GLCS, 197 Albion St Surry Hills. Call Heather, 899 1101, Marie 360 3250.

Parent's Group (and relatives) A support group for the parents or relatives of PLWAs. Every 2nd Wednesday at 12.30. 5th floor, Notre Dame Bldg. Burton St Darlinghurst. Call Linda Barr 339 1111 (page 248) or Marie Pettitt (page 256) to indicate attendance.

Partner's Group A support group mainly for partners of people who are in/outpatients at St Vincent's. Every 2nd Tuesday, 6-8pm. Please phone Chris Connole 339 1111 (page 345) or Lesley Goulburn (page (255) if you're interested.

Positive Women Individual or group support for and by HIV/AIDS positive women. Non-judgemental and completely confidential. Contact via Women and AIDS Project Officer or Women's HIV Support Officer at ACON, 283 3222, TTY for the Deaf 283 2088.

PO Box 350 Darlinghurst 2010.

Positive Young Men A support group for positive gay men under the age of 26. Groups run for 6-10 weeks at a time. Groups are run by Fun and Esteem and the HIV Support Project. For information phone Aldo or Brent 283 2599 or HIV Support 283 2453.

Quest for Life Foundation Emotional support and education for people with life threatening diseases, their families, loved ones and health professionals. Support groups, meditation/relaxation classes, one-to-one counselling. 37 Atchison St - Cross West. 906 3112.

Shoalhaven HIV Support group Meets first and third Tuesdays in the month from 6pm to 7pm. This is a peer support group facilitated by an HIV+ volunteer. It is completely confidential. Call (044) 23 9353.

Sydney West Group: a Parramatta based support group. Pip Bowden 635 4595.

PRACTICAL HELP

ACON Housing Project Offers help with accessing priority public housing, transfer advice, homelessness, private

rented housing/share housing, housing discrimination and harassment. The Housing Project Officer is available by appointment, call 283 3222, ext. 246. 188 Goulburn St, Darlinghurst. PO Box 350, Darlinghurst, 2010.

Badlands Residential harm reduction service providing a safe, non-coercive space for up to ten people at a time, who are at high risk of HIV transmission or may be HIV+. Residents are mainly injecting drug users and/or may be sex workers. 382 - 384 Bourke St, Surry Hills 2010. 360 7661.

Bega Valley HIV/AIDS Volunteer Carer Group Provides emotional and practical support to PLWHA, their family & friends living in the Bega Valley area. Call Ann Young (064) 92 9120 or Victor Tawil (048) 21 8111.

Bobby Goldsmith Foundation A community based, registered charity providing direct financial aid to people with advanced HIV/AIDS to help pay bills, some vitamin costs and child care assistance to approved clients. 4th floor, 376 Victoria St, Darlinghurst, 360 9755.

Central Coast Positive Support Network (PSN) Trained volunteers providing practical home/personal care for people with AIDS. Inquiries Peter (043) 23 71 15 or Paul (043) 20 3399.

Community Support Network (CSN) Trained volunteers providing practical home/personal care for people with AIDS. 283 3222.

CSN Blue Mountains hands on practical help for people with HIV/AIDS. Call Robert (047) 87 7984.

CSN Newcastle Call Rosemary Bristow, ACON Hunter Branch. (049) 29 3464.

CSN Wollongong Call Daniel Maddadu, (042) 74 3908.

Hands On Massage and Reiki for PLWHAs, Training of volunteer masseurs. Call Richard 660 6392

Legal Project (AFAO) Legal advice and advocacy on HIV/AIDS related problems. Call Michael Alexander 283 3222.

North Coast- Wollumbin CARES Community AIDS Resources and Support. Call Simon (075) 36 8842.

Tiffany's Transport Service For PLWAs (in the Sydney area.) 360 2043.

IS YOUR LISTING CORRECT?

JOIN US IN THE FIGHT AGAINST AIDS. SUBSCRIBE NOW.

PLWHA Inc. (NSW) is part of a world-wide movement to empower people with HIV infection, their friends, supporters, family and lovers to live full, creative and meaningful lives free from fear, ignorance and prejudice.

Help yourself and others affected by HIV to create a positive, friendly and supportive environment in which we can all live with HIV & AIDS — join PLWHA.

FIRST NAME _____ LAST NAME _____

POSTAL ADDRESS _____

_____ POSTCODE _____

PHONE _____ (W) _____ (H) _____

- I wish to apply for membership of PLWHA Inc. (NSW)
 - I wish to subscribe to *Talkabout*
 - I wish to renew my subscription to *Talkabout*
 - I wish to make a donation of: \$ _____
 - I enclose a cheque/money order for \$ _____
 - I am on a low income and wish to receive *Talkabout* for free
- In the interests of your confidentiality

I agree to have other members know my name and address

Yes No

I am publicly open about my membership Yes No

Annual rates are

Membership \$2

Subscription donation to *Talkabout*
(optional for people receiving benefits)

Individual \$10

Organisation (up to 4 copies) \$20

(up to 10 copies) \$30

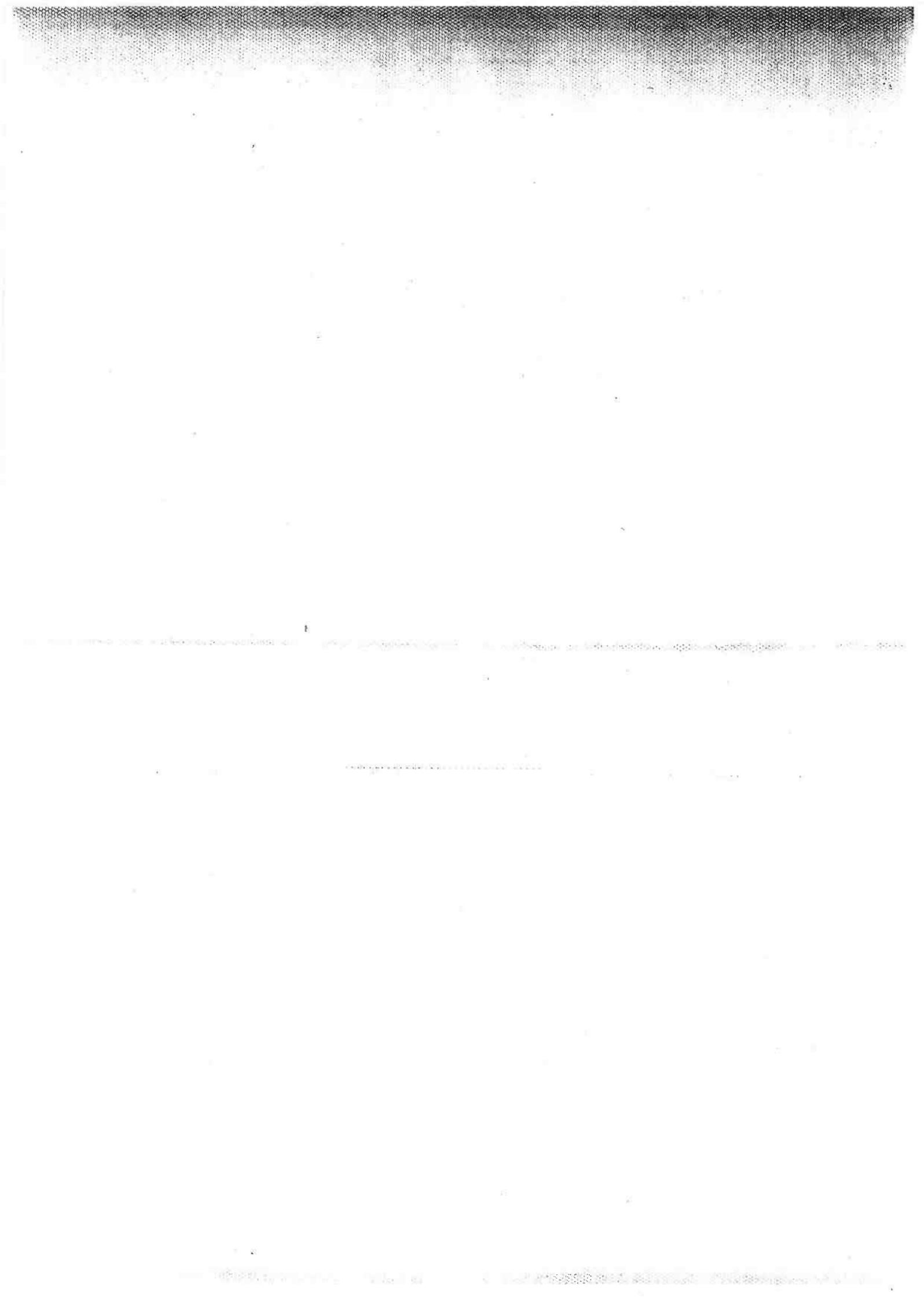
Please specify number of copies _____

If you want more than 10, call us.

Please forward this completed form to PLWHA Inc. (NSW),
PO Box 1359, Darlinghurst NSW 2010.

Make all cheques payable to PLWA Inc. (NSW). Donations \$2 and over are tax deductible. We will send you a receipt.

SIGNATURE _____ DATE _____



HIV *living*

THIS MONTH

INFORMATION NIGHTS

6.30pm - 8.30pm

AIDS Resource Centre

188 Goulburn Street

Darlinghurst

Wednesday October 14

Recreational drug use and safe injecting

Drug use, abuse, dependency and addiction ... harm reduction
Drugs and progression to AIDS?

Wednesday October 21

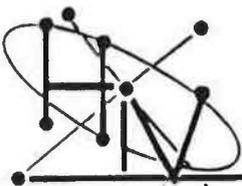
Sex issues

Sex after a positive diagnosis ... what's safe and what's not ... disclosure and
telling your partner. Other STDs and the reinfection theory

Wednesday October 28

Overseas travel

HIV friendly countries and those with restrictions ... how to carry AZT and
other necessary medications ... insurance coverage
What vaccinations do I need?



• **SUPPORT PROJECT**