

Talkabout

Newsletter of People Living With AIDS Inc.(NSW)

Where we speak for ourselves

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Photo: Jamie Durbar

Volunteers at one of ACON's World AIDS Day stalls in Castlereagh Street

After the party's over, it's back to the everyday for PLWAs

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Commonly Used Abbreviations:

PLWA: People Living With AIDS
(NSW) Inc.

PLWAs/PWAs: Primarily people
infected with HIV. Also sometimes
used to include others affected by
the virus.

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Living Well 3 - A Personal Response (I)

This has been the third conference for people with HIV and AIDS that I have attended. This is very much a personal response to some of the developments that are occurring in the people with HIV and AIDS movements.

I thought I would write a letter to raise some of the issues so that maybe we can start talking about them.

1. "Risk Group" Competition. Given the changing nature of the epidemic and following on from events at the National AIDS Conference in Canberra, the issues of working together were certain to be paramount. I came away from Adelaide with the impression that in terms of people with HIV and AIDS, many of the issues of working together are not as difficult as I thought. There seems to be a reasonable spirit of working together and solidarity between different groups for people with HIV. I got the distinct impression that perhaps other (dare I say people without HIV) people from other movements were imposing those agendas and

are not listening to or representing the people with HIV and AIDS from their movements or cultures.

2. Whose conference is this? There were a couple of presentations by people involved in the fight against AIDS who were clearly identified as people working with people with HIV and AIDS rather than people with HIV and AIDS. Some of these presentations were highly offensive to me as a person with HIV. Watching a person with HIV change overheads from the floor while the executive director of a national organisation spoke at a conference of people with HIV and AIDS made me think "whose conference is this?". I'm not suggesting that the conferences should be restricted, after all we want to be listened to, but maybe only we can speak.

3. Future conferences. After three conferences, I think it is time we got beyond the telling of personal stories. Yes, they are important and they have a role and it's important we tell then and we can learn from them and each other. But hearing the same sorts of stories for three years without going on to devising programs and political strategies to deal with what the personal

stories are telling us is a real failure. Perhaps, in the next conference we have to deal with our different needs - some of us want to tell our stories and share experiences, others of us are over that and want to have some more analytical and political discussions about what to do about the huge issues in treatments and discrimination facing us as people with HIV and AIDS.

Ross Duffin

Living Well (II)

Having attended the recent LIVING WELL III conference hosted by the NATIONAL PEOPLE LIVING WITH AIDS COALITION, I feel there were some outstanding issues raised and discussed that could afford wider publicity, discussion and action.

1. Most states and territories seemed to be reporting a lack of co-ordinated and accessible emotional support programs for people with HIV/AIDS and their carers, lovers and families. This resulted in the conference becoming a vehicle for much emotional discharge and personal testimony at regular intervals. Should we

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have to wait once a year for a safe environment to vent these feelings or should this be available when and where needed.

2. The appalling lack of any attempt at education strategies for people living with HIV infection and the confusion between support and education. When this is coupled with encouraging news on the treatments front, one wonders how people will access such treatments if the affected communities are not being informed.

3. I found the level of homophobia, misogyny, userphobia and factionalism within the ranks of the HIV infected quite disturbing. Surely issues of gender, sexuality, race and substance use should have

been worked out in the 60's and 70's. This division in our ranks can only be destructive and we need to be a united front in the battle that still lies ahead.

4. In many forums we heard that people with HIV infection are calling for inclusions in positive sexuality programs. The feelings and comments I was hearing were that our AIDS councils taught us "HOW TO USE CONDOMS" in '85 & '86 and have reinforced it ever since but that sexuality issues for those of us with HIV extend beyond the brand names of Ansell and Wet Stuff.

5. I was concerned at what seemed to be the widening gap between the people with HIV infection and the unin-

fected. There can be a fine line between self determination and separatism. People with HIV rightfully demand empowerment but if this is done with the exclusion of people on the basis of serostatus we risk alienating valuable, supportive allies.

6. Again and again the issue of the federal laws surrounding drug availability in Australia was raised. It becomes exhausting to continually restate the obvious facts that there are some therapies that could be preventing the illness and death we watch our peers experience every day. We suffer this degrading treatment as a result of archaic and reactionary drug evaluation regulations.

7. A major issue being reported by almost all PLWA organisations across the country was the low level of membership participation in PLWA activities. It is now too late in the epidemic for people to read their newsletter and pass quiet comment on relevant issues at home.

Our PLWA organisations are uniformly poorly funded and rely heavily on the input of their membership. These organisations cannot accurately claim to be representative of the HIV affected communities if the community members are not themselves contributing to the process of consultation.



WORLD AIDS DAY: At the Quilt unfolding at the Overseas passenger terminal, Sydney.

Photo: Jamie Dunbar

8. The living well conferences are extremely valuable forums for people living with HIV/AIDS to meet on a national basis and discuss common and specific issues that are affecting our lives, to exchange information, to see each other as a visible and vibrant community with a wealth of energy and talent, to offer each other support and encouragement and to devise strategies for change.

9. Finally, the organisation and coordination of such an event is a daunting task and accolades of appreciation and thanks must be extended to the committee and staff of the National People Living With AIDS coalition, especially Levinia Crooks. **CHEERS LEV!**

Andrew Morgan

TAKE MORE PILLS OR DIE - or why I don't do early intervention

Project Inform's flag motto - It's never too early to take charge of your health - is one I could not agree more on. However, the question remains, it seems to me, exactly **how** one does this.

Listening to Martin Delaney's authoritative words on early

treatment for HIV infection at the Living Well III conference stirred some uneasy feelings for me. His argument is eminently logical. One does not wait to deteriorate in health before one begins intervention. Taken to its logical conclusion, one begins "treatment" the moment one is infected. But "intervention" for Delaney is of one kind only, pharmaceutical drugs. In Australia, as with most western countries, this means AZT. We do not know the long term effects of such drug use, but we presume that something better will come along. In the mean time, it's the best we've got.

But what does this mean on a practical and experiential level for those of us who are well and HIV infected? I myself have advocated in the past to get to the point where we are now in terms of early access to AZT. But our advocacy was built on the notion of **choice**.

I have been aware for some time that we were manoeuvring ourselves into the difficult situation of being faced with choice but with no skills or experience with which to exercise that hard won freedom. How where we to decide when to commit ourselves to medical regimens for the rest of our lives? The commitment



Photo: Jamie Dunbar

WORLD AIDS DAY 1990: Geraldine Turner, one of the celebrities who donated her time to CounterAid, found some friends on Oxford Street.

has enormous implications for us. It potentially locks us for the rest of our lives into the machinery of medical intervention and surveillance, to doctor visits, blood testing, questions and answers, and pill-taking. I fear we have something of our freedom to lose in this commitment. Many of us intuitively know this and resist the message for early intervention, even when knowing fully the logic of the argument.

Delaney seems to have taken the difficulty of that decision away from us. We no longer have the choice to decide when to start taking such drugs. The time is now. We no longer have the freedom to explore alternative paths to health without the risk of ridicule. I have never been big on meditation, but I avoid taking pills at every opportunity, even for a humble headache.

My point is that I feel AIDS activists and educators have accepted the medical model to the dangerous exclusion of a broader conceptualisation of illness and health. In modern-speak this includes the whole gamut of things we euphemistically call "lifestyle".

Taking pills and joining trials may become a "lifestyle" for some, but it won't be for me until I've got real

good evidence that my health is: 1. in danger; 2. the available treatments offer a relatively safe and sure path to a quality of life; and 3. do so without throwing my life to the mercy of medical professionals who seem to appreciate little else about life, health, illness, and death, but the scientific challenge of keeping bodies alive for as long as possible regardless of the costs.

I'm tempted to be very ideological here and add a final point - 4. I'll be convinced and happy when AZT is as freely available to me as it is to the vast majority of

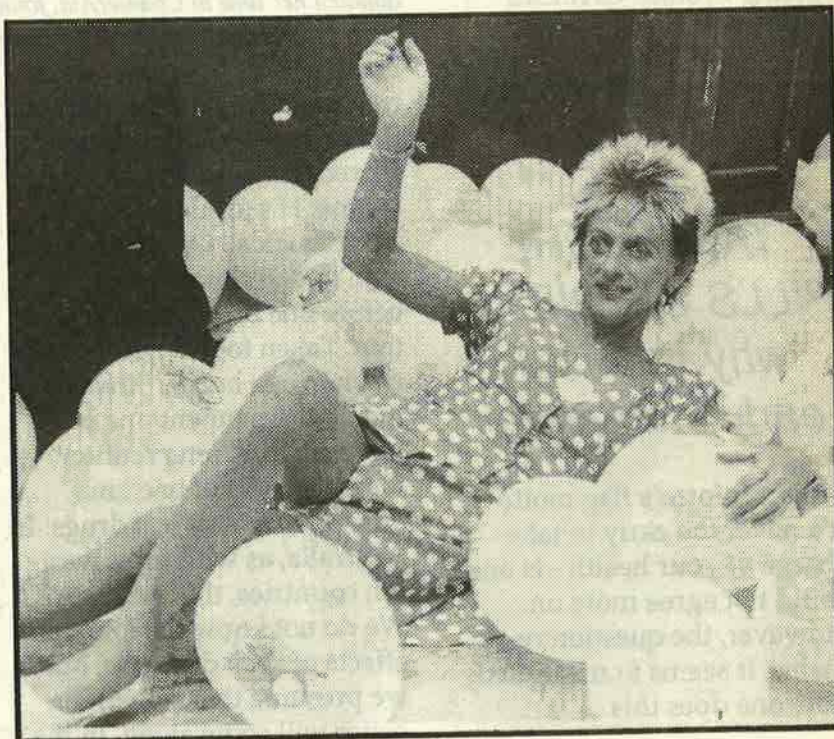
people with HIV in the world who have never seen the sight of an antiviral capsule. Maybe then there will be real choice.

Robert Ariss

Letters to the editor are welcomed. Please try not to exceed 350 words for a letter. Longer pieces will be considered for publication as articles.

The deadline for *Talkabout* #13, March/April 1991, is 10.00am, 14 February.

Send letters to PO Box 1359, Darlinghurst 2010.



WORLD AIDS DAY: Zsa Zsa relaxes at the PLWA Tea Dance.

Photo: Jamie Dunbar

PLWA (NSW) Committee News

1. Services Forum. As part of World AIDS Day activities PLWA(NSW) hosted a forum on services for PLWAs. Issues discussed included treatments, grief and loss, access issues for PLWAs and issues for IDUs and women. PLWA(NSW) is taking a number of initiatives as a result of the forum - watch this space for further details.

2. Tea dance. PLWA(NSW) also hosted a tea dance as part of the World AIDS Day activities. Who could have believed that the dowdy garage at ACON (generally known as the Siberia where smokers are sent) could be made to look so spectacular.

3. Hospital services. The PLWA(NSW) committee is gradually visiting each of the major hospitals with dedicated AIDS wards to discuss issues relating to service provision. We bring up any major problems that have been brought to our attention and discuss a complaints and advocacy procedure for each hospital. So if you're aware of any major problems, let us know.

4. Treatments. Overseas news on treatment advances continues (See article on Martin Delaney in this issue). The question is, when do Australian

PLWAs start to benefit from these advances. PLWA(NSW) has written to Federal Minister Howe about these issues and unless we receive a satisfactory response will be taking other actions to ensure PLWAs can benefit from the overseas good news.

5. New Convenors. Robert Ariss has resigned from the position of convener of PLWA(NSW) after two years of very hard work. Robert will remain on the PLWA(NSW) committee. PLWA(NSW) has appointed three acting co-convenors until the next Annual General Meeting. They are Amelia Tyler, Stuart Linnett and Ross Duffin.

6. Get involved. The above issues only represent a few of the issues that the PLWA(NSW) committee has been concerned with. There is lots to be done. PLWA(NSW) is a committee of volunteers. Your help would be welcome. Ring the PLWA office to find out what you can do.



World AIDS Day a great success

World AIDS Day, marked by over 300 separate events around the state, was a great success, according to WAD coordinator Rod Thorpe. "The Counter AIDS celebrity fundraiser was an outstanding success", he said, "raising \$100,000 and generating huge media attention and goodwill. The benefit of Counter AIDS contributed to HIV/AIDS awareness and the lowering of prejudice towards people with HIV cannot be underestimated."

The AIDS Memorial Quilt was displayed at the Overseas Passenger Terminal, and it is estimated that approximately 5,000 people came to see it.

The Boy's Own Bake-Off, held on the Sunday, raised over \$7,000 for the Bobby Goldsmith Foundation. One of the prize-winning cakes (Most Edible), was received with enthusiasm at the PLWA Tea Dance held that evening. (Thanks Don Baxter!)

THERE'S MORE TO TALK ABOUT THAN JUST READING IT

There's the Newsletter Working Group
which is responsible for planning
each issue.

If you would like to get involved in
this group, phone 283.3220, or
come to the next meeting,
4.30pm, Wednesday, January
9th,

on the second floor of the ACON
building, 188 Goulburn
St. Darlinghurst.



HIV support groups: your questions answered

HIV Support Groups are organised by the HIV Support project, a co-ordinated effort between the AIDS Council of NSW, People Living With AIDS (NSW), and the HIV community to provide support and information to HIV infected people. Russell, Peter and Kim all did HIV support groups last year. Peter and Kim were in the same support group. They spoke to Jill Sergeant about what the groups are like.

Why did you decide to go to the support group?

Russell: I found it beneficial just sitting in a room with a whole lot of people who you know exactly what their status is. In fact, because of that, the first two or three weeks were almost more beneficial than the later weeks.

I think I decided to go along because I was in a low patch and looking for support that I wasn't getting from friends.

Peter: I went along because it's a matter of identifying where you get your nurturance from and this group seemed right for me.

I'd been doing Ankali work for almost three years and felt that Ankali helped me confront a lot of my fears and acknowledge my own needs. I'd also been doing psychotherapy. I'd started to look at myself in a carer role and neglect my own needs.

I wanted to connect more with other positive men to relieve some

of that isolation that I think we often feel. I also wanted to regain sexual power, and I felt a group where we talked about sexual issues would help me do that.

Kim: When I joined the group I'd only known that I was positive for six weeks. I came along to one of the ACON Information Nights and after that came along to the group.

Having a lover who's negative, I felt that I needed to get in touch with others in the same situation; who would support and help each other in any way we could.

The first night we were all apprehensive, but I still went home feeling I'd got something positive out of it. Even though there were negative and upsetting parts, overall it was really positive. In the group roundup at the end of the eight weeks it seemed that everyone felt it had overall been a positive experience.

We also formed various friendships with each other. We

all feel rather protective of each other now, I think. I certainly do. I hope we keep meeting once a month or so.

Russell: I understand you when you say you felt protective. There was a real major issue that everyone was confronting in the group - that's a pretty strong bond.

The group was pretty diverse - it's amazing that you can be so frank with people who are so different. You wouldn't be able to do it in another situation.

Peter: Our group was diverse too, but even though there were all these different backgrounds, by the end of it there's that sense that you have a peer identity and that's good. It's great at times when you feel in a degenerate state and life has no meaning, to have people who can help get you out of that state and into something more meaningful. People can make changes inside themselves.

Russell: Support groups are a stepping stone.

Were you all in all-gay-male groups?

Kim: Ours was all gay men.

Russell: We had a girl in our group and a bisexual man. I think it was a great thing, and I got a lot out of that.

What do you talk about in a support group?

Russell: The obvious thing is issues to do with safe sex. The most emotional things are talking about discovering your HIV status and how you reacted. I'd talked about that with other people before, but others hadn't. It was the first opportunity for them and it was all very confidential.

Peter: Confidentiality is absolutely essential, and I felt that it was definitely there.

At each group meeting we'd do a roundup of our experiences of that week and the interaction in the group in relating to those experiences ensured that we covered a lot of issues. We didn't so much have to set a topic, as everything ended up being covered anyway.

We talked about relationships, contagion, coming out to your family, sexuality, work and stress issues, isolation and discrimination, drugs, lifestyle changes, information (we had a naturopath come and talk to our group), AZT, comparing our experiences with treatments.

We also had lots of fun.

Russell: There were lots of times we laughed.

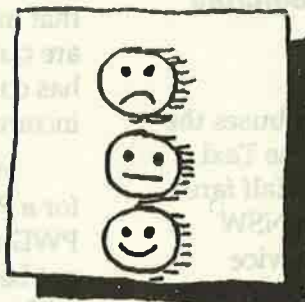
Kim: We actually had groups where we spent half the time laughing!

Russell: I was glad the group wasn't structured. It was pretty much 'come in and talk about our weeks', the good and the bad. The group decides its own course.

Peter: The facilitators didn't impose things on us. They took a non-directional approach.

Russell: The facilitators seemed to see it as their support group too. That was great. Everyone's in the same boat.

Kim: There's no stand-over pressure of any sort, and another



Graphic: Body Positive

good thing about the support group is that no-one's outwardly judgemental.

The facilitators are also HIV positive, aren't they?

Peter: Yes, and that made it much more appealing to me to go along. I did a Being Positive group at Albion Street where one of the facilitators was negative, and that made me feel - angry, in a way.

Kim: I think that's a fairly critical aspect of it. I think if a facilitator's negative they're not drawing from the same experience.

Peter: I know that I feel much more comfortable in that situation.

Would you do another one?

Russell: I would consider doing another one if I wanted support of that kind again in the future. It's enough for now.

Kim: I'm certainly satisfied for the time being. I'm now doing the facilitator's course now because I want to be involved and help other people - to give some support back really.

Peter: I'd do another group but I'd also be interested if there were any specific goal-oriented groups. But I'd go back if no other support was available. There needs to be something ongoing, even if it's just this newsletter that's being sent out now by HIV Support. One of the things that happens in the groups is that these all-encompassing issues come up and you wonder - why am I only discovering this now? When it seems like a common experience to others in the group. If you identify needs within the group, how do you go on from there?

Russell: A guy in my group used to say HIV+ people are the most 'in tune'. He was talking about being gay and coming out, and then later, if you're positive, there's a second coming out.

Kim: The support group is very helpful in respect of that second coming out.

Peter: It also provides the opportunity to develop intimacy with people. So much of my experience in the gay scene has been 'taking', rather than giving, and the group gives the opportunity to give love, compassion, sharing....

Kim: I'm sure it's helped a lot of people. It does work. Guys will say, "I was having a lousy week and I've been really looking forward to coming in and seeing you guys".

Got wheels, will travel

Anyone who has been incapacitated in mobility at any time will appreciate the difficulties of travelling and the added costs involved. Michael J. Winter passes on a few tips on wheelchair travel.

For those people unable to use buses the only alternative available is to use the Taxi Subsidy Scheme (ph:(02)339 0200). Half fare vouchers are available to anyone in NSW with mobility problems. The taxi service provided by most companies for people with disabilities (PWDs) is on the whole very good, however planning is needed when an outing or visit to friends is intended.

In Sydney the cab has to be booked by calling 339 0200. You must have the exact address of where you are going and an area of pick up where a stretched special vehicle, Metro Cab or van can access for loading and unloading. There is a fee of \$1.00 for booking, plus usual meter charges (which can include loading and unloading time). Most drivers are trained in handling most types of wheelchairs, but do advise them of the type of chair or other such equipment that you have. It is always advisable to telephone ahead to your destination, for you may arrive and have paid a substantial taxi fare to discover the address is totally inaccessible.

The added costs of disability are such that just simple rides from say Bondi to Sydney City cost the user up to six times the cost of a bus fare. It is advisable to book your return fares, but this does restrict instant decisions to go on to somewhere else or decline invitations to parties etc.

Even using vouchers, taxis can prove extremely expensive for people on invalid pensions, so an outing is a special event which one has to budget for. (It is hoped that those non disabled reading this will be aware that improper remarks to a PWD when they are out often spoils the outing for them and it has cost that person maybe one fifth of their income.)

When an able bodied person is planning for a PWD they need to be aware that the PWD may have exhaustion problems, or may not be able to cope with long travelling without toilet stops.

The PWD may have to empty urinary bags or need to be moved to stop sores from the pressure of sitting in one place. All these things need to be taken into account.

Similarly, the person should be aware that in hot or cold weather a person sedentary in a chair may get too hot or cold. Fluids intake is essential in hot weather, and maybe carry a rug in cold weather.

Travelling on trains presents various problems. In the Sydney Metropolitan area it's almost impossible to access trains with an electric chair, let alone the stations, as many have escalator egress and/or steps of some number.

There are a few outer metropolitan stations which are accessible, but these are few and far between, and situated in places where most of us don't want to go, let alone access the Scene in Oxford Street or Newtown.

It is not always advisable to carry a PWD up a flight of stairs. The person in the chair is responsible for any injuries that 'willing

hands' may incur, and many people (and chairs!) are heavy. If you drop a PWD then you may be liable for any injuries they incur.

Travelling on country trains is not too bad with proper planning. The XPT has special seats available in the buffet for PWDs and especially those who need a chair for mobility. At Central Station on Platform One there is a transfer chair available from the Station Master's office. An aisle chair is available on the train. You have to be quite slim to use it however, and need an aide with you to propel it.

There is also a toilet for PWDs which has a hand rail, set behind the bowl and to the right, to assist in rising or sitting. This will prove difficult if you need assistance as toilets on trains are not much bigger than a broom cupboard.

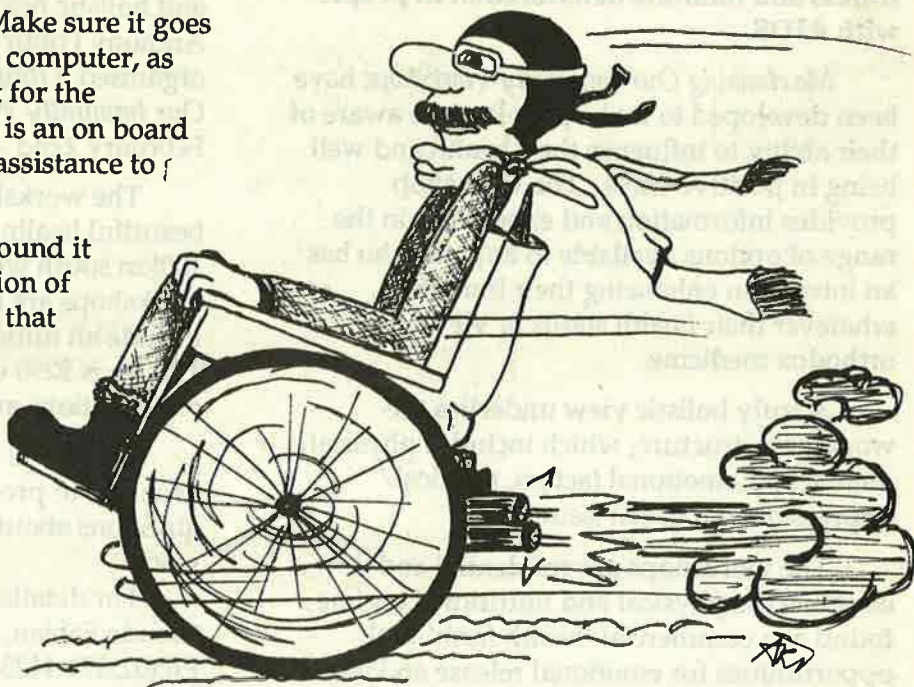
When making your booking, (and remember those on pensions can get a ticket for \$10.00 within NSW)*, inform the booking clerk that you have a wheelchair or other mobility aid or equipment. Make sure it goes on your ticket and onto their computer, as this information is important for the conductor of the train. There is an on board service for PWDs who need assistance to get around the train.

When planning I have found it invaluable to contact the station of destination and inform them that I will be arriving with an electric chair and may need assistance especially when I have travelled alone. If the station is unstaffed inform the conductor, who will muster assistance from train personnel. It is important, if your chair is in the

baggage car, that the personnel are aware of it and that it has to be unloaded for you at your destination.

I always put a tag on my chair with my name, destination, seat number and a warning for staff not to play with the electrical controls. This may seem patronising but it is surprising the number of people who think it is a toy and not a valuable and costly piece of equipment, and an extension of one's legs.** I have arrived at some destinations to find the batteries flat and that staff have played with it in the baggage car, leaving the power on to drain away so that mobility was severely disabled.

Through the Taxi Council it is possible to find out whether the area you have chosen to go to has a special vehicle in their fleet. They are always pleased to forward the name of the company and its telephone number. Always book ahead for the vehicle, tell them which train and time you arriving and what sort of



chair or how many passengers there are.

Finally, when booking your accommodation ring first and ask them if they are indeed accessible. There have been great improvements over the past few years, however special needs may require you to get in contact with the local neighbourhood or community services department to get loan of items as shower chairs. Most areas have a Tourist Office, which, on request, will send details of accommodation which may have modified units available for PWDs. Bon Voyage!

* There is a reciprocal agreement in Victoria and most of Vic Rail is accessible. Vic Tour and the Yooroola Society in South Melbourne can provide information for PWDs. The taxi service is not very good.

** For those without mobility problems, always remember the PWD in a chair is a person first and the chair an extension of lack of limbs or functions of those limbs. Because the limbs do not function it doesn't mean the person in the chair is unable to function so please do speak to us, we're not ogres.

Maximising your immunity

Several recent American studies point to the benefits of a healthy lifestyle and positive mental outlook both in slowing the development of HIV into AIDS¹ and reducing illness and immune deterioration in people with AIDS.

Maximising Our Immunity Workshops have been developed to make people more aware of their ability to influence their health and well being in positive ways. The workshop provides information and experience in the range of options available to anyone who has an interest in enhancing their immunity, whatever their health status or views on orthodox medicine.

A truly holistic view underlies the workshop structure, which includes physical, mental and emotional factors, political/ oppression and green issues.

The workshops are residential and combine the physical and nutritional regime found at a commercial 'health farm' with opportunities for emotional release and an

understanding of how to reverse the ways in which oppression can damage our self esteem and health.

British freelance counsellors, trainers and holistic health consultants in HIV/AIDS Anthony Hillin and Peter Tamm have organised a four day residential *Maximising Our Immunity Workshop* in Australia February 22nd - 26th, 1991.

The workshop will be held at Kyabra, a beautiful healing centre with mineral springs 100km south west of Sydney. The workshops are non-profit making and fees include all tuition, accommodation and food. The fee is \$290 or \$145 concession. (\$490 for organisations and people on high incomes).

There will be some free introductory evenings to provide opportunities to ask questions about how the workshops will work.

For details and booking forms, contact Claude Fabian, PO Box 441, Rose Bay 2029, Ph:(02)371 4423 or (02)371 7421.

Work in progress

The One Extra Dance Company has never been noted for any reluctance to take on 'difficult' issues and their new show, *Three Messiahs*, to be presented in Sydney next March, is no exception. Artistic Director Kai Tai Chan says that the overall theme is "to reflect what's happening to us in the 80's and 90's. Times are changing so fast". It's impossible, of course, to tackle such a theme without touching on AIDS.

Three Messiahs is in three parts, covering issues around motherhood, migration, drugs and sexuality, with the third section focussed on AIDS. "It's a very difficult thing to do", says Kai Tai, "It's a sensitive area. I think it needs to be talked about, it's still very much in a back corner, but most people know someone affected by it. I know quite a few people who have it, and it is something we have to face.

"Because I'm gay it's always on my mind. I'd rather tackle an issue than say it's too hard. I don't set out to offend. I believe in bridging, sharing the human condition. I live in so many minority groups myself! I like to think there is a common bond but often people don't see across barriers.

"It's our task to communicate to a general audience. You need to find an angle which could move them, touch them. I think the key is the human element. People tend to find it difficult to empathise - they say "it's nothing to do with me".

"I don't want to exploit

the situation. I'm very conscious of not taking advantage of it. I don't want to be voyeuristic. I don't necessarily think reproducing the reality [of AIDS] is essential. I'm interested in how people deal with it.

"I want to draw out the positive side. If you give something depressing to an audience you have to suggest what they can do about it. Maybe having to confront death forces you to review your life, to shed excess baggage. Perhaps it gives people a heightened sense of living.

"Maybe the answer is in religion. I'm not religious, but some people find comfort in it. If you don't understand something you can dump it on a god. The piece will have a calm religious atmosphere. The music is religious music - Black American spirituals, Bulgarian chanting.

"I think we're quite brave to tackle it - it's part of our lives and we can't not tackle it. There are lots of gay choreographers and directors but not a lot of works reflecting that. At least I'm diving in. It's important in the arts that things be reflected. I'm going ahead to explore how to do this. One might as well be brave.

"It will be just a short piece. I want to acknowledge that it's here with us; maybe get some exquisite, moving images that are relevant to us all - and something positive as well."

Jill Sergeant



Kai Tai Chan : "I'd rather tackle an issue than say it's too hard."

AIDSPEAK

and the press gang

1985 was not a good year if you were gay. But if you happened to be a newspaper-owning billionaire like Mr Rupert Murdoch, it was a very good year indeed. In the tabloid newspaper coverage of AIDS in 1985, media hysteria achieved new and dizzying pinnacles. For a while, the press made it seem as if 15 years of gay liberation had not happened.

In the AIDS coverage of the mid 1980s, the game was played to the rules set by the entertainment specialists. Anything that was entertaining got a run. When AIDS stopped being entertaining, they stopped writing about it.

Now the rules are different because, by and large, the only people writing about AIDS with any regularity are those who want to provide accurate information. They are not the same people who wrote the panic headlines of 1985. They did not put DIE! DEVIANT DIE! across the front page of a popular tabloid paper. They did not create and feed the public's fear and hatred of "AIDS carriers". And they were not responsible for setting the emotional attitudes to the media in which many people with HIV, and many of our AIDS organisations, are still stuck.

Many of our habitual complaints about the practice and language of AIDS reporting, though once sharply relevant, are now increasingly beside the point.

In his book *And The Band Played On*, San Francisco gay journalist Randy Shilts defines AIDSpeak, the dialect which is deemed acceptable in any discussion of the disease. "The linguistic roots of AIDSpeak," Shilts writes, "sprouted not so much from the truth as from

what was politically facile and psychologically reassuring. Semantics was the major denominator of AIDSpeak jargon, because the language went to great lengths never to offend."

Shilts gives some examples: "AIDS victims could not be called victims ... 'promiscuous' became 'sexually active' ... the most-used circumlocution in AIDSpeak was 'bodily fluids', an expression that avoided troublesome words like 'semen'."

In Sydney, a new phrase has been added to the list of no-nos. According to some ACT UP representatives, people with AIDS are not to be referred to as "AIDS sufferers". But surely, anyone who has seen a friend die from this horrible disease must have seen them suffer. Of course people with AIDS are AIDS sufferers, and we are not well served by this ban on a sympathetic and descriptive term. The position of some ACT UP people on this term is difficult to understand when one sees it used by the organisation's founder, Larry Kramer.

It is a mistake to assume that a reporter's use of a word like "victim" is intended to impose a limiting, passive role on those of us with AIDS and HIV, or that it will be interpreted that way by the reader. We are the only ones who try to wring every speck of real or imagined meaning out of articles on AIDS: other people just read the paper.

In articles which are not about AIDS, you will notice that "victim" is used frequently, and almost always sympathetically, in a vast range of situations. Would we seriously expect someone whose house has been robbed to object to being called a "victim of crime?" Would any of

for AIDS victims
NEW YORK — The New York skyline dimmed on
museum visitors gazed silently at

More women to be victims as spread of AIDS widens

Death reaper

—A and a beautiful six-
rough contam

Living with
a death
sentence

of sympathy
AIDS victims
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us worry about being called an "accident victim" if we were hit by a bus? It may not be great writing, but I cannot regard it as offensive.

Larry Kramer, trying to mobilise the anger of American gay men, wrote: "We are not the cause of AIDS but its victims". Absolutely correct. But why is it okay for Kramer to refer to "victims" and for no-one else? Are we really so timid that we need to see ourselves described in euphemisms?

This is what I think:

* Language is important, and it does have a function in shaping attitudes. Therefore, we should demand accurate language, not euphemism. We are decent and worthwhile people and if we are described accurately that will show.

* I suspect that what we find confronting about a term like "AIDS sufferer" is not "sufferer" but "AIDS". Is our reaction at least partly because we are ashamed of having AIDS, or the AIDS virus?

* People who have HIV and AIDS are victims, just as much as anyone else who has to face a disaster which is not their own fault. AIDS victims are not only that: they have the usual range of human characteristics, which may include anger, empowerment, determination and brown hair.

* We should reconsider the demands we have of journalists, in the knowledge that we are dealing with a substantially different group from the one which worked us over so thoroughly five years ago. If someone uses the term "AIDS" to describe someone who does not have

category four HIV infection, that is an inaccuracy. If it seriously changes the meaning of a story, the reporter should be gently but firmly told. If someone uses the term "AIDS carrier", they should perhaps be asked when was the last time they referred in print to a "flu carrier" or a "gastro-enteritis carrier".

* As someone who has been a reporter for an unpleasantly large number of years, I can tell you that the best way of changing the way a journalist does anything is by a polite, gentle but firm letter from a person with AIDS or HIV pointing out why a particular word, sentence or story should have been written differently. Write to the reporter. Letters to the chief executives of large organisations usually don't make it beyond the professional letter-answerers. Executives are used to getting such letters; individual reporters aren't.

Some journalists, like Alex Mitchell of the Sun Herald, seem to have a particular agenda and are unlikely to respond positively. Many will. If, for good and cogent reason, you see something you think is damaging, do something about it. Whingeing among ourselves will change nothing.

This epidemic has moved so fast, and the news has been so uniformly bad, that it's difficult to see an improvement when one comes along. I think the journalism on AIDS has improved amazingly in the past five years, and I think there are a number of reporters who actually care about what is going on. Not all, but some. Let us not be so fond of the political liturgies of the past that we fumble the present.

Martyn Goddard



THE CLINIC

PART 7

"My name is Peter and I'm an alcoholic and a junkie and I've been clean now for 25 years except for that little bust I had last week".

These words bring Martha back to reality "God these boys are so fuckin' melodramatic. I bet he's been standing up at meetings saying that kind of stuff for years. Oh well I guess that's what meetings are for. What am I doing here - good for the soul but the rebellion will have to wait, I've got to find Rebecca and that silly queen Neill....."

Meanwhile..... at a secret location known only to the team of 10, Rebecca sits in a room looking out of the window at the distant hills. "It's time for your medication dear".

"Stuff your medication prick, you know what you can do with that" - as she kicks a bucket of water across the room at the nurse. "You can't keep me here and as for those two phoney nurses across the hall, I know they're cops, I can smell a pig a mile away. I'm leaving and you can't stop me. This is a free country and I want to ring Geoff McMullet he's my friend and he'll fix you lot".

"Shut your face Rebecca! There are no phones, no visitors and no leaving until we are satisfied you'll never work again".

As the very overbearing nurse sits on her and forcibly administers her medication, "you'll be having one visitor tomorrow morning - the big boss from the Health Department and they'll tell you when you are free to go. Get it into your head now, you have been detained under the Public Disgrace Act and these are your rights - none".

"You can get fucked, I know my rights and you can't make me stay".

In a neat suburban cottage not far away Bruce the

Chief Executive Officer of the Niagara Rest Home is having Sunday dinner in front of the tele with his family and a special news bulletin comes on. "Rebecca the AIDS prostitute has been taken to a new AIDS facility with a specialist team of 10 hand picked people to care for her needs". Bruce glances across at his wife. "Isn't that nice, a specialist care team in a specialist centre to care for her"



Meanwhile.... at a secret location known only to a team of ten....

Suddenly the phone rings. "Bruce, this is Sister Obese - get over here quick our quiet little nursing home has been invaded by cops masquerading as nurses, Doctors behaving like cops and a crazy woman they call Rebecca. You've got to do



While Rebecca pinned her hopes on Geoff McMullet, Sister Obese was afraid Hunch and his henchmen might get involved....

something about this, any minute Geoff McMullet and his 20 second team, Yarna Airvent and her Common Affair team not to mention Hunch and his henchmen will arrive. The patients, you know they're all old, dementing and hallucinating enough already. This will just send them over the top and I'll have to spend the whole night running around pumping them all full of largatil."

Bruce interrupts - "but but I thought they had set up a special unit for her"

"You don't believe everything you read and hear in the media do you Doctor?"

"I'll be right over!" (How dare they do this in my hospital without telling me.)

Very early the next morning.... "Wake up

Rebecca, it's time for your medication and you've got to get ready for your special visitor and you had better behave yourself."

The door opens and in walks the Health Department official. "Rebecca this is Dr. Eel, she is going to tell you how long you have to stay here".

Dr. Eel hands Rebecca a letter and explains..."You have been detained under the Public Disgrace Act because you didn't tell your clients you were HIV positive.

"You can't keep me here" Rebecca screams. "I use condoms and I can't help it if the fuckin' mugs take them off".

Dr. Eel continues..."you will remain here for 5 days and then you must undertake counselling and you must never work again...."

Rebecca interrupts. "I've had you lot, telling me what I can and can't do. I'm going to ring Geoff McMullet, he'll fix you lot.

Sister Obese who is sitting with hyperdermic primed: "don't you understand, that's why you're in here. It was that story you did on 20 seconds, Geoff McMullet is no friend. He likened you to a "serial killer". Don't you know you have been scapegoated and the media has used you to force

the Health Department into using the Public Disgrace Act.

"Bullshit, he's my friend and so is that nice lady from A Common Affair and the Channel 69 news. They gave me money and bought me clothes and took me to see my son, more than all the fuckin' social workers and do-gooders in Sydney have done for me in my entire lifetime." Rebecca's mind wanders..." Don't you think I looked like Marilyn Monroe?"

Martha wakes up with a start. "What in the fuck am I going to do? At least Rebecca hasn't been murdered, she's been hanging out with some pretty heavy characters of late. I've got to find Neill, I wonder if he saw the news last night. I bet he's up the Cross, probably had to score before he could get his head around this one."



Martha was worried.

Martha searches the Cross and still there is no sign of Neill. She approaches a worker friend of Rebecca's. "Have you seen Neill?"

"Yeah he was here this arvo, said something about going to be tested. By the way, if you see that bitch Rebecca, tell her her days are numbered I only cracked it once last night and there hasn't been any business today. Tell her there is a contract out on her—she's fucked business for all of us. If she comes into the Cross she's dead."

It's a cold rainy night and as Martha approaches the AIDS bus she sees the back of Neill getting on board and all the other boys huddling together under the awning to keep out of the rain. "God I'm glad I don't have to do this myself anymore."

One of the counsellors is standing in the doorway. "Can you tell Neill I have to speak to him?" Neill appears in the doorway and Martha can't help herself "What are you doing having another fuckin' test for?"

"Well you never know, maybe they made a mistake."

"What, four times! I don't think so Neill. Get your arse into gear we've got to do something about Rebecca. The workers want to kill her and the public would like to see her locked up for the rest of her life, you saw the news last

night didn't you?" "Yeah sure, but what can we do about it? And we don't know where they are holding her anyway."

Ring ring.... the mobile phone on the bus rings..."Yes" Dr. Sparkle the counsellor says.... "What, where, Rebecca...the Niagara Nursing Home". Martha looks at Neil "Did you hear that?"

"Yeah" says Neill. "At least we know where she is now but we need some help if

we're going to break her out. Let's go find the Users for Users Union."

"Who the fuck is the Users for Users Union?" says Martha.

"They're kinda like what ACT UP is to the queens."

by Clarissa Goodbodine and
Venue Queen

**To be continued
if you dare.....**

**Will Neill and Martha
succeed in their quest to
find the Users for Users
Union's secret location?**

**How long will Rebecca be
detained at the Niagara
Nursing Home?**



**Will Sister Obese have the
nervous breakdown he
deserves?**

**Will Bruce the Chief
Executive Officer of the
Niagara Nursing Home
have time to fill his valium
script before reclaiming
his hospital?**

**Will the patients at the
Niagara Nursing home
remember this as better
entertainment than
A Country Practice?**

**Will the police (cleverly
disguised as nurses) who
didn't want to be there in
the first place head for
the hills?**

**Will the Users for Users A
Team break her out?**

**Your chance to make it happen at THE CLINIC!
Every episode of The Clinic is written by a
different person (or people). If you would like to
write the next episode of The Clinic, phone Jill,
Talkabout co-ordinator, on 283.3220.**

Good Health

US AIDS patient uses marijuana to ease pain

An AIDS patient had received a government-approved shipment of marijuana to help ease the pain of the disease, the New York Times reported in November. A group called the Alliance for Cannabis Therapeutics is promoting the legalisation of marijuana for medical uses, and claimed that in this case the drug had reduced nausea, vomiting and weight loss, and that it had restored the man's appetite.

The American Food and Drug Administration has allowed the use of marijuana by patients in at least two dozen cases since 1976. It is classified as a Schedule 1 drug, making it available only for research. In 1988 an administrative law judge recommended that marijuana be made available by prescription for the treatment of life threatening diseases and in some other cases. The recommendation was rejected by the Drug Enforcement Administration, but this decision is being appealed.



A Brush with danger

Waiting until a toothbrush is worn out before replacing it may affect the health of the entire body, according to a report in the Readers Digest health and Fitness New Service. The well-used toothbrush may harbour bacteria and yeast associated with pneumonia, stomach ulcers, strep throat, sinus disease, upset stomach and diarrhoea.

Bacteria and viruses thrive where there is food and water, and when present, all that is needed is a point of entry - a slight scratch by a toothbrush may be all it takes. These bacteria may be on the toothbrush because bathrooms are not very hygienic places. "When someone flushes the toilet", says one expert, "those germs aerate over the bathroom." Sharing of toothpaste is not a healthy practice either, as the brush may leave germs on the tube.

Healthy people should switch toothbrushes about once a month, while those with immune disorders, heart disease or other serious medical conditions should do so more frequently. Cold sufferers should change brushes at the first sign of recovery to avoid reinfection.

- from Vancouver PWA Newsletter

How to short circuit the hospital system

In September I started attending Immunology B clinic at SVH. This was when I started AZT.

I had had little experiences with SVH ancillary services - pathology, dispensary and casualty, and was less than content with their attitude and service.

The people in ImB and ImB Treatment Room have been and are nothing but charming and supportive - with one exception. I wasn't told to expect to feel absolutely RS, as if hit by a UTA bus, after a blood transfusion. It was explained that I felt this way because my body was using its energy to 'kick start' the blood. (In January I had AZT toxic anaemia with a Hb of 5.8, hence the transfusion.)

I digress. The point is I wouldn't and still will not let the pathology technicians at SVH bleed me. The only person permitted to do so is my GP. When she does it I don't end up in pain and with bruises on my arm.

This was more than satisfactory with my Immunologist... I would be bled by my GP, on the Monday before the Thursday I attended the ImB clinic, collect the results from my GP on the Tuesday/Wednesday, to take them with me early on the Thursday morning.

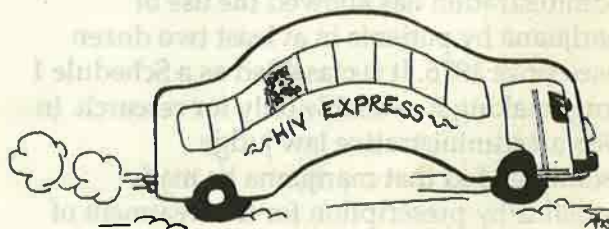
I later arranged for the results (from Macquarie Pathology Laboratory) to be faxed to me at work. One less trip to the GP. One less bit of unnecessary use of energy.

I tried to have the results delivered by Macquarie Pathology to SVH. The delivery was made by 1.00pm on the Tuesday after being bled on the Monday, but the SVH

records department could not get the results on my file by Thursday morning when I consulted with my Immunologist.

I travel by public transport - from home to SVH it takes two buses with a walk at both ends and in the middle - about one hour. My GP is but ten minutes walk, on the flat, from home (and she does house calls if needed). I can then catch a bus and be at work by 9.30am, the start of 'core-time'. Due to delays at SVH I cannot ever get to work on time if I was to be bled by SVH pathology; I can't afford a half day sick ever fortnight.

I am now to participate in the ddi trials. Macquarie Pathology will fax results to the MRC/INSERM ALPHA ddi TRIAL office, or anywhere else required for that matter on their dedicated fax.



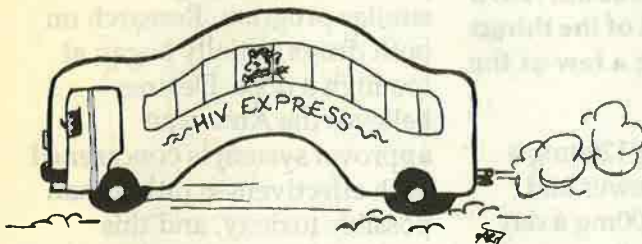
I spoke with one of the pathologists at Macquarie, he could understand my situation and could foresee no problems but for one. He asked for faxing details to be included with each and every pathology request form. I assured him that would not be a problem as I could prepare a fax cover sheet and include a copy of such with every pathology request.

I have yet to test this last bit of procedure.

Until recently SVH were the only ones able to do the T4 count. Now, under the supervision of David Cooper, Macquarie

Pathology can do this test and it's matched with those of SVH. SVH is still necessary to do P24 antigen.

To save confusion when my blood, collected by my GP, is sent to SVH for analysis, I have 'acquire' labels produced/used by SVH that contain my name and MRN (Medical Record Number).



I have prepared similar labels on my computer at work that contain my name, medicare number, clinic code number and other relevant information, to be placed on the vials of blood bound for Macquarie Pathology. This makes life a bit easier for my GP and saves confusion at the labs.

Both sets of labels are kept on file at my GP's.

As it turns out the ddI Trial wants their blood analysis to be done by SVH lab to keep the trial results/findings uniform. Still one problem. My GP has sent my blood to SVH for T4 count for years. She now has to send four vials instead of the usual one. SVH has supplied me with the necessary instructions for my GP, forms, vactainers and more labels.

A point that my GP brought to my attention is when patients participate in drug trials GPs tend to lose contact with them. This is brought about because the patient needs to consult with the person conducting the trial for their health management.

With PLWAs this has its drawbacks in as much as when the PLWA becomes ill, eg. to the point of not working, and needs medical attention the GP is the one who does house

calls, etc and at this stage is out of touch with what is happening with that particular PLWA.

So by involving my GP in the drug trial, by taking blood etc, not only does it become easier for me as a PLWA, but it gives my GP some idea what is happening for me when she needs to know.

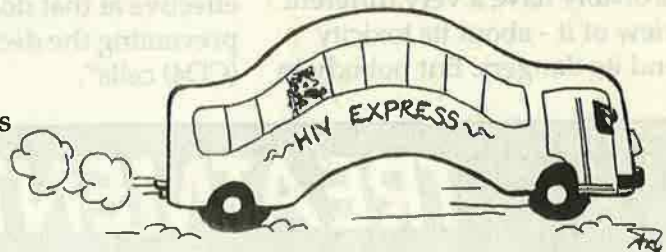
Another part of SVH that needs to be side stepped, as well as a good shake up, is the outpatients' dispensary. Unfortunately we can't get our AZT and ddI anywhere else. I'm usually in and out of ImB by 8.30 and the dispensary is not open until 9.00am (and then there is an immediate delay of 45 minutes). I have a friend who is in administration at Outpatients. I ask her to put my AZT script in and when they open another friend who works at SVH and lives close by, collects my medication and I then collect it from him at a time convenient to us both.

With a little collective pressure I feel that the hours and the service could be improved; and to the benefit of not only PLWAs.

The only other problem I have to solve is transport. The bus from the Transport Service seems to be only for those not working. The bus run does not start until 8.45am. My appointment is for 8.30am. I try to get there earlier, 8.00am, only to be attended to earlier.

If a little more support was available for PLWAs who are still working, we may be able to stay in the workplace a little longer.

The importance of keeping the likes of PLWAs in the workplace is another debate.



Significant Advances in AIDS Treatments

Martin Delaney, Executive Director of Project Inform, was the keynote speaker at the Living Well 3 Conference held in Adelaide over the weekend of November 24th and 25th. Project Inform is an organisation providing AIDS related treatment information, advocacy and conducts research into some therapeutic agents. Martin is one the best communicators about AIDS treatments in the world. It is impossible to cover all of the things Martin talked about so this article will summarise a few of the most significant items.

When to start treatment

According to Delaney, "The best that can be offered today is that whatever level of immune function you've got at that point when you start treatment - that's about the best you can hope to maintain. If you had 700 T-cells why would you want to wait until you had 500 before doing something about it, if you had 500 why would you wait until you had 200. The name of the game is to prevent the decline, not simply to prevent the onset of symptomatic illness."

Dosage of AZT

The dosage of AZT has been a major question. Says Delaney: "If we were still talking about 1200mg a day of AZT I'd probably have a very different view of it - about its toxicity and its dangers. But nobody in

the States is using 1200mg a day of AZT and fewer and fewer are using 600mg a day. In the last six months a number of studies have come to light suggesting that the drug is also effective at 300mg per day. The idea of using AZT was always to find the optimum balance."

Many people in Australia are on doses of 1000mg a day, particularly people who have continued on from the AZT high risk trial and people who are participating in the AZT low risk trial. Delaney argues, "I don't see why you would want to take one pill more than you need to and certainly if things like the p24 antigen test are any indication then AZT is effective at 300mg and in the studies presented so far it may actually be more effective at that dose in preventing the decline of T4 (CD4) cells".

ddI and ddC

ddI has been available in the expanded access program in the United States for over a year. ddC has just gone into a similar program. Research on both drugs initially began at too high a dose. Delaney believes the American approval system is concerned with effectiveness rather than possible toxicity, and this leads to drug companies slanting in favour of higher dosages.

When ddI first became available through the expanded access program, Project Inform, on advice from the National Cancer Institute, immediately advised people to halve the dose. Delaney says "Our experience is that people who followed that advice had a very low incidence of side effects. Those who did what they were told, however, walked like lambs to the slaughter and had a rather severe incidence of side effects."

Combined Trials - The Best News So Far

The results from a study using AZT and ddC in combination

TREATMENT NEWS

were released two weeks before Delaney came to Australia. Delaney says "This is the best results we have seen from any of this class of drugs. And I say the best in terms of the weight gain that the patients experienced, the clinical conditions they reported, the freedom from opportunistic infections and perhaps most surprisingly the best T-cell increases that we have seen."

100% of the patients experienced a T-cell increase of 50 points or better and an average of over 160. In order to gain entry into the study patients had to have below 200 T-cells, and the average for the group was under 100. The other significant thing was that the T-cell count was still well above baseline 12 months out. A number of similar studies are under way in the US and a combined ddI and AZT trial is showing similar results after six months.

As a result of this information, for people who can get ddI or ddC, from the patient point of view, the standard of care has become AZT plus ddC or ddI.

This has lead to the fight for approval of ddI and ddC in the United States. According to Delaney, "Best case, we believe, and I think it's a pretty realistic one, is that ddC and ddI will be

approved for wide scale use in the States around March, 1991."

Delaney: "The idea of AZT was always to find the optimum balance."

A worldwide approval standard

If ddI and ddC are approved in early 1991 in the United States the question becomes how long will we have to wait in Australia for ddI and ddC approval. According to Delaney "There is no rational reason why a drug company, or a drug, or the patient community, or anyone should be asked to wait while different standards of approval be acted out in one country after another. It's ridiculous. If the drug in its home country has to meet tough standards as they do in the United States then that ought to be good enough for Australia. I think we need a

"We need a worldwide community of interest and activism around this"

worldwide community of interest and activism around this so that in fact we move towards a single world wide standard so that once a drug is approved anywhere, AIDS

patients anywhere on this planet should have the same rights of access to that drug."

Towards the 'designer' drugs

For years, people have talked about having something better than AZT, ddI and ddC -

the nucleoside analogues. A number of new drugs are about to begin phase 1 trials in the United States. These include the protease inhibitors, the TIBO derivatives and a drug designed to suppress the TAT gene protein of the virus. These are all drugs that have been specifically 'designed' for the HIV and hold a great deal of promise, both in terms of being more effective and less toxic.

Compound Q

Project Inform has been heavily involved in Compound Q research. It's a very difficult drug to study because of difficult questions about how to use it and its potential toxicities. However, it holds a great deal of promise and potential. It is quite different in its mechanism from other drugs and is in effect like a chemotherapy for HIV, killing infected cells rather than suppressing the virus itself.

(Continued overleaf)

Sexual Health Clinic: St George Hospital

A new clinic has been established at the St George Hospital as a beginning of new resources for the area in HIV/AIDS and sexually transmitted diseases. Prior to the clinic the area had been recognised as being under-resourced especially with the new demands of HIV/AIDS.

Dr Carmella Law, the clinic's director, has worked extensively in the area of STD especially at Sydney Hospital's clinic. She is recognised as an expert on wart virus, STDs and bowel infections in gay men.

Mr Stuart Linnet, the senior social worker, has worked for four years as an AIDS counsellor and has helped set up the units at Westmead and Prince Alfred Hospitals. He is one of the most experienced counsellors in AIDS in NSW.

They are backed up by experienced nursing and laboratory staff who are able to give treatment and undertake tests.

The clinic offers a full range of services in the areas of STD and HIV. This includes testing

of and treatment for STDs; testing and treatment for HIV/AIDS infections; counselling for patients, their friends and relatives; education in these areas for the community and hospital; resources for the area to develop further services for STDs and AIDS.

In the near future, the clinic will be expanding its services.

Appointments for medical or counselling services can be made on 553 2742 or 553 2743. See *Talkabout Diary* for further details.

Treatments

Continued from Page 23

Compound Q is just beginning phase 2 studies in a number of United States centres.

Opportunistic Infection Drugs

Two advances of significance that Delaney reported on were for two of the most significant opportunistic infections - PCP and MAI. Burroughs Wellcome have a new drug for PCP, currently known as BW566, which not only suppresses the organism (which is what the other

drugs do,) but seems to kill it. A new drug for MAI, an infection that is currently very difficult to treat, has been discovered and is called chlorythromycin. Trials of both these drugs have commenced.

Immune Restoration

There is a national conference occurring on immune restoration in the United States in December. According to Delaney "We must find out what we need to do to restore the immune system in late stage AIDS. We'd like to think that everybody out there is working on that but they aren't."

The 'C' word

Says Delaney: "Remember a few years back everyone told us that a cure was never going to be possible, it couldn't be possible. All the scientists we work with told us that. Now, they're all willing to use the 'C' word when talking about where we're going with this disease. It's not like it's going to be easy or available at your chemist next week but the potential for a cure, for eradicating the virus from your body is now accepted point of fact by most of the researchers who said just a few years ago it wasn't possible."

- Ross Duffin

NEWS

GLOSSARY OF AIDS TERMS

Part One A - K

AIDS(Acquired Immune Deficiency Synrome): defined by the Centre for Disease Control in Atlanta, USA (CDC) as "The presence of a reliably diagnosed disease at least moderately predictive of cellular immunodeficiency, in the absence of an underlying cause for reduced resistance to the disease". It is believed the primary aetiological agent of AIDS is HIV.

Anemia: Condition of having a low number of red blood cells.

Antibody: Immunoglobulin (blood protein) produced by the immune system in response to foreign antigens in order to neutralize them. The antibody produced in response to HIV is ineffective in neutralizing the virus in the long term but serves as a marker for the presence of the virus. Antibodies take up to 3 or more months before being detectable by the available tests, hence the "window period."

Antibody positive /Ab positive /sero-positive: those found to be positive to, or have antibodies to HIV present in the blood. Those found to be Ab+ are at risk of developing AIDS though the probability of progression is unknown. Estimates range from 30-100%.

Antibody negative /Ab negative /seronegative: those found to be negative to, or not have antibodies to HIV, (you can be infected but not have antibodies).

Antigen: any foreign substance in the body which stimulates the production of antibodies.

Antigen test: a test to detect the presence of HIV antigens in the blood.

Antigen positive: a positive antigen test result, interpreted to indicate an increased risk to developing AIDS.

Antigen negative: a negative antigen test result indicates no free HIV present in the blood. Interpreted to indicate low risk of developing AIDS.

Antiviral: A substance that stops or suppresses the activity of a virus. AZT and DDI are examples.

Asymptomatic HIV infection: state of being infected with HIV but showing no expressions of immunosuppression. Those with asymptomatic infection appear healthy but are capable of transmitting the virus to others through blood, semen, vaginal fluid or breast milk.

Australian Drug Evaluation Committee(ADEC): Peak federal body assessing and approving applications for trials and marketing of new therapeutic substances.

AZT intolerant: condition of experiencing severe side-effects of the drug and unable to safely continue use.

Candidiasis (Candida): A yeast like infection caused by *Candida albicans* infecting mucus membranes, skin and internal organs. A common opportunistic infection in people with HIV.

Category I, II, III & IV: New classification system for HIV infection introduced in 1988. Roughly, I is sero-conversion illness, II and III are asymptomatic or minor infections, and IV is major opportunistic infections corresponding to full AIDS.

Clinical trial: The controlled administration and monitoring of an experimental treatment, for example through an approved institution such as a hospital, to determine the efficacy of the substance. Phase I trials test for toxicity and dosage. Phase II tests, among a limited human sample, a drug's precise effect. Phase III involve

up to thousands of human subjects to confirm effectiveness and side effects.

Clinical Trials Exemption Scheme(CTX): Process whereby applications for new clinical trials are reviewed and approved.

Community AIDS Trial Network (CATN): Proposed initiative in Australia to test new treatments for AIDS with the assistance of GP's and community groups. Based on models established in the US.

Cytomegalovirus (CMV): A virus related to the herpes family of viruses. In mild manifestations can cause aching, fever, sore throat, fatigue and enlarged lymph nodes. In severe infections can cause blindness, chronic diarrhea and death.

Co-factors: Substances, elements, of lifestyle or environment which are thought to possibly contribute to the development of HIV disease eg. recreational drug and alcohol use, smoking, poor diet, high stress or repeated viral infections. Only smoking has so far proved to be related to disease progression.

Combination Therapy: The use of two or more types of treatment in combination, alternately or together, to achieve optimum results and reduce toxicity eg. AZT together with DDI or DDC

Commonwealth Trials Advisory Committee(CTAC): Advisory body to the National Centre in HIV Epidemiology and Clinical Research.

Cryptococcosis: Potentially fatal, opportunistic infection in people with HIV caused by an infectious fungal agent. Manifestations include headaches, blurred vision, confusion, depression, agitation or inappropriate speech.

Cryptosporidiosis: Protozoan parasite causing diarrhoea.

Dementia: Officially Group IV-B HIV infection. Symptoms include memory loss, visual disturbances, motor impairment and personal changes.

Diagnosis: Process of determining the cause and nature of an illness.

Early Intervention: The interruption of disease progression at the early stages of infection in order to prevent anticipated illness.

Food and Drug Administration(FDA): The agency of the US government which controls and regulates the human testing of drugs before marketing.

Haemophilia: Hereditary blood disorder which prevents blood clotting due to a deficiency of Factor VIII, a blood coagulation factor. People with haemophilia in Australia were at risk of HIV infection prior to April 1985 when the blood supply was secured through routine HIV testing of the national blood supply.

Hepatitis B: Liver inflammation caused by the Hepatitis B virus.

Herpes: inflammation of skin caused by herpes viruses. Herpes Simplex (HSV) I & II are common opportunistic infections in people with AIDS, the dormant virus being activated by immunosuppression.

HIV(Human Immunodeficiency Virus): A human retrovirus considered by most to be the main cause of AIDS.

HIV Infection: State of being infected with HIV as indicated by a positive HIV antibody antigen test. Initial infection is frequently accompanied by a brief flu like illness (Group I) followed by a period of asymptomatic infection of variable duration (Group II) to mild immune impairment possible accompanied by opportunistic infections (Group II & III) to severe immune impairment(Group IV).

HTLV III: Name originally given to HIV by Dr Robert Gallo of the US National Cancer Institute.

Immune deficiency(immuno-deficiency): Inability of the immune system to resist infection. In AIDS and HIV related illness this is caused by immune suppression due to the action of HIV.

Immune Restoration: The rebuilding of the body's immune system.

Immune suppression(immunosuppression): Inducement of immune deficiency, either deliberately (eg in transplant operation to prevent rejection) or by disease, drugs, stress, ageing, malnutrition or other factors.

Immune system: The body's mechanisms to resist infection. Lymphocytes, a class of white blood cells, recognise and destroy antigen. In HIV related illness, a subset of T-cells is affected by HIV causing immune deficiency.

IPU: Individual Patient Usage. Use of an unapproved drug can be obtained through the system in Australia on special application by your doctor to the Commonwealth. Foscarnet is one drug which has been made available this way.

Intravenous Drug Use (IVDU), or Injecting

Drug Use (IDU): Injection of non-prescribed, recreational drugs such as heroin, cocaine or speed. Estimates put the Sydney IVDU population at 15,000. HIV can be transmitted to IVDUs through the sharing of unsterilized needles and syringes. HIV infection among IVDUs has been described as the "second wave" in western countries, following on from infection among gay men.

Karposi's Sarcoma (KS): One of the most common opportunistic illnesses in people with HIV disease. Manifests as raised red or purple blotches on or in the body. Treated with chemotherapy or interferons.

The Glossary will be continued in the next issue of Talkabout.

PLEASE ADVISE US OF ANY ERRORS, OMISSIONS OR NEW TERMS.

TALKABOUT DIARY

Talkabout Diary is intended to publicise any regular events like meditation or self defence classes, or support groups, or anything else you want people to know about. Because *Talkabout* is a Bi-monthly publication, it's a bit more difficult to publicise one-off occasions, but we can try! Just send your information to *Talkabout* by post, or phone it through, (283.3220) or drop by to the office.

HANDS ON

is a group of trained volunteers who can offer a FREE massage to all PLWAs. If you would like a massage, or if you would like to join **Hands On** as a volunteer, contact our co-ordinator, Richard, on 660.6392(h) or 477.8255 (w)



New sexual health clinic at St George Hospital

A new clinic for HIV/AIDS and STDs, staffed by Dr Carmella Law, social worker Stuart Linnet, and experienced nursing and laboratory staff.

The clinic is at present open on Tuesday 3.00pm - 7.30pm and Friday 9.00am to 12.30pm and is situated at 36 Belgrave St Kogarah. All service is free and confidential.

Appointments for medical or counselling services can be made on 553 2742 or 553 2743.

TALKABOUT DIARY



MEDITATION AND RELAXATION CLASSES

With **Mac McMahon**, at the Albion St Centre, Tuesdays, 6pm. These are free and open to everybody.

1 + 1 = 3

ALL WOMEN PARTNERS OF MEN WHO HAVE SEX WITH MEN

ACON is setting up a support group for women who are or who think they are partners of men who have sex with men. This group will provide support for women in an informal, safe atmosphere, where you can talk with other women who may also experience confusion, isolation, loss and stigma.

Please contact **Súln ní Chrochuir** (Women & AIDS Project) or **Sara Lubowitz** on (02)283.3222 or (TTY)283.2088 10am - 6pm Monday - Friday.

HIV INFORMATION NIGHTS FEBRUARY 1991 SEX, DRUGS & LEGAL ISSUES

FEB. 5 Sex

Let's talk about sex in light of HIV infection

What's safe, what's not?

What about my current/future relationships?

Apart from HIV what can be passed on if I'm immune suppressed?

What should I tell my partners, if anything, and when?

So what is the HIV reinfection theory?

FEB. 12 Drugs

Why should I cut down on booze & drugs?

Which drugs if any show a faster progression to AIDS?

I like drugs they relax me!

What's the difference between use \ abuse \ dependency and addiction?

What is harm reduction?

If I decide to cut down where do I get support?

FEB. 19 Legal Issues.

What are my legal obligations, if any, now that I'm HIV positive?

Discrimination! What is it? how do I take action against it?

What are my rights in the hospital \ medical system?

Is a will necessary?

What is power of attorney?

Where do I find legal advice and assistance?

6.30 - 8.30pm

AIDS RESOURCE CENTRE
188 Goulburn St, Darlinghurst

CONTACT LIST: AIDS ORGANISATIONS AND SUPPORT GROUPS

GENERAL

Australian Federation of AIDS Organisations (AFAO): Umbrella organisation for Australian state and territory AIDS Councils. (06)247.3411.

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 (02)283.3550. PO Box A1242, Sydney South 2000.

AIDS Council of New South Wales (ACON): The Council 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. (02)283.3222.

ACON Hunter Branch: PO Box 1081, Newcastle 2300 (049)29.3464.

ACON North Coast Branch: PO Box 63 Sth Lismore 2480. (066)22.1555.

Albion Street AIDS Centre: (Sydney Hospital AIDS Centre) Main Sydney clinic providing ambulatory care, HIV testing and counselling. Also conducts experimental AIDS treatment trials. (02)332.1090.

Bobby Goldsmith Foundation: A charity organisation, established in 1983 in the name of the first Sydney man to die of AIDS, providing financial and material assistance to people with AIDS. (02)360.9755.

Civil Rehabilitation Committee Family Support Centre. HIV education for families of prisoners at Long bay Jail. Call David Bunker (02)289.2670.

Community Support Network (CSN): Trained volunteers providing practical home/personal care for people with AIDS. Established in 1984. (02)283.3222.

CSN Wollongong: Contact Angel Carrasco, (042)762.399

CSN Newcastle: Contact Andrew Hope, ACON Hunter Branch. (049)29.3464.

Deaf Community AIDS Project: Contact Colin Allen at ACON (Sydney) (02)283.3222, or (TTY only) (02)283.2088.

Euthenasia: Voluntary Euthenasia Society of NSW Inc. PO Box 25 Broadway, 2007. (02)212.4782.

Friends of People With AIDS: A peer support group for friends, lovers, partners and spouses of people with AIDS. Provides emotional support. Starts 7.00, at Maitraya day Centre, 396 Bourke St, Surry Hills.

Living Well Support Groups: For long term HIV positive people. Contact HIV support officers (02)283.3222/2453

Metropolitan Community Church (MCC): International gay church. Ph: (02)638.3298.

National Centre in HIV Epidemiology & Clinical Research: Federal research centre conducting trials for AIDS treatments and other AIDS related research. (02)332.4648.

National People Living With AIDS Coalition (NPLWAC): PO Box 1359 Darlinghurst NSW 2010. (02)283.3535.

North Coast "Positive Time" group: a support and social group for PLWAs in the North Coast region. Contact ACON North Coast Branch (066)22.1555

NSW Anti-Discrimination Board: Takes complaints of AIDS-related discrimination and attempts to resolve them by a confidential process of conciliation. Currently employs a full time AIDS Project Officer Sydney (02)224.8200. Newcastle (049)26.4300. Wollongong (042)26.8190.

NSW Users and AIDS Association (NUAA): NUAA is a community/peer based organisation concerned primarily with harm reduction, including HIV prevention and support of HIV+ people, advocacy, general support, referral and community development. Contact Julie at 24 Darlinghurst Rd Kings Cross. (02)357.1666.

Parents' Group (and relatives): A support group for the parents or relatives of people with AIDS. Please phone to indicate attendance. Aileen Goss, 2nd Floor 276 Victoria St Darlinghurst 2010. (02)361.2213. Every 2nd Thursday 2.00 - 1.30pm.

Positive Women's Support Group: Contact Women in AIDS Project Officer (02)283.2222.

Quest For Life Foundation: offers emotional support and education to people with life-threatening diseases, their families and loved ones and the health professionals who care for them. Support groups & meditation/relaxation classes are run at Crows Nest and Albion Street Clinic on Thursdays. Counselling on a one-to-one basis is also offered. (02)906.3112.

Quilt Project: Memorial project for those who have died of AIDS consisting of fabric panels and completed by friends and lovers of those to be remembered. (02)283.3222.

Penrith PLWA Support Group: Support, information & referrals. Phone Wendy at penrith Youth Health Centre: (047)21.8330. Meetings

are held weekly.

SACBE - El Camino Nuevo: A group to educate the Spanish speaking community about AIDS. SACBE is also a Spanish speaking community support network. Contact Pedro Manzur, (02)283.3222.

Sex Workers' Outreach Project (SWOP): 391 Riley St, Surry Hills NSW 2010. (02)212.2600.

Start Making Sense: Peer support group for young men under 26 who have sex with men. Runs workshops, drop-ins and outings with the emphasis on fun. Contact Brent or Tim for further information between 3.00 - 6.00 most afternoons on (02)283.3222.

Sydney West Group: A Parramatta based support group. Contact Pip Bowden (02)635.4595.

Transfusion Related AIDS: A support group for people acquiring HIV through a blood transfusion. Please phone to indicate attendance. Parramatta Hospital, Marsden St Parramatta. Meetings are held on the last Tuesday of each month at 10.30am. Contact Pam or Claire (02)635.0333 ext.343.

Red Cross BTS: Contact Jenny (02)262.1764.

Transport Service for PLWAs (in Sydney area): Contact Andrew on 360.2043.

ACCOMODATION

Share Accomodation Register: for people affected by HIV/AIDS and others seeking accommodation. Free, not restricted to HIV+ people. For details Ph: (02)283.3222.

DAY CENTRES

Blue Mountains PLWA Support Centre - Operates Wednesday from 11.00am - 2.30pm - lunch served. Fridays from 6.30 - 9.30pm - dinner served. Tuesdays from 10am/noon for individual or group counselling. For further information Ph: (047)82.2119.

Newcastle (Karumah): Operates every Thursday from 11.00am - 4.00pm at McKillop House, Carrington. Contact John (049)62.1140 or the Hunter Branch of the AIDS Council on (049)29.3464.

Sydney (Maitraya): Daytime recreation/relaxation centre for people with AIDS run partly by volunteers and funded by the NSW Department of Health. 396 Bourke St, Surry Hills 2010. Enquiries: (02)361.0893.

HOSPITALS

Prince Henry (Special Care Unit): Anzac Parade Little Bay (Sydney) (02)694.5237 or (02)661.0111.

Prince of Wales: High St, Randwick (Sydney) (02)399.0111.

Royal North Shore: Pacific Highway, St Leonards (Sydney) (02)438.7414/7415.

Royal Prince Alfred Hospital AIDS Ward: Missendon Rd, Camperdown (Sydney) (02)516.6437.

St Vincents Hospital 7th Floor South (AIDS Ward): Victoria St, Darlinghurst (Sydney) (02)361.2236/2213.

Sydney STD Clinic HIV Service: Monday 8.30am - 12.00 noon. Sydney Hospital, Maquarie St, Sydney. Appointments Ph: 223.7066.

Westmead Centre (Westmead and Parramatta Hospitals): (Sydney) Phone (02)633.6333 (Westmead); (02)635.0333 (Parramatta). Fax (02)633.4984.

PLEASE LET US KNOW OF ANY RELEVANT CONTACTS FOR THE NEXT ISSUE

JOIN US IN THE FIGHT AGAINST AIDS SUBSCRIBE NOW!

PLWA 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 AIDS.

First name: _____ last name _____

Postal Address _____

_____ P'code: _____

Phone: _____

I wish to apply for membership of PLWA Inc. (NSW):
Y/N

I wish to subscribe to TALKABOUT*: Y/N

I wish to make a donation of: \$ _____

I enclose: \$ _____ total

In the interests of your confidentiality:

I agree to have other members know my name and address: Y/N

I am publicly open about my membership: Y/N

Annual rates are:

Membership of PLWA Inc. (NSW) \$ 2.00

* Subscription donation to TALKABOUT: \$10.00
(Individual) (Optional for people receiving benefits)

* Subscription donation to TALKABOUT \$20.00
(Organisation)

Please make all subscriptions to TALKABOUT and/or memberships of PLWA payable to PLWA Inc. (NSW).

Please forward this completed form with all subscriptions/memberships to PLWA Inc. (NSW), PO Box 1359, Darlinghurst NSW 2010.

Signature: _____

Date: _____

INFORMATION NIGHTS FOR HIV INFECTED PEOPLE

TUESDAY: 15 JANUARY

1. HIV INFECTION AND THE IMMUNE SYSTEM:

What the immune system is, and what a virus is
How the virus is spread *What the virus does in your body*
How your body reacts *What is likely to happen once you are infected*

TUESDAY: 22 JANUARY

2. MONITORING & PROPHYLAXIS:

What does monitoring mean? *What makes it worthwhile*
The basics of what you need to know about monitoring
What is prophylaxis? *How will it help you?*
What illnesses can be prevented by using prophylaxis?
How will you know if you need it?

TUESDAY: 29 JANUARY

3. TREATMENTS & DRUG TRIALS:

What are drug trials? *How will they help you?*
The need for drug trials *What drugs are available*
The pros and cons of drug trials *What medical treatments are available*
Whose choice is it anyway?

The evenings commence at 6:30 pm and will end by 8:30 pm each night.
You don't need to make a booking, just turn up on the night that interests you.
The information sessions will be held at the

AIDS RESOURCE CENTRE
188 Goulburn St, Darlinghurst

HIV Support is a project of the AIDS Council of New South Wales
PO Box 350 Darlinghurst NSW 2010 Ph: (02)283.3222, 283.2453
Fax: (02)283.2199 TTY:(02)283.2088