

ISSUE #37 JUNE, 1990

Boycott!



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White Spot, Kentucky Fried Chicken Unfair

The Board of Directors of the Vancouver Persons With AIDS Society have unanimously called for a boycott of those businesses operated by White Spot Restaurants after investigation of a complaint that White Spot Restaurants Limited had terminated the employment of a person with AIDS, based on nothing other than his disability.

He met with his boss and told her he had AIDS, asking for a demotion to a less stressful position, such as Waiter. White Spot refused to demote him, saying it was against their policy to do so. Instead they offered him the opportunity of quitting or being terminated. He refused to quit and White Spot terminated him.

We find it outrageous that people capable of working are being fired from their jobs, that customers are refused service because of these employers' ignorance and bigotry. All employers have to learn that HIV is not casually transmissible in the workplace--or in any place.

Call Advocacy at the Vancouver PWA Society for further information. Take your lunch, dinner or breakfast business elsewhere! Please! No more triple O sauce! No more 'finger licking'!

David Lewis
Advocacy Committee

NEWSLETTER

GMHC Boycotts SF Conference

Gay Men's Health Crisis of New York City voted to join the boycott of the 6th International Conference on AIDS in San Francisco. The growing list of world organizations and governments that are not attending is, in large part, due to the work of members of our organization phoning and travelling around the world urging the growth of the boycott. We commend and support all people who choose to not attend this conference.

David Lewis



Attention! Health Fund Changes

Members should be aware that the Board has changed the Complementary Health Fund. To qualify you must be a full member, and have a monthly income of \$1200 or less per month.

Homeopathic services, previously excluded from CHF, are now eligible expenses. For those who use the fund to buy vitamins, the PWA Society is now buying direct from manufacturers and at a discount from Kripp's Pharmacy. To get your vitamins through the CHF you must come to the office and get an authorized purchase order from Yvonne.

Watch for new services to be introduced soon, including Vitamin consultancy and invited speakers.

Office Furniture

Thank You BC Hydro

A sincere thank you to Ian Tate and the people at corporate affairs at BC Hydro for their generous donation of attractive, sturdy office furniture.



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Board Decisions



Ed. Note: The newsletter has asked the Secretary of the Board of Directors of the Vancouver PWA Society to supply us with a monthly summary of board decisions, in response to a member's request found in the lounge suggestion box. Complete meeting minutes are available for member's inspection in a binder kept in the office. Here is the report for this month.

The Board of Directors of The Vancouver PWA Society meets every other Friday morning at 10:30 am in the Boardroom, 1447 Hornby Street. All members are welcomed to attend Board Meetings.

The Board is the primary policy-making organ of the Society, and has been active in managing the organization since its inception.

Recent actions of the Board included the White Spot Restaurants Kentucky Fried Chicken boycott, new regulations for the CHF, suspension of the V-meals program in favour of providing meals on a daily basis to volunteers working at the office, approval of Easter's Sundays as a program of PWA Society, and many others.

We voted to hire Terry Nelson as Media Coordination Assistant, and to create a new Hiring Committee for future personnel hiring. Terry Leitch was reappointed as Speakers' Bureau Coordinator, and Michel Arsenault was identified as official French-media spokesperson (with David Lewis and Alex Kowalski as the English-media spokespersons).

Sparse funds have required belt-tightening in many areas, and we have voted to suspend travel benefits for now.

The work of the Society gets done through the five standing committees of the Board (Advocacy, Finance, Personnel, Programs and Executive), with the added assistance of the paid staff (currently 4 1/2 people). Our paid staff are

Chris Sabean, Jackie Hegadorn, Yvonne Mallard, Terry Nelson and Carol Lowen (who recently resigned from her Volunteer Coordinator position).

To discuss any issues with the Board, please feel free to come and participate as a member at the meetings. Or call Alex or David at the office. We have attempted in the past to establish a Member-Board caucus where direct communication from the membership to the Board was established on a regular basis—but it was not well attended and fizzled out. Get involved! Come to the Board meetings! We want to hear your opinions!

David Lewis

Advocacy Report



We have been inundated with reports of HIV/AIDS discrimination this month.

Most notable was a bank's cancellation of a member's credit card when they discovered he had AIDS! Discussions with senior management of the bank involved got the man's card reinstated, with a statement from the Bank that they would not enforce such a policy against people with HIV/AIDS in the future.

VanCity Insurance Services Ltd. was accused of terminating two employees because they had HIV/AIDS. Discussions with the senior management of VanCity Insurance Services Ltd. were productive and resulted in an agreement to provide a "golden parachute" to one of the ex-employees, as well as an agreement to work with the PWA Society to develop employment policies and HIV in the Workplace seminars to prevent such occurrences in the future.

White Spot Restaurants (also owner of Kentucky Fried Chicken in BC) are accused of terminating the employment of a Manager in training who has AIDS, for no reason other than his HIV status. They are also accused of refusing

service to a person perceived to have AIDS. The Board of Vancouver PWA Society unanimously voted to urge supporters, members and all others concerned with people with HIV/AIDS not to do business with White Spot and Kentucky Fried Chicken Restaurants in BC.

We have a case of a child-custody battle where one ex-spouse is trying to have a court declare the other ex-spouse unfit to have visitation or custody of a child because the one spouse has HIV.

And there's the case of a member who was evicted from his apartment simply because the manager found out he had AIDS! A long court battle was settled in the member's favour, but the living conditions became so intolerable he moved anyway. Now the new landlord (after having talked with the old one) is creating the same problems for the tenant.

For further information on any of these issues, or to register your own HIV/AIDS Discrimination Complaint, please contact Advocacy staff at 683 3381.

Advocacy meets every Monday morning at 10:30 am at PWA offices. Meetings are open to all interested persons.

David Lewis

Boycott!

La France décide à son tour de boycotter la conférence de San Francisco sur le sida!

LITEN THE VECTOR STORY LASS? VAR BOIKOTT AV USA SPRER SEG!

BOYCOTT OF THE INTERNATIONAL AIDS CONFERENCE SPREADS

Travel restricted AIDS checks

Conference Boycott Widens

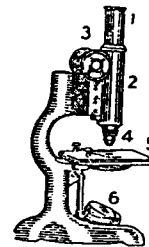
INCIDENT DE FRONTIÈRES

AAAI boycotte la 11^e Conférence sur le sida

ACW To Join Boycott

Following the lead of the Vancouver PWA Society, a growing number of international organizations have pulled out from the 11th International Conference on AIDS in San Francisco.

AIDS Treatment Highlights



The following articles were selected and condensed by Chuck P., who assumes sole responsibility for their accuracy.

Oral Interferon-Alpha 99 AIDS Patients Claimed to be Symptom-free

"Ninety-nine of 101 AIDS patients are free of symptoms after eight weeks of treatment with an oral alpha interferon formulation, a Kenyan medical researcher told a meeting in Japan. CDC AIDS WEEKLY first reported details of this trial in the February 26, 1990 issue (page 18).

"Davy K. Koech, director of the Kenyan Medical Research Institute in Nairobi, also said that 11 of the patients became seronegative for the HIV antibodies after treatment.

"According to Biotechnology Newswatch, Koech said that of the 99 patients who responded to treatment, 66 suffered from fatigue, 71 had low appetite and weight loss, 49 had diarrhoea, 49 had fever, 23 had lymphadenopathy, 47 had oral sores or ulcers, 47 had "other infections", and 25 had a skin rash. After eight weeks of treatment, all of these symptoms were reported to be completely resolved; most symptoms resolved after only four weeks. None of the patients were taking Zidovudine (AZT) or any other AIDS treatment.

"I don't believe my own data, but in four weeks this treatment can eliminate most of the symptoms associated with AIDS", Biotechnology Newswatch quotes Koech as saying at the meeting.

"A clinical report of the first 40 patients treated by Koech will be published in the June issue of the journal *Molecular Biology*.

"According to a report by Lawrence K. Altman in the *New York Times* (April 4, 1990; p. A10), Koech said that these 40 patients had an average weight gain of 10 pounds and huge increases in the number of CD4 cells: an average increase of 557 cell/mm³.

"The alpha interferon used in the study is administered by means of a lozenge that is dissolved in the mouth, a novel means of administration not used in previous studies of the drug. Very low doses—two units per kilogram body weight daily as compared to the total daily doses of one million to 35 million units currently being studied in AIDS clinical trials—were used in the Kenya trial.

"Joseph M. Hassett, an immunologist at New York's Mount Sinai Hospital, has told the *New York Times* that, pending hospital approval, he will conduct a six-week, placebo-controlled trial of the oral Interferon-alpha formulation at Mt. Sinai with 35 AIDS patients. Twenty-one patients will receive the drug and 14 will receive placebo.

"My gut feeling is that the magnitude of the benefits will not be as great [as those reported in the Kenyan study]', Hassett is quoted as saying in an interview with the *Times*. 'If it only stimulated appetite or relieved fatigue, it would be very useful'.

"I don't believe my own data..."

"According to *Biotechnology Newswatch*, Hassett said although Koech claimed that oral Interferon-alpha cleared up all symptoms of AIDS—including *Pneumocystis Carinii* pneumonia (PCP)—the Kenyan researcher was "evasive" when asked whether patients with Kaposi's sarcoma (KS) responded to treatment.

The *New York Times* reports that clinical trials of oral Interferon-alpha are planned by U.S. Navy doctors in the Philippines and by the World Health Organization (which has been

careful not to endorse the product) in Cameroon, the Congo, and the Ivory Coast; trials involving cancer patients and patients with non-AIDS immunodeficiency are planned at the University of Texas M.D. Anderson Cancer Center in Houston"—by Daniel J. DeNoon, C.D.C. AIDS WEEKLY, April 16, 1990

Comments from Chuck: Is oral Interferon-alpha a 'magic bullet', the AIDS cure we've been seeking for so long? I recall something my daddy used to say (so what if he was younger than me): "If it sounds too good to be true, it likely isn't".

Interferon-alpha by injection has been approved in the USA as a treatment for KS for some time now. Injectable Interferon-alpha is available by prescription in Canada. We have put together a comprehensive Interferon-alpha Information Pack, which is available at our new library, or phone 683 3381 and we'll mail it to you.

Oral Interferon-alpha is not available in Canada. We will keep you updated.

AZT = Poison = Death?

"Critics maintain that many people are unable to take AZT because of its severe side effects. One writer went so far as to call it 'a poison' which should not be taken under any circumstances. A similar argument will undoubtedly be made against other anti-virals, like ddI.

"This argument seriously misrepresents the clinical picture of AZT treatment. In fact, AZT is effective in slowing viral activity and maintaining health in far more people than it adversely affects. This is well documented by four years of medical research and can easily be verified by consulting the medical literature. AZT is no panacea, but distorting its side effects does not detract from its good record and merely does a disservice to those considering taking it.

"A related argument dismisses the therapeutic effects of anti-virals as too short-term ("a few years") to be worth considering. Like the previous argument, this view represents personal opinion rather than scientific fact.

"True or not, the argument must sound callous to sero-positive people who are taking AZT for that very reason. Leaving aside the question of whether it's two years or 20 (I tend to the latter view, myself!), time becomes very important when you discover you are HIV-positive, and even a few years can mean a lot. We have every reason to believe that second generation anti-virals will improve on AZT and ddI, perhaps leading to a drug which eliminates HIV from the body completely. If this is true, then a few years make all the difference in the world."

Dan Worduck

XTRA

April 1990

Comments from Chuck: I have read everything I can get my hands on AZT for years now, and never once have I heard of a single patient who died from the side effects of AZT. A far cry from the large numbers who have refused to even give AZT a chance and have died of AIDS-related illness. Your doctor is able to monitor and to moderate the side effects experienced by some AZT users. In addition, two recent studies have concluded that, of those who commence early AZT therapy, fewer than 5% will need to discontinue AZT due to severe side effects.

Neopterin and HIV Replication

"Neopterin is a substance produced by certain cells of the immune system - macrophages - during inflammatory disorders including virus infections and also cancer. Scientists have noted that as HIV infection worsens, levels of neopterin increase, reaching their highest in AIDS.

Researchers at the University of Innsbruck, Austria, as well as the Karolinska Institute in Sweden, have conducted a study on 93 HIV infected people to see if there was a relationship between neopterin and HIV replication. Thirty-nine subjects had no symptoms while 54 had persistently swollen lymph nodes. The scientists

took blood samples and tried to culture virus from the subjects' blood cells. They measured the replication of the virus by sampling levels of the viral enzyme RT (reverse transcriptase). They also measured blood levels of neopterin using test kits.

Their results indicate that increases in blood levels of neopterin are associated with the ability to culture HIV and also with the ability to culture virus of an increased capacity to replicate. *Journal of Infectious Diseases* 1989;160:724-725. These results strongly suggest that high blood levels of neopterin may reflect a high rate of viral replication. Thus neopterin may become a substitute marker of viral replication as cell culture techniques are time consuming and expensive. The chemical is relatively easy and inexpensive to measure (using test kits). Neopterin could be used by physicians to help monitor their patients' health and, also in clinical trials to test the usefulness of anti-viral agents. Neopterin test kits are made by Henning-Berlin, Berlin, West Germany, the kits are called Neopterin RIAcid. Plans are under way to have kits (similar to those mentioned here) available in Canada by late Spring, 1990."

Sean Hosein

AIDS Action Now

Feb., 1990

ddI Questionnaire

All people taking ddI are asked to phone David Lewis at the PWA Office (683 3381) for a supply of the monthly side-effects questionnaires. We are asking all members to complete these once a month in order to give us a chance to compile information about frequently-reported side effects.

David Lewis

Catastrophic Rights by John Dixon



An important new book has hit the stands, and we're told its first printing sold out.

John Dixon's new treatise "Catastrophic Rights" covers areas of critical concern to PWAs. This book succinctly makes the strong case for people with HIV/AIDS having access to "experimental" treatments, such as is the intent of Canada's Emergency Drug Release Program.

Dixon, president of the BC Civil Liberties Association, uses humour (wry sometimes), sarcasm, and incredible compassion, insight and sensitivity to the real issues confronting PWAs in our struggle to survive.

From the first chapter which broadly paints the canvas upon which the rest of the book is drawn, Dixon entertains, educates and never bores the reader with this topic that some might consider "dry".

A warm introduction and dedication to Kevin Brown and Greig Layne touches upon the inspirational people behind Dixon's decision to explore this subject.

This is a "must read" book for all persons with HIV/AIDS, and those interested in how we really think. Available for \$12.95, plus \$3.00 shipping/handling, directly from

Vancouver PWA Society,
Attention: Advocacy,
1447 Hornby Street,
Vancouver BC V6Z 1W8.

Published by New Star Books.

David Lewis

Third Annual AIDS, Medicine and Miracles Conference

Over the weekend of May 3 to 6, 1990, approximately 500 people attended the "AIDS, Medicine and Miracles" conference in Boulder, Colorado. Two people from Vancouver attended the conference as individuals. There was no official representation or sponsorship from any Canadian group.

The key-note speaker was Elisabeth Kubler-Ross who outlined a holistic approach to AIDS in her address "AIDS: The Ultimate Challenge". Dr. Kubler-Ross identified four quadrants of the whole being: the physical, emotional, intellectual and spiritual.

The conference featured a variety of approaches to health care in all of these quadrants, ranging from traditional medical information and current drug therapies to acupuncture, herbal medicines and attitudinal healing. Presenters included Martin Delaney of PROJECT INFORM, Rick Flinders, MD. of the RISE program, George Melton, author of "Beyond AIDS: A Journey Into Healing", Adan Rios, MD., Charles Steinberg, MD., Mwalimu Imaru, D.Min. and many others in various fields of expertise.

This conference presented a positive outlook for people affected by AIDS, recognizing the pain associated with loss and grieving while holding it in perspective. The therapies presented were suggested as complementary therapies in conjunction with a total health plan.

A report on the conference will be submitted to the Board of Directors and be available at the PWA Coalition office as well as a copy of the February, 1990 Maryland Medical Journal entitled "AIDS: Living Long, Living Well - An idea whose time has come".

Bob Humphrey



Decisions

The decision to change a course of treatment is difficult under any circumstances. When there is only one treatment established as effective in slowing disease progression in AIDS, it is particularly daunting to consider alternatives. Here are some personal accounts of decisions taken by Vancouver PWAs who have considered switching from AZT to ddI.

Armed with Results

I have not done well with AZT, as I am susceptible to anemia to the point of requiring transfusions. That my anemia was due to the side effects of AZT was demonstrated when I had to do without the drug.

Twice I travelled to the USA, where a regressive immigration policy makes it imprudent to carry your medication through customs inspection. Imagine the fear and trepidation I felt as I prepared to participate in the last unfolding of the AIDS Memorial Quilt in Washington, DC, knowing I would be without any AZT the whole time I was away. Well, I felt so much better without the drug that I decided to ask my doctor what other treatment I could switch to. I used the PWA library to inform myself. I signed up for blood tests available through the Vancouver PWA Society (for a description see Issue #33 "Tracking the Virus..."). Armed with test results indicating that the virus was increasingly active in my body despite AZT, I had a discussion with my doctor and we decided to apply me for ddI on the Emergency Drug Release Program (EDRP).

On the whole, the change has been beneficial. I have more energy and feel much better since switching. Continued monitoring suggests that, even though I have been dealing with persistent fungus and skin infections, that the underlying viral activity has subsided.

To decide and to live with my decision to switch to ddI would have been much more difficult without the information available from

Quantified p24 Antigen, Beta₂ Microglobulin and Neopterin testing.

Douglas Starratt

Decided Not to Switch

I started on AZT 1200mg/day in January 1988. Within two months I developed severe anemia and required a transfusion (three units packed red blood cells). At this point my doctor took me off AZT for a month, then started me back on 600mg/day. Within a month I developed anemia again, and required another transfusion. My doctor cut me off AZT for a month again, then started me back on 400mg/day. Within two months I developed anemia again, and required a third transfusion.

At this point my doctor and I talked it over and agreed that I would stay on 400mg/day of AZT, with transfusions as required. I required 14 transfusions in 1989, but was able to stay on AZT throughout the year, and suffered no illness or indications of disease progression. At the beginning of 1990, my T-helper count was 420, versus 260 when I started on AZT exactly two years earlier.

When ddI came available I qualified for it because I had suffered severe recurring anemia due to AZT. My doctor and I discussed whether I should switch to ddI, and he left the final decision to me.

Luckily, almost a year earlier I had started regular blood-testing to help me determine if AZT was working effectively for me. In addition to T-cell tests, the tests I utilized were the quantified p24 antigen tests, the beta₂ microglobulin tests and the serum neopterin tests

Since early 1989 I have had all of these tests done every several months. Had it not been for the information gained from these tests, I might well have decided to switch from AZT to ddI. In any event, because the various tests indicated that low-dose AZT was working well for me, and I had suffered no illness or symptoms of disease progression on AZT, I decided not to switch to ddI.

I have been on AZT 29 months now, and am waiting for more information to come out on the effectiveness and side effects of ddI. I continue to monitor my condition, and if it starts to deteriorate after so long on AZT, or if future studies indicate that ddI is more effective than AZT, I'll likely switch to ddI. For the time being, I'm not rocking the boat.

Chuck

Sensible Route To Take

I had been using AZT for 27 months, but could not tolerate it any longer as it was causing muscle damage to my legs and depleting my white blood cells. The alternative offered to me was ddI. My physician explained to me that ddI was totally experimental but that there was some hope that it would be helpful as an antiviral agent, and that possibly the side effects would be less than those of AZT. My physician told me that the decision to take ddI was entirely mine. In November of 1989, I decided to try ddI. I figured I had nothing to lose. I started at 250mg every 12 hours and cannot say that I felt better or worse for it for the first four months. In my fifth month on ddI I began to feel much better physically. Basically I had much more energy.

However, I also developed a great deal of agitation, anxiety, sleeplessness, and a feeling that I could not cope with the smallest of tasks. At that point I stopped ddI to see if the symptoms would go away, and within two to three days, these symptoms dissipated substantially. Although my physician prescribed sedatives during this rough time, these did not work. He suggested reducing the dose of ddI to 167mg every 12 hours. This has also been quite unsuccessful. I have remained on 167mg of ddI every 12 hours and when I feel I cannot tolerate the side effects, I stop the ddI until I feel I am ready to start again. My physician feels this is a reasonable and sensible route to take, and he has never pushed me one way or the other with regard to this drug. It feels good to know that I am in control of the dosage, and I feel this is the only fair way to be treated by my physician with regard to ddI.

In summary, I cannot say for certain whether ddI is working for me, but it seems to be my best hope for an effective antiviral at the present time.

Robert Long

Playing with our Lives

I stopped AZT some months before ddI became an option for me. I had been on AZT some two years when I stopped it in January 1989. I doubted that it was of any continued benefit. My p24 antigen test was through the roof, as was my Beta₂ Microglobulin. The tests that I had been able to get through the Vancouver PWA Society show no appreciable difference prior to going off AZT and after, when I was not on any other antiviral.

As June and the Montreal Conference came and went, ddI began to emerge from the cacophony of possible contenders. In the fullness of time the Health Protection Branch of Health and Welfare Canada gave me and my doctor approval to access ddI through the Emergency Drug Release Program. Bristol-Meyers and the USFDA had other ideas. After much lobbying, Bristol-Meyers finally released the drug in October to a very restricted number of Canadians. The criteria were and continue to be restrictive and arbitrary. I feel, like so many others, that Bristol-Meyers and the FDA are playing with our lives.

I appear to tolerate ddI well. My T4-cell count, though still very low, has made a small but encouraging rise. I have gained weight and appear to be thriving. I don't know if ddI is responsible for all or part of my relative good health. I can't know if ddI has been of any benefit to me. It wasn't a question of AZT versus ddI. At present AZT is the "standard of care".

It concerns me, however, that there are others who have exhausted AZT, and for one reason or another cannot choose ddI. I am extremely grateful that I have a physician who acknowledges my autonomy and at the same time helps me to seek options where there appeared to be none.

Greig Layne

Ongoing Events

Mondays:

Advocacy Committee Meeting: Meets at 10:30 am in our offices to deal with access to treatments, human rights, political and legal issues. Members are encouraged to attend and get involved.

Art Therapy Group Use the visual arts to explore personal issues and concerns. No experience necessary -this is not an ordinary 'Art Class'. Facilitated by an experienced Art Therapist, Noel Silver. Contact the PWA Society office for further information.

Buddy Support Group: For buddies, sponsored by AIDS Vancouver. Meets every second Monday at 7:00 pm June 4th and June 18th at AIDS Vancouver, 1272 Richards Street, Vancouver, B.C.

Tuesdays:

Low Impact Aerobics for people with HIV. At Barclay Manor (Barclay and Nicola) 4pm Tuesdays and Thursdays. For more information call Jackie at 683 3381

Personnel Committee Meeting: Meets at 10:30 am at the Society's Offices - works to provide policy and assistance in organizing human resources (volunteers and paid staff). You may have a talent or experience that would help. Contact Michel A. at 683 3381.

Meditation Class "Living in Each Moment" From 2 pm - 4 pm This class is open to people living with HIV, friends and supporters. For more information and location, please contact Kristin at 872 0431.

Women and AIDS Drop-in 7:00 to 8:30 pm For women to seek out information and support concerning AIDS/HIV First and third Tuesdays of each month at Vancouver Women's Health Collective, No. 302, 1720 Grant Street. Call Jackie at 683-3381 for details.

PWA Support Meetings: 7:30 - 8:30 pm, at the PWA Coalition Living Room Lounge. These meetings are open to PWA/PWARCs only. Discussions about concerns held by the group at the time of the meeting. A good place to talk about your fears, concerns, and triumphs.

Wednesdays:

Program Committee Meeting: Meets at 10:30am at the Society's Offices to develop and facilitate individual programs such as RISE, Support Groups etc. Members are welcome and encouraged to participate. Contact Jackie.

Partners of Persons with HIV/AIDS and Family and Friends of persons with HIV/AIDS. Both groups will meet every Wednesday 7:30-9:30 pm at St. Andrews-Wesley Church. Rooms to be posted. Call Bridget MacKenzie at 687 5220 or Joy Moon at 299 4828 for more information.

Healing Circle: 7:30 sharp - 9:00 pm on the first floor lounge, room 113, of the Comox Building of St. Paul's Hospital. Come and experience some loving time, deep relaxation, meditation, bodywork & the joy of sharing. Co-ordinated by 3 professional facilitators: Lela, Donald and Maria. This weekly event is open to all members, their friends, supporters, etc. For further information contact Donald at 682 2989

Thursdays:

Finance Committee: Works to ensure proper financial procedures and puts forward funding proposals. Anyone with this kind of expertise or those interested are urgently requested to contact the General Manager, Chris Sabeau or the chair, Alex Kowalski.

Executive Committee: Meets 10:30 am every Thursday at the Society's Offices to coordinate the business of the Society and to prepare for Board Meetings.

Aerobics for people with HIV. See Tuesdays. Register 683 3381

Empowerment for Living: 7-9 pm group for persons living with HIV, ARC, and AIDS offers support and empowerment, sharing, prayer, meditation (and everything the Holy Spirit gives us). Our atmosphere is friendly, confidential and informal. Call Christ Alive M.C.C. Church office at 681 8525 weekdays for further details.

Get Over It: AA Meeting of special interest to HIV concerned persons. 7 pm in PWA Coalition's Living Room Lounge.

Narcotics Anonymous: New Hope. Open to HIV positive or negative. Meets every Thursday, 8:30 to 10 pm, in the PWA Coalition's Living Room Lounge. Narcotics Anonymous 24 hour Helpline 873 1018.

Body Positive Support Group: For those testing HIV positive. Confidential Discussion Group meets Thursday evenings at 7:30 pm in PWA offices. For more information contact Kenn Mann at 683-3381

Coping with Loss and Grief: Sponsored by AIDS Vancouver Meets the First and Third Thursdays of each month, from 7:30 to 9:30 pm at St. Andrews Wesley Church Library at Nelson and Burrard. For more information call Joy Moon 299 4828.

Fridays:

Board of Directors Meeting: The Board of the Vancouver Persons with AIDS Society meets every second Friday at 10:30 am at the Society Offices. Meetings will be June 1st, 15th and 27th. Open to all interested members. This your opportunity to stay abreast of Coalition activities, and have a voice in our future. The four standing committees (Advocacy, Finance, Personnel, and Program) are always open to new volunteers, and welcome your participation.

Movie Night: get together at 7:30 pm in the Living Room Lounge video screening at 8 pm. See poster in the lounge for this week's attraction. Munchies provided.

Saturdays:

Body Positive Drop-in: Open to all HIV infected persons or persons with AIDS/ARC to meet others for support and to seek out information. Held in the PWA Society's Living Room Lounge Saturdays from 11 am until 3 pm. For information call the PWA Society at 683-3381.

Other Events

Living Room Lounge: our relaxed drop-in centre is open Monday to Friday from 10 am to 5 pm for members and their guests.

Referral information available at the office during office hours (10 am to 5 pm) for people looking for medical services, alternate therapies, and other services

Monthly Medical Forum: A forum for the medical community and consumers of those services (our members and other concerned individuals). First Wednesday of every month at 7:30 pm at Gordon Neighborhood house. The topic for Wednesday, June 6th is Legal Medical Issues.

Tai Chi: Instructor is Lim. Times and places to be announced. For information and registration call Michel A. at 683 3381.

Chiropratic Workshop: Wed. June 13th in the Living Room Lounge. The speaker will be Dr. Richard May.

PWA Social Night Sunday, June 17th, at the Shaggy Horse, 818 Richards Street, from 7pm to midnight. Snacks by Doll & Penny's, live entertainment. For Persons with HIV and their friends and supporters. Treat yourself to your very own Fun-Raiser!

Tuesday Night Specials: Starting Soon!

Smoking Cessation Program starts on Monday June 18th. To register call 683 3381

Deadline for Submissions for July Issue of the PWA Newsletter is Friday, June 8th, 1990.



How AIDS Changed My Life

Ed. note: The Reverend Neil Gray runs the Anglican Chaplaincy in St. Paul's Hospital, extending caring and friendship in a non-judgmental way because he believes that as part of a compassionate Christian response, the Church must learn to come to where there are lessons to be learned, where people are hurting. Among these lessons that PWAs can offer to the Church are the need to de-mystify theology, the celebration of sexuality in loving relationships, the perception of sexual minorities as people with much to offer, and the humility to accept that caring and compassion extend outside the Church. Recently,

he attended a conference for care-givers in Calgary where he gave the talk from which the following excerpts are taken:

"AIDS has changed my life in several important ways. It has made me grateful for the goodness of my life, impatient and angry with the Church and reverent in a new way before God. More significantly, it has freed me to talk about my gratitude, impatience, anger and reverence. It has shown me that there is nothing wrong with that.

My experience in the Hospital is that most people who say that they are 'not religious' are engaged in an unconscious effort to purify God.

"None of us will get out of here alive'. Until I worked with people with AIDS that reminder was a fairly isolated one. Death was something that happens to old people. I belonged to the generation that began to believe that death was being driven back. We had wonderful advances in medicine, transplant surgery, bionic limbs and vaccinations. We took vitamins, pumped iron, jogged and flossed our teeth. Yet suddenly hundreds and thousands of young people were dying, in less than two weeks last year I took three AIDS funerals, none of the people who had died was older than me. I am 37.

"Every second of every minute is precious—do not waste it. As the writer of the Book of Ecclesiastes says: 'Go, eat your bread with joy and drink your wine lustily. Let your clothes be fresh and clean and your head oiled. Enjoy happiness with someone you love, all the fleeting days of life that have been granted you under the sun, before the days comes when your breath returns to the God who gave it to you.'

"I am impatient with a Church that does not relate to life as it is lived. People with AIDS are dealing with deeply theological issues—pain and suffering, disfigurement, lack of control and independence, weakness, guilt, death, judgment, heaven and Hell.

"We need an honest attempt to talk about God, our life and death and what happens afterwards in a way that can be understood. Perhaps we should try scratching where people actually itch!

"I am angry at the way in which religion (or more especially religious people) frequently masks the face of God, particularly in the AIDS crisis. The Christian life is seen as a neurotic drive for perfection—which can frequently result in hatred for ourselves, because we fail, and vindictiveness for others. We need to remember that God's perfection is shown in brokenness, availability and self-giving love.

"My experience in the hospital is that most people who say that they are 'not religious' are engaged in an unconscious effort to purify God. They are quick to point out the neurotic and immature aspects of our faith.

Psychologists and Psychiatrists tell us that attempts to force people to change are harmful and destructive. Can this be said to serve to glory God?

"This is especially true in looking at the Church's attitude to homosexuality. The Church needs to listen to science, which tells us that people do not choose and cannot control their sexual orientation. Psychologists and psychiatrists tell us that attempts to force people to change is harmful and destructive. Can this be said to serve to glory God?"

"I have always known with my head that Jesus suffers with and through his people. I now know it with my heart. There is such a powerful physical similarity between the typical person with AIDS and Jesus in his Passion. It is almost an icon. Christ in His Passion and Death. He did not fight or hide or run away. He told his disciples to put up their swords. There was no revenge or retaliation. It all ended with his arms open wide on the cross."

Delivered by Neil Gray as a part of a Conference held in Calgary for AIDS Caregivers.

*Cabinets in Bathrooms
overflowing
Drugs for life
and anger
Secret Fears
lonely, decaying
Shelf life
extended
beyond mine
Child Proof CAPS
I cannot OPEN
and you Tell me
I'M
complaining*

Richard Hofmann



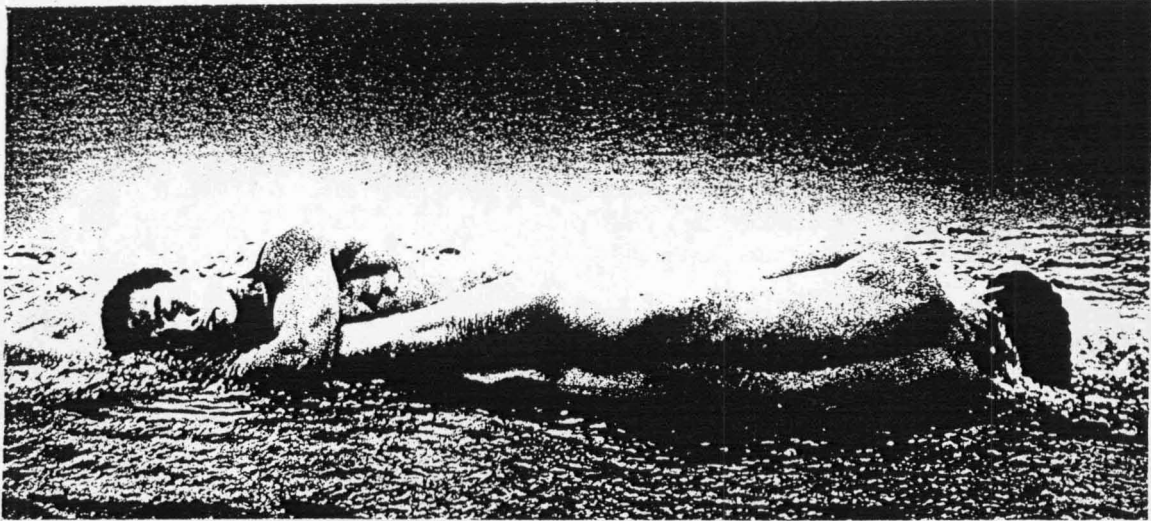
EDWARD ROSS BAKER

March 23, 1944 – April 1, 1990

Ross lived in Toronto until 1971, when he decided to give the West his best. He started his own company in Vancouver. Ross was a very kind and loving man. He was a Big Brother for a number of years. He took the time to help several PWA's...he was one of the founding members of McLaren House in Vancouver. Ross had a style of his own. He had a great sense of humour and always had a joke even up to the end. He is survived by three brothers in Toronto. He was my best friend and I will miss him but his memory will live on in my heart.

Pearse Murray

Living & Dying in Each Moment



From the time I was with Joseph two years ago to the time I spent with Luis last fall, I have undergone a lot of change in my reactions towards someone who is dying, and toward death itself. There really is no birth and no death—things just go on in this mysterious process of transformation. With Joseph, there was a kind of separation. I felt like "You are dying. I am watching. You are suffering. I am the helper." But somehow with Luis, there was the feeling that we were in this together.

With each breath, there is a birth and death. I consciously live in each moment and I consciously die in each moment. So when I was with Luis I didn't have the sense that Luis was dying and I was living. We were both living and dying together moment after moment.

I have also changed in my reactions to pain and suffering. When Joseph was in pain, I would be running to the nurse demanding some medication to stop the pain as soon as possible. I never stopped to ask him what he needed. Maybe all he wanted was for me to hold his hand. It is because

we are afraid of our own pain that we run to help other people get away from theirs.

There can be a strong sense of helplessness when you are with someone who is dying. When I was with Joseph, I was constantly changing his sheets and fixing his bed as a way to relieve my own anxieties, fears and sense of helplessness. I wasn't really doing it for him.

But with Luis, I could just be with him. He said that I was the only person who wouldn't come in and immediately say, "How are you?" Luis said to me, "How can I answer that?!" But he never got angry at anyone for asking. He was very patient with people's difficulties. Sometimes I would go into his room and just sit down next to him and say nothing. It was quite a lesson for me to be able to just *do* nothing. All Luis wanted was for me to *be* there with him. So I learned just to *be*.

I learned to let go of that need to control, because being with someone who is dying is such a completely uncontrollable situation. With Joseph, I still tried to have some sense of control by

changing his sheets or getting more pain medication. With Luis, I admitted to myself that I had no way to control the situation whatsoever, so when I changed his sheets or went to the nurse for meditation, I was doing it for Luis, not for me.

When all else fails, when all the technology of modern medicine cannot keep someone alive, there is always love. People ask, "But what can I do? I feel so helpless." I just say that for me, the one thing I can always do is to love. And that love flows much more easily the more we let go of the need to control. The moment that you have that need to control, the heart and mind start to wrestle. The heart has a boundless capacity to love, but the mind comes in and says, "No! You can only go this far. There is a fence, a boundary past which you cannot go." It's a silly game we get into.

I learned so much about love and about openness. He was very sick and vomited quite a bit. There was one time that he vomited all over his bed sheets and the nursing staff was trying to clean up Luis and his sheets. Luis was just sitting up in his bed, kind of wide-eyed, saying, "Oh, wow!" He responded that same way when he passed a lot of gas. But what struck me was that when I gave him his favourite juice, fresh honeydew juice, he responded with that same, "Oh, wow!" He had an ability to be with the most unpleasant experience or with a pleasant one with that same kind of wide-eyed wonder. Just, "Oh, wow!"

When I was with Luis I didn't have the sense that Luis was dying and I was living. We were both living and dying together moment after moment.

Luis did so much growing and healing in those six weeks. A lot of people think that healing only takes place if the body get better physically. But there are so many ways to heal. There is so much new age talk about "Knocking out AIDS with..." this or that, or "Exceptional patients beat AIDS," etc. It can make those

people who die feel like losers or failures. But I have never seen anyone heal and open his heart to the whole of living and dying as I saw Luis do. As Stephen Levine says, "Some of us heal into life and some of us heal into death." Luis courageously stepped into the unknown.

When all else fails, when all the technology of modern medicine cannot keep someone alive, there is always love. People ask, 'But what can I do? I feel so helpless.' I just say that for me, the one thing I can always do is to love. And that love flows much more easily the more we let go of the need to control.

He certainly had his times of struggle, but he kept working the whole time, working to open to the unknown, to open his heart to whatever came his way.

Luis asked that his friends have a party rather than a memorial service. And so we did. He also asked that at the party, we listen together to his favourite song in Spanish which translates, "Thank you life, for all that you have given me."

So this is how I try to live each day, saying "thank you life, for all that you have given me." Whatever happens, whether it's wonderful or difficult, I always try to respond with a simple, "Oh, wow!"

Lim



Kudos of the Month!

Our Office Warming reception was well attended and a good time was had by all. Many thanks for the gift of plants and flowers from the following: Bob Wiggins, Dave Miles, Peter Hargreaves, Elizabeth Strain, James Trenholme, Plants Plus Richmond, AIDS Vancouver, Flowers by Grayce, Terra Plants and Flowers, BC Coalition of the Disabled, Art Knapp on Hornby, The Flower Studio. Bouquets of Thanks to All of You!!

We are grateful for the gift of food or beverages from the following: Isadora's Cooperative Restaurant, Major the Gourmet, Canadian Springs, Wayne Sober, Kettle of Fish, Burard Deli. Bon appetit!

This month we want to acknowledge the excellent ongoing support and donations from Uniglobe Classic Travel 421 1178

Tell Us!

We recently received funding from Health and Welfare Canada to conduct a Program Review of our Society. The Review will assist us to better understand our current impact and future needs and will develop an external report as a resource tool to help other groups begin or expand their own programs, and to help policy makers better understand the contribution and needs of community based organizations such as ours.

The researchers will review the Society's effectiveness, our responsiveness to members' needs, and our relationship with other HIV/AIDS programs and organizations. Their research will include reviewing key programs, procedures and policies. In particular, they will



Photo: John Kozachenko

Smiles and Hugs at the Vancouver PWA Society's new office Warming Reception at 1447 Hornby Street

be conducting interviews with Board Members, Program Coordinators and many of our members to determine how our programs, services, policies and procedures affect our membership.

Project co-ordinators Steve Goldberg and John Collins will be contacting as many of our members as possible. We invite you to be completely open and say what you honestly think when you answer their questions, so that this review can best improve the way our society serves our members.

Judy McGuire

ddI Member Questionnaire

All people taking ddI are asked to phone David Lewis at the PWA Office (683 3381) for a supply of the monthly side-effects questionnaires. We are asking all members to complete these once a month in order to give us a chance to compile information about frequently-reported side effects.

David Lewis

Eating Hints

Are You Just Not Hungry?

- Try ice cream mixed with ginger ale or your favourite carbonated beverage as a drink. Or try a milk shake or frozen yogurt.
- Eat small meals more often.
- Keep snacks handy for nibbling. It's been proven that people eat more food when it's easily available. Leftovers make good snacks.
- Reply on foods you really love during your not-so-hungry periods. Chicken soup and spaghetti with meatballs were mentioned several times as favourites at this time.
- Vary the colour of foods served on a plate. Arrange it attractively. Add garnishes such as orange slices, a slice of tomato or a sprig of parsley to make food more appealing.
- Concentrate on making your meal more enjoyable in every way with attractive settings, bright surroundings and good company. Soft music may help make mealtime more pleasant.
- Chamomile tea has been known to stimulate the appetite. Also look into other herb teas that calm your stomach, help digestion or in general stimulate your appetite.

Reprinted from "We are all in this Together", Newsletter of the PWA Coalition of Tucson Arizona.



Photo: John Kozachenko

On Saturday, May 12th, leather title-holders from throughout the Pacific Northwest joined with Ms. and Mr. Leather Vancouver in a lively erotic fantasy fund-raiser for the Vancouver PWA Society and Easter's Sundays.

Wishes Fulfilled



Leather Star, a fundraising organization in the Pacific Northwest, has a desire to grant the "last wishes" of endstage PWAs in Oregon, Washington, Idaho, Montana and BC. Since last November, Leather Star has granted three such wishes in the US, reuniting families, helping with travel and accommodation. To date no one has applied from Canada. Anyone wishing to do so, either on their own behalf or on behalf of others, should contact Martin Rooney, Puget Sound Mister Leather 1990 at (604) 688 9162 (message phone).

David Lewis



Stop Smoking!

The PWA Smoking Cessation Program will begin again on Monday evening, June 18th, at 5:00 pm (till about 7:15 pm) in the PWA Living Room Lounge, 1447 Hornby Street.

The 8-week program is an effective way to stop smoking forever, without gimmicks, humiliation, or cost! Valued at \$550.00 per participant, the program is once again offered free to PWA full members.

To register, please call the PWA office at 683 3381 and leave your name and number. You must be willing to commit to 8 consecutive Monday evenings and have a real desire to stop smoking. The group is limited to the first 8 registrants, with a waiting list thereafter (and possibly up to 12 will be allowed based on space).

David Lewis, MA., R.C.C. will facilitate the program, and may be contacted for more information at the PWA office 683 3381.

David Lewis

Legal, Medical Issues

Focus of Monthly Forum

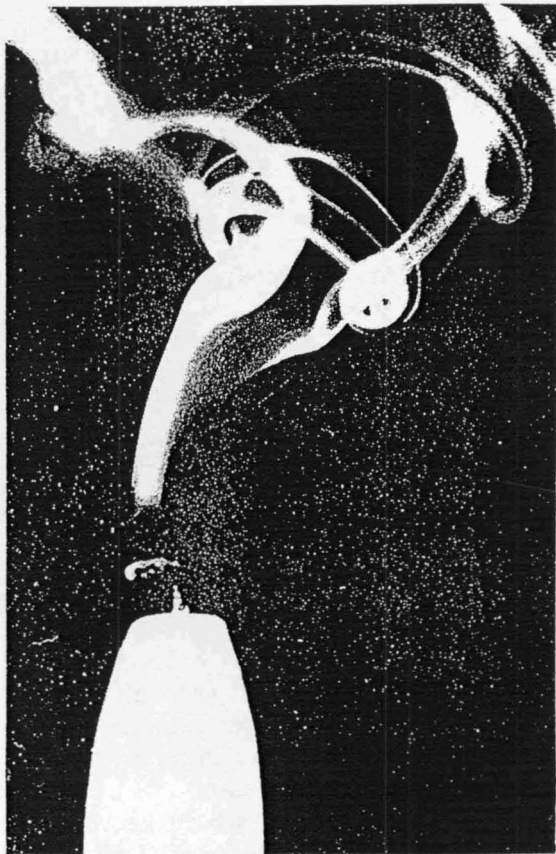
The June Monthly Medical Forum will feature guest speaker attorney Kevin Robb from Smith & Hughes. Kevin will be addressing the important matter of legal/medical issues.

The Forum will be held on June 6th, at 7pm at Gordon Neighbourhood House, 1019 Broughton.

Medical Forums On Audio Tape.

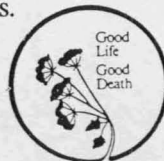
All Monthly Forums are being retained on good quality audio tape recordings. These are available in the library at PWA office.

Euthanasia: Choice in Dying



The Wednesday, August 8th Monthly Forum will feature a guest speaker from The National Hemlock Society talking about euthanasia.

Mark the date down now, Wednesday, August 8th, from 7pm at Gordon Neighbourhood House, 1019 Broughton. Admission will be free to PWA members, and \$1.00 Donation requested from others.



On Our Shelves HelpLine

New Books in the PWA Library

Take These Broken Wings and Learn to Fly--Dietz and Hicks.

The Courage to Grieve--Judy Tatelbaum
Way of Hope--Kushio, Michio--Macrobiotics and Health

The Web that has No Weavers--Ted Kaptchuck--Oriental medicine explained for the West

Inner Health--Neville Drury--various alternative therapies

Introduction to Homeopathy:
Medicine for the 21st Century--Donna Ullman.

Everybody's Guide to Homeopathic Medicine
Cummings/Ullman

Books

There are several very worthwhile books about for your perusal this summer:

"Healers on Healing"--New writings by over 30 healers from Stephen Levine to Carl Simonton to Louise Hay to Bernie Siegal and Shakti Gawain, edited by Richard Carlson PhD.

"Coping with Candida Cook Book"--by Sally Rockwell, Nutritionist. Also a tape--"How to control Candida yeast overgrowth--Overcoming Candida"

"The Hero Within" by Carol Pearson. "Six Archetypes We All Live By"--a wonderful book about co-responsibility in the evolving of our self
"Emmanuel's Book"-- a manual for living comfortably in the cosmos--by Pat Rodegast (recently gave workshop in Vancouver)

Frank F.

Assistant Librarian

required to assist in the smooth management of the Library. Duties include checking books in and out and maintaining materials. Time involved is 4 to 8 hours per week.

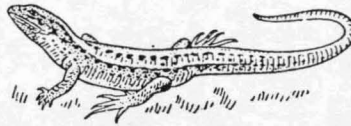
Lounge Manager

to maintain the PWA Lounge on a regular basis. Duties include ordering supplies and monitoring Lounge schedule.

Prison Outreach Co-ordinator

to identify and visit members who are in prisons for support as well as advocacy. To establish contact with key staff in social work, medical and administrative positions. Peer counselling or social work background an asset. Vehicle required.

If you are interested in these or other volunteer opportunities, please contact the Coordinator of Volunteers at 683 3381



'LoungeLizards'

Needed to Look after the PWA Living Room Lounge

Qualifications include: creativity, good communications skills, tolerance, sense of humour, ability to remain calm under pressure and to work with people's differences, dependability, reliability and security consciousness.

Apply for this interesting Volunteer Position with Jackie at the office.

Staff Credits

Editor:

Douglas Starratt

Art Director:

Lim P. H.

Typesetting:

John Liesch

Proofreading

Chuck Philbrick

Douglas S.

Copy Typists:

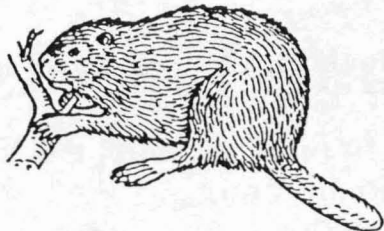
John Liesch

David P.

Production Manager:

Michel Arsenaault

Many thanks to the crews who photocopy, collate, stuff envelopes, and keep us going. If you want a volunteer assignment that's fun and rewarding, come join us on the lively Newsletter team!



THE VANCOUVER PERSONS WITH AIDS SOCIETY NEWSLETTER IS PUBLISHED BY THE VANCOUVER PERSONS WITH AIDS SOCIETY. OUR OFFICE IS AT 1447 HORNBY STREET, VANCOUVER, B.C. V6Z 1W8 PHONE (604) 683-3381 FACSIMILE 683-3367. THE VANCOUVER PERSONS WITH AIDS SOCIETY IS A REGISTERED CHARITABLE ORGANIZATION (REVENUE CANADA REG. #0760124-11-27)

THIS NEWSLETTER MAY REPORT ON EXPERIMENTAL AND ALTERNATIVE THERAPIES BUT THE COALITION/SOCIETY DOES NOT RECOMMEND PARTICULAR THERAPY. PLEASE CONTACT YOUR PHYSICIAN BEFORE TRYING ANY NEW TREATMENT.

OPINIONS EXPRESSED ARE THOSE OF THE INDIVIDUAL AUTHORS AND NOT NECESSARILY THOSE OF THE BOARD OF DIRECTORS OR THE VANCOUVER PERSONS WITH AIDS SOCIETY.

NoticeBoard

Stamp Collectors PWA with too much time on my hands will turn your stamps into food and clothing for less fortunate Persons with AIDS. I'll catalogue and auction older stamp collections and give 75% of all profits to PWA for those in need. For information, call Brad at 733 5439, or if you prefer, drop off the stamps at the PWA office to Jackie at the reception desk. You're giving me something I enjoy doing and at the same time raising more for donations where the need is really great.

Drivers We frequently need friends with trucks or vans to transport a variety of items, light furniture, supplies, etc. If you are willing to volunteer some time with a truck or van please register with Jackie at the office.

B.C. Ferries Disabled Passes are available to disabled persons by writing to B.C. Ferry Corporation, 1112 Fort St., Victoria, B.C. V8V 4V2. Attention: Public Relations. A note from your doctor must accompany the request.

Are you on UIC? Do you want to work at the PWA Society's Fund-raising office? Jobs are available for people on UIC. Call Joe Ford, 688 WALK.

Teddy Bears: we need a few good bears for the Living Room Lounge. Donations of cuddly critters gratefully accepted for duty in the Lounge or Hospital.

Room for Rent in HIV+ household with two dogs. Looking for HIV+ person in late 20's - 30's. Expenses divided three ways. \$375 rent includes utilities. Phone Dan or Denny at 439 1209.

Folding Deck Chairs: donations gratefully accepted.

Super Blue-green Algae available through Complementary Health fund. Call Stephen McManus at 683 3381 for details.

Bill Robson Art Show opening June 27th, at the PWA Society Board Room and running two months.