

VANCOUVER
PERSONS WITH AIDS
SOCIETY



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NEWSLETTER



Housing Crunch

One of the most serious problems facing people with HIV and AIDS is that of affordable housing. Frequently members find themselves living in apartments or homes they can no longer afford to stay in as their incomes drop due to disability.

When we were healthy and employed it was easy to locate affordable housing. Often times, members then find themselves ill and unable to work, with their incomes dropping to \$658.00 per month (from GAIN for the Handicapped), which leaves them unable to continue living where they were--where, perhaps, the rent alone is more than \$658.00 per month!

A search begins for affordable housing, and little, if anything, shows up. We know of members doubling and tripling up in one-bedroom apartments to split the rent in order to be able to afford to go on living with a roof over their heads.

All housing in Vancouver is difficult to find, let alone affordable housing. Last year when it was announced that McLaren House would possibly be opening up 32 more units of affordable housing for PWAs in 1991, we were swamped with over 100 phone calls from members asking how they could access those 32 units! It is readily apparent that the need is overwhelming for housing that's clean, comfortable, affordable.

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We have participated in several rallies recently attempting to draw attention to the critical housing needs of our members. We went to Vancouver City Council Chambers recently with the BC Coalition of the Disabled and other groups to demonstrate our concern that PWAs urgently need affordable housing---Now!

We also took part in a march from Denman Street to Robson Square where a rally was held to voice our concern for adequate, affordable housing.

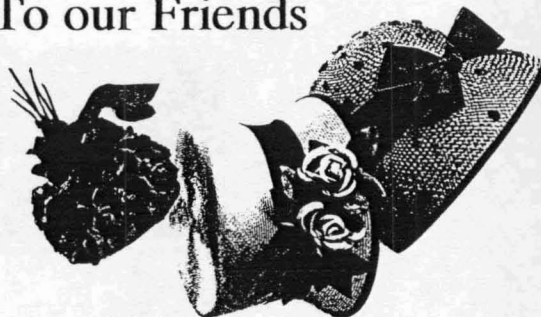
The solution to the lack of affordable housing in Vancouver is not going to be easy to reach. But we must visibly, aggressively be seen to be constantly advocating for this crucial need of a majority of our members.

David Lewis

ACT UP

An open meeting for the formation of a Vancouver Chapter of ACT UP--AIDS Coalition to Unleash Power--will be held on Saturday, July 21, 1990, from 1:00 pm to 3:30 pm at 3205 West 11th Avenue, Vancouver, BC. For information, call (604) 732 7975

Hats Off! To our Friends



Sincere appreciations are in order for the following businesses, organizations and entertainers who recently hosted fantastic fund-raisers for our Society. Our heartfelt thanks go out to: Bill Munroe and Doll & Penny's for those hot nights in the city during 'A Month of Wednesdays', Stella May, the Dot Party people and the Odyssey for another fabulous Dot Party. Bob Ross and Mama Karen from Celebrities, a club that has been helping PWA's since we opened our doors. Two other groups who have been supporting us over the years, the English Bay bowling League and the Dogwood Monarchist Society. Thank you all! All donations received go directly for programs and services which enhance the lives of people with HIV/AIDS.

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PWA Review and Evaluation Project

The PWA Review and Evaluation Project continues to document the success of the Society and to gather information about how we can become an even more successful self help/self care organization. For the past several weeks, Steve Goldberg and John Collins have been interviewing Staff, Board and volunteer members about the successes and problems that challenge the Society. They are also drafting a Membership Questionnaire that all PWA members should plan on filling in and returning to the Society Offices.

In the next few weeks, Steve and John will schedule a series of group interviews with a number of Society members, sometimes as part of the Saturday Drop-In, sometimes as part of a Program meeting, and sometimes at a specially scheduled time. Chuck and Dan will help lead these Focus Discussion Groups. Members should plan on joining these one-hour long discussions to help steer the direction of the Society. Judy McGuire is coordinating project administration and is responsible for writing and editing the Review Reports. Call Judy to ask about specially scheduled times and to sign yourself up for a focus discussion group.

Advocacy Report

The Advocacy Committee has been actively pursuing complaints of discrimination against members with HIV and AIDS. We have seen cases of employment discrimination, housing discrimination and medical care discrimination--all of which are getting a lot of attention from us.

The White Spot/Kentucky Fried Chicken (in BC only, except Prince George) boycott is growing as more organizations join in and lend their support. We are also endorsing the boycott called in the USA against Philip Morris Company and, specifically, against Marlboro Cigarettes. If you must smoke tobacco products (which is really not a good idea to begin with), then choose brands other than those of Philip Morris--and specifically, Marlboro. Philip Morris has spent a great deal of money funding the political career of Senator Jesse Helms--one of the singularly most homophobic and AIDS-negative politicians in the USA.

Our Advocacy meetings are every Monday morning at 10:30 am in the Board Room at PWA. To get involved, simply show up and participate!
David Lewis



Boycotts in Effect

All people with AIDS and those concerned with the needs and rights of people with AIDS are asked to support the following current boycotts:

- White Spot Restaurants in British Columbia
- Kentucky Fried Chicken outlets in British Columbia (except Prince George)
- Marlboro Cigarettes and other products of Philip Morris Company
- Coors Beer
- Shell Gasolines
- Bristol-Myers Products

For further information about any of these boycotts, contact Advocacy at 683 3381.

PWAs Come Together in Madrid



The 4th International Conference for People with HIV and AIDS was recently held in Madrid, Spain from May 22 to 27, 1990. Over 500 PWAs attended from all over the world.

Locally, we had seven members present: Alex Kowalski, Don DeGagne (one of the conference organizers), Pei Lim, David Lewis, Kevin Robb, Rick Waines and a member who works with AIDS Vancouver.

It was a most phenomenal experience to meet people from all over the world and compare how our lives are with theirs in their own countries.

While it is true that we are light years ahead of persons from many central and South American countries as well as many African nations in terms of access to treatments, psychosocial support services, etc., we are lagging very far behind the Scandinavian countries, Holland, Germany, and Great Britain in our response to AIDS here in Canada.

The plenary of the conference called on all people to denounce any country that has laws that restrict the free travel of people with HIV and AIDS. The attendees endorsed the boycott of the San Francisco conference. Endorsement of the boycott of Marlboro cigarettes and other products of the Philip Morris Company was also given.

Workshops were held by local Vancouverites, with David Lewis facilitating a very large

group on the issue of "Grief and Grieving"; Pei Lim on "Asians and AIDS"; Rick Waines on "Hemophilia and AIDS"; Kevin Robb on "AIDS Legal Issues"; Don DeGagne on "International Travel and Discrimination", and Alex Kowalski on "Self-Help Groups".

The 5th International Conference for People with HIV and AIDS will be held in 1991 in Strasbourg, France (headquarters of the European Commission).

David Lewis

How are We Doing?

The PWA Society needs to hear from you!

PWA members have been asking for a stronger say in the programs, activities and priorities of the Society, and now is your chance. As part of the Society's Review and Evaluation, the Staff will be sending you or handing you a questionnaire to fill in and return. Remember, this means YOU: whether you are a full member, associate member, group member, volunteer, staff person, or even friends and family of a PWA member. People who come in for Complementary Health Fund cheques or who just stop in to visit and use the Lounge or Library facilities will be able to pick up a questionnaire from Yvonne. Other members may receive a copy of the survey by mail, or can telephone and ask to be sent a copy. The PWA Staff and Board need your ideas and your ratings of current services, programs and activities, so be ready to help the Society expand its offerings and fine-tune its programs by filling out and returning the questionnaire promptly! Anyone who has complaints, suggestions or recommendations for helping the Society to improve its activities and services should fill in a questionnaire! Stand up and be counted!!



Photo: John Kozachenko

The 7th International AIDS Candlelight Memorial was held on Sunday, May 20th, in over 300 cities throughout the world. Here in Vancouver more than 600 people gathered in an emotional and moving tribute to those who have died of AIDS as well as those of us living with AIDS

PWA Society's History

In the Making Today

Special recognition to Chuck Philbrick and Dan Cotton who are assembling the early history of the Society from old files, minutes of meetings, newsletters, newspaper accounts, videos, tapes and special interviews with some of the Senior Members of the Society. As part of the Society's Review and Evaluation, Chuck and Dan are documenting the month-by-month and year-by-year

growth and development of the Society. If you know of a special event or were involved in a significant milestone of the Society's development, call either Dan or Chuck at 683-3381 and tell them about it. Remember, if you keep it to yourself, it can never become part of our History!



AIDS Treatment Highlights.

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

ddI: Advance Over AZT?

"A study released in May, 1990, by doctors in Boston and Rochester, NY, furnishes yet another set of optimistic data concerning the anti-AIDS [sic] drug ddI.

"The doctors used various doses of the medication to treat 70 PWAs, three-quarters of whom reported small weight gains and a sense of improved well-being.

"Physical symptoms also diminished in one-quarter of the group, and for many patients, virus levels dropped significantly while white blood cell counts jumped.

"ddI may represent a major advance over AZT, at present the only approved treatment against AIDS and HIV, the virus that triggers it.

"AZT impedes red blood cell production in the bone marrow, and people on AZT frequently have to quit the drug because of anemia.

"This is not true of ddI, which has the additional advantage of persisting in the body longer than AZT. Rather than following AZT's strict six-times-a-day regimen, patients taking ddI need only ingest a dose every 12 to 24 hours.

"Controversy has erupted concerning ddI in the past few months because of the high death rate experienced by the 8,000 desperately ill people receiving the drug through a "parallel track" program independent of the supervised clinical trials.

"The study did confirm that ddI has some

serious side effects. Five of the 70 patients developed pancreatitis, a sometimes fatal syndrome that is at the centre of concern about ddI. Its symptoms include abdominal pain and vomiting.

"In addition, eight of the study group had their daily activities disrupted by painful tingling and burning sensations in their extremities.

"Only the larger, longer-term studies now under way can determine ddI's ultimate safety, noted Anthony Fauci in commenting on the study.

"Fauci is the director of the National Institute of Allergy and Infectious Diseases and the government's top AIDS scientist"

Bay Area Reporter
May, 1990

Oral Alpha-Interferon in Question

Note: For a complete explanation of Oral Alpha-Interferon, see the info pack in our Library or see the June issue of the PWA Newsletter.

"No one, including its advocates, knows how the treatment could work. The dose is tiny compared to what is used in other interferon treatment. The drug might be absorbed under the tongue, or there might be interferon receptors in the mouth; some kind of cascade of effects must be produced. But so far these are only speculations, not supported by evidence.

"The scientific study of 40 patients includes a table showing T-helper counts over 270, with 18 being over 700. The mean T-helper count for these 18 patients--almost half the total patients in the study--was over 1000 before treatment began. Many if not most of the 40 patients would be expected to be asymptomatic.

"But patients were accepted for the study if they were HIV-positive and had certain symptoms which might be AIDS-related. The symptoms were: appetite loss or weight loss; fatigue or weakness; mouth sores or ulcers or candidiasis; fever; diarrhoea; respiratory tract infection; night sweats; lymphadenopathy; and skin rash. (The average

patient had 5.2 of these symptoms. Two in this study were HIV-positive but asymptomatic; the others did have symptoms.)

"It is possible that some of these asymptomatic patients in fact had no AIDS-related symptoms, but instead had ordinary, minor infections which caused the fever, diarrhoea, appetite loss, rash, night sweats, etc. Being HIV-positive and having symptoms which can be AIDS-related, they were included in the study and started on oral interferon treatment. Then they recovered--just as they would have if they had no treatment at all--and were counted as having all their AIDS symptoms go away after the treatment."

John S. James
April 20, 1990

Compound Q: Preliminary Results of Project Inform Study

"The majority of study participants had an average increase of 60 t-cells after 150 days of treatment. The top 25% of participants showed t-cell increases of up to 400 after 150 days.

"By using historical data, researchers concluded that, on average, patients had been losing T-cells at a rate of .3/day before treatment began. With the use of Compound Q, however, patients showed an average T-cell gain of .6/day. This is a statistically significant increase.

"Another exciting result of this trial is that after treatment with Compound Q, eight participants had all their blood counts return to normal. Project Inform will do follow-ups on these to see if they remain normal after all treatments have stopped.

"Despite the encouraging results, project Inform cautions that Compound Q can cause serious side effects. Allergic reactions, seen in about 10-15% of the study participants, can be life threatening if not treated correctly by medical personnel."

Being Alive, June, 1990

Beta₂ Microglobulin Levels

Predictor of Disease Progression

"Beta₂-microglobulin (B₂M) is a protein that is found on the surface of nearly all cells of the body. When stimulated in laboratory experiments, white blood cells produce B₂M. Although the exact role of B₂M is not clear, its association with many different parts of the immune system suggests a role for this chemical in the functioning of the immune response. Blood levels of B₂M depend on the functioning of the kidneys. Thus in cases of kidney failure levels of B₂M are high. Elevated levels of B₂M also occur in other disease states unrelated to kidney function, such as cancer and viral infections and, in particular, HIV infection.

"We report results of a study conducted in the San Francisco area. There were 962 men in the study group recruited between 1984 to 1987. The researchers examined the relationship between B₂M levels, HIV infection CD4-cell count and progression to AIDS. Nearly half the men (388 subjects) were infected with HIV on entry to the study. During the next 3 years of follow-up 65 out of the 388 subjects (17%) went on to develop AIDS. At entry 593 non-HIV infected subjects had an average B₂M level of 2.01 mg/L. In HIV + subjects who did not have AIDS the level was 3.00 mg/L and in those with AIDS it was 4.09mg/L.

"The scientists divided the group in to two sections: those with CD4-cell counts of 500 or more; and those whose CD4-cell count was less than 500. When B₂M and CD4-cell counts were taken together, 19/29 or 66% of men on entry whose B₂M levels were above 3.80 mg/L and who had CD4-cell counts less than 500 developed AIDS within 3 years. This is in contrast to 8/140 men or 6% who had B₂M below 3.80 mg/L and more than 500 CD4-cells who went on to develop AIDS within 3 years. According to their calculations high levels of B₂M (more than 3.80 mg/L) and low CD4-cell counts (less than 500) taken together are associated with an 18 times increase in the

likelihood of AIDS developing. When the same levels of B₂M are combined with high CD4-cell counts (over 500) the risk is 4.2 times. The authors note that calculations of the time it takes to develop AIDS were not based on time of infection but rather the level of the "surrogate markers" (CD4-cell, B₂M) at time of study entry. Thus B₂M could be used by physicians to help determine where in the spectrum of HIV-disease their patients are located"

AIDS Action Now
Toronto
March, 1990

Note: B₂M, P24 Antigen and Neopterin testing is available through the Vancouver PWA Society. Call 683 3381.

CMV Retinitis

One PWA's Experience

Without an interest in or aptitude for science, the information you have on HIV and its treatment is often barely comprehensible. You lose the facts and are susceptible to rumours. Who needs to listen to idiotic friends and PWAs who should know better tell you about people in other places who have shed the virus through macrodiets or some machine in Europe? So after a few years and a major opportunistic infection, I became proud and withdrawn from peers, and altogether a good soldier for my doctors.

Then I got Cytomegalo virus (CMV), a viral retinitis that causes blindness. It's another little gift from HIV-land that never bothered us before. It came on me as an eye that was becoming occluded with dots and a central veil. My general practitioner first dismissed it but a week later sent me to an eye specialist. Fifteen minutes after dilation I was out on the street again, a brief resume of St. Paul's eye clinic policy ringing in my head, and a decision instinctively made to follow its path. I could begin daily injections that would only block the virus spreading, such treatment to be administered at the hospital. But the doctor recommended that I could

simply monitor the good eye for symptoms and let the virus go. It doesn't always spread. The clinic favours the latter.

What would you do? Get a catheter attached and troop to the hospital everyday, taking a strong medicine that can gobble blood cells? I hit a limit of tolerance. Daily trips to the hospital? No visits out-of-town?

I would take the eye clinic line and wait--if it didn't spread, O.K. If it did, at least I would have had some months of freedom. Very stoic. But dismissive pride was combined with ignorance. I did not have all the information. For one thing, my bad eye was not defunct, and I assumed that its light and partial vision would continue. Medicine at that point may have saved the only partially ruined eye. But I had no idea of how total the shutdown of the affected eye would be for almost two months. In the beginning what I was to live with felt manageable.

The doctor, quickly laying out a policy I could hardly grasp, was acting solely as a bureaucrat, while I, picking up on what seemed to be a considered casualness, accepted his easier route.

Then a couple of things happened that radically changed my situation. I kept getting stronger instead of fading away. That meant a surge of optimism. ddI was doing something. Correctly or not, I had only heard blindness mentioned as an affliction of final days. Therefore, I felt judged and condemned. Then the eye utterly closed down. No light, nothing. Perspective is shot, especially for close range skills like cooking and eating. Peripheral vision is shot, making driving a really busy task as your head is twisting all over. You're very uncomfortable in crowds. Balance is off--watch out for the good china!

Live with it, it's just physical, you might say. But the very worst is mental. The more you understand sight the more you worry about CMV attacking the remaining good eye. You believe you have warning, but as the doctors never tire of saying, "every case is different". For the first time in the course of this disease I have felt infirmity. Avoiding the grind of visiting the eye clinic every

day is nothing compared to getting a hard, thoughtless shove through an open door to decline and disablement. Losing an eye is that bad.

This is a case where the Americans are clearly ahead of the game mechanically but using the same science. They allow DHPG, the drug that blocks CMV, to be administered by the patient, thus preserving his independence. The decision to risk the healthy eye or face a complicated medical treatment is not difficult. For Vancouverites, Seattle means a cross border thicket of contacts, insurance companies, laws and expenses, impossible or at least daunting. The PWA newsletter has not addressed accessing US treatment; you're on your own. We need to lobby for BC recognition of home drug treatment.

A. V.

[Ed. Note: If any of our readers have gotten access to treatment in the US and wishes to share their experience, we would be pleased to print an article.]

Hospital Peer Support



How Can I Really Help?

Another member is not feeling well. Another friend is in the hospital. Shall I become involved or not, and if so, how deeply? How much pain to let in, and whose?

The choices before us seem limitless. One choice is to deny it. When I push pain away, ironically, I invite in another kind of pain. I begin to feel dry, empty, bored and alone in my insulated apartment. With my door closed to the pains of others, I banish that which would release my natural compassion and engagement with life. I end up needing heart to heart resuscitation.

How do I get involved? It's one thing to have one's heart engaged. Quite another to have it overwhelmed or broken. So what is the strategy?

Perhaps the strategy for dealing with suffering that is most familiar to us is that of "Professional Warmth". Many professionals even believe that is it appropriate "not to get involved". Of course it is understandable how this "professional warmth" has evolved. It is a survival strategy. But it is no answer because our hearts pay the price. Caregivers and receivers alike.

How do we become humble students working on ourselves to become more effective instruments of compassion? How do we begin to face our own pain and suffering?

These are some questions we will be exploring in the workshop. The workshop will also have guest speakers addressing pain, therapeutic touch, basic practical nursing skills, grief, death and dying and more.

Hospital peer support is a new program of the Vancouver PWA Society. If you are in the hospital please remember that we are here and we care. When you feel like visitors we'll send someone from the hospital peer support team. Perhaps we can offer some relief to your regular care team. Maybe hearts that have known pain can meet in mutual recognition and trust. Or just some company.

All members and associate members are invited to join. (It costs only \$25 to become an Associate member.) You give as much or as little as you like.

All interested volunteers are invited to the hospital peer support workshop in late July. It will be a good opportunity to meet other members of your team. A safe place to explore issues, share experiences, give and receive support.

If you are interested, please leave your name and phone number at the Vancouver PWA Society for Lim and I'll get back to you as soon as I can.

Thank you for your consideration.

Lim

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:

Adult Children of Alcoholics: Special Interest to Gays and Lesbians, HIV+/- Adult Children of Alcoholics is a 12 step support group for adults recovering from specific behaviour pattern established while living in alcoholic, addictive or otherwise compulsive family environments. This group will meet Tuesdays, from 7:00 pm until 8:30 pm in the PWA Living Room Lounge, 1447 Hornby Street.

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

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.

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.

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.

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. Coordinated 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 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.

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 July 6th, and 20th, and August 3rd, 17th and 31st. 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 7:00 pm at Gordon Neighborhood house. The topic for Wednesday, June 6th is Legal Medical Issues.

PWA Social Night Sunday, July 15th, 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! For info call Michel at 683 3381.

Lesbians and Gays with a Disability Monday, July 30, 1990, 7:30pm West End Community Centre, Stanley Court, 870 Denman St. For more information, please call Dan Guinan at the BC Coalition of the Disabled, 875 0188.

Deadline for Submissions for August Issue of the PWA Newsletter is Friday, July 6th, 1990.

Lighten the Load

A mother stays with her son during the day while his lover works. She sees that her two other children are very upset about their brother's condition. She knows they need to talk but she finds that, right now, all of her energy is going to her son who has AIDS. She is experiencing a lot of guilt about not being available to the rest of her family and wants to know if anyone else feels this way.

Facing the situation one day at a time

A young man leaves his job in Alaska to come and share an apartment with his cousin in Burnaby. He decided to make the move when his cousin left his job due to an increase in the number of HIV-related problems he was experiencing. The close relationship these men enjoyed while they were growing up remains the strongest family tie each of them has. The new living arrangement is working well, but not knowing much about HIV/AIDS, the newcomer wants to know what he can expect in the future.

A group of four form a 'carefamily' for a friend who lives in their co-op. Each week a different member of the carefamily attends the support group to report on how they are managing and to pick up that week's handouts for the others to read. They say that the support they get from the group is enabling them to continue to care for their friend at home--where he would like to stay until he dies.

A step-father is here in Vancouver from England. At night he sleeps in his step-daughter's apartment. During the day he stays with her at St. Paul's Hospital. He is here on an open ended ticket; facing the situation one day at a time. Apart from his phone calls home, the support group has become his major source of support and comradeship.

None of the characters above exist. They have been constructed from the many stories we hear in the Family and Friends Support Group.

The beauty of a support group is that by simply talking about what is going on for you, someone else feels better for hearing it and you feel better for having said it. Hearing the experience of someone who is living with AIDS in their life, just as you are, can be more helpful than a well meaning friend, counsellor, or coping with AIDS book. And telling your story to others can, somehow, lighten the load.

Most often someone in the group has been thinking, feeling, or acting the same way you have recently. Hearing what is working for them can suggest new ways of coping for you in your situation.

Also, as support people, we often have thoughts and feelings that we keep to ourselves for fear of burdening others. Yet the key to being fully present with those we love is allowing ourselves to stay with our experience; both the pleasant and the unpleasant. In the support group everyone can relate to how difficult it is to stay open to powerful emotions. Hardly a meeting goes by that we don't remind each other that our feelings are neither good nor bad. They are just E-motion or Energy In Motion which needs to be expressed.

Telling your stories to others can, somehow, lighten the load

Choosing to seek support outside the immediate unit of people surrounding someone with HIV/AIDS can be a very important decision. Although, thankfully, the climate of public opinion is changing, AIDS can still be a disease of isolation--for those who care as well as the patient. Our support group promotes feelings of connectedness. At every meeting, as well as the informal sharing of experiences, AIDS-specific information regarding available resources and coping strategies for caregivers is distributed. Those who attend the meetings describe the group as "a real plus".

Joy Moon

Family and Friends

This support group for family and friends of persons with HIV/AIDS is sponsored by AIDS Vancouver. It meets every Wednesday from 7:30 to 9:30 pm at St. Andrew's Wesley Church at Burrard and Nelson. It is run on a drop-in basis and is free of charge. A professional counsellor facilitates. For more information, please call Joy Moon at 299 4828.



The Last Canto

*HIV Seropositivity
what do I Love and
where did I get you?
That I misplaced my core
journeying through the world.
The thoughts clash
and are fragmented
and that I attempted to make an awakening.*

Anonymous

Art Therapy



You do not need to be an artist to express yourself creatively. The PWA Art Therapy group has been meeting since September 1988 and the group usually has six members. The group is facilitated by Noel Silver, a certified Art Therapist, artist, and mental health worker. If you are interested in joining, please contact Noel at 685 5240. Noel has been contracted by the PWA Society and the sessions are free to PWA members.



Time to Work Out

Hi Guys. I'm just home from the PWA exercise class, and enjoyed it so much, and feel sooooo good that I thought I'd sit down and write this letter to tell you all about it.

"Aerobics" is a misnomer for this class, because really it's not. It's an exercise class, not aerobics. Even though I was a big exerciser before I got sick, doing aerobics classes three to four times a week and doing my weights at the downtown Nautilus, I hadn't been doing anything for the past couple of years. That kind of activity is sort of beyond my reach now, and like many of us, I too suffer from bouts of apathy, despair and inhibition about my body. No, you don't find me taking off my clothes in public locker rooms any more. Especially those filled with gorgeous muscle hunks. Anyway, all of that, combined with being in convalescence from my most recent illness, that kept me laid up on the couch for almost a month, I had my doubts about this class and my own abilities.

As soon as I saw the room and met the instructor I realized that all my worry, self doubt and fear were for naught. First of all, if you get there a bit early you get to hang around in the lovely, peaceful and beautifully restored Barclay Manor. Sitting in those great huge rooms among all that beautiful blond wood and the stained glass and plants gave me a real sense of history and permanence, and quality, pride of craftsmanship. God, the West End must have been a beautiful place when it was all beautiful new homes like that!

Anyway, I found myself visualizing my body as having some of those kinds of qualities: endurance, permanence and pride. It was lovely.

When the sun came out again, I went out into the little garden in the backyard. It's sort of in the Japanese manner, and although I couldn't spend much time in it, it seemed like a quite magical place: an enchanted garden, complete with faeries living in the bottom. Another very beautiful little oasis quite far removed from the hustle and bustle of the apartment towers surrounding that block.

But then it was time to work out.

I explained a bit about my history, both of exercise and physical activity, and my particular AIDS history to Maggi. She's a very open minded, sensitive person with a real positive energy about her. Not at all pushy or aggressive about it the way some of those pert little gym bunnies can be. She seemed to be quite well informed about HIV/AIDS, too, which helped me build my confidence in her. Then, bless her soul, she said right up front, "I really respect the kind of courage it must take to live with AIDS. I'm inspired by it, and I try to incorporate it into my own life." I was bowled over. I mean here is this paragon of strength and health and calmness telling me that she tries to emulate me? And there was nothing phony or insincere about it. No condescension here. Just an open, honest and sincere gesture of respect. It was a really nice ego stroke, and I felt great. Really alive again.



So then it was time to start exercising. I was the only person there that day, and in a way it was kind of nice to have Maggi all to myself, especially since I felt that I've forgotten a lot about form. It would have been nicer still if a half dozen or so of my PWA brothers and sisters were there for encouragement and support and to increase the fun value of the class too, maybe next time.

Maggi is very good about adjusting the intensity level of the class to the lowest ability of those present so that everyone can participate fully and hopefully everyone gets a chance to feel stimulated and challenged. She asked me some sensible questions about my abilities and what I

wanted from the class, and she listened attentively to my answers. She heard what I said, the message behind the words.

I can't take anything too hard on the ankles and knees, and nothing that jars my organs. After being in bed for a month I really needed something to loosen my muscles, especially my back which is often painfully stiff and sore.

So that's what we did. About twenty minutes of slow, easy, gentle and gradual warm up, just to get the blood flow going and then about forty minutes of nice gentle stretching, working at loosening up all the major muscle groups especially my hips and back. No sit ups, and no cardio. Even though I've had PCP three times and still continue to smoke, I never got chest pain, never lost my breath and was even able to maintain a conservational level throughout. And boy, did I feel wonderful when we were through. Not the picture of radiant good health I once was, perhaps, but certainly the best I've felt in a long, long time.

This class is a really wonderful thing, totally free of all the ego trips and head games often associated with working out. Very unthreatening. In fact, very relaxing and soothing, and invigorating. An excellent means of health maintenance and promotion of general well being. I highly recommend it to everyone, no matter what your particular health condition, self esteem and image of body appearance and function is. Anyone can do this class, and feel good about it and themselves. And I'm sure that everyone can come up with two dollars per week. In fact, in terms of positive health benefits, it's hard to find a better return for your dollar.

The WECC has been very generous about subsidising this program, but unfortunately we are in danger of losing it through lack of participation. Maggi told me that I was the only person who had been in the last three weeks, and really, we can't expect them to keep up a program that no one goes to. They are going to try and keep it going till the end of June or the middle of July when people start taking their holidays and then, hopefully, start up again in the fall.

So come on out and take advantage of this great opportunity, I hope to see you all, in the basement room at the back of Barclay Manor, just off the garden every Tuesday and Thursday afternoon, from 4 till 5. And good luck with your own health recovery.

Michael P.

P.S. Since this article was written the class has indeed been cancelled for the summer. But let's really get out there in the fall and show the world what PWA's can do. Let's not let this opportunity slip away from us. See you in September.

M.P.



Fitness for PWAs

Topic of July Medical Forum

7 pm Gordon Neighbourhood
House, 1019 Broughton,
Wednesday, July 4th

The July Monthly Medical Forum will feature Maggi Cheetham speaking about "Fitness for PWAs".

This important topic has many implications for members to consider.

August's Monthly Forum will feature Cheryl Smith from the National Hemlock Society talking about "Euthanasia: Active/Conscious Participation in Dying". This Special forum will be held at 7:00 pm on August 8, 1990.

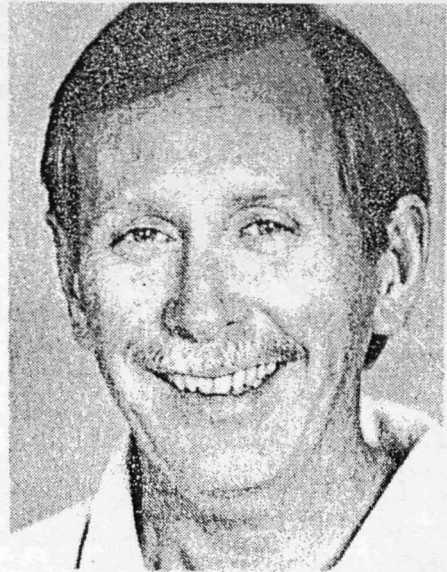
The Monthly Medical Forums are available on audio tape at the PWA Library within a few days.

Support Group For Lesbians and Gays with a Disability

A support group for Lesbians and Gay men with a disability will start meeting this July. We will share experiences with each other and provide support and encouragement.

Lesbians and Gay men with any type of disability are invited to come and talk about being Gay in the disabled community and being disabled in the Gay community.

The group will meet on the last Monday of every month, starting on Monday, July 30, 1990, at 7:30pm. The meetings will be held in the West End Community Centre, in the Stanley Court, 870 Denman Street. For more information, please call Dan Guinan at the BC Coalition of the Disabled, 875 0188.



Sean Stephenson
1942 - 1990

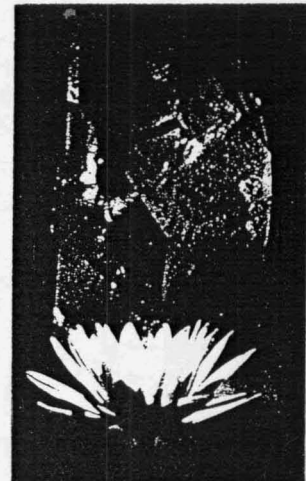
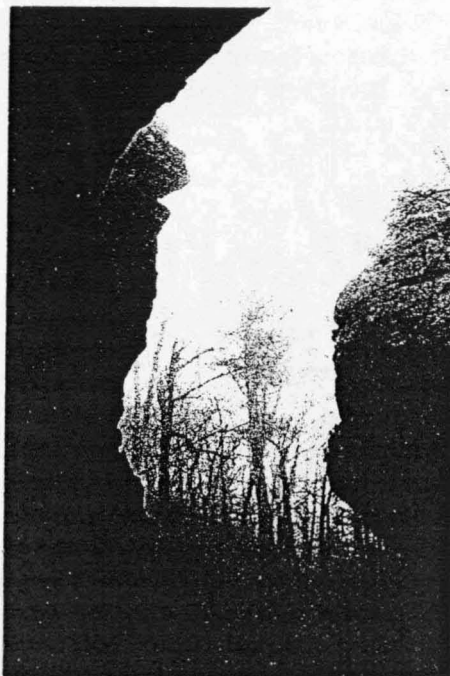
We are saddened to learn of the death of long term member of the Vancouver PWA Society, Sean Stevensen.

He will be missed in the boardroom, on retreat, and in the Meditation group. Here are some words spoken at his memorial service:

*The last rays
of a setting sun
bathe pink
the lotus
in a still blue pond
serene
beyond my reach*

*Breezes waft
their fragrant smell
with echo
of some far off
temple bell*

J.



Confessions of a Bystander.

I remember 4 1/2 years ago in October, 1985, when I first found out I was HIV sero-positive. Although I looked real great at that time (I have photos to prove it), I had a general feeling of malaise, so the doctor checked my T-cells and immunological counts for the first time. In October, 1985, I had 220 T-cells. It was not a cheery prognosis! Nevertheless, in my mind having a full-blown AIDS diagnosis at my age, which was 25, was incomprehensible, so I was determined to all ends to maintain my ARC status. Thus, I submerged myself into all the alternative and Holistic therapies along with an average daily dose of Mega Vitamin C, about 40,000 mg daily. To this day I have diligently maintained that exact daily dose of Vitamin C.

All through the mid to late 1980's, my T-cells continued to drop, along with other immunological readings, but I still had no major opportunistic infections. I felt like a 'bystander' as a member of our Coalition. By December of 1988, I had 10 T-cells, and by January of 1990, I had 5 T-cells. Almost 5 years had passed with my having under 200 T-cells. But, of course I had been totally 'preventative' with early intervention with low-dose AZT, and PCP prophylaxis with Septra/Bactrim as well as the Mega Vitamin C!

I even wondered myself how long one could survive without any opportunistic infections and virtually no immune system.

However, that all ended in May 1990, when I was diagnosed with a quarter sized B-cell lymphoma on my left triceps. Precious Jesus, after 55 months of severe ARC and relatively good health I was no longer a 'bystander' in a sense.

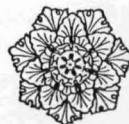
My point in all of this, I guess, is that it really is a long road to hoe! I feel fortunate and lucky beyond belief, but at that same time dealing with your HIV strategy really is a major task, chore, and job that requires great perseverance and dili-

gence. My personal commitment to dealing with HIV has been relentless.

In terms of my B-cell Lymphoma, it is minor and can be readily treated, and two of my closest friends at the Coalition had Lymphoma 3 years ago and are alive and well and Surviving and Thriving with AIDS!

My other point is that with early intervention and treatment with a bit of hard-core work, HIV disease really does appear to be becoming a chronic, manageable illness even at this point in time. I have a lot of determination to 'stand by' for the next 5 years and I don't think that is an unreasonable expectation based on current and upcoming medical therapies. Perhaps I'll write "Confessions of a Bystander, Part III" in January 1995.

NIGHTTIME



*I watch
my desk
my chair
and see them
fly past to
History
no morbid
dreams
or sultry
loves
but warmth
of things and
people
cherished
without words
pieces of heart
removed
as they pass
into memory
ending in
smiles of
Joy and Sorrow*

Richard Hofmann

Meditation Seminar

There will be a meditation seminar held at the PWA Society Living Room Lounge on Saturday, July 14th, from 4:30pm to 7:30pm. The Healing Tao is a practical system of self development that enables the individual to complete the harmonious evolution of the physical, mental and spiritual planes.

Through a series of ancient Chinese meditative and internal energy exercises, the practitioner learns to increase physical energy, release tension, improve health, practice self-defence, and gain the ability to heal oneself and others. In the process of creating a solid foundation of health and well-being in the physical body, the basis for developing one's spiritual potential is also created. While learning to tap the natural energies of the Sun, Moon, Earth and Stars, a level of awareness is attained in which a solid spiritual body is developed and nurtured.

The ultimate goal of the Tao practice is the transcendence of physical boundaries through the development of the soul and the spirit within man.

Just Start Talking

We need a list of recommended books for the creation of audio books that would assist those people with HIV who are visually impaired. There is a group of people who would be willing to read and record these books dealing with AIDS and the psychological and social aspects for the seeing impaired.

Please leave any suggested titles in the Library. Please make certain that we have the title, author, and if possible, the publisher.

Thanks for your assistance.

Information Packs

We have available in our Library more than 20 Information Packs containing lots of information relating to various treatments, testing, monitoring your condition, nutrition and more. Some of the most helpful Info Packs are:

- AZT
- ddI*
- P₂₄ Antigen, Beta₂ Microglobulin, Neopterin and T-cell testing*
- Acyclovir*
- PCP Treatments and Prophylaxis
- Oral Alpha Interferon/Interferon for KS*
- Positive But Healthy--Monitoring Your Condition
- CMV Retinitis--Detection and Treatment*
- Vitamins and Nutrition*
- Candida and Oral Manifestations of AIDS*
- Severe Weight Loss

Those Info Packs marked with asterisks (*) have been recently updated, and You are welcome to visit our Library any time during business hours, or phone us at 683 3381 and we'll mail them out to you.

Chuck P.

Kudos of the Month

Thanks to our friends Patty, Lance and Barb at Starbucks on Denman for their kind donation of coffee--some of the best in the city!

Special thanks to the Donors, Volunteers and Knitters at the United Church on Hastings for knitting the wonderful afghans for our members in the hospital and at home!

Library News

The Library is in the process of setting up a detailed classification system for all materials in our resource centre. That system will enable all users to find exactly what they are looking for very quickly. This cataloguing project has become possible through a Federal Summer Student work program which enabled the Society to hire Michael Habetler. In the course of the project it is becoming painfully clear that approximately 20% of the Library's materials, i.e. books, periodicals, video tapes, etc., are Missing. Would everyone please make a special effort to return what PWA Society's library materials they may have at home so that we can include everything in our new catalogue.

Library Committee



PWA Needs Your Skills

The Society urgently needs volunteers who have any of the following skills: Newswriting, Word Processing, Data Entry, Research and Documentation, Proposal and Report Writing, Telephone Interviewing, Peer Counselling, Fund Raising, Homecare Delivery, and Graphics and Layout Skills. If you have any of these skills, call the Society Offices at 683-3381 and tell them that you wish to volunteer your services to the Skills Bank.

We Need Talented People! Now!

HelpLine

Plumber

A Volunteer who has advanced plumbing skills is needed to repair the sink in one of our bathrooms. Please contact Jackie or Chris.

Library Clerk

Library assistance is required on Saturday's 11:00 to 3:00. Please contact the Librarians Ted or Vicki. Some library experience an asset. Library orientation provided.

Fundraiser

Like to meet people, get involved with the entertainment and cultural communities and help PWA? Join our fundraising efforts! Phone Chris and attend our Finance Committee Meetings, Wednesdays at 3:30.

Suggestion Box

Read with Interest

A suggestion box has been placed in the lounge for receipt of members' ideas and suggestions.

We received a note asking us to paint over the racist graffiti on the wall of our building. Thanks to our volunteer Gerry P. it's been done!

A concern about the removal of the photos of Kevin Brown and Warren Jensen from the wall at the top of the stairs was voiced through the suggestion box. This member's suggestion resulted in a dialogue between the writer, the Program and Personnel Committee and members. The outcome was an alternative place being selected to display the photos. The framed photos of all three PWA Society founders including Taavi Nurmela now all hang in the entrance hall at the foot of the stairs above the plants donated by Knapp's on Hornby. A decision which pleased everyone. Let us hear your suggestions!

Staff Credits

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Many thanks to the production and assembly crews for recent issues of the newsletter, including Andre T., Chris M., Dave W., Robert L., Gerry P., Richard C., 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

Saturday Drop-In: Saturday social/info sharing drop-in held in the PWA Lounge from 11:00 am to 3:00 pm every Saturday. Meet over people with HIV, many who come in from the suburbs for this program. The library is open, peer counsellors are available, snacks and refreshments are provided. The roof deck is open for socializing if the weather co-operates. We look forward to seeing you on Saturday!

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

PWA Summer Bar-B-Que Prepare now to attend the PWA Society summer Barbecue afternoon, from 1 pm till 6 pm on Sunday, August 19. This year the Barbecue will be held at the home of David Lewis (phone 683 3381 for the exact address), and is open to all members and staff and friends of PWA. Bring your own food to barbecue. More details next month.

Gay Games Tickets a limited number of tickets to the opening and closing ceremonies of Gay Games are available free of charge to full PWA members. Only one ticket per member will be given, on an "as available" basis, while they last. To get your ticket, please call Jackie at the office, 683 3381

Walking canes needed at the office for distribution to our members. Please leave them with Jackie or Michel.

Answering Machine: Active PWA Volunteer is looking for a donation of an answering machine. Can you help? Call Jackie.

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.

Roommate for PWA Let's find a two bedroom apartment in the West End. Contact Douglas S at 683 3381.

ddI Questionnaire take a few moments to share your experience. Contact Advocacy 683 3381.

Folding Deck Chairs: donations gratefully accepted.