



ISSUE # 21 JUNE, 1988

Newsletter

CANADIAN AIDS CONFERENCE

reported by Benoit L.

Time has come for action! That is what stands out as a result of this year's Canadian Conference on AIDS, held in Toronto June 16 - 18th. More than 500 professionals, caregivers, and community based groups representatives and Persons with AIDS were in attendance, including four from the PWA Coalition and one from McClaren House.

Mounting anger towards the federal inaction against AIDS was palpable at the conference, especially among persons with AIDS and their supporters, who made a strong showing. The Mulroney government was denounced for its lack of funding against AIDS. In comparison with other countries, the commitment of Canada in the fight against AIDS is pitiful. The federal government was also blamed for not allowing PWA's access to experimental drugs and treatments. Despite the many problems of having clinical trials in Canada, solutions can be explored, like the possibility for Canadian PWA's to be included in U.S. trials, and the easier access to new drugs on compassionate grounds, when the only other option is death.

Unfortunately, "our" minister of health, Jake Epp, did not show up at the conference, sending a deputy minister instead, with no encouraging message what so ever. Not surprising though: apparently Mr. Epp cannot yet pronounce the word AIDS without blushing. Mr. Epp was not the only politician not in attendance. They all were. How is it that none of the three major federal parties has come up with a global, and adequate plan to fight AIDS? How many votes are we worth? Is it an issue here? Let's not forget an election is due soon.....

To depict the anger of PWA's and supporters, the highlight of the conference turned out to be a very loud demonstration of 300 people in downtown Toronto. Jake Epp was burned in effigy, under the shouts of "Fire Epp Now!", "Silence equals death!", and "AIDS Action Now!".

CANADIAN AIDS CONFERENCE : continued

Back at the conference, Alastair Clayton, from the Federal Center for AIDS, promised to convey the message of delegates to the minister.

The conference was dissapointing on several aspects. Among others, the fact that there was nothing on treatments and therapies upset many PWA's

A private meeting was held at the end of the conference, for PWA's from across the country. Due to the fact that most Coalitions, or PWA groups are in the process of being born, it was decided against setting up a national coalition of people with AIDS, for the moment.

My personal feeling of the conference is that there is a "re-appropriation" of the debate by PWA's and community based groups volunteers. Someone has to take the lead of action, and we seem to be gaining momentum on that specific aspect. Let's now prepare and make a strong showing again next year at the International Conference on AIDS in Montreal. In the meantime, let's keep reminding "them" that "we" are there.....

" THE LIVING FACES OF AIDS " SUCCESS :

Our photographic display, " The Living Faces of AIDS ", with it's portraits of 35 Coalition members, was a big success, reminding delegates that people are living with AIDS, and are hoping for action. Thanks to Nicholas and Alex for doing such a great job in preparing the display, with titles in both official languages. The Coalition, in particular, the Advocacy Committee and the photographer would like to express thanks to all the PWA/PWARC's who allowed us to use their faces - we made a difference, receiving nothing but positive feedback from conference co-ordinators, particapants and spectators. Currently, the display will travel to Stockholm for the International Conference on AIDS, and other national interest is being considered. All participants are to assured that prior to any additional use of their photo, they will be contacted and asked for approval.

Any participant who has not received their individual photo, you can pick them up between 1 - 5 pm at the office. Should this be inconvenient, give us a call at 683-3301, and we will drop it in the mail.

For those of you interested in purchasing additional prints for family and friends, arrangments can be made through the photographer, Nicholas Gray, through the office.

GET INVOLVED : THE COALITION NEEDS YOU ! :

All of us possess talents that we can share. Whether it be computer skills, organizational abilities, or exotic talents, the Coalition encourages all members to come forward and help us maintain our strength and services. The four standing committees - Advocacy,- Personel - program - and Finance - can always use volunteers in planning and executing the programs and services. It is a great way to bolster your own support network, and makes it easier and more enjoyable for all of us. So.....get involved!

PROGRAM

Our committee meets every Wednesday morning at 11:00 am, at the Coalition office. We do need help to organize upcoming activities, such as retreats, one day excursions,, and camping trips. Get in touch with Benoit if the idea sounds interesting to you. Volunteers are also needed to host Pot Luck dinners held the third Saturday of each month. June is covered, but we do need a commitment for July 16th.

On June 8th, we are sponsoring a talk by Tom O'connor, author of " Living with AIDS ". We also look forward (in September) to a talk by twp PWA's travelling around America to spread awareness and information

Our " Health related financial assistance " now covers admission to floatation tanks. Information on eligibility to our assistance program is available in the office.

For members having to stay in the hospital, we are trying to make it easier for you to use our financial assistance to cover t.v. rental. What you have to do is : Have your T.V. connected, having it billed to the PWA Coalition (giving your membership #) the Coalition will be billed monthly, and you will fill out a financial assistance request form. The cost of the T.V. will be deducted from the \$200.00 eligible to you through this program.

The Coalition wishes to express special thanks to " Plantarium ", on Homer Street, for offereing to do plant service free at the I.D.C. (the clinic at St. Paul's). The Coalition has provided the plants, following the offer.

We do appreciate and invite more contributions from private businesses. So, get in touch with us if you have a good idea.

FINANCE

An anonymous donation of a computer/printer system as been received by the Coalitior in loving memory of John Gerard Bonia. Our mailing list, which exceeds 450, is now computurized (as you may have noticed by this months Newsletter labels), and it's exciting to leard the system, and all the useful tasks that it will perform for us. Thanks to Marty and Justis for their time at the keyboard. Although Kevin Brown is in the hospital for the zillionth time, we called him up so he could hear the letter quality printer zip out those labels. Get well soon, Kevin, so we can teach you how to bang out your letters on this new system.

Thank you donor, for a machine which is constantly in use.

Operational Funds : We have received bridging funds from the Health Promotion Directorate to carry us through July. The Mayor's Task Force on AIDS has made it's recommendations, which include financial support for community based agencies, such as PWA and AIDS Vancouver. The Health Promotion Directorate and the City of Vancouver have in hand our requests for operational funds.

COMMITTEE REPORTS : continued

We look forward to secure core funding to allow us to hire a daily operations manager, and to make our building wheelchair accessible, (or move to a building that has an elevator). We find a steady rise in demand for support services, peer counselling, and information on treatment. With several thousand Vancouverites testing positive for HIV, we know there is a place for community based organizations for years to come. At present we attract an average of 110 person hours per week of volunteer labor. This is all supplied by people with AIDS/ARC.

We welcome newcomers and provide a place for people with the disease to make a positive contribution in the struggle to live longer. The message is one of hope when your life is threatened, and help when you are in despair. Stick together and fight like hell for the right to new treatments that can pro long our lives, and fight for the right to work and live in the community just like anyone else.

UPDATES : UPDATES : UPDATES : UPDATES : UPDATES : submitted by Chuck P.

PHONES : We continue our efforts to get phones installed in the single rooms at St. Paul's, on wards 7A/7B/8A/8B. Cellular phones have been investigated, but they are far too expensive. We also tried a new cordless phone, and depending upon the amount of interference at the particular time, a single cordless unit will suffice for up to three rooms. Although far from ideal, this may be our best solution for the time being.

Unfortunately, we have not yet received approval from the administration at St. Paul's to get the necessary phone lines installed. At present, St. Paul's prohibits phones in private rooms, except when the patient is from out of town, suffers a terminal illness, and his/her family agrees to pay the installation costs plus disconnect the phone when he vacates the room. We are hopeful that St. Paul's will make an exception for us, by allowing us to install several phone outlets, from which we can use cordless phones. We expect a decision any day now, so keep your fingers crossed.

T- CELL : At present the B.C. Medical Services Plan does not cover T- helper tests, and St. Paul's refuses to foot the bill for such tests after a patient starts on AZT. For those of us who want to use " Immune Modulators ", or " Boosters ", - for example Isoprinosene (which is available in Canada) - this situation is intolerable. How can you evaluate the effectiveness of modulators if you cannot get the necessary tests done? We have been pressuring our doctors and St. Paul's on this, and they have finally decided to support us. An application to extend Medical Plan Coverage to these tests is presently before the provincial Ministry of Health. A decision is expected shortly.

DRUGS : **DEXTRAN SULFATE** : This is one of the most promising AIDS treatments. Recent studies have shown that (in the test tube), it works as well as AZT against the AIDS virus. It appears to be relatively non-toxic and harmless, and has been available across the counter in Japan for 20 years. Researchers yet aren't certain yet about the mechanism of it's antiviral action, but there

UPDATES : UPDATES : UPDATES : UPDATES : continued

DRUGS : DEXTRAN SULFATE :... are indications that it may inhibit reverse transcriptase. This possibility is currently being conducted at San Francisco General Hospital.

We contacted George Usher, the president of Dextran Products Ltd., in Toronto. FDA Canada recently rejected his company's application to market Dextran Sulfate as a food. The Feds insist that the Canadian Manufacturers conduct multi center clinical trials before marketing their product in Canada. Mr. Usher is presently working in this direction, but the costs, and the length of time involved (several years) make it difficult for a small company such as his. In any event, he likes the idea of our Coalition members participating in such a trial, and he will keep us updated.

We also contacted the Alliance Buyers Club in San Diego. They have a set up where by they buy the Toronto Company's Dextran Sulfate, but delivery is made to Mexico (everything is available there!). They bring it back across the border to San Diego, from which we would obtain it. Their problem is that, so far, it is only available in powdered form. They have not perfected the art of coating it enterically and in precise dosages, - but they are close to success, and will keep up updated.

Next, we called the Drug Inspection Division of Customs Canada. So far as importation goes, Dextran Sulfate has " no status ", which means we are not prohibited from importing it for personal use. Any Canadian can have up to a six month supply mailed to him/her from outside Canada, so long as it is intended solely for personal use.

Summary : Dextran Sulfate is manufactured in Canada, but it is unlawful to buy it, or sell it for human consumption in Canada - but, it is lawful to possess or consume it in Canada. Got that? The result is, that if we want to get ahold of this Canadian product, it must first be shipped to another country, where we must buy it and then ship it back to Canada...

Round and round federal red tape goes, and where it stops, nobody knows!

NEWSLETTER : NEWSLETTER : NEWSLETTER : NEWSLETTER :

The production and distribution of the Newsletter occurs during the last week of each month, with story submission deadline being the 20th of the month. Volunteers are encouraged to come forth and assist with the writing, typing, collating and mailing of our paper, that is a truly valued aspect of the Coalition's work, and editor Nicholas Gray appreciates all assistance in getting it done and getting it out. So, if you feel you have something you want in the paper, or just want to help, contact Nicholas through the Coalition office at 683-3381.

DAY TRIP TO HARRISON HOT SPRINGS :

Sign up now for our one day trip to Harrison Hot Springs, on Sunday, June 12th, 1988. There is no limit (yet) on the number of people we can take there. The Coalition will arrange a car pool, so if you have a car, and can take passengers, give us a call! We will leave Vancouver early morning, as it is a two hour drive. In Harrison we are planning a Barbecue (tentatively in Sasquatch Provincial Park). We also would like to arrange canoe and rowboat rentals for the day. There is a mineral pool open all day, a few kilometres away in Harrison itself, so bring your bathing suit! We will return to Vancouver early evening.

This event is coming up very soon, so please call us so we can arrange cars and food.

The program committee welcomes your suggestions for future one day trips.

RETREAT :

From July 18th to the 21st, The Vancouver Persons with AIDS Coalition will hold its fourth retreat for PWA members. This time it will be a Manning Park Lodge, about a three hour drive from Vancouver (2 hours if Benoit is driving!), in Manning Provincial Park.

There we will stay in a secluded fourteen bedroom lodge, (all to ourselves), with all meals catered by the lodge. Activities include horseback riding, canoes, a barbeque, hiking, volleyball, and lots more. Because the house " only " has fourteen bedrooms, some of us will have to share rooms, but there will be plenty of space to get away from everyone if that is what you want. So, stop by the office, check out the photos of the lodge, and sign up!

THIRD ANNUAL WALKATHON :

The PWA Coalition is holding it's third annual Walkathon on SUNDAY, JUNE 26th, 1988. Svend Robinson MP, will join us for the 10K walk around the Seawall.

Registration will begin at 10:30 am in front of the English Bay Bath House. The walk will begin at 11:00 am, moving clockwise around Stanley Park, finishing up in Devonian Park. This 10K walk is designed to raise money by having as many friends as you can sponsor you per Km. BEG them if you have to!

Please call the PWA Coalition office at 683-3381 for pledge sheets and advance registration. SO, LETS ALL GET OUT THERE, GET THOSE PLEDGES AND SHOW OUR STUFF !

AUTHOR OF " LIVING WITH AIDS " LECTURES :

Tom O'connor, author of " Living with AIDS ", will be giving a lecture sponsored by the Vancouver Persons with AIDS Coalition. The book is currently available at Little Sisters, or on loan from our library. The lecture will be held at GORDON HOUSE, 1019 BROUGHTON AVE, WEDNESDAY, JUNE 8th, from 7:00pm to 9:00 pm. Donations will be accepted but this is optional.

ONGOING EVENTS : Weekly Activities

SUNDAY : HEALING CIRCLE :

Every Sunday evening at 7:30 pm, in Room 113 (Main Floor) of the Comox Building at St. Paul's Hospital, 1056 Comox.

Lead by a Coalition member, this one hour comprises two visualisations, and hands on therapy.. This is an excellent opportunity relaxation, healing, and getting centered.

MONDAY : BOARD OF DIRECTORS MEETING :

Monday mornings at 11:30 am at the Coalition office, 1170 Bute Street.

Open to all members interested. This is your opportunity to stay abreast of Coalition activities, and have a voice in our future. The four standing committees , (Advocacy, Finance, Personel, and Programme) are always open to new volunteers, and welcome your participation.

TUESDAY : " LIVING IN THE MOMENT " MEDITATION CLASS :

Tuesday afternoon from 2:00 to 4:00, this class is open to PWA/PWARC's, sero-positives, friends and supporters. Insight meditation teaches us to be mindful and present in every circumstance in our lives, and helps us to develop equanimity and calm. Time is spent at the beginning of each class exploring issues particular to AIDS.

For firthur informnation and location, please contact Kristin at 872-0431

: SUPPORT MEETINGS :

Every Tuesday evening from 7:30 to 8:30 pm at the Coalition office, at 1170 Bute Street.

These meetings are open to PWA/PWARC's only. Discussions surround concerns held by the group at the time of the meeting. There are no specific topics, just a chance to talk in a comfortable, supportive atmosphere.

WEDNESDAY : DROP IN CENTER :

In addition to being open from 1:00 to 5:00 weekdays, the Drop-In Center is now open Wednesday evenings from 7:00 to 9:00, at the Coalition Office, at 1170 Bute Street.

There is no meeting as such, just an opportunity to meet other PWA/PWARC's have a cup of coffee and check out the library. So if you can't stop by during the day, make sure you stop by on Wednesday night. See you here!

ONGOING EVENTS : Weekly Activities : continued

THURSDAY : TAI CHI CLASS :

Thursday evenings from 7:30 to 8:30. Contact office for location. (683-3381)
Open to Coalition members and friends.

Tai Chi is an ancient chinese technique of " meditation in motion ". It is a gentle exercise that helps balance the energy through the body.

: "GET OVER IT " Alcholics Anonymous Meetins :

Thursday evenings at 7:00 pm in the Coalition Drop-In Center, 1170 Bute St.

These meetings are open to all - HIV positive, PWA/PWarc's, friends,lovers and supporters.

MONTHLY MEMBERS MEETING :

Monday, June 6th, 1988 at 11:30 am, at the Coalition Drop-In Center.

All members are invited to attend. Chairpersons from the four committees will give an update of activities and answer questions regarding various projects and programs. Members are invited to give their input on current issues being dealt with. We see the monthly members meetings as an occasion for members to get information and voice their suggestions on Coalition projects, activities and services.

ANNOUNCEMENTS / PERSONALS :

HAIRCUTS : Haircuts available at my home for members of the Coalition for the low price of \$6.00 Call Terry at 687-6551 for a relaxing haircut, coffee, and pleasant conversation. Available evenings and a couple afternoons.

REIKI : A gentle yet powerful healing art which is excellent in the management of fear, pain, and stress in general. This is offered to Coalition members free of charge. Please leave a message with Jackie (683-3381).

RIBAVIRIN : For information and possible obtainment of Ribavirin (anti-viral)
Contact Chuck (681-8362)

PWarc wishes to buy tent for political action ie: camping out on legislature lawn.
contact John K. through the office. (683-3381)

PWarc has copper enamelling kiln, enarnels and copper for sale. Contact John K.
through the office. (683-3381)

HEALING : Healing sessions done privately in a relaxing, peaceful environment. Just sit in a chair and relax, and be charged with soothing energy. If needed, hospital and house calls can be arranged. This is a volunteer service to PWA/PWarc's.

For more information, please Jackie at the office (683-3381)