



Issue # 11, August 1987

Newsletter

THE VANCOUVER PERSONS WITH AIDS COALITION

WHO, WHY, AND WHAT WE ARE

by Kevin Brown and Nicholas Gray.

Is your awareness of the Vancouver Persons with AIDS Coalition limited to those moments when you find yourself at yet another fundraiser? As you're digging into your pocket, do you ever ask yourself just what happens to the money? All around a community is responding to a call, but just what is it that they help us do?

We are a Coalition of Persons with AIDS or ARC who have come together to find alternative ways of dealing with our dis-ease. About 1 1/2 years ago, the Coalition grew out of the weekly support meetings the PWA/PWARC's held for themselves. It was felt not enough was being done, and we knew that control had to come back to us, if we were to see positive changes in our lives. Taking back the POWER became one of the key principles of the Coalition.

Loosely based on a Woman's Health Collective, all members have the opportunity to participate in, and be directly involved in the Coalition's operation. This concept works well with PWA/PWARC's where circumstances of the dis-ease may remove some, but never all members of the collective. While presently we are predominantly homosexual, we do not perceive ourselves as a "gay" organization. A person's sexuality should never enter into their fight for survival, and we must remain a safe place for anyone who may find themselves so diagnosed to come.

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HOT HEAVENLY BODIES ————— TICKETS ON SALE NOW! ————— \$10.00 ADVANCE!

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WHAT THE COALITION IS : continued from page one ;

Often there has been confusion about the relationship between the Coalition and AIDS Vancouver. While we are two distinct entities, we share similar goals and objectives. We have an excellent working relationship and compliment each other in dealing with the AIDS crisis in the province. AIDS Vancouver is primarily a service provider : educating the public, offering support services - phone lines, Buddies, home care, financial and emotional support. The Coalition is a group of PWA/PWARC's working together to help ourselves. As a collective it is never them and us. It is just US!

In the early days, we put a face to the dis-ease, allowing the community to see that we were people, not statistics. We showed that there was quality and dignity to our lives, and as our pamphlet states, there is " Life after Diagnosis ". By forming a collective, we are stronger, and can accomplish that which an individual can not. Together we are a lobbying force, pressing the issues of experimental anti-viral drugs, (such as AZT), and the building of a viral testing laboratory. While not the primary function of the Coalition, lobbying continues with anti-discrimination legislation, creation of a hospice, and fighting ill placed concepts such as quarantine.

The Coalition has two main sources of funding. A grant of \$27,000.00 comes from the Federal Health Promotions Directorate. These monies go to rent, furniture, hydro, phone, postage, salary of one employee, and travel expenses to and from conferences. Under no circumstances can these monies be used to fund alternate therapies. These monies come from the community. Through fundraising events and private donation, we are able to provide monies to actively help those dealing with AIDS or ARC. We sponsor workshops, have support groups and healing circles, circulate this newsletter, as well as subscribe to various source papers that provide AIDS information. We also maintain a library and drop in center, provide a speakers bureau, and are members of the Canadian AIDS Society, and associate members of the USA based National Assoc. of People with AIDS. We respond to the media, and lobby when we have to. We explore, and offer financial assistance in the exploration of alternate therapies. The Coalition and the community work hard raising funds so we can explore our options without going broke. If there is a therapy that you believe you will benefit from, but it is not covered by insurance, talk to us. In the past we have paid for massages, counselling, vitamins, workshops, books, tapes, food supplements, and offered retreats. We are open to what ever you think will improve the quality of your life. Right now we have the money, but YOU have to ask for it.

Asking for assistance holds no obligation. It is not necessary to get involved with the Coalition to receive help. For some, working with the Coalition is part of their therapy. And being involved doesn't mean you have to work in the office, face the media, or socialize. It can be as simple as reading this newsletter. It can be asking for, and accepting help. We are people working with and for each other. In any group so structured, there will always be those that get involved, and those that stand back. Either position is fine, as long as you know the Coalition is there, and willing to help.

HOW DO I ASK FOR ASSISTANCE?

Coming into the office, and reaching out that first time is always difficult. There is no "Emily Post's Guide to AIDS Etiquette", but know that we have all gone through it. You will find that we are a friendly group sharing a similar diagnosis, supporting each other with positive attitudes and energy. Asking for funds is simple. We have a standard funding request form in the office. If you can't make it in, call us, and we'll put one in the mail. Names and details are confidential, known only to the project co-ordinator. Requests are approved at the Monday morning business meetings, and monies are distributed as available. Our only request is that you fill out an evaluation of your therapy, so that we can share the information.

ADJUSTMENTS IN POLICY :

The July 6th Business Meeting brought forth the following refinements to Coalition Policy :

ALTERNATIVE THERAPY FUNDING : maximum request remains \$200.00 per month. Yearly total should not exceed \$1000.00. Exceptions to this must be presented at the business meeting, and will be considered on an individual basis.

OFFICE VOLUNTEER ORIENTATION : The following orientation of the Coalition is now required before working as an office volunteer; attend one open and one closed support meeting, one business meeting, and one afternoon in the office with a trained volunteer.

PUBLIC SPEAKING VOLUNTEER ORIENTATION : Before representing the Coalition at a speaking engagement, one must complete the Office Volunteer Orientation, and accompany a speaker to at least one engagement. Speakers representing the Coalition will be placed at the discretion of the Project Co-ordinator.

WORKSHOP WITH LINDA GALLOWAY :

On July 9th, ten people participated in the Coalition sponsored workshop with therapist Linda Galloway. While the all day intensive hovered around primarily AIDS related concerns, it was not limited by them. Linda's workroom quickly became a safe place where we could share our feeling, react, and grow. While one is not scheduled at this time, it is the Coalition's intention to hold another workshop with Linda at a future date

DON'T FORGET TO COLLECT YOUR WALK - A - THON PLEDGES !

On July 7th, changes to the Health Act were introduced to the legislature that would enable Medical Health officers to deem our sexual practices unsafe, order us to stop, and if disobeyed, could order the PWA into " isolation, modified isolation, or complete quarantine, such quarantine to last no longer than one year. " Reaction from local PWA's (this one included) was uniformly in opposition. Within hours of the early morning announcement, those on the front lines could be seen and heard responding to all media.

While Health Minister Peter Dueck said the bill does not mention AIDS specifically, it would be one of the first diseases put on a list to be covered by these new rules. Abuse, he assured us, would be controlled by the use of the courts as an enforcement agency. A glance at the current governments record with AIDS related concerns does not make me feel secure. This little " re-wording " of the Health Act may be where it starts, but hwere will it lead us? Have we so easily forgotten the tragic consequences of the Japanese? Or the Jews? We cannot permit powers like that to be had by any agency of the government. Today it is just a threat, and that is where it must stop.

Irregardless of the long ranging implications of this misplacement of power, my concerns are of the immediate consequences. How does this affect the actual health of the Person with AIDS/ARC? What will this threat do to the state of mind of the person in the midst of handling this dis-ease? Losing control over ones life is a very real concern. Those of us that have come to deal with AIDS - from testing positive to serious illness - do not need to know that Big Brother can come in and make sweeping decisions about our lives. The emotional toll of this threat will damage our spirit, our self-worth...the most important element in our recovery. At the low point in my own illness, if this had hung over me, I don't know that I would've found my way to wellness. If the illness had occurred in quaratine, without the support and love of the community, family and friends, I don't know that I would've bothered getting well.

And what of the undiagnosed masses? Is this designed to make them feel safe? That the crisis has been handled? Will they continue to get tested? Or treated? Should this dis-ease move underground, it will be detrimental to us all. Lack of awariness will allow it to spread easier. Without accurate information, how is the medical community expected to diagnose, treat, or educate us? And education is crucial. Control of this dis-ease is not going to come from frightening people into compliance. A person with AIDS/ARC, or testing positive must know that being honest, seeking treatment, and providing information to the care givers, will not lose control of their life to a government agency. We, as PWA/PWARC's must demand the opportunity to be responsible adults. In any encounter each person has the opportunity to protect them selves, only we must know how. Responding as though AIDS were a cancer that we can cut from the fabric of society is not going to resolve the issue. Facing it, Talking about it, teaching what we know will lead us to the answer. To the more Victorian, that may seem wrong, but it will save lives. I wish no one had to deal with AIDS, but we do. As a community, as a people. But we must do it with awareness, not ignorance.

VANCOUVER TO HOST THE THIRD CANADIAN AIDS CONFERENCE

The Third Canadian AIDS conference will be held in Vancouver from February 18-21 of 1988. The Vancouver Persons with AIDS Coalition and AIDS Vancouver will co-host this coming together of people from across Canada, the USA, and the world. Being one of the earliest communities to feel the impact, and respond to the threat, Vancouver is one of the best organized cities in the world. This will be an invaluable opportunity to learn, grow and share information, experiences and expertise. Held on the UBC campus, the theme of the conference will be " AIDS : Today and Tomorrow ".

Currently, a steering committee is being formed to co-ordinate the conference, and various work groups will focus on specific elements , such as : registration, billeting, agenda, publicity, site hospitality and transportation, etc. There is always a lot of work to be done in preparing a project of this size and scope, so be assured that everything you can do to help will be greatly appreciated. For more information about how to come involved, please call Ken Mann at AIDS Vancouver (687 - 2437) or Sharon Holtzberg at the PWA Coalition office, (683 - 3381).

THE 1987 GAY PRIDE PARADE

Although the PWA Coalition exists to reach out to all Persons with AIDS/AAC, often we are dismissed as a " gay " organization. Labels or not, the gay community has been the hardest hit, and has responded with the strongest support. It is with Pride that we show our support and join in this years Gay Pride Parade on August 3rd. The Parade route will follow Beach Ave from Stanley Park to Rainbow Park, with entertainment to follow.

H O T h e a v e n l y B O D I E S

The PWA Coalition's fundraising event of THE year will happen Saturday, August 8th, at the COMMODORE BALLROOM. Doors will open at 8 : 00 pm, and entertainment hosted by the legendary Billie Monroe will be at 9 : 00 and 11 : 00. Dance the summer night away on their spring mounted dance floor, and help us continue our work! Advance tickets available for \$10.00 the PWA Coalition office, Little Sister's Bookstore, and

The Castle Pub. Tickets will be available at the door for \$12.00. For further information call 683 - 3381, or stop by the Coalition office at 1170 Bute. We look forward to sharing one HOT and HEAVENLY evening with you all !

CREATING A VANCOUVER AIDS/ARC RESOURCE BOOK : by Nicholas Gray

How to best cope with AIDS/ARC in Vancouver raises alot of questions. Questions not always easily answered. I know when I was first diagnosed, I hoped to find one source of information that could help me, but none existed. Working together, we can change that.

To this end, a committee has been formed to compile a Resource Book for the newly diagnosed. Modeled on " Striving and Thriving with AIDS " put out by the New York Coalition, (copies available in the office), the intent with ours will be coping with the dis-ease in British Columbia. Areas to be covered run the gamut from emotional, sexual and spiritual responses, to the medical, legal and financial questions. Anyone interested in sharing their dealings with this dis-ease are invited to write about it, or if you have any information regarding a service or benefit available to the PWA/PWARC, let us know.

Not all of us feel we can write, but have pertinent thoughts to share. To include as many of us as possible, I am looking to get together with those of us willing to be taped in a free associative discussion about the dis-ease. Information taken from this session would be used in the book. The discussion would follow a variety of aspects of the dis-ease, such as : telling family and friends, emotional responses, sexuality, dealing with doctors and hospitals, drugs and side effects, spirituality, dealing with death and the business of dying...and living...things that eventually will come up for all of us. Sharing our thoughts will make it easier for others to find their own, personal way of coping. This will be a valuable resource for the Coalition to offer.

If you are interested, check out the New York Coalition's book, and talk to us. See where you might fit, and we welcome the input. More information is available through Kevin, Benoit, or Nicholas at the Coalition office.

A COUPLE PERSONAL NOTES.....

PWA looking for a tennis companion. I am not a professional, and it is mainly for the exercise and the fun of it! Skills are unimportant. If interested please contact with name, phone number and the best time to call. Respond to : P.O.Box 136, 1215 Davie Vancouver, B.C. V6E - 1N4, " Drawer E "

I'm " Singing for Health ", and it's working! Now I need some MUSIC! Looking for a pianist who will work with me to develop a small cabaret type act. I've got energy and ideas, but little cash. If interested contact Nicholas at the Coalition office - 683 - 3381

HOT HEAVENLY BODIES hot heavenly bodies HOT HEAVENLY BODIES hot heavenly
8 : 00 PM AUGUST 8TH, THE COMMODORE BALLROOM. TICKETS ON SALE NOW!

GALIANO RETREAT

May 1-3 : Eight treatments, and things were going great! This weekend nine of us went on a three day retreat to Galiano Island for some rest and relaxation. Had a good trip down, and a nice little ferry ride, but it was my first trip away from the nest, doctors and the hospital since I started treated, and I guess I was just too wound up. I suffered my first severe reaction , and was I scared to death! I lost all feeling/sensation in my knee joints, ankles and wrists. I felt helpless for hours. At 4:00 am Saturday I decided I had to determine if I could force myself out of bed and take a few steps. It took ½ an hour of determination, but I did it. I made my few steps! Greatly relieved, I didn't push the situation. I took it easy for the rest of the weekend. Just rested and slept. The other guys were great. They kept a watch over me, and that was very comforting. Thanks guys!

Upon my return, I headed over to the family physician to discuss the reaction/side effects. After discussions with my onocologist, it was decided I had reached my maximum tolerance for one drug in particular, so we dropped it from my treatment program. Feelings had left my fingertips, wrists and lower arms, and that left me depressed. Tears flowed for no reason, except perhaps the feeling of lack of control. Now that it is over, I feel much better and higher spirited.

Treatment Nine found me real tired of this stuff. My energy is down, and I tire quickly. Still, no problem with weight loss or nausea, and I decided to even out the hair loss....I shaved my head. Doesn't look all that horrible, either!

My tenth treatment starts this week, and I start coming off some of the drugs. At this moment I don't know that I could recommend this type of treatment to others. In my own situation, I felt I really didn't have any choice. It's tiring, and there are times when you feel you are going through hell, and others when you don't feel too bad. When it is all done I intend on following up with Natureopathic medicine, as an alternative to clinical methods. I think they have some good points to offer : proper diet, herbs, cleaning out the system and nourishing the body with proper vitamins and minerals, and other formulas for boosting the immune system. It just seems to me that clinical methods/doctors use drugs and poisons to kill, where Natureopathic physician will use any alternative he/she can to cure symptoms. To me, this is a much brighter, pleasing approach to getting well again, and healing ones self.

Glen Gilmore

BABA TAAVI'S SPIRITUAL CORNER :

Spiritual Exercise of the day ;

Lift up thine eyes, unto the hills. Now lift down again. Repeat until eyeballs get tired.

Baba Taavi

ONGOING EVENTS

Sunday Nights : Healing Circle :

The Healing Circle has been cancelled for the duration of the summer. Watch for it's return in the September Newsletter.

Monday : Business Meeting : 11:30 am :

Open to PWA's and PWARC's . This is the best way to share the responsibility and decisions in the Coalition. Meetings are held at the Coalition office, 1170 Bute St.

Tuesday : Self - Support Group : 7 : 30 to 8 : 30 pm. :

Open to PWA's and PWARC's only. Focus is on emotional reactions to specific topics.

August 4 : Use of free time after leaving work.

August 18 : Work : do we stay or quit?

Tuesday : Holistic Therapy : 7 : 30 to 8 : 30 pm. :

Open to everyone. These meetings explore a holistic approach to health.

August 11 : Rusty Sage will speak on Homeopathy and it's role in stimulating the immune system.

August 25 : Sheila Elliot will speak about Oyurvedic Medicine, and vitamins.

Tuesday night meetings are held at St. Paul's Hospital, Comox Building - 1056 Comox, Room LM-5, in the basement. Groups meet from 7 : 30 to 8 : 30 pm.

Holistic Committee :

The next meeting of the Holistic Committee will be held on Tuesday, August 4th, at 10 : 00 am. Phone the office for details and location.

LATE BREAKING NEWS ON AZT :

On July 23rd, a meeting was held between the Vancouver Person's with AIDS Coalition, AIDS Vancouver, and Burroughs Wellcome, manufacturers of the drug AZT, (Retrovir). One of the outcomes of this meeting was that restrictions on the drug are loosening. Anyone, from sero - positive to AIDS (PCP and some KS) can receive the drug, upon approval for use by their doctor.

For more information, contact Sharon at the Coalition office : 683 - 3381.