

Newsletter



"One Starry Night"

It was a magical evening on November 9th, when many of Vancouver's finest entertainers performed at the Arts Club Theatre in a benefit to assist the Persons With AIDS Coalition.

This incredibly successful event was filled with electrifying energy by both the performers as well as the audience. After three hours of fabulous entertainment and raffles there was thunderous applause from the audience when it was announced that \$8,000.00 was raised that evening. This was the most money ever raised for the Coalition at one time.

Many thanks go to the community for their strong sense of support, caring and love.

AIDS Vancouver extends an invitation to PWA's wishing to attend a newly formed therapy group. This weekly drop-in meeting, facilitated by a psychologist is available commencing Thursday, December 11th. It will be held from 3 till 5pm at St. Andrew's Westley Church, 1020 Nelson St. (entrance on Nelson). The group will continue for an eight week trial period on the following dates: Thursday's, December 11th. and 18th. Monday's, December 22nd. and 29th. (due to holidays) Thursday's, January 5th. through till January 29th. For further information contact Michael Walsh at AIDS Vancouver: 687-2137.

Well, maybe our outrage, expressed to the provincial government, over their rejection of the AIDS Vancouver hospice proposal, is having some benefit. The government seems willing to talk about and even fund a hospice program in Vancouver now. We have been invited to attend a meeting on Dec. 10/86 with Joyce McKay, director of Continuing Care in B.C., to discuss the details of the new hospice. If all goes well we could have the very first government owned and operated hospice program in Canada for persons with AIDS! We will keep you posted.

The Toronto Star Nov. 16/86

Don't pity us, patients tell AIDS conference

By Lillian Newbery Toronto Star

Seven men with AIDS told a crowd of 300 this weekend how they live with the disease and asked the public to treat them as people first.

They want to be known as "persons with AIDS" or PWAs — not "AIDS victims" or "AIDS patients."

They don't want to be pitied. Although some have made funeral arrangements, they want to concentrate on living.

The men spoke to a conference at the University of Toronto sponsored by the Canadian AIDS Society, an alliance of 20 community committees, hosted by the AIDS Committee of Toronto. About 300 delegates from across Canada are attending, including committee volunteers, health-care workers, representatives of religious and educational groups, government officials and people with AIDS (acquired immune deficiency syndrome).

The disease, which harms the body's natural disease-fighting system, is nearly always fatal. Neither cause nor cure has been found.

Kevin Brown of Vancouver said people with AIDS have formed coalitions in Toronto and Vancouver to try to "take control, to try to be in charge" of their lives.

The men's experience with the virally spread illness varies.

James St. James, 32, who's had AIDS for three years, has been in hospital 17 times, but resumed his acting career and will open in a new play in January.

To the Toronto actor, affectionate friends and a "family" of

'We have right to live and die with dignity and compassion'

health-care workers at St. Michael's Hospital are important.

Taave Lind, diagnosed two years ago yesterday, has never been hospitalized. For him, spirituality is the key element of life.

Although he tried to live a spiritual life before, after diagnosis he had to "wrestle with my faith, get in touch with a higher power."

Spirituality "isn't something people with AIDS talk about," he said, but "when else are you going to talk about it? Pretty soon it will be too late."

"Humor is probably my best way of coping," said another Toronto man, who asked to be identified only as Jim.

Pity worst

Some people tend to overcompensate and "practically fawn over" a person with AIDS, he said. "The smiles ooze out. It's irksome because it's patronizing."

Instead of asking a person with AIDS what you can do for him, make some concrete suggestion, he advised. "If you are close to a person with AIDS, a simple suggestion that thoughts or prayers are with them creates a strong mental cushion."

And he advised: "Don't pity. Pity is the worst thing in any illness."

"Let PWAs take some authority and strength," said St. James. "If it's not necessary to get that glass of water, let him do it. It gives him a sense of accomplishment."

One young man with AIDS, who said he's "the only one around" in Edmonton right now because "everybody else has died," said his greatest loss has been the loss of the future. "How long does it take before your future comes back?"

That depends on the individual, Jim said, but first you make plans for one day, then for a week, then for six months hence.

Chris Natge of Toronto cited the support of his sister and friends for helping him through pneumonia, although once his symptoms disappeared it was easier for them to deny his diagnosis.

Brown praised Vancouver doctors ("They cry every time one of us is lost") and AIDS organizations ("It's very touching people care about us that much").

Linda Boyd, of the AIDS Committee of Toronto, who ran the meeting, asked the men to identify "good stuff" that has happened since their diagnoses.

"The advantage is life has become so precious each day. Flowers are better, friends are

closer, the air smells better," said St. James.

He's been able to separate "friends who really love me from the ones who were there for the goodtime Charlie" and his relationships have an added, deeper quality.

Lind said people often wonder how they would stand up in a crisis. "I realize I'm coming through with flying colors... I have made this a learning experience, because what else am I going to do with it?"

Cried all day

Brown, who was diagnosed with AIDS June 5, 1985 ("You remember the day, sort of like your birthday"), says he spent the day crying and then decided he had nothing to be ashamed of and began reading all he could about the illness.

"I chose to put control into my life," he said. "We have the right to live and die with dignity and compassion. I learned to respect my body. I met fabulous people and found inner strength."

"If I do at some point die, I know I've lived a more quality life because of this."

Brown said he spent "a year feeling I was a regular typhoid Mary and my touch would kill," but on a visit to San Francisco last summer, he met a man who was willing to sleep with him if they were careful. Then he realized "I'm not a leper in the 1980s; people can touch me."

"We're really not dangerous. We still have hearts. We still fall in love, we need companionship." Jensen cautioned that safe sex,

which includes using condoms, is in the best interests of the person with AIDS, who is at risk from any infectious disease.

Telling people you have AIDS "is like coming out of the closet (revealing homosexuality) all over again" with the same fear of abandonment and hate, Jensen said.

"Personally, I don't get too caught up in the melodrama of it," he added, but some people "want to see you wallowing in self-pity and all the rest."

Before he got AIDS, Jim said, a major crisis in his life was "running out of mouse before a dinner party."

After diagnosis, he feared treatments, wondered whether a cough meant a developing infection, fussed over whether he would regain the pounds he shed. "I began to realize how strong fear can be," but decided the easiest way to cope is to "realize I'm not dead."

"I don't see how people can cope without friends."

Neil Douglas said he's had a full life and isn't afraid of dying, except for the effect on his family and friends.

Lind said he isn't afraid of death. "I used to work as a nursing orderly and wrapped up a lot of bodies."

"It isn't death so much as the fact of dying. For someone who used to be quite suicidal, getting the news of my diagnosis was not a thrill. Gay men used to have this romantic thing about dying."

"One of the nicest things is I know when I die I will be surrounded by people who love me."

The Toronto Sun Nov. 16/86

AIDS: When the tears dry

By LINDA BARNARD Staff Writer

Seven men suffering from AIDS received a standing ovation yesterday at the Canadian AIDS Conference in Toronto after they candidly discussed how they coped with the deadly illness.

Whether the crowd stood out of respect, compassion or sheer admiration wasn't clear. But certainly, no one was unmoved by their honesty.

"I spent the first day crying," said Kevin, 37, of the day he was diagnosed in Vancouver 17 months ago. "But then I found out crying was boring. So I quit."

James, a Toronto actor, said he was "on top of the world" just before he was

diagnosed. After 10 years of work, an acting award had brought five job offers. But he was too ill to work.

He said he was diagnosed three years ago and believes he has lived longer than any other Canadian with AIDS.

"Unfortunately as this disease is, and as terrifying, I've tried to find an advantage," James said. "Life has become so precious. Each day, the flowers become more special, friends become more special. The air smells better — even in Toronto."

The poignant talk from the panel about their lives extended into the audience of 250, including a young man from Edmon-

VICTIMS SPEAK UP

ton who said he was the only one with AIDS left living in that city.

"I seem to be the only one right now, everyone else has died," he said softly. "What I wanted to know is, how long before your future comes back to you, if at all?"

Taavi, a Vancouver man diagnosed 2 1/2 years ago, said many people with AIDS turn to spiritual comforts.

And the biggest hurdle isn't death, he said. "I've seen enough people die."

"I'm not afraid of death," added Neil,

another victim. "I'm upset about it because of my family, but I've had a very interesting life. I'm not afraid of death now that it is in front of me."

Some of the panel members said they were still intimate with lovers and felt the closeness helped them.

"I went for a year thinking I was Typhoid Mary, my touch would kill," said Kevin. "This disease is only transmittable in certain ways, and if you're careful, why shouldn't you share human intimacy?"

Comments on Conference

The Canadian AIDS Conference, which took place in Toronto on November 14 - 16th, was a time for community organizations, public programs and agencies involved in the fight against AIDS to come together and join forces. This was a very positive time to learn and share information. The message was clear that AIDS can be controlled through sexual behaviour and social understanding. There is no reason for celibacy, a change to heterosexual behaviour or a modified behaviour.

There was a very strong sense that AIDS has affected each and every one of us, giving us a chance to grow, be involved and take a very positive stand. AIDS has put more focus on our lives and made us decide what really is important, so that we can then get rid of the negative in our personal lives. Hopefully this type of continuous channeling can lead to an even greater networking of ideas.

Sharon Holtzberg

I'm glad I had the opportunity to attend this conference. I wanted to make a contribution, and I believe I did, especially at the panel discussion where each of us spoke and then answered questions from the assembled crowd of 250. Many said the panel was the highlight of the conference.

Warren

To be honest, I did not go to the conference with unbounded enthusiasm; a whole weekend spent with concerned, caring people who are also into organizations, seemed too much to take. However, I was persuaded that it was my duty to represent the spiritual and holistic side of our Coalition, (Would I lie to you?) Anyway it was a free trip.

So, naturally, it turned out to be a worthwhile venture after all. The networking was great, with people from all across the country, (Lots of dynamic women involved in AIDS organizations.) Our P.W.A. panel went over very well. And a good time was had by all.

Some minor quibbles, such as the workshops not being able to be in any great depth due to time limitations. I noticed this especially in the one I was involved in, on "Wellness," which covered several alternate therapies very quickly, including a hasty relaxing guided visualization.

But at least alternate therapies were included in the conference. I was hoping to glean more information at the conference about what other areas of the country were doing with alternate therapies; but it seems that we in Vancouver are more active than other groups, (Yes, Virginia, the West Coast is different.) However, one of the participants in the workshop, Ellen Lipsius, has had great success using primarily Macrobiotics, she now has three clients in remission; which means that I'll have to take another look at macrobiotics, (Maybe we can get Doll and Penny's to put brown rice on the menu.)

Probably one of the greatest benefits of the conference is that, due to our participation, the voice of persons with AIDS/ARC will be heard in future issues that involve us.

Aside from the conference, I enjoyed meeting members of the Toronto Coalition, attending the support meeting, and meeting members of AIDS Committee Toronto; I even got ideas for our meetings here. (Incidentally, all the people in both the Coalition and ACT are wonderful warm, loving human beings..... and yes, they do get a copy of this newsletter.)

So there you go; after all my kvetching, I'm glad I went.

Taavi

The National AIDS Conference was a valuable experience for me. The key to its success was the fact that not only did PWA's attend, but that PWA's made a significant contribution to the conference. PWA's played an important role in helping others better understand our illness - we are helping to shape the perceptions surrounding this disease.

I believe that PWA's should be equal partners with our health care workers and with those who provide social services. This conference was a step towards that goal. Margaret Somerville, who teaches ethics and law at McGill University, spoke of a new model for medical practice to follow, 'Therapeutic Alliance' where the patient and the doctor take equal responsibility in finding solutions to problems. This alliance could be extended to include patient and government as well. The result of all this is putting control back into our lives - realizing that we are not helpless and at the mercy of others. To take charge of your life again can also bring fresh hope into it and just maybe we will have a fighting chance to stay alive.

Ongoing Events

An item of interest came after questioning Prof. Allan M. Brandt (of Harvard University) who was the keynote speaker at the conference. It appears that formation of PWA Coalitions in North America, may be a response unique in medical history, by patients attempting to deal with this health crisis. Rarely have patients taken such an active role to help shape their destinies. So we came away with a sense of achievement and a certain sense of pride.

It was interesting meeting with Greg Smith, co-ordinator of the National AIDS Center, again. He was one of our chief protagonists when the Coalition, in its advocacy role lobbied for the release of AZT in Canada. We sat on a panel together to discuss experimental drugs, issues of access and ethnics. Greg and I are like old sparring partners, but we have developed a healthy respect for each other. Getting the government to listen to us and take us seriously is a major step!

Finally, I came away from the conference feeling that Vancouver certainly seems to have its act together - AIDS Vancouver, the AIDS Care team of doctors, the supportive community and the PWA Coalition are leaders in Canada.

Kevin Brown

Open Forum

An open forum will be held to discuss the Canadian AIDS Conference that was held in Toronto from November 14th. through till the 16th. of 1986.

It is open to everyone and will be held in the auditorium at the West End Community Centre from 7:30 till 10:30 pm on December 17, 1986

In Memoriam

We wish to acknowledge the donations that we have received:

In memory of GORDON TURNER from Story Travel and from an anonymous donor.

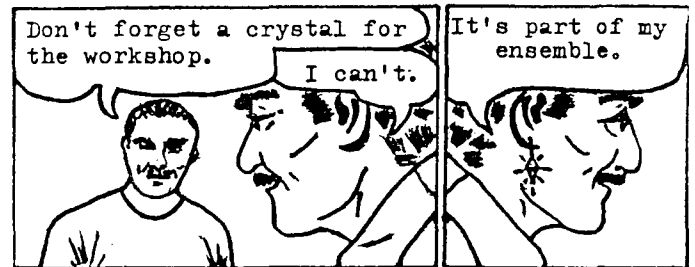
In memory of FRED LYONS from Story Travel.

Sunday nights: Healing Circle. Open to PWA's, PWARC's, friends and supporters. An hour of relaxation, visualization, and sharing of healing energy. It's from 7:30 till 8:30pm at the VGLCC, 1170 Bute St. For details call our office.

Tuesday nights: PWA's & PWARC's meetings. Every other meeting is closed to just PWA's and PWARC's. Other meetings are open to all, and feature guests with backgrounds in alternative therapies. The meeting on December 2nd. is open and will feature Dr. McLeod, who will be informing us about zidovudine (AZT). The following open meeting is on December 16th. and will feature John Matsen, who is a Naturopath. For the immediate future, all of our Tuesday night meetings will be held from 7:30 till 8:30 pm at the VGLCC, 1170 Bute St.

Wednesday and Friday nights: Tai-Chi classes. Learn the ancient chinese "meditation in motion". You may join the class at any time. Open to all, from 7:30 till 9:30pm at the VGLCC, 1170 Bute St. For details call our office.

N.B.: admission is free to all ongoing events.



Services

Legal services: free consultations are available to PWA's and PWARC's. Call our office for details.

Alternative therapies: if you want to see a practitioner, attend a workshop or follow a treatment that you think might help you stay or get well? The Coalition will help you, up to a maximum of \$200. Call for details and let us know in advance.

Resources: the Coalition has audio tapes, video tapes and documents that might help you in coping with your situation, or that might provide you with the information you're looking for about treatments, drugs, diet, alternative therapies etc...
Feel free to ask us.

Home Care Nursing

Nursing care in your home can help you maintain your independence during periods of illness. You can call the Health department yourself or get your doctor or the hospital liaison nurse to call.

A nurse will come to your home to assess your needs. The nurse will coordinate home care for you based on your needs. There is more than medical support. The nurses provide nutritional counselling, financial assistance information as well as emotional support to PWAs, their families and significant others. As your at home needs change, the nurse may call in a home maker to assist with bathing, laundry, shopping, meal preparation, etc. There is a nominal cost for homemaker. The nurse can arrange for an occupational therapist to get you a hand bar or bath stool to make you more comfortable in the bath. The nurse will adjust her visits according to your needs. She may make a phone call or visit more than once a day in order to monitor your case. In consultation with your doctor, she will help you manage your medications. This resource is available to the sick at no charge. The aim is to make it easier for you to manage at home by teaching self care and connecting you with other resources as necessary. Home care nursing can be reached through any BC Health Unit or by speaking to the liaison nurse at your hospital. So, with a little loving care, we can cope at home.

Sleeping Buddies

Excerpt from a letter to Rick

In Louise Hay's workshop, during the six-minute hug, she asked gently: "Is there someone in your life who holds you the way you're held right now?"

It became clear to me that I, we need to create contexts of unconditional love. A week later, the idea emerged from a casual conversation after a Tai Chi class: Sleeping buddies, beyond fears and embracing love. Some nights can be lonely, scary, sad, or peaceful and joyful. We don't have to spend all those moments, all the time alone. Perhaps one way of starting something like this is a "pyjama party" where you could bring your teddy bear and share your favorite fairy tales?

Love Your Life, Heal Yourself

"I do not heal anyone. I teach people to love themselves, and as they learn to love and appreciate who they are, wonderful changes occur for them!"

This is the basic philosophy of the teachings that Louise Hay presented to over 200 people in a weekend workshop held November 15 and 16 in Portland. The workshop was made up of an incredible mixture of mothers, fathers, children, gay men and women, and as one person so beautifully said, of "persons with immune challenges". Several Vancouver people were present and so warmly received in a weekend filled with intense love and emotion, that it was sad to leave our friends in Portland that final day.

The work of Louise Hay is very simple. To some even too simple. But as she says in the beginning of the workshop, she provides a safe and loving environment for all people to come together and grow to love themselves for who they are. One of the exercises was hugging someone for six minutes, another looking into someone's eyes for six minutes as well and holding their hands. Believe me, it's not as easy as one thinks, but the glow one feels inside is great. The workshop was put together by Jim Case and Darrell Dubois (both diagnosed persons) and founders of Life Link, a support and service group dedicated solely to persons living with Aids, and other life threatening illnesses. I applaud these two men for the warmth and generosity they provided and look forward to seeing them both and our other new friends at the Louise Hay workshop taking place in Seattle, January 31 and February 1.

For more information on this workshop as well as materials by Louise Hay, some of which is in our library, call or drop into the Vancouver PWA Coalition office.

And as Louise says: "Love yourself, you're worth it!"

Baba Taavi's Spiritual Corner

Life is a soap opera. But you can always change the channel.

AZT At Last

I'm certain that there are a few out there who have not heard that AZT (Azidothymidine), an anti-viral drug, will soon be available for testing in Vancouver. Hurray!! (at the time of printing the drug was expected to be in the city by Monday Dec. 1/86.)

If you are interested, please talk to your own doctor about going on the protocol or contact Dr. Alistair McLeod (688-1388) who is in charge of the study.

The Canadian protocol does seem to be better than the one being studied in the U.S.A.

The following are some points of interest:

a) Patients with PCP (Pneumocystic carinii pneumonia) qualify for the test even if you have had multiple attacks of P.C.P.! (the studies in the U.S.A. only allow one occurrence of PCP)

Talk to your doctor, they seem open for discussion.

b) You must take initial blood work and urine analysis. (white blood cell count must be over 1000 and hemoglobin count must be over 9) Blood work will follow every week once on AZT.

c) Something to consider - you are not allowed any other drugs (not even an aspirin) for several weeks before taking the drug (a clean out period) and for several weeks after starting AZT. They will slowly re-introduce other drugs if you need them. There do seem to be some exceptions though. Talk to your doctor if this requirement seems a little frightening.

d) They are using smaller dosages of AZT, two 100 mg. capsules every four hours. This may reduce the possibility of adverse side effects but hopefully still provide similar benefits to the U.S.A. study. If severe side effects do result, they will reduce dosages to help you better tolerate.

e) There will be no 'blind test placebo'. If you are on the test, you will get the drug.

f) The protocol may be extended in Jan. or Feb. to include patients with A.R.C. (AIDS Related Complex).

Our congratulations go to the Federal Health Ministry, the Vancouver AIDS Care team of doctors and the PWA Coalition for helping to bring AZT to Canada.


Score one for the good guys!!

Home Care Nursing Study Needs You

The provincial department of Health wants to interview PWAs to better understand our needs should we require home nursing care. The information collected would be used to prepare the nurses in training for the special physical and emotional needs of PWAs. The study will begin in January with an initial interview and follow-up in one month and six months. You can join or quit the study at any time. The department hopes to interview 60 PWAs over the next 18 months. You may choose when and where you wish to be interviewed. You can use a pseudonym if you wish. We have a copy of the study questions at the office if you want to look it over first.

Know Your Rights

This column will explore what benefits PWA's and PWARC's are entitled to.

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Ms. Pat Stephens
B.C. Ferry Corporation
Tsawwassen Terminal
Delta, B.C. V4K 3N2

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