

Valley AIDS

Action

Newsletter of the
Valley AIDS Concern Group

28 Webster Court, Kentville, Nova Scotia B4N 1H2 (902) 679-3515 #2 December 1993



This is the second issue of our newsletter. With this issue we bring news on promising treatments and stories of the courage of people living with AIDS and HIV. Their courage in dealing with AIDS should carry ample warning to those of us who are not infected to follow the simple steps required to avoid exposure to HIV.

We have continued our work - educational, support and lobbying. We also held our first AIDS **WALK** from Wolfville to New Minas on September 25th.

We have also participated in consultations on the development of the newly released Provincial AIDS Strategy - a document that still fails to meet many of the needs of people living with AIDS/HIV and puts Valley residents in the situation of having to travel to Halifax to access the new anonymous HIV testing site being established there. Testing sites in the Valley are still forbidden from offering much needed **anonymous** testing.

Once again we invite your contributions and look forward to exchanging news and views on AIDS in future issues of Valley AIDS Action, dedicated both to AIDS prevention and providing support to those already HIV+. Our goal for all of us is survival!

Treatment Hope

By Gary Kinsman

During AIDS Awareness Week in October I went to Halifax to hear a talk by Dr. Bernard Bihari, a noted New York City AIDS researcher. He has done a great deal of work with Community Research Initiatives and has a large private practice of over 500 people living with AIDS/HIV. The meeting was sponsored by the Nova Scotia Persons With AIDS Coalition. I found that what Dr. Bihari said made a lot of sense and offered an empowering perspective of hope for the survival of people living with AIDS/HIV.



Dr. Bihari's approach to treatment has proven quite successful in his own practice. This approach focuses on the stabilization of the immune system in HIV infected individuals. HIV infection leads to major suppression and deterioration of the immune system (the body's defence system against infection). This is combined with the vigorous use of prophylaxis to prevent the development of a range of opportunistic infections in people whose low T4

cell count (a primary marker of immune function) makes them vulnerable to these infections. It is to be remembered that it is these infections which actually kill people with AIDS. Bihari recommends preventative treatment not only for PCP (pneumonia) which is now often accepted and undertaken, but also for MAI, CMV, Toxoplasmosis and other infections where indicated by low T-4 cell counts or other diagnostic markers.

Dr. Bihari believes that HIV is necessary for the development of AIDS but also believes that cofactors (such as herpes viruses and mycoplasma) can contribute to and speed up the development of HIV infection and AIDS. Management of these co-factors is therefore an important part of Bihari's proposed treatment plan. While Bihari sees the importance of an anti-HIV treatment that can stop the spread of HIV from infected to uninfected cells he believes the usefulness of the AZT family of anti-virals which is still being relied on by the medical establishment "has crashed." Drug companies have wasted years of research and development on AZT and related drugs. Bihari now only prescribes AZT for cognitive impairment.

Dr. Bihari is hoping for the develop
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ment of an anti-viral treatment which will stop the spread of HIV and which will have a low level of toxicity. If the spread of HIV can be stopped then it should only take the body 7-8 years to eliminate the virus since most cells in the body are replaced during that time period.

In the meantime he focuses on immune stabilization and the prevention of infections which will allow people to live long enough to see a more effective anti-HIV agent. These important areas have unfortunately not been a major focus of research by the medical establishment. Dr. Bihari also supports his patients working on their diet, doing exercise, doing meditation, avoiding alcohol and recreational drugs, and recommends vitamin and mineral supplements, chinese herbs and acupuncture.

More specifically Dr. Bihari recommends the use of Naltrexone, Antabuse and possibly Tagamet as immune modulators to help stabilize the immune system and prevent further immune suppression. Naltrexone, which is the most important immune modulator, for instance, in small doses once a day before bedtime stimulates production of endorphins that enhance immune functions including the ability to fight off infection. Endorphins are generally low in people living with AIDS/HIV and stimulating their production improves the immune system.

Regarding antiviral drugs, Bihari points to the possible benefits of hypericin and to anti-HIV treatments that interfere with points in the HIV life cycle without breaking the DNA chain, that are not cancer causing, that will not trigger resistance in HIV and which, unlike the AZT family, do not have major side effects. In terms of managing co-factors Bihari recommends the use of acyclovir to fight off herpes infections.

Regarding opportunistic infections Dr. Bihari along with other community AIDS researchers and with the support of the AIDS Coalition to Unleash Power (ACT UP) in New York City developed a research programme that would have treated people for PCP and three of the other opportunistic

infections. Unfortunately, this research plan fell apart when the different drug companies who had patents on the drugs that were to be used did not want to cooperate with their competitors. Their companies' profit rates came before better treatment combinations for people living with AIDS/HIV.

Bihari has since implemented this approach in his own practice with very promising results. Bihari has tracked the response of 105 of his patients for a number of years. Among the 73 who followed all of the recommendations on preventative treatment for infections there were no major infections and only 4 cases of mild PCP. Among the 32 who failed to follow all of the recommendations there were 17 infections, 19 hospitalizations and five deaths. Beyond prophylaxis for PCP Bihari recommends fluconazole for fungal infections, clarithromycin and possibly rifabutin for MAI, and high doses of acyclovir for CMV retinitis and related infections.

In Nova Scotia and in the Valley there may be problems with getting doctors to accept this treatment approach given that much of the medical elite does not support it, or is not familiar with it, but people's lives are at stake and this approach has shown its effectiveness. There may also be problems with access to some of the treatments and the costs of some of these treatments could be prohibitive. This again points to the need for people living with AIDS/HIV to have free access to the treatments that can prolong their lives. Bihari urged people living with HIV/AIDS to become "activists for your own care." For more information on Dr. Bihari's approach to AIDS treatment contact James Shedden at the Nova Scotia PWA Coalition at 429-7922. The Valley AIDS Concern Group has copies of Dr. Bihari's paper "Management of HIV Disease: One Physician's Approach" that we can send to you if you contact the office.

The Valley AIDS Concern Group does not endorse any particular treatments but supports full access to all treatments.

Massage Therapy for AIDS/HIV

by Nancy McKinnell, RMT

Massage therapy is one of the ancient healing arts. With the rise of technology and modern medicine it lost much of its popularity. However, it is finding its way back, as people are exploring the more "natural" approaches to health, wellness and quality of life. Massage is a means of stimulating the muscular, nervous, circulatory and lymphatic systems of the body through touch. By stimulating the body's systems, the body is encouraged to work more efficiently. In my work with persons living with HIV and AIDS, massage therapy has proven beneficial in assisting the lymphatic system, which cleanses the body of toxins and other "unwants" that can seriously hamper the immune system. As well, massage helps in restoring normal functions of muscles and joints, reduces swelling, and can have an overall restorative effect on the body. It can be helpful in relieving stress and fatigue, as well as being a natural path to deep relaxation.

Nancy McKinnell is a certified massage therapist who has been in practice for three years. Her main practice is in Halifax, but she is also available on a "have-table-will-travel" basis in the Windsor-Wolfville-Kentville area. If you have any questions or would like more information on massage therapy, you can call Nancy in Halifax at 422-0087 ex. 45, or at her home at 757-2011. The Valley AIDS Concern Group and the Nova Scotia PWA Coalition can provide financial assistance for persons living with HIV or AIDS interested in receiving massage therapy. For more information, please contact either the Valley AIDS Concern Group in Kentville (679-3515) or the PWA in Halifax (429-7922).

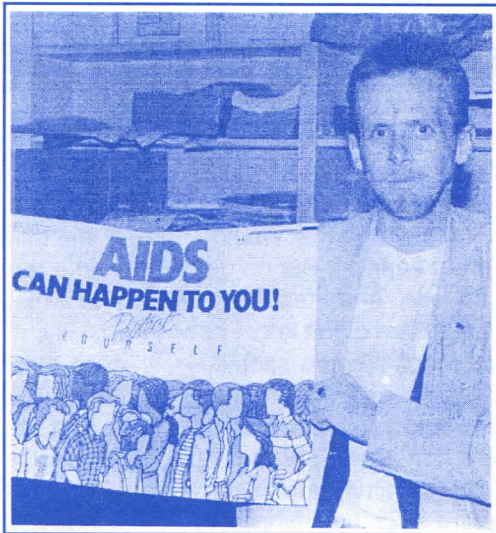


Photo courtesy: The Hants Journal

Robert Nunn 1963-1993

Rooting through your personal life for heroes, the people who inspire you, has an element of surprise to it. That's part of the fun - they materialize as if by magic. In the fall of 1992 one of those surprises crept up on me.

It was late evening, after a long day of work. A few of us gathered at a friend's apartment to plan a holiday meal together. Our small group represented support for people living with HIV infection or AIDS.

Across the coffee table by a bowl of huge handmade chocolates a skinny new guy was hugging his mug against the cold, his sock feet bunched up under him on the couch.

Rob's big blue eyes were full of fire and mischief, his complexion was a bright lobster-red - with some dark splotches. His grin was enormous and frequent. He laughed easily. His hair stood up straight, a blond head of quills that made one wonder if he was plugged into a wall socket. I began to enjoy his company immediately. Clearly, he liked to talk, and was fun to listen to - thoughtful and expressive and full of good natural wit.

Robert Nunn had come back from his job in the west of Canada to live at home in the Valley after he had tested HIV+.

His resolve on returning to Nova Scotia was to appreciate and share whatever remained to him of his good health. On good days - which were fairly numerous in the winter of 1993 - he was as exuberant and outgoing and active and funny and warm and as

lovable as a human being can be. On very bad days he cautioned that it could always be worse. But he had his sights on bouncing back into high form.

He drove himself from the Valley to Halifax on clinic days, often staying over with his brother in the city. He devoted an enormous amount of time and energy working for the Valley AIDS Concern Group - attending conferences, speaking to school and church groups, shuttling to meetings, giving interviews and participating in a variety of public forums.

When Robert spoke about living with AIDS he did so with candour and in terms we could all understand. He answered sensitive questions in a forthright manner - with his trademark grin and good humour lurking nearby.

Following a hectic winter of travel and talks, we began to worry that he might be overdoing it. He assured us that it was all connected with making his own life worthwhile. He had given himself over entirely to the task of raising our awareness of AIDS in our community and beyond.

In June his health took a sudden downward turn and he didn't rebound. It was frightening for him, his family and for us - his friends. He continued to muster the strength he could to meet his speaking obligations, but soon he had to slow down and try to get his energy back on track. The goal he set for himself was to get to the marriage of his brother in Ontario - set for early summer. He vowed to go in a

wheelchair if he had to. Besides, he wanted to catch Phantom of the Opera as well.

When the wedding rolled around he was weak but fierce in his determination to go. With the help of his family he went - and enjoyed himself. What's a little health when your only brother's getting married?

Upon his return from Ontario he spent most of his time at home. His energy remained low. With the help of a cane he made it to a midsummer meeting of our group, and drove himself to our barbecue. He sat, as if listening, beginning to turn in on himself.

After coming to know Robert as being feisty and gregarious, our contacts with him now brought us in touch with his brittleness, his vulnerability and the loneliness that he carried with him. In the summer (as in tough periods prior to that) care for Robert fell to his family, and mainly to his mom. She knew he wouldn't have long to live and her care for him, hour by hour, continued until early September when he died in the hospital.

Now, months later, I think of Rob and his mom quite often. I think of what he gave our group, his friends, our community. His courage and incessant teasing and high spirits suggested to me what a healthy person should be able to do. He inspired each of us by his actions to reflect on what makes our lives meaningful.

Rob was a good friend and I am missing him. He was fifteen years younger than me. Hardly fair. When we gather as a group Rob's spark is very much in our midst. He belongs to our hearts more intensely than ever. And when I think of him and his mom I think of people bigger than life, and I'm grateful.

In the days following Robert's death, my youngest daughter gave me a bug-eyed troll with spiked hair and a wide grin. It has an uncanny resemblance to a hero of mine. It sits in a jar of pencils on my work table, smirking at me. At the end of the day I'm tempted to give him a wink, to whisper aloud, "Good night old blue eyes, I sure do miss you."

Gary Collins

An activist's life continues

Interview by L. Charlene Vacon

There are things that touch us and change the conditions of our lives so greatly that we become changed people in the process of dealing with them. When Mary Ganong's husband, Reid, became HIV-positive, the couple found themselves in such a situation. It was often a difficult time that took much endurance and perseverance, qualities that Mary was not found wanting.

Through her experiences, Mary has become very active on AIDS issues in her community, and now volunteers with the Valley AIDS Concern Group. This warm, often fiery, woman invited me into her home to talk about some of these experiences. I asked Mary when they found out that Reid was HIV-positive.

"In March - No! December '85," she responds. "He received the blood in March after a triple bypass. A child died. And [the doctors] didn't know why. So they performed an autopsy and found that this child was HIV-positive. Then they started to check back and found that the child had received a blood transfusion. They checked and found six people that had received part of that plasma.

"The donor was a regular donor. He thought he was doing a good thing. He was devastated! He didn't know he was HIV-positive. Can you imagine? All that at one time? And then we found out who had received the plasma. The doctor came up to the house and took blood from both of us and then we found out that Reid was positive. I was negative. I have had subsequent tests and I was still negative. Fortunately."

The news that Reid was HIV-positive was devastating. "Reid more than myself went into denial," Mary says. "He did not want to tell anyone. He was ashamed because of the situation that prevailed at that time - the Eric Smith situation, the way people reacted, the negative attitude. He, for some reason that wasn't his fault, was ashamed. I didn't tell our children for two years! He didn't want anyone to know. I told them without his permis-

sion. He was very angry with me.

"We didn't tell his sister; we didn't tell anyone. Now I know that there were people in this area that would have been great support. But he didn't want to tell anyone. And I felt the same way. Look! We didn't know how people would react. I asked people, especially people with children, afterwards, 'How would you have reacted?', and they were honest enough to say, 'I don't know'. At that time there wasn't the education. It hadn't developed to the point that it's at now. Which isn't very far. Still, it was totally new. We handled it ourselves. We got no counselling before. We got no counselling after."

I ask Mary about the Valley AIDS Concern Group and the kind of role it plays in supporting family, friends and people with AIDS themselves. While she is active in the group now, in 1991 when Reid died, they hadn't known about the group.

"We could have really used it previous to that," she says. "You need someone that you can pour your heart out to.... You don't want them to tell you, 'Oh, never mind! It's going to be alright.' No! You know it's not going to be alright. You just want a hug."

Mary describes herself as a "huggy person". She says she and Reid found some of the health care workers were cold, making a difficult situation worse. Yet, though some were cold, there were many people who were feeling, caring, and responsive. It was to these people that Reid and Mary would turn.

"Very frankly I blame the Red Cross more than I blame anyone else."

When Reid developed lymphoma, they met a naturopath. The prognosis with the cancer was grim. And with chemotherapy, they fully expected a number of side effects. But "thanks to Lois Hare and thanks to Sue Robinson, a far-sighted individual - she gave us a print-out of the chemo that Reid was going to get. The print-

out was the chemo - the toxicity, what organs the chemo attacked. We brought that in to Lois. She took it home on the weekend and set Reid up with a regimen of vitamins and herbs and a diet that would counteract the toxicity. If it was going to attack the liver, there was something that would counteract it. He had no reactions during the chemo! He was never nauseous. He was never constipated. He didn't have diarrhea. All these things that people have - he lost his hair - but he was never sick."

The herbs, the special diet, the vitamins - all these things didn't come cheaply. Mary says they "wrote out a real hefty amount every time." What's worse, she says, is that many people are denied this care because of cost. "We could afford it. Unfortunately, there are lots of people who can't. It's very expensive. Very expensive!"

Along with the wonderful and helpful people, Mary also talks about the people and organisations she encountered that were not so wonderful. When I ask her about the Red Cross, she holds nothing back.

"Very frankly, I blame the Red Cross more than I blame anyone else. They knew the process [for testing blood for HIV antibodies] was there. They should have said, 'We're not going to take any more blood until we get the testing.' True?" she demands. I nod my head, thinking she's right on. Mary explains why she thinks this took place, "My theory is: So? Big Deal! A bunch of gays will die. A bunch of drug users will die. Who cares? We're better off without them. But they didn't realize what they were doing."

After Reid got the blood transfusion, and after they found out he was HIV-positive, they never heard from the Red Cross. Mary says, "The hospital - never heard from the hospital. Never heard from the surgeon. After Reid died, I got a letter from the hospital asking for funds!" Mary's voice rises and she pauses, emphasizing this bizarre situation. "Well! I wrote back on the back of that letter everything that was in my heart. The way we were

isolated, ignored. What were they scared of?? I wrote that this happened in their hospital. We got nothing from them. Oh, I really let it out! And I did get a letter of apology from the administrator saying that he was sorry and the last sentence gave me some hope. He said, 'If this should ever happen again, I assure you we will handle it differently.' "

Mary continues, talking about the treatment from the surgeon in that same hospital, "When Reid was in the hospital, the resident was taking his record and he said, 'Who was the surgeon?' I was very vocal about the lack of support. The intern said he couldn't believe that this surgeon had never responded to Reid's situation. So, he saw the surgeon on the floor and he said, 'I have a patient of yours and his wife downstairs. Do you know what happened to them?' They never told him! He came downstairs with the tears running down.... He took Reid's hand and my hand and said, 'I swear to you, I didn't know. You must have thought that I didn't care.' And I said, 'That's exactly what we thought.' He said, 'I thought I was giving him life. And I gave him death.' They never told him! Now that's six years. They were scared of malpractice I guess. I don't know."

I ask Mary if she feels that the latest compensation package settles anything for her, and she returns to the theme of malpractice. "Frankly, I would prefer to have my husband back. How? How can they settle anything? The only thing that I wanted was acknowledgement. So, this is a way of acknowledging that malpractice was done. The same way as you sue someone in court. It's a way of acknowledging that they were wrong."

Mary was the second person to receive the N.S. Special Assistance Package. She says the only reason she got it as soon as she did was because she pushed for it. "I didn't just get the compensation sent to me. I pushed.... I called a lawyer. I called Robbie Harrison, who sent a letter on my behalf. I sent a letter. I met the Minister [of Health]. If I hadn't pushed, I'd probably still be waiting."

"You have to be obnoxious. You have to be an ogre in order to get

things done. If you are nice and polite, and you say, 'they made a promise. They'll come through with it' In the letter I wrote, I said, 'I'm 77 years old, and I'd like to get this while I'm still around!' "

There is lots of advice and guidance to be taken from what Mary says and does. Indeed, one of the areas she works in now is educating people, in schools, hospitals, and wherever she can, about AIDS. There are some things in particular that she wants people to learn from her situation:

'I'm 77 years old, and I'd like to get this while I'm still around!'

"I want [people] not to be panicky or terrorized by the knowledge that [AIDS] exists, but to educate themselves as much as they can. Mostly the thing that I want is for people to throw off this terrible attitude of homophobia. I really believe that because of people's attitudes that finding a cure and going ahead on the whole AIDS thing has definitely suffered. There has been no support from the public. It is not a 'gay disease'. And even if it was a so-called 'gay disease', it deserves our attention and people deserve our support. I find that there is an awful lot, still, of homophobia. This bothers me terribly. When I do speak to the schools this is definitely brought up. People are people and they have to learn to accept. Having been ... at the receiving end of discrimination, because I'm Jewish, I can appreciate to some extent. I can't appreciate it completely, but I have been at the brunt of discrimination. We don't have to do what other people do. We don't have to accept philosophies. We don't even have to like people. Just accept the fact that everyone is a human being and accept them for what they are. That is my philosophy. And that's the way I hope I live."

a project of the Community Health Promotion Fund



Department of Health

Anonymous Testing

The Valley AIDS Concern Group and all other community based AIDS groups in Nova Scotia (and in North America as a whole) have come to support anonymous testing as the best means of delivering HIV testing to those most likely to test positive.

Anonymous testing means that the person seeking an HIV test can go to a testing site without having to give her or his name. They will receive pre and post test counselling on AIDS/HIV and risk reduction but will never be required to give a name or MSI number.

Studies in the United States and experiences here have shown that many people who have participated in high risk activities are reluctant to be tested if it means their identities will somehow be passed on to government or local health officials. Experiences like that of Eric Smith, an HIV+ teacher whose confidential medical file was leaked to the public, have served to reinforce that perception in Nova Scotia.

After 6 years of lobbying by community groups the Nova Scotia government has finally come to support anonymous HIV testing as well but is only committed to setting up one site in the province - in Metro Halifax. Anyone wanting to be tested outside Metro can still be required to give their name. What this means is that a Valley resident who wants to be tested can go to a doctor (or an established testing site like the Red Door in Kentville) and give their name - with the resulting fear that their identity will become public knowledge. Or they will have to travel to Halifax for an anonymous test (and return 10 days later for their results).

The Valley AIDS Concern Group is pleased that the province has finally seen the importance of anonymous testing but is deeply concerned that plans around its implementation do not take into account the specific needs of Nova Scotians outside the Halifax area. We are being offered an entirely different service from that available to residents of Metro. This cannot be justified. Why should government officials have the right to know our individual test results when Metro residents are allowed and even encouraged to be tested anonymously. The VACG will continue to push for the adoption of anonymous testing across the province.

Loving with AIDS

Valley AIDS Action welcomes submissions from people living with AIDS/HIV on any social, political or personal aspects of AIDS they want to write about. Yves contributed this piece written by his lover, Wade.

When Yves came into my life eight years ago AIDS was very new, and I knew very little of this disease living in a small community in the Valley. I remember in meeting Yves after being alone and lonely so many years that I told myself that I would take just one chance for happiness. I myself was very afraid of the thought of getting AIDS, and many many times I had myself thinking that I had AIDS. I used to wake from my sleep in a fright of fear that I was going to die from AIDS. But having Yves with me over the years my fears left me. We both seemed so good so healthy. I cooked good meals and did my best to fatten Yves up to look good and healthy. I remember thinking and saying to friends that I was one of the lucky ones. I took a chance for my happiness and I won.

Then one year last November Yves was diagnosed with AIDS. My world came crashing down. In March of that year my dear mother passed away so I was still in the mourning process, and it hit me that my companion was dying from AIDS and with that thought without a doubt I also would die from AIDS. I panicked, cried and found myself just sitting like a dummy, looking out our windows at all the beauty in our yard - the birds at the feeders, the mountain, the snow etc. thinking that it shall never be so beautiful for me again, without Yves in my life. Yves was the one who even with his own struggle of living with AIDS, also helped me to learn for the first time in my life to live one day at a time and never destroy all the beauty of that day of life, in thinking what might happen tomorrow. Yves has taught me much in our eight years together, and living has been one of the best gifts of all. I never worried of what family or friends thought about AIDS in our lives.

From the age of a young boy my family spoke of their problem in dealing with tuberculosis - the fear in the community of that disease and all the problems my family encountered in caring for those they loved dearly knowing there was no hope for them. So I find myself repeating their strength in caring for the one I love, with this disease. My greatest fear of AIDS and dying is that I shall not do all things right. That I shall not have the strength to care for Yves in a way that is best for him and myself. There are times that I still worry about tomorrow. When he has a cold, or I see he can't eat the way he should or when he is sick to his stomach every morning I sometimes find I have to be careful not to be at him all the time for I should not destroy his beauty of the

day with my fears of tomorrow. There are many things in my life I would change if I had the chance but the one thing I would never change is Yves coming into my life - with or without AIDS. So far, I have not tested HIV+, but if the time comes that I do, I am thankful that I have the strength to deal with it and not to be as frightened as I was in the past. I am sure if we could pick our own deaths it would not be with or due to AIDS. It makes me very upset to see so little done by government about AIDS and for the people who have it. As this disease progresses and touches the lives of people they love, maybe more will be done. And I have no doubt that AIDS is progressing. And for my Yves I also hope that living with this disease, with all its ups and downs, will, in the end, have earned him his death with dignity. Until that time, living with AIDS and all the fears of this disease, I shall always try and see the beauty of the day for Yves and myself.

Wade C. Newcombe, Wilmot, NS

I'd like to help out with the Valley AIDS Concern Group.

Name: _____

Address: _____

Phone: _____

- Please put me on your mailing list.
- Please contact me for volunteer work; I'm interested in doing...

I've enclosed a donation of \$_____.

AIDS Nova Scotia's Men's Project - 1993

In September AIDS Nova Scotia renewed the Men Who Have Sex With Men Project (MWHSWMP). Commonly called The Men's Project, it is funded through the Province of Nova Scotia's Department of Health. It is focused on helping men who have sex with men strive for overall health through the development of positive self esteem and the adoption of healthy sexual behaviours. In 1991-92 the Men's Project focused on men who have sex with men that do not necessarily identify themselves as being "gay". The project acted as Nova

Scotia's coordinating contributor to the Men's Survey, the Canadian Survey of Gay and Bisexual Men and HIV Infection.

One of the key recommendations of the Men's Survey is to "find creative ways of funding and fostering educational initiatives for men in smaller towns and cities." This is an important need that will be addressed through this project. Currently, the Men's Project is in the process of developing local interest groups in each area around the province. For more info. contact AIDS Nova Scotia: 425-4882.