Breakfast With Willy

Willy Willette is a Street Educator at The AIDS Project of Portland. He also volunteers by doing HIV testing and counseling services through The AIDS project. This interview was conducted over a sensational breakfast of waffles, eggs and coffee in downtown with Mary Shotwell, the Coalition’s summer intern. It is intended to reveal a Street Educator’s perspective on the current state of AIDS in Maine and Willy’s visions for the future.

MS:  Why do you do the kind of work you do?

WW: I look at the work I do as being a privilege. Prevention is such a privilege to be there trying to stop the virus before it gets started. The rest of the jobs I’ve ever had I have always been on the other end - working in rehab centers, children’s homes - doing “catch-up.” I really enjoy this work and think it is important that correct information get out there - people need to know what is going on.

MS:  How is it different now than when you first were on the street?

WW:  Awareness... In the neighborhoods I work in, HIV is a reality to them. It is not happening to somebody else out there. The neighborhoods I work in are most low-income with a high use of drugs and alcohol. They realize that HIV is in their neighborhoods and they need to do something. But, if I went to a different neighborhood in Portland or Lewiston, it would still be - “it’s happening to somebody else out there.”

On the whole though, there is a change in attitude with almost everybody I work with, especially in detox and rehab centers. They know someone who is HIV positive, where that wasn’t true before. It is really changing.

MS:  Do you see more HIV infected people on the street?

WW:  Yes. Because many of the people that were using before I even got there or doing unsafe sex are now finding out that they are infected. The number of heterosexual people I see has really increased. They just weren’t on the records 2 years ago.

MS:  What do you think about needle exchange?

WW:  I am 100% behind needle exchange. It is the only way to slow or stop the spread of HIV. It is not going to stop IV drug use, but one of the statistics I like to use is:

New Orleans has approximately the same population as Boston as far as drug use. In New Orleans you can buy needles over-the-counter. The rate continued to page 8
From My Corner of the Office - Healing Hearts: The Concert for AIDS!

What an evening! Have you ever been to the Old Whaling Church in Edgartown, Massachusetts? It's a lovely building, located right in the heart of town and on Friday evening, July 19th, it was full of people gathered to support the AIDS Alliance of Martha’s Vineyard. I usually spend my time attending Maine AIDS benefits, but my sister told me about this special program, and so, I drove down to the Island to join with others who are working to make life better for people living with the AIDS virus. The first people shared folk songs that put those gathered in a pretty mellow frame of mind and gave us a lot to think about. BUT, after a short intermission, the mood changed — dramatically!! Outside the church we could hear the sound of drums and whistles, and the sounds grew and grew until the church reverberated with the music of Die Kunst Der Drum. Dancing and hand clapping, the audience was transformed from a passive group of people immersed in their thoughts and! memories to a life affirming, energy charged positive force for change. There were several other artists that shared their talents that evening and each had a contribution that went far beyond chords and notes. It was the blending of gifts from the Island people to support the installation of a 24-hour AIDS hotline on the Vineyard. The group that brought the night to a close was Miracle Cure. So many smiles, so much enthusiasm, so much hope — and the last song repeated the words “Call me, when you need a friend” over and over until I could sense it lifting like a bright cloud to float out the windows of this sacred old place and float gently through the community calling those to reach out and help all people who are struggling so valiantly against this horrible disease. I’m glad I had a chance to squeeze in a few hugs from Brian and Tony, and promise all that I will try to slip quietly out of Maine every once in a while and head down to the Wintertime Coffee House in Vineyard Haven for some R and R. Thanks to you all for an evening to remember. June

Press Release – For Immediate Release

HIV+ Support Group in Gardiner

Dr. Karen Kalustian’s office and Merrymeeting AIDS Support Services are co-sponsoring a group for individuals who are HIV-positive. This group will meet the first and third Wednesdays of every month beginning on July 17, 1991. The meeting time is 1:30 – 3:00 P.M. and is open to anyone who is HIV-positive. For more information and/or directions, please contact the MASS office at 725-4955 or Bobby at 549-7983.

HIV infection is often lonely as well as debilitating. A support group gives people an opportunity to meet other individuals who are in similar situations, and to share their experiences in a safe, supportive environment. A person with HIV or AIDS is not alone, and a support group could help to make a difference in a person’s life.

THE PWA COALITION OF MAINE

and

THE LIVING ROOM NORTH

are located at

377 Cumberland Avenue
Portland, Maine 04101
Phone: (207) 773-8500

Hours Open
Monday - Friday
10:00 AM - 4:00 PM

Lunch Served
Mon/Tues/Wed/Fri
12:00 AM - 1:30 PM

Wednesday Night Dinner
6:00 PM

Some extended hours
call for extended hours

Special Events Posted
Please Check Calendar

MAILING LIST

To preserve the confidentiality of those on our mailing list, our list is NEVER given to other organizations. The newsletter is mailed with only The Living Room North and street address as the return address. We encourage those interested in the newsletter to add you name or organization name to our mailing list. We appreciate your need for privacy by not printing a reference to AIDS on the outside mailer.

DISCLAIMER

This publication is designed to present information to people with AIDS and AIDS-related conditions and concerned friends, and is not to be regarded as providing medical advice. The appearance of information in this publication does not constitute an endorsement of that information by the PWA Coalition of Maine. Consult your health care provider for medical advice before undertaking any treatment discussed herein.

The appearance of any person’s name or image in this publication does not imply anything about their health status or sexual orientation. Views expressed herein are those of the by-lined author and do not necessarily express the views of other authors, the PWA Coalition or any other organization.
CRUISE
THANKS

As in all the last many fundraising events, when it boils down to the last minute, things usually end up running fine. And for our second annual Boat Cruise this was no exception.

Plans started in early spring. Things were going well and everything seemed to be just fine until I received a phone call from June early one morning. She started the phone conversation with "Did you read the front page of the morning newspaper?" I reply "We don't get morning newspapers in West Newfield, why what's up since I last talked to you yesterday?" Well, she starts, I'm going to give it to you just like I heard it. I haven't read this myself but a friend of mine just called and read me the story on the front page of the Portland Press Herald. It reads Longfellow II is sold. As I gasp for air I yell, They sold our @ boat. Well as it turned out The Longfellow II was sold because of some economic problems and creditors...you know the story. Now this leaves us two weeks to revamp the cruise. Luckily another ship was available with Casco Bay Lines and so we changed plans in mid-stream and plunged onward. At this point tickets were selling great. It looked like we would have a full boat. As we got closer to the day of the cruise we began taking reservations and holding tickets for people to pick up at the dock. We had also planned to sell left over tickets at the dock. The morning of the cruise I wake up early (not because I am excited about the cruise...but because I am snooping around the house for my birthday presents), then I look out the window and I scream "We are having the worst typhoon in history on the day of our cruise". Within ten minutes the phone started ringing with the question, "Is the Boat Cruise still on?"

At that point I wasn't sure there was a boat or a dock still left in the harbor so I started calling and find out it isn't that bad in Portland and the cruise is still on. The weather held back just enough for our cruise and everything was just fine. It stopped raining just before we boarded the ship and it started raining just as we started to dock. Look at the bright side, the fog wasn't as bad as it was last year.

So the Boat was a little different than last year...and the weather was quite a bit different than last year but all and all the cruise was a lot of fun.

Thank-You's are in order for all who helped produce a fun event and so the list starts off with the entertainment: Thanks to our Disc Jockey, John Hussey for all of his great music. Our other musician on board was a folk guitar musician named Martin Swinger who played on the upper deck, thanks to you for your great music. Next on the list would be the food committee. My first thank-you is to Chuck Sawyer who took charge of all the food arrangements. He gathered and prepared all the food for the cruise. I would have been lost without him. Thank you Chuck. A special thank you goes to Sheryl Smith, the friendly Nabisco Representative who donated all the crackers for the cruise. And thanks to Shaw's and Shop-N-Save for their donations of cheese, fruit and all the other goodies at the food table. Thanks to Randy for the great birthday cake (a huge four story cake). Thanks to everyone who helped in ticket sales - Ralph, David, Cindy, Chuck, Gordon, Tim, Tom, Max, June, Carl, Sean, Mickey and any others I have forgotten. Thank-you to all of you who sponsored tickets so that PWA's could enjoy the cruise. In all we had 22 PWA's who received sponsored tickets, thanks to your generosity. And last but not least, thank you to everyone who joined us on the cruise. Your support made the cruise a great success, and plans will be starting again in the spring for another cruise. We hope you all had a great time and we thank-you all in helping us in our fundraising events.

Rick Brooks - Boat Cruise Chairman
The NAMES Project/Maine would like to thank all those people who participated in the 50/50 cash raffle about the "Keep The Love Alive" boat cruise on August 4th. A special thank you to Michael D’Angelis, Dan Stevens, Debb Freedman for helping to sell the tickets. And a big congratulations to Gary Chasse for winning the raffle.

The NAMES Project/Maine is looking for a wide variety of volunteers to join our group. If you have seen the AIDS Memorial Quilt, be it a small display or a large one, then you know the impact it has on those who experience it. Our needs are in all areas; helping with displays around the state, fundraising, accounting, media, video and slide presentations, minimal office procedures, grant writing, and just sharing the stories and the love that is part of the Quilt. Anyone interested in wanting more information, should come to one of our Quilt workshops (described below), or call Debb Freedman at 846-3667 or David Ketchum at 934-4997. We look forward to meeting you and helping you to — "Keep The Love Alive".

The NAMES Project/Maine has Quilt workshops the first and third Sundays of every month at "The Sewing Shop", 461 Stevens Avenue, Portland. If you have been thinking about making a quilt panel for someone who has died from AIDS, please join us. If you have already made a panel or a special design with the rest. Making a panel for someone who has died from AIDS time for healing and a you are unsure and would making a panel, please join us on one of the above-mentioned Sundays. If you have the desire and the need to make a panel, we have the expertise. If you need more information, please call Debb Freedman at 846-3667 or David Ketchum at 934-4997 or call the NAMES Project/Maine office at 774-2198 and leave a message.
# September 1991

**THE PEOPLE WITH AIDS COALITION OF MAINE**

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377 Cumberland Ave. Portland, ME 04101 (207) 773-8500
8/14/1991
MEDICAL UPDATE
JUNE 3, 1991
SALK VACCINE AS IMMUNOTHERAPY AND NEW TREATMENT FOR HIV-RELATED LYMPHOMA

presented by Alexandra Levine, MD and reported by Jim Stoecker

Dr. Alexandra Levine, chief of the Division of Hematology at USC, was the guest speaker at the June 3 Being Alive Medical Update. Dr. Levine discussed both her study of the Salk vaccine as immunotherapy and her work with treatment protocols for HIV-related lymphoma.

THE IMMUNE SYSTEM RESPONSE TO HIV

As background to her Salk vaccine report, Dr. Levine briefly sketched what we know about the immune system’s response to HIV infection. When a person is infected with HIV, the body responds in two ways. One is to build antibodies against HIV. The second is a cell-to-cell recognition of HIV, where the killer T-8 cells are supposed to recognize the virus-infected cells and kill them.

Shortly after HIV infection, the body makes antibodies, and their level stays high for years. Cell-mediated immunity, however, begins to fall slowly, early on in the course of HIV disease. Nonetheless, for a period of time after infection, the immune system “wins.”

As time goes on, the ability of the immune system to recognize HIV and fight it off becomes depleted. This is when the person moves from asymptomatic to symptomatic HIV disease. The level of antibodies falls precipitously as illness sets in. The host becomes weaker while the virus becomes stronger.

IMMUNIZING TO PREVENT HIV DISEASE PROGRESSION

At some point the body’s immune system loses the upper hand. We then intervene with chemotherapy, by using such antivirals as AZT, DDC or DDI. Before that point is reached, however, we want some form of immunotherapy to boost the immune system and forestall the progression to serious disease. The HIV vaccine, developed by Dr. Jonas Salk, offers a possibility for such immunotherapy.

The Salk vaccine consists of killed whole HIV with the viral envelope removed. The theory was that if a seropositive person was immunized with this vaccine, this might force the immune system to respond by building antibodies against this safe form of HIV. This would buy the individual another “latency” period where antibody levels are high and symptoms are minimal.

IMMUNOGEN TESTING BEGINS

Testing of the vaccine on seropositives began in October of 1987 at USC. The first group was chosen because they appeared to be at the point of progressing to serious illness. Those who appeared asymptomatic were ruled out, since there was no way to know if the vaccine was safe in humans or not. The first group of nine people proved that the vaccine was safe, and eventually the study was opened to about 85 people, ranging from asymptomatic to mildly to moderately symptomatic.

FOLLOW UP RESULTS

After almost three years of trials, the vaccine has proven safe. No side effects or adverse reactions were experienced. Two of the 85 have developed opportunistic infections, one has died while the other is still living. Six people developed KS during the course of the study. Weight of the study group remained stable. Beta-2 microglobulin also remained stable over time.

NO ANTIBODY RESPONSE, BUT CELL-MEDIATED RESPONSE NOTED

The antibody titer of study subjects did not fall during the study. But, contrary to what researchers had expected, antibody level did not go up. The subjects were not making an antibody response, but some 60% were making a cell-mediated response.

When killed HIV is injected under the skin, most HIV+ people show no response. This is consistent with the fall off in the functioning of the T8 killer cells. For the majority of those immunized with the Salk vaccine, however, there was a positive result to the skin test, a response of the body’s T8 cells. Dr. Levine characterized those with a positive skin test as people for whom the vaccine “took.” For these people showed stable CD4 counts over time, as well as a lower overall viral burden.

NATIONAL TRIALS UNDERWAY

The USC study showed lack of toxicity in both the short and long term. And, although not a controlled study, the results in the stability of CD4 counts and in the lessening of viral burden were promising enough to warrant further studies. About six months ago, national trials with placebo controls got underway and are still ongoing. Dr. Levine predicted that it would be a year or two before the vaccine is generally available. First the placebo-controlled trials must be completed and the data must be reviewed by the FDA.

NEW TREATMENT PROTOCOL FOR HIV-RELATED LYMPHOMA

Lymphoma is a cancer that is a late manifestation of HIV disease and is a sign of strong immune suppression. With the development of prophylaxis and better treatments for opportunistic infections, lymphomas being seen more and more in HIV+ people.

The standard treatment for lymphoma among non-HIV infected patients has been an intensive regimen of chemotherapy. Physicians have found, however, that this proto-
Win $700 for your Fantasies

Start pulling your wildest costumes together now... The Great Pumpkin Halloween Masquerade Ball has upped its first prize to a whopping $700. There's also a $100 prize for the best carved pumpkin, and several great secondary prizes. The party is scheduled for Thursday, October 31 at the Sonesta's Ballroom, with music by Papa Loves Mambo.

Proceeds for the Halloween party will benefit the People With AIDS Coalition (PWAC) of Maine.

Last year's event was one very hot party ... the costumes were stupendous! If you weren't there last year, you missed the party of the year - don't lose out this year. Prizes will be awarded in the following categories: Best Couple, Best Group, Best Historical, Campiest, Scariest and Best of Ball for the $700 prize. Also, Best Carved Pumpkin for a $100 prize.

Tickets will be available for $12 in advance, $15 at the door, at the following locations around the second week of October: Sonesta Hotel, Drop Me A Line, Octavias, Raffles, Victory Deli, both Whip & Spoon locations, and PWA Coalition. But better yet, instead of buying just one ticket, why not gather some friends and order a V.I.P. table - reserved seating in the balcony with special "trick or treat" amenities. Prices are 4 for $100; 6 for $150; 8 for $200; and 10 for $250. Call the PWAC for details!

Want to help? We need decoration assistance - in pre-planning, and also in last minute labor during the day of the 31st. We also need people to hang posters and sell tickets. We're open to suggestions, volunteers, in-kind or cash! Whatever else you do, be sure to be there!

This party is truly a community effort. Many thanks to all our sponsors - at this writing, they include the Portland Art Directors Club, the Sonesta Hotel, WMGX Radio Station, and the Maine Health Foundation.
Dawn Francis, your Campaign Coordinator, would like to bring to your attention the following information regarding the upcoming 2000 election:

The New Mexico Campaign for the Environment is launching a $100,000 campaign to bring environmental issues to the forefront of the election season. This campaign will feature a series of public forums, rallies, and media events designed to inform and mobilize voters on environmental issues.

The campaign will kick off on September 15th with a rally at Civic Plaza. Dawn Francis will be present to discuss the campaign's goals and plans.

For more information, please contact Dawn Francis at 505-555-1234.

Dawn Francis
New Mexico Campaign for the Environment
col does not work and is not well tolerated by HIV infected patients.

Regular intensive chemotherapy further suppressed the immune system and caused other opportunistic infections. In one study, some 78% of HIV+ people treated for lymphoma came down with PCP.

Researchers began to think that less might be better for HIV-related lymphoma and began to study the use of small doses of the same chemotherapy regimen. Early studies showed a far better response at the lower doses. Dr. Levine cited a complete remission rate of about 50% among those studies.

Another study used a combination of GM-CSF and increased chemotherapy. The thought was that GM-CSF would help to forestall further immune suppression. In this study, the response rate was still about 50%, but the incidence of other opportunistic infections dropped to 18%.

Now a USC study is underway to compare the low dose chemotherapy alone to a regimen of GM-CSF with the standard intensive chemotherapy. Dr. Levine concluded by saying that HIV-related lymphoma is treatable and may even be curable.


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**Peptide T Phase II Trial**

If you are HIV+ and experiencing concentration and memory problems, this study may be right for you. Earlier Peptide T studies demonstrated improvement in mental function tests among patients experiencing problems with concentration and memory. Phase II trials of Peptide T are now recruiting at LAC/USC Medical Center. For more information call Bob Herr at 213.226.4643

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**Support Group for Persons Infected with, and Affected by HIV**

Time: First Wednesday of Each Month at 7:00 P.M.

Place: Little House of Prayer
River Road, Biddeford

For further information call: Mrs. McKenzie 282-6501

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**Thank you's from the Coalition**

The PWA Coalition would like to acknowledge with heartfelt thanks the anonymous donors who sponsored tickets for PWA's for the August 4th Sunset Harborlight Cruise.

And we would like to thank the following businesses and organizations that sponsored tickets for PWA's: Blackstones, The Chart Room, Limelight and Harbor Masters, Inc.

And in addition—we wish to thank the Harbor Masters for the fantastic food donated every month. It really spruces up our lunch menu!

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**Newsletter Subscription**

The Scoop is published by The People With AIDS Coalition of Maine. The newsletter is offered to any individual, business, school, church or other interested parties free of charge. It is important that we have your full and complete address to insure that you receive each issue. The U.S. Postal Service will not forward or correct any name/address changes, nor will they deliver any mail with incorrect information. Please keep us informed of any changes by mailing the form below.

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**NAME**

**GROUP / BUSINESS NAME**

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**CITY / STATE / ZIP**

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- NEW SUBSCRIPTION
- DELETE NAME FROM MAILING LIST
- NAME / ADDRESS CHANGE

Mail completed form to:

PWAC—377 Cumberland Avenue, Portland, ME 04101

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**CONTRIBUTIONS**

The PWA Coalition of Maine appreciates your interest in its activities and programs. We also appreciate your donations of food, clothing, and used household items.

If you would prefer to make a financial contribution, please send your check or money order made payable to:

The PWA Coalition of Maine

377 Cumberland Avenue

Portland, Maine 04101
Breakfast With Willy — continued from page 1

of HIV infection through IV drug use is only 3%. In Boston, a needle costs $5.00 to $20.00 and injection through IV drug use is 39%. Making needles available prevents the spread of HIV.

Unfortunately - and this is sort of a cop-out - if I exchanged needles, I’d be fired within 30 minutes. Maybe someone else would come in but I wouldn’t have a job. Not only would this be a loss for me personally, but it takes a long time to build up trust, and it would be a loss for the people out on the street who benefit from my services.

MS: Doesn’t doing coke or crack spread HIV just as much as IV drug use because people don’t keep track of their behavior when they are high.

WW: Right. In my opinion, HIV is going to be spread through people getting high and having unsafe sex. It is not going to be spread through IV drug use. People just going out, getting under the influence of alcohol or drugs, and doing unsafe acts. That is the number one way it has been spread, and will be spread. Most people have had sexual encounters because they have been drunk. Alcohol abuse and unsafe sex go hand in hand as far as I am concerned.

MS: When I’ve gone out to heterosexual bars in the Old Port, it is still like 1960 - why haven’t people figured out what’s been happening in the past 10 years?

MM: My saying is: “everyone looks good at 2:00 AM.” That’s what happens.

MS: What is a good way to reach this group of people?

WW: I hate to say this, but the only way to reach this group of people is that somebody has to die. Somebody who is in a heterosexual relationship. Somebody who had “good-old, plain-old sex” and got infected and then died. That is the bottom line. You can talk until you are blue in the face.

If I went down to the Old Port and did a survey on safe-sex, I bet 80% of the people down there could tell you the correct answers. If you did a survey on usage - I bet only 10% would use safe-sex guidelines. They have got to know someone who is infected by the virus. That’s the bottom line - people know the information. It’s that we don’t teach communication skills.

People still believe, and I don’t think its just Maine, I think it’s rural America, HIV can’t happen to us. We still operate under the fallacy that HIV infection only happens to gay men, blacks, IV drug users, and prostitutes.

Prostitutes are a good example of misinformation - they have one of the lowest rates of infection, if they are not IV drug users. Maine and nationwide they really do have a very low rate of infection, except if they are IV drug users and that is a whole different situation.

MS: How many IV drug users do you think are currently infected?

WW: Estimate, between Portland and Lewiston, somewhere in the area of 15 to 30 are infected and that is a pretty high percentage out of only about 200 IV drug users between those two cites. 2% is the average percentage, for a rural state we are average in IV drug usage.

The other thing that really scares me - 96% of all the people who are infected don’t know. That is really scary.

MS: What population do you think that this is?

WW: It think it is everybody. Not any particular category. I don’t know - I have no proof of that - it’s just a gut level feeling. 95% of all people infected don’t know about it. This is one of the things I say when I do my rehab and safe sex talks - you don’t have anyone to blame, you have to take responsibility for yourself.

I really do try to impress on people that there are not bad people out there infecting people, they just don’t know they are infected. The point is that you need to take responsibility for your own body. I have been doing HIV counseling for 4 years now and, not most, but a lot of people who come in and test positive don’t really believe that they are positive.

MS: Why do you think they come in to be tested?

WW: Curiosity, peace of mind... just to see.

MS: How long ago would you say they were infected?

WW: A long time ago - in the last ten years.

MS: Have they changed their sexual practices in the last ten years?

WW: Some have and some haven’t. Some of them are just not sexual anymore. There are a lot of people out there who are just not having sex. Younger people are not going into IV drug use because of HIV and what it does.

MS: What do you see, as far as the programs that need to be done for IV drug use in Maine - What are your dreams?

WW: Giving out needles, no ifs, ands, or buts. We need to pass out on the average day 10 to 15 needles a week... Maybe in the beginning 35 to 40, but then it would level off.

About dreams...What are we going to do with all the kids that are homeless? AIDS is the number one killer of women of childbearing age in New York State. Statistics I’ve read say 80% of those people are single parents - who is going to take care of all of those kids?

By 1995-96 AIDS will be the number one killer of child-bearers nationwide. Again, most of the women are single women with children and we are not doing anything with that information. We are going to have millions of kids with no place to live - no primary caregiver. I see a whole orphanage system opening up and those kids are not going to be HIV positive.

It’s already happening in Africa, the grandparents are picking up the kids. They have a more communal system than we do. Right now in this state there are kids that are not HIV positive whose parents are dying. It is not the grandparents job to parent their grandchildren.

We have to have orphanages. There is no such thing as families in this country. The family structure we used to know is gone. We have to look ahead and start building. We can’t wait like we do with everything else in this country - until a major crisis and then we react.

Condoms in every bar for free. Massive training of bar tenders, waiters, waitresses who work in bars to make sure that they have correct information. If they hear incorrect information they can say, “look, this is what is right.” I think it should happen in all bars, gay and straight.

Schools...We need to teach basic self-esteem. Start at 1st grade, this is primary, and we need to teach communication. If we had good self-esteem classes, people would learn to feel good about themselves and

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they wouldn’t have to feel bad about who they are and what they do. Also, schools should offer classes about our bodies being a good thing. Sexual abuse is another thing we’re really beginning to make a correlation with HIV infection. A high percentage of people that are infected have been sexually abused. Also, an immediate thing that needs to be done is talking about blood brothers and sisters to kids, and schools are not doing that.

Drug Rehab...Not that it is for everybody, but to put people back in their old neighborhoods is just disastrous. Especially to put them back in a place where there is no work. In Lewiston right now, unemployment is unbelievable. I think you will find in the next census it will be the highest unemployment in the state. What I find is that most people could probably make it - if they weren’t put back in their old neighborhood. It’s like putting an alcoholic in a bar.

I don’t think that the gay population does very much with what I call heterophobia (the phobia of straight people). This is one of the things we need to work on - prejudice. We’re not very accepting in this country of people who are different from us - no matter who it is. I think that people need to respect other people’s boundaries...One of the things we need to keep saying is that this is a human disease. The people who have AIDS have to believe that - I don’t think they believe it.

My prediction is that by the turn of the century, the gay population is only going to be 20% of the PWA’s [People With AIDS]. We need to get away from just PWA’s or volunteers that are supporting everyone - we need a support network that works for, and with, everybody. That is what our goals should be.

It think it all amounts to self-esteem. How much do we care...what kind of communication do we have with our parents, our teachers, our friends - how well do we like ourselves?

An Update on Rob’s Job

I am Rob* from Portland, with an update on my job search: still nothing yet. I have had a few positive leads but so far I am still available for work. This is to remind you that the PWA Job Find Bulletin Board is still up at the Coalition.

(remember in the summer issue I asked: How many PWA’s are out there looking for work — part-time, full-time, temporary, and permanent? I think that there are many community organizations, businesses, churches and individuals who would like the opportunity to hire PWA’s talent. PWA’s Job Find Bulletin Board would make the match between the employee and employer.)

If you know any employers who need work done, please suggest they send in the information for us to post. If you are a PWA and are interested in employment, keep in mind our bulletin board at the Coalition.

*Rob is not his real name.

24 Hours to Cure AIDS


On midnight of Saturday, September 21, 1991 at Fitzpatrick Stadium Track in Portland, Maine, 37 year-old Westbrook resident, Rock Green will start a 24-hour long non-competitive run to benefit The AIDS Project and the PWA Coalition of Maine. His goal? To raise $10,000 or more in personal and corporate sponsorships to assist the two AIDS resource centers in Southern Maine as well as raise community awareness of AIDS as an epidemic, and create an opportunity to involve as many people as possible to join together as a community in a positive statement of caring, compassion and concern.

Shortly after the death of a friend by AIDS earlier this year, this 4-time participant of the Boston Marathon and 2-time winner of this Casco Bay Marathon decided to take action against this deadly epidemic. His role, after preliminary fundraising efforts, will be to take the inside lane at midnight of September 21st and begin his 24 hour run. Your role?? To come and watch, walk or keep pace with Rock as his statement echoes throughout the city of Portland. A statement of caring and concern put into action. You will be joining runners from the Portland area, children and adults who have heard this challenge to become involved — and responded!!

If you are not a walker or runner, I bet you could help out in many other ways. For example: count Rock’s laps, help sell refreshments, offer time at the information booth or help collect pledges from those who wish to make donations to fight AIDS. Actually, by just being there, you are supporting the efforts of this man. So, if you’re a night person — come in the middle of the night and, under the light of the full moon, watch this man put his conviction into positive action. Or, if you’re a daytime person, there’s lots of time for you to stop by and be part of this unusual event. Come and help...come and watch...either way, you’re life will undoubtedly be touched by this moving tribute to the life of Chris Meanor, a very special man who struggled with the AIDS virus and left his mark on the hearts of many.

AIDS Caregiver Retreat

There will be an AIDS caregiver’s retreat at Pilgrim Lodge on Cobbossecontee Lake in Litchfield, Maine, Saturday and Sunday, September 28th and 29th. There will be a small registration charge, and registration forms can be picked up at The AIDS Project, The PWA Coalition, Maine AIDS Alliance, or Hospice of Maine, 175 Lancaster Street, Portland, Maine. For more information call: 774-4417.
Your Neighbor? Your Brother? Your Son?

He went off to camp this summer. Baseball cap in place, sleeping bag carefully rolled, clothes all washed, folded and placed in his duffle bag. Never been to camp before, he said. “Excited?” I asked. A brief nod of his head was the reply. No grin. Just a solemn look in those little boy eyes. A look reflecting the unspoken words. Words that said—

“I couldn’t tell anyone I was going to a camp because it’s a camp for kids with AIDS. It’s another secret I carry. And when I come back, it will remain a secret except I can talk about it with my mom—
or maybe tell half-truths to my buddies and hope they won’t ask too many questions.’

He sat in silence, reading a book as we drove up to camp—every so often looking out the window. A quick stop at McDonald’s. “Hungry?” I asked. A polite “No thanks—I’m o.k.” You see—he didn’t have very much money and his pride stood between a growling stomach and a Happy Meal.

I pulled the car into the camp parking lot and he insisted on carrying in his own gear. I watched the boy survey his surroundings and ‘heard’ his thoughts— ‘So this is camp. Will I know anyone? Will I be well the whole week I’m here, or will I run out of energy, and have to miss all the fun. If this camp is here next year, will I be?’

I drove home—tears in my eyes—tears of anger that he had so much to carry—carry in secret. Tears of grief that he was so solemn at a time that should be so much fun. Tears that this could be the first—and last year he went to summer camp.

JS

O.U.T. – Open Up and Talk
A new resource for children with AIDS

July 7 1991,

Dear AIDS Organization,

I just wanted to take the time to thank you all for helping me make my dream a reality. By you sponsoring us in going to Washington D.C. we were able to meet families from all over the United States.

While there Autum asked me why was she the only kid in Maine who has AIDS? I told her she wasn’t. She then asked why we didn’t know them? I told her because they were doing the same thing we are, we’re not telling anyone we have AIDS. She said that it’s not fair that we can’t tell anyone I told her she is right. It’s not fair!

Autum was like a normal child in D.C.. She was in a safe place. My children left there wanting to talk to kids in their state, and left D.C. with friends from other states. While in D.C. we also met people who were networking families and children together in their community. I left there knowing I wanted this for my family and community. So now I’m asking for you to help me start a family/children’s network. I am not a college graduate or a business person but I am a mother of children affected by AIDS. For 4 1/2 years I have looked for families who understood what it is like to have children affected by AIDS. I know families have and still are doing the same. By starting a network they won’t have to look far. I have talked to other families and some of the AIDS organizations and they all think it is a great idea. We can show the children they are not alone and that we care.

After years of putting together AIDS organizations for adults it is time to do the same for the children. I hope to hear from all of you soon. I would like to get together and fill you in on some of the idea’s we have about the network.

As you all know we had a camp for children affected by AIDS. At this camp the families and other people got together and made the network a reality. We are waiting for the state to open up again and we will apply for our non-profit number, which we already have the money for. We also have a board together made up of families and other people from the community. We also have a promise of a check of $1000.00 when we get off the ground so we can get started. Our second meeting is set for July 10, 1991. After that I can fill you in on more about the network. While at the camp we allowed the children to come up with names for the network. They and their families agreed on the name of,

O.U.T. Which means:
OPEN UP AND TALK

I will be writing again and letting you know the progress of the Children’s Coalition. For the time being it will be run out of my house. This means we have to wait for us to move to Portland. The move will take place Aug 1, 1991.

As I said before I will be in touch soon.

Thank you,

THERESA C. DANNEMILLER
The Matlovitch Society

Fall Calendar 1991

22 August: Rev. Rosemary Denman: Minister, activist, author, defrocked by the Methodist Church for being lesbian . . . “Spirituality and Sexuality”

12 September: Dr. Howard Soloman: Historian, writer, professor & co-chair of Lesbian/Gay/Bisexual Caucus at Tufts University . . . “Studying Lesbian and Gay History: Where Do We Begin?”

26 September: Majorie Love: Executive Director, The AIDS Project . . . “Out At Work: Small Town Lesbian Executive Moves to the Big City”


14 November: Dr. Marvin Ellison: Professor of Christian Ethics and Director of Theological Studies, Bangor Theological Seminary, co-author of recent paper on sexuality in the Presbyterian Church . . . “Common Decency: A New Christian Sexual Ethic”

12 December: Lois Reckitt: Legislative Chair, Maine Coalition for Family Crisis Services, moderating a discussion on “Domestic Violence in the Lesbian and Gay Community”

Programs are held: Third Floor Conference Room
Portland Public Library, 5 Monument Square
7:30 - 9:00 P.M.

A Summer of Brothers

Mary Shotwell was the Coalition’s first summer intern. This fall she will be going into her second year at Harvard Divinity School.

Dear Brothers (and Sisters too!):

When I first came to the Coalition in early June I was very weary inside. Exhausted from my first year at divinity school, my spirit and body just wanting a rest. Instead of putting out energy, it seems, I been the recipient of all of you energies all summer. You are the brothers I didn’t even know I needed (a few sisters too!) You all taught me that ministry is about receiving.

I have many memories of wild, crazy, sad, angry, hilarious moments and can’t write them all, but I have a few highlights you might recall...

My second week, I still felt new and a little shy. As an offering I bravely attempted a marble cake for Wednesday night supper. The middle caved in, the inside erupted making huge craters, and frosting everywhere. I was mortified (they’ll send me back!) I wanted to throw it out. You wouldn’t let me. You told me it was fabulous, an exquisite volcano cake (to memorialize the recent Philippine volcanic disaster, no doubt.) How timely, you said. And is was gone, honesys, straight into your bellies with big smiles and, “when is your next cake, girl?” You lifted me up.

We went for a walk in your garden, I think a very personal space for you. Each new growth you pointed out and you patiently answered all my questions. I can see clearly why you are so alive. After, one of the all time best vegetarian meals I have ever eaten (a sacrifice for you, an intense meat eater) served with fresh herbs from your garden. You nurtured me.

You trusted me with your faith. You are the most alive people I know. You are the brothers I don’t have but you accepted me just the way I am. You kept me grounded.

You made me a hero. You made fun of my Quaker wardrobe even when you saw it face to face at the laundry mat. You dress like a fashion model and I like a Goodwill Queen but you accepted me just the way I am.

You cried something that would make me laugh. You made me laugh. We laughed all the way through The Lodging House BBQ. My stomach hurt from laughing especially when the plate you had painstakingly filled up with every kind of dessert slid accidently in the garbage. You went on undeterred and filled up that second plate: Why not? You’re hot! You shared your passion for laughter.

My favorite disaster was the exploding, bouncing, quaking, shaking washing machine. Chatting upstairs we heard strange loud noises. The three of us ran downstairs into the Coalition basement. Thump, thump, thump that thing was ALIVE! I dove into the bathroom and turned it off as the top bounced high in the air. Don’t go in there, don’t go in there, you yelled. I came out in one piece. You cried. Something in the Coalition Newsletter, and T. tickled me and we laughed, laughed, laughed.

You made me a hero. You made fun of my Quaker wardrobe even when you saw it face to face at the laundry mat. You dress like a fashion model and I like a Goodwill Queen but you accepted me just the way I am.

Every time I struggled to open something, the fridge, the file cabinet. I sweat, and sweat, and then despairingly, regretfully ask you for help. You only touch it and it opens. We always laugh then. Your patience, clarity, and calmness kept me grounded.

Confidentially you told me about your belief in God, and I was surprised. I never tried to put that between myself and anyone. I had been considering that I had been spending too much time laughing while people are dying. You trusted me with your faith.

(I took a workshop my last week, with an AIDS healer, John Calvi. from Putnam, Vermont, and he said something like: all the passions live in the same neighborhood, joy, fear, anger, love. If you visit one, chances are good you can visit another that lives nearby.)

I stopped worrying about being in the wrong neighborhood. You lifted me up. You nurtured me. You laughed wicked hard with me. You made me a hero. You accepted me just the way I am. You kept me grounded. You trusted me with your faith. You are the most alive people I know. I no longer feel tired, but quite blessed by you, brothers I love you, Mary.