The Scoop, Vol.3, No.5 (May 1991)

June Seamans
PWA Coalition

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MAY 1991

NAPWA REGION 1 CONFERENCE
HERE IN PORTLAND

by Thom Alan

Nutrition and HIV, visualization, herbs and healing, vitamin therapy, and women and HIV, just a few of the topics for discussion during a three-day regional conference to be held in Portland.

After months of planning, The PWA Coalition of Maine will play host to the Region 1, NAPWA Northeast Regional Conference, May 17 - 19, 1991. This will mark the first time that NAPWA, (National Association of People With AIDS), has chosen to sponsor a conference in Maine. Region 1 covers most of the Northeastern United States, and planners expect visitors from as far away as New York state, Massachusetts, Rhode Island, Vermont, and this year even Nova Scotia.

The focus of the Spring conference is to address the physical, emotional, and spiritual needs of persons living with HIV. This intensive weekend of workshops will cover a wide variety of self-help skills that each person can tailor to his or her specific living needs. Workshops have been carefully planned, to include a wide variety of subjects, and to provide as much information as possible in limited time.

Each of the workshops will be facilitated by a person who has a proven track record in his or her area of expertise. Since the conference is for people currently living with HIV, the focus will be very specific...How do I live with AIDS?

Living with AIDS touches more than just one area of a person’s life. Besides a nutritional diet, appropriate medical treatment, physical therapy, vitamin therapy, and perhaps alternative medicines, substance abuse issues, and spiritual needs will need attention. Some of these areas of concern for a person with HIV have never been addressed. We too often go through our lives making quick decisions, and snap-judgments, taking little time to think of the long-term effects on our future.

However, for people with HIV, the issues change quickly. It becomes essential to extend life, and to insure a quality living for that period of time. (A proper diet is not always considered when thinking of what to have for lunch.)

They may still be seeing the same Family Physician that their entire family has used for years. That extra beer has never been a problem, so why not have another? Their church hasn’t given them much support through the years, so they just stopped going, and try not to think about that part of their life.

Now, faced with the threat of dying, things take on new light, and the answers to questions are, for some reason, not as easy as they used to be. What has changed? For the person with AIDS....everything.

People’s attitudes on AIDS have, surprisingly enough, not changed at all that much. The stereotypes of people living with AIDS continue to be a stumbling block for the people living with the disease. The notion that “AIDS is only contracted by GAYS and IV DRUG USERS” still runs rampant.

The full impact of AIDS in women and AIDS in children has not yet set in. It is still not possible for persons with AIDS to tell just anyone that they are sick. Friends who used to come around, all of a sudden don’t come around anymore. Family members who used to be close, seem to shrug their shoulders or pull away a bit, and they don’t call as often as they used to. And having to cope with this life-threatening disease on top of all that is a heavy load for anyone to carry.
The skills that this conference will touch on will enable and empower the participants: empower them to move forward, to make decisions, to make more decisions, to organize their lives better and easier, and to take more control of their lives. We think that they will go away from the conference with enough information, and with enough of the skills needed to tackle the issues that may not have been clear to them until now. Sometimes, just knowing that others are struggling with the same things in their lives is encouragement enough.

Don’t get the wrong idea; the conference won’t be all work. The PW A Coalition has put together an information packet for conference-goers that will introduce them to everything happening in Portland during that weekend. Maps of Portland attractions, entertainment, hotels, and meeting places will be included in the packet. In addition, several break periods are scheduled during each day of the conference to allow for refreshments and discussion. All meals are included in the conference. Meals are being provided throughout the weekend by the PW A Coalition of Maine, Portland, and the Immanuel Baptist church of Portland.

The NAPWA conference is being limited to a total of 50 people. Registration is required by May 3, 1991. To guarantee space, I suggest that you get your registration form in quickly, as the spaces will be filled quickly. Conference registration and a Conference schedule is included in the information on page 6 in the center portion of this newsletter.

AIDS can be a very lonely disease. To be able to pick up the pieces of your life and go on is probably the biggest test of all.

**ALMOND EYES**

*by the mother of a child with AIDS*

" Somehow I knew
She had AIDS."

In 1986 my boyfriend’s family called me to tell me he was dying of AIDS, and I should get tested. In 1986 the doctors didn’t think that I would test positive for the AIDS antibodies, because women just didn’t get AIDS.

I called my doctor and set a date to be tested. After two weeks, my doctor’s office called me and told me I should come in for the test results. They told me I had AIDS and that I had one year to live.

After hearing I had AIDS, I had another worry, my daughter, who had been born during our relationship. The doctors felt, due to the fact that she was two years old and still alive, there was no way she could have been exposed to the HIV virus. Maybe because I wanted to believe that she was safe, I didn’t push the matter further.

In January, 1987, my little girl became sick. I took her to the doctor and was told she had the flu. I went home and watched her get worse. Two weeks went by, she was no better. I took her back to the hospital. This time I told them her father was dying of AIDS and I had tested positive for the virus, and this time I wanted her tested. I was sure, somehow, that she, too, had AIDS.

The hospital put us in a part of the hospital that was no longer being used. After two hours in this empty room, they found a doctor who would treat my daughter. He was a very caring man, decided to admit her to the hospital, and ran the battery of HIV tests. After four days she was well enough to go home.

A week later we went for the results of the tests. The doctor told me her test showed she had been exposed to the virus. I thought my world had come to an end. I was told my daughter was going to die.

I knew I had to stay alive to keep her alive. My little girl became very sick, but fought off the illnesses.
ALMOND EYES

Continued from Page 2

Today my daughter is five years old; in a few weeks she will be six. The doctors never thought she would make it to school age. By the grace of God, and my daughter’s will to fight the disease, she is going to see her sixth birthday.

I look into my little girl’s Almond Eyes and see the gift God has given me. Her Almond Eyes give me the strength to educate young people to the dangers of AIDS. I let them know that AIDS can happen to them if they are not safe. She has shown me that having AIDS doesn’t mean I’m dying, just that I have to make new decisions for my life, to insure a healthy life for the time that God allows for me.

A birthday for us is a very happy time... it means we have beat AIDS one more year. It is also a scary time for us. The oldest living child with AIDS is eleven this year. This means that I may have only five more years with my little girl. I know I should be thankful for what God has given us, but I wish she didn’t have to die.

Through my little girl’s Almond Eyes I have learned how special life is, and how important my family and friends are.

To all of you who have been told that you are dying of AIDS, tell them “No... I’m living with AIDS.”

With Love,

The Mother of Almond Eyes

A DELICIOUS FRAPPE’

by Eric Loranger

With Summer fast approaching, many of us are concerned about looking “good”, which in our crazed society translates “thin”.

However, for those of us who are HIV+, it’s important to keep on a few additional pounds in reserve, just in case we unexpectedly need them.

Toward this goal, indulge yourself in this nutritious, as well as delicious, frappe’. In a blender mix:

- 8 oz. whole (or no less than 2%) milk
- 2 eggs
- 1-2 tablespoons malted milk powder
- Dash of Vanilla
- 4 scoops of French Vanilla ice cream
- 1 packet Carnation Instant Breakfast

Mix Together... and enjoy!

MAY WISH LIST

The wish list for the next few months will take on a different look than in the past few issues of The Scoop.

The Furnishings Committee for the Coalition met in mid-April to discuss plans to re-furbish “The Space” over the next few months. We decided to go at it one room at a time. So for the next few issues we will publish just the items needed to complete work on the project under way.

This month, in preparation for the up-coming conference in May, we will be working on the living room. We would like to make the room as comfortable as possible, yet versatile enough to use during meetings or dinners.

The list of items needed is as follows:

- Four 84” long sofas
- Four club chairs
- Four six foot banquet tables
- 25 folding chairs

As you can see, there’s not all that much needed to complete our re-decorating. If you have any of the items above, and would like to donate them to the Coalition, call us at:

The PWA Coalition of Maine

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

Remember... All donations are tax deductible!

THANKS AGAIN!!
From My Corner of The Office
by June Seamans

The past few weeks I've been writing letters and making phone calls, working on getting the NAPWA Conference all squared away, and a thought came to me in the middle of all this confusion - for people living with HIV, the decade of the 80s was a time of giving ourselves away - to agencies, physicians, fears, whatever.

Now as I enter the decade of the 90s, I see a time for taking ourselves back. The movement toward self-empowerment has begun to take hold.

Whether it is action through involvement with a group or on our own, slowly we have come to believe that we do indeed have control over our lives. PWAs are questioning medical treatments, social security allotments, and have begun charting their own courses.

The people who have worked to put this conference on, the people who have agreed to act as presenters, support persons, the time spent redefining our direction - all point toward this spirit of empowerment. We have truly become people LIVING with HIV, not people accepting a terminal diagnosis.

Maybe it's Spring in the air and that's why I can sense this, or maybe I am an optimist...or just maybe this is the reality of today. Whatever it is, I know it's neat...and I want to see more where this came from!

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THE PWA COALITION
OF MAINE

and

THE LIVING ROOM NORTH

are located at

377 Cumberland Avenue
Portland, Me. 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 your name or organization name to our mailing list. We appreciate your need for privacy and will protect your right to privacy by not printing references 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 providers 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.
COALITION ELECTS NEW V.P.
by Thom Alan

In a unanimous vote, the Board of Directors of the PWA Coalition of Maine, nominated and elected Max Bartunek to the position of Vice-President of the Board.

Max is originally from North Dakota, has been in Portland for the last 2 1/2 years, and has served as a member of the Board of Directors since December of 1990.

I had a chance to talk with him earlier this month, and was surprised that one person could be involved in so many areas that support the Coalition, so I thought I'd write something about him in this month's newsletter.

When he first approached the Coalition to offer his time, I'm sure we had no idea that he would be able to bring so many talents with him. "I really didn't know where I could make a difference," he told me. "I wanted to be a positive presence, but wasn't sure where I would fit in." Well, it didn't take long for him to get in gear.

He became involved with the AIDS Quilt, and from there moved on to an active role in projects such as the M.A.A. Walk, raising much needed funds for the Coalition; the Bike-A-Thon (for which to date he has received over $700.00 in pledges); the NAPWA Conference, and workshops in the U.S. and Canada on AIDS Mastery, (A project that Max is actively involved with, and hopes to bring to Maine in the near future).

Probably the most striking thing about Max is his warm smile. After talking with him it becomes clear where it emanates from. Max has an agenda for his life that includes more than just getting by. His philosophy is that whatever you choose to do in life is possible as long as you are willing to put your heart and soul into it.

What is it that you see in most of the people we serve? "I think it is the feeling that life is over now that they know they are infected with the HIV virus. This is definitely not the case...there is life after Diagnosis. How do I know? I've seen it in the faces of people who have picked up the pieces of their lives, and decided to make the best out of the time they have. I know that each person has the resources within themselves to keep their self respect, and project a person who is whole, and loveable, and still capable of loving others."

"My goal for the people we serve at the Coalition is to see that every person that comes through the door gets the chance to visualize themselves as important, and that they have friends that they can rely on, and that they have a chance to realize their full potential here."

Max has impressed me as one who really believes what he talks about, and lives it. His positive attitude affects many people, as it did me...I'm sure the Board made a good choice.

If all of that wasn't enough...Max even takes the trash out at the Space every Wednesday evening after dinner...Tom Lyons jokes with Max that he's delighted that we finally have a Vice President in charge of all the Coalition trash...what a guy, huh!

THE AIDS PROJECT
THURSDAY LUNCH
11:45pm - 12:45pm

Did you forget?
Every Thursday we serve a delicious hot meal with bread, salad, and yummy desserts!
Come relax and chat with friends and staff over one of our tasty and nutritious dishes.
And...the coffee's always hot!!

Call ahead if you need a ride...

We also have a freezer full of delicious, individual, pre-cooked meals for you to take home and enjoy.
All prepared by the folks at First Congregational Church in South Portland.
The NAPWA Northeast Regional Conference is being organized this year by the PWA Coalition of Maine at The Living Room North, in Portland, Maine. The conference is intended for people with HIV only.

The focus of the Spring conference is to address the physical, emotional and spiritual needs of persons living with HIV. Presenters from Maine, Vermont and Massachusetts will offer workshops on nutrition and HIV, visualization, herbs and healing, vitamin therapy, Chinese medicine and acupuncture, healing the spirit, AIDS and substance abuse, networking in New England and Canada, and a forum; Women and HIV.

All meals will be provided, and housing and mileage costs will be partially underwritten through a grant from NAPWA.

Conference spaces are limited to 50 participants, and people are encouraged to register as soon as possible.

A conference packet including a map of the Portland area, hotel arrangements, and detailed information on the workshops will be sent upon receipt of your registration.

Registration is required by May, 3, 1991 to guarantee space. If you have any questions, call the PWA Coalition of Maine at: (207)-773-8500.

**NOTE**

The AIDS Candlelight March and Memorial Service will be held beginning at 6:00 PM on Monument Square in Portland. All conference attendees are invited to attend.

**SCHOLARSHIPS**

A limited number of scholarships are available to defray a portion of the housing and travel expense.
PRE-REGISTRATION  
NAPWA NORTHEAST  
REGIONAL  
CONFERENCE  
MAY 17-19, 1991  
Hosted by the PWA Coalition of Maine

Name

Address

City/State/Zip

Telephone

HOUSING INFORMATION

Requests must be received by May 3, 1991. Cost is $25.00 per person, all meals are provided.

___ I will share with others registered
___ I want to share a room with:

Special Needs

___ Signing for Hearing Impaired
___ Wheelchair Accessibility
___ Other _________________________________________

Donation

___ I cannot attend the conference, but want to contribute to its success with a donation

Volunteers.

There is still need for more volunteers to assist with set up for the conference and for food planning and preparation. If you would like to help give us a call: (207)-773-8500

PEOPLE WITH AIDS  
COALITION OF MAINE  
377 CUMBERLAND AVENUE  
PORTLAND, MAINE 04101  
(207)-773-8500

The PWA Coalition of Maine represents people from across Maine now living with HIV and AIDS. As PWAs we have a unique and essential contribution to make to the dialogue surrounding AIDS. We are actively participating with full and equal credibility to help shape the perception and reality surrounding this disease.

We work actively with other AIDS services and community organizations to enhance services already provided and to present AIDS with a human face. We offer hope, our hands, and our hearts - for the tradition of neighbor helping neighbor is the essence of our humanity.

LIVING ROOM NORTH

Our drop-in center in downtown Portland, Maine, serves the needs of persons living locally as well as those who must travel long distances for medical treatment. By offering a safe space to meet with other people living with HIV infection, we can facilitate the unique and vital support that PWAs can offer each other.

THE SCOOP

In our efforts to reach out state-wide, we print a newsletter that informs organizations working with PWAs on the local, state, and country level about our drop-in center and other programs that may be of special interest to them.
From The Editor's Desk

by Thom Alan

I’m sure that you’re aware that it isn’t easy to compress your thoughts each month into an 8 1/2 X 11 piece of paper, and still cover all the things you need to. It’s also not easy to keep from bitching; after all, I’ve got a captive audience.

Well, this month I’ve decided to take time not to bitch; instead, I want to focus on a more positive side of things at the Coalition.

I’m speaking about some of the incredible people that I come in contact with each day. These people sometimes seem to be part of the furnishings. (If you’ve seen some of the furnishings at the Coalition lately, you’ll know that they are becoming worn and tattered.)

And sometimes, I suppose, these people have the same look. But the most outstanding thing about them, is that they are there. And strangely enough, most of the time they look pretty good; at least for me it feels good to see their faces when I come through the door.

To acknowledge a person for who they are is not to say that there aren’t things about them that rub you wrong. But it’s a chance to highlight the positive, to say thanks, that’s really nice, and I’m glad you did that... God knows I don’t have the time.

When talking about David Charity, Tom Lyons, and Barry Prentice, you immediately think of them being right in front of your face every time you go through the door at the Coalition. These three people literally keep the doors open week to week. Their efforts are almost taken for granted, and the second one of them goes home for five minutes, someone asks where they are. I guess that’s because we all depend on them so much.

These guys never seem to ask for much. I’m not sure if that’s because they’ve been there so long, or that they just know where everything is, and how to get things done themselves.

I’ve always thought a person’s time is as good as money, and these guys have given a bundle! But for them it doesn’t seem like that big of a deal.

So guys, if no one else mentions it to you, I really appreciate who you are. You keep me laughing in the face of everything that’s going on, and my job is a lot easier by you being there...Thanks!!

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 mail with incorrect information. Please keep us informed of any changes by mailing the form below.

NAME

GROUP/BUSINESS NAME

ADDRESS

CITY STATE ZIP

TELEPHONE (optional)

☐ NEW SUBSCRIPTION

☐ DELETE NAME FROM MAILING

☐ NAME/ADDRESS CHANGE

Mail completed form to:

PWAC 377 Cumberland Ave., Portland, Me. 04101

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 a money order made payable to:

The PWA Coalition of Maine

377 Cumberland Avenue
Portland, Me. 04101
The following is a schedule of appearances this month:

**COLBY COLLEGE - WATERTOWN**
May 2, 1991
10:00 AM - 3:00 PM
Contact: Nicki Vaydeboncure - 877-7931

**COLLEGE OF THE ATLANTIC**
**BAR HARBOR**
May 6, 1991 through May 9, 1991
For Times contact:
Martha Greenley - 288-5015

**CATHEDRAL CHURCH OF ST. LUKE**
**STATE STREET - PORTLAND**
May 19, 1991
6:00 PM - 9:00 PM
8th Annual International AIDS Candlelight Memorial
Contact: David Ketchum - 934-4997

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**A STORY FROM THE QUILT**
*by Debb Freedman*

Once upon a thyme, and not so long ago, a daring or foolish young princess set out to share with the world a life form unlike any other.

She had sent out a call in the kingdom, a call spread by the eagle by day and the owl by night, for any human being who had lost someone to this new illness;...to search their hearts for the words, pictures, patterns that would remind them of the person lost, now to be found.

You have the power to create this new life form, but in doing so, you must give it away. Not many had the courage, at first, to trust this call for life. The process brought many tears and doubts. How could something made of fabric, paint, and paper live? But their hearts were so full of the loss, just writing a name brought a smile and they could begin to remember, each in their own way.

Every day and night the eagle and the owl would come by, everyone's eyes to the sky, and ask if they were ready.....not yet. Yet a strange thing happened; as people began looking to the sky in their fear of the panel being taken to soon, they began to notice the coming of the evening star; the changes in the color blue of the sky until it appears, the pattern of the stars at night and the morning star at daybreak.

It gave them the courage to let go. Yes, the star lives on, even if you don't see it all the time. So each time the evening star appears...they can remember...each in their own way.
8th International AIDS Candlelight Memorial and Mobilization

8ème Commemoration et Mobilization Internationale pour une Solidarité avec les Malades du SIDA

8a Vigilia y Mobilización Mundial en Solidaridad con las Víctimas del SIDA

8a Vigília e Mobilização Mundial em Solidariedade aos Portadores da AIDS

Sunday, May 19, 1991

Join us:

6:00 PM  CANDLELIGHT GATHERING AT MONUMENT SQUARE - PORTLAND AND MARCH TO ST. LUKE'S CATHEDRAL - ON STATE STREET

6:30 PM  MEMORIAL GATHERING AT ST. LUKE'S CATHEDRAL

* The Public is encouraged to participate
* The Memorial Gathering will be interpreted for the hearing impaired.

A Worldwide Day of Solidarity for People With AIDS Organized by

MOBILIZATION AGAINST AIDS
1540 MARKET STREET, SUITE 160
SAN FRANCISCO, CA, USA 94102
TEL 415-863-4676 FAX 415-863-4740

GAY AIDS ACTIVISM
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FOR ADDITIONAL INFORMATION ON EVENTS CALL: (207) 773-8500

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