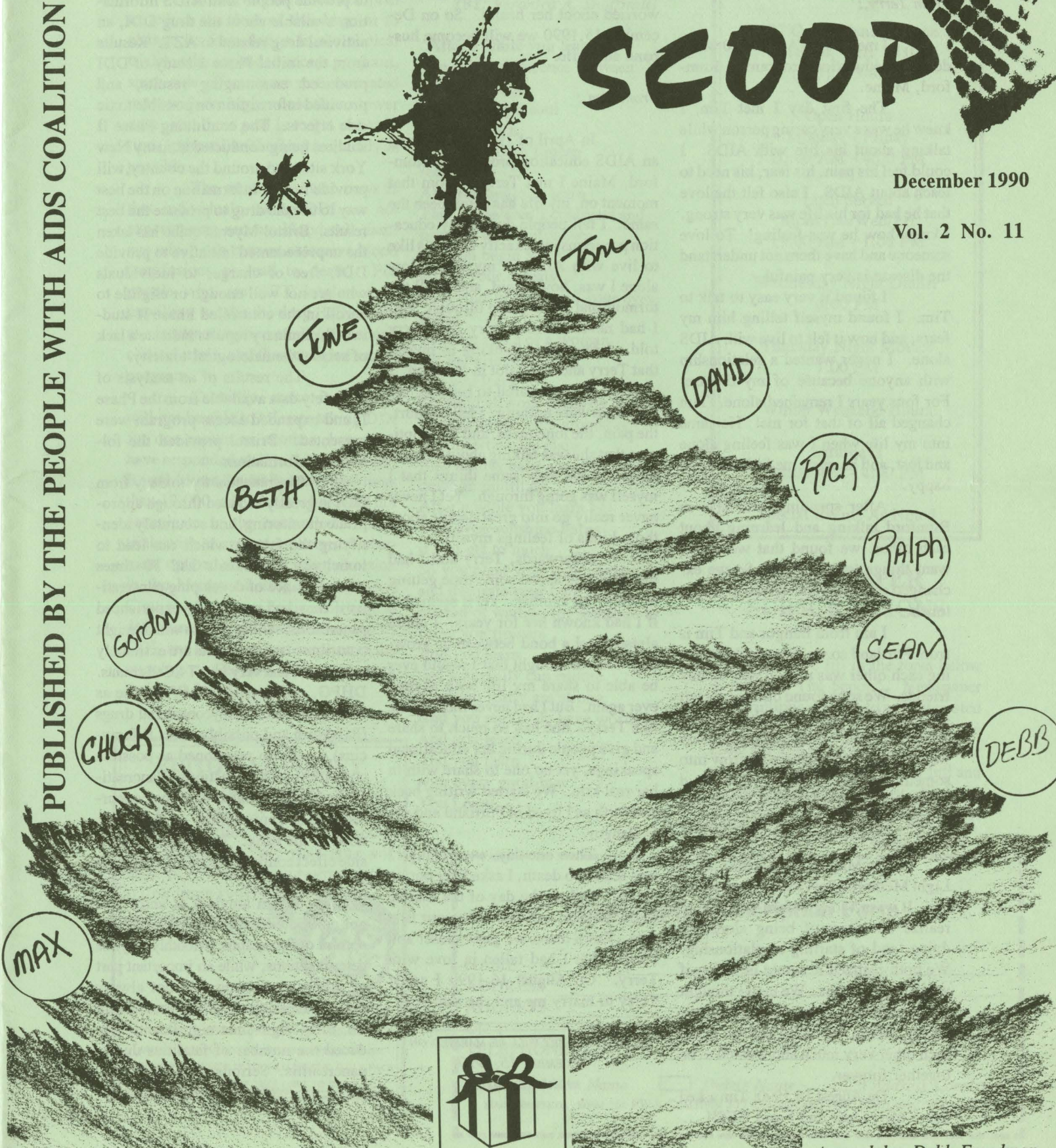


PUBLISHED BY THE PEOPLE WITH AIDS COALITION OF MAINE

THE SCOOP

December 1990

Vol. 2 No. 11



Tom

JUNE

DAVID

BETH

Rick

Ralph

Gordon

SEAN

CHUCK

DEBB

MAX



Artwork by: Debb Freedman

THERE IS LIFE AFTER AIDS

From Terry,:

I met Tim in April 1990 while doing an education program in Rumford, Maine.

The first day I met Tim, I knew he was a very caring person while talking about his life with AIDS. I could feel his pain, his fear, his need to teach about AIDS. I also felt the love that he had for his life was very strong. I knew how he was feeling! To love someone and have them not understand the disease is very painful.

I found it very easy to talk to Tim. I found myself telling him my fears, and how it felt to live with AIDS alone. I never wanted a relationship with anyone because of my disease. For four years I remained alone. Tim changed all of that for me! He came into my life when I was feeling alone and lost, and he made me feel alive and happy.

After spending two days in Rumford talking and learning about each other, we found that we didn't want things to end there. So we exchanged addresses and agreed to stay in touch.

I am from Bangor and Tim is from Portland so we thought that writing each other was a good way to stay friends. We soon found out that we felt and thought the same way about alot of things. It wasn't long before we knew we wanted our friendship to grow into something more. Still, we were afraid of hurting our friendship by becoming lovers. Yet we also knew we wanted to be together.

On May 20, 1990 at the Candle Light Memorial Service we started dating. It wasn't long before we came to realize our fears of being alone, of dying, and of starting a relationship. We both realized it would be easier if we joined together. We never thought about marriage, just about being together. Soon, we found that we loved each other very much and wanted to be together forever.

On August 16, 1990; Tim asked me to marry him and I said YES!!....

We wanted to wait until May of 1991 for the next Candle Light Service but I wanted my youngest daughter (who is also a PWA) in the wedding and was worried about her health. So on December 15, 1990 we will become husband and wife.

From Tim,:

In April of 1990 while doing an AIDS education program in Rumford, Maine I met Terry. From that moment on, my life has never been the same. I tell people during my education programs just exactly what it's like to live with AIDS in my life. How alone I was, how afraid, and of all the turmoil that I was going through. But I had never heard a story like Terry told. I remember thinking to myself that Terry and I had alot in common. I also felt that compared to her life, my problems were nothing. I felt the hurt, the pain, the loneliness, and the emptiness that she was talking about because those are the very same things that I myself was going through. Yet I never really go into great details about those kinds of feelings myself.

Afterwards, Terry and I had the chance to spend some time getting to know one another. Yet it seemed as if I had known her for years. I could already feel a bond between us growing. I never thought that I would ever be able to share my life with anyone ever again. But I had never met anyone like Terry. She had so much to share and give people during her educational speakings, yet no one to share with in her real life. We started writing back and forth as I lived in Portland and she in Bangor.

Then one day, even though I was scared to death, I asked her out on a date. And on the day of the Candle Light Service, we went out on our first date. From there, we grew closer and I knew that I had fallen in love with Terry. On August 16, 1990 I asked Terry to marry me and she said yes.

TIM AND TERRY WILL BE MARRIED ON
DECEMBER 15, 1990
IN BANGOR, MAINE

DDI UPDATE

CRI held a forum on July 31, to provide people with AIDS information available about the drug DDI, an antiviral drug related to AZT. Results from the initial Phase 1 study of DDI produced encouraging results, and provided information on possible toxic side effects. The continuing Phase II studies, being conducted at many New York sites and around the country, will provide further information on the best way to use the drug to produce the best results. Bristol-Myers Squibb has taken the unprecedented initiative to provide DDI, free of charge, to individuals who are not well enough or eligible to enroll in the controlled Phase II studies. Preliminary reports indicate a lack of serious hematological toxicity.

The results of an analysis of the safety data available from the Phase II and expanded access program were presented. Bristol provided the following information:

The potential for toxicity from DDI is greatly reduced through appropriate monitoring, and accurately identifying the factors which can lead to toxicity. Individuals had 30 times greater chance of developing pancreatitis if they had previously experienced pancreatitis. Other factors which might contribute to side effects are extremely poor health and very low T4 Cell counts. DHPG, and possibly CMV disease as well, and some antimycobacterial drugs (Rifabutin and possibly other Rifamycins) were also mentioned as possible cofactors in toxic reactions. Pancreatitis was not associated with the concurrent use of Pentamidine, or the higher dose of the drug. The most common side effect continues to be diarrhea and/or stomach upset.

Serum amylase at entry was not correlated with subsequent development of Pancreatitis. Monthly amylase determinations, while an important part of safety monitoring, did not always detect pancreatitis. Close monitoring for early signs has significantly reduced the number of fatalities due to pancreatitis. Serious peripheral

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neuropathy is avoidable by discontinuation of the drug at the earliest symptoms.

Bristol-Myers does not plan to reduce the dose of the drug, or to change its formulation in the clinical trials or the expanded access program, since side effects were not associated more with the higher dose than a lower dose, and their goal is to get registration (approval) of the drug as quickly as possible.

The most important news is that individuals taking DDI are not experiencing serious blood cell damage which can require extensive blood transfusions or lead to death. For people who are AZT intolerant or unwilling to take the drug, DDI exists as a treatment option available through clinical trials, and the expanded access program.

Certainly, some individuals will not be able to tolerate taking DDI for one reason or another, but many have responded well to the drug so far. Bristol-Myers Squibb has provided more than 10,000 individuals who could not participate in the controlled clinical trials with an, as yet, unlicensed treatment option, an unprecedented action in the history of drug development. Continuing clinical trials will help to determine the ultimate usefulness of DDI, and increased participation in the ongoing studies will help us to reach that goal faster.

AFTER A WHILE

(BY: Veronica A. Shoffstall)

"After a while you learn
The subtle difference between
holding a hand
and chaining a soul
and you learn
that love doesn't mean
security
And you begin to learn
That kisses aren't contracts and
presents aren't promises
and you begin to
accept your defeats
with your head up and your eyes
ahead
with the grace of a woman
not the grief of a child
and you learn
To build all your roads on today
because tomorrow's ground is
too uncertain for plans
And futures have a way of falling
down in midflight
After a while you learn
That even sunshine burns
if you get to much
So you plant your own garden
and decorate your own soul
instead of waiting for someone to
bring you flowers
And you learn
that you really can endure
That you really are strong
And you really do have worth
And you learn
And you learn
with every good-bye
You Learn..."

The PWA Coalition of Maine
Living Room North

IS LOCATED AT

377 Cumberland Avenue
Portland, ME 04101
(207) 773-8500

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

Luch Served
Mon/Tue/Wed/Fri
11:00 AM - 1:00 PM

Wednesday Night Dinner
6:00 PM

Thursday Night Movies
7:00 PM

Winter Weekend Hours

Saturdays
11:00 AM - 4:00 PM

Special Events As Noted

NEWSPAPER SUBSCRIPTIONS

Please fill in the form below to receive "The Scoop". Newspaper subscriptions are free to any interested individual, group, or business. In order for you to receive the newsletter you must provide us with your full and complete address. The Post office will not forward this newsletter if you move. Please keep your address up to date.

EDITORIAL POLICY

THE PWA COALITION NEWSLETTER MAY REPORT ON EVENTS THAT ARE GOING ON WITHIN THE STATE OF MAINE (AND ELSEWHERE), BUT THAT DOES NOT MEAN THAT WE AGREE OR PARTICIPATE IN ALL OF THESE EVENTS.



IF YOU SEE SOMEONE WITHOUT A SMILE
GIVE THEM ONE OF YOURS.

(AS THE NEW PUBLISHER OF THE NEWSLETTER MY ONLY RESPONSIBILITY IS TO INCLUDE THE SMILE FACE AND THIS IS THE FIRST TIME I GET TO DRAW IT.)

Newspaper Subscription Form

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MAIL COMPLETED FORM TO: PWA COALITION 377 CUMBERLAND AVE. PORTLAND, ME 04101

CHRISTMAS CHOIR

(Caroling, Caroling)

Can you sing? Can you play an instrument? Why not join the group now forming at the PWA Coalition to start their Christmas Caroling Choir. Join together with Ed Wiemert and David Charity and all the gang to get together for a good time and celebrate the holiday season. For more information please contact the Coalition for practice times and dates. (207) 773-8500.

ADVERTISEMENTS

This advertisement space is provided FREE of charge to PWA's on a space available basis. All ads are subject to edit for reasons of space.

LOW INCOME APARTMENT.

Low Income Apartment to share. Available November 7, 1990. Luxury highrise apartment located in downtown Portland. Looking for quiet, non-smoking, male-or-female, to share great apartment with me, my two cheshire-like cats and one playful pooch! Your own private room in a luxury highrise apartment with pool, sauna & health club. The large sunny room is carpeted and has plenty of storage space. Rent is \$163.00 per month plus heat, hot water and utilities (electric, cable, and phone average about \$50.00/mo.) This apartment is a real find!!! For further information contact:

CHRIS AT 874-2843

(income must be under \$8,000 per year and verifiable.)

HELLO NEW FRIENDS

This is your note, the words I'd like to share are true. If my brother Vinny were around today, he'd be here too.

The friendships you 'all here have shown me, and my family, we are ready to share back to you all.

E.J. & Lynne

(E.J. & Lynne are new friends to the Coalition. Stop by and meet them.)

BOARD RETREAT

NOTE TO ALL BOARD MEMBERS

Our annual board retreat has been scheduled for Saturday January 12, 1991. Please mark your calendar and save this day for a very important meeting. The meeting will be held at Debb Freedman's home in Yarmouth. Contact the coalition for directions. This meeting will start early in the morning and will continue through till 6:00 PM or later. This meeting will establish our budget (and budget shortfall) along with some important goal planning. Each member from the board of directors should plan to attend and be prepared with input for future growth and development projections. Lunch and snacks are to be brought to the meeting for a little picnic as we will only break for a short lunch. After the business is finished (and not a moment before) we will most likely all go out for dinner together. If you have input to this retreat please let one of the Executive Board Members know so that an agenda may be drafted. Hope to see EVERYONE there.

NAPWA NOTES

For any PWA/HIV person who is interested in public speaking/AIDS educational speaking, NAPWA is looking for you.

NAPWA has sent the Coalition information about their growing speakers bureau. They receive calls throughout the country, from large corporate groups to local youth group meetings, requesting someone to speak to their groups concerning AIDS education. While some of these engagements involve honorariums, they always give the speaker the sense of satisfaction knowing they have changed the lives of their audience.

For more information or to receive an application and survey, please contact the Coalition or call Christina Lewis at NAPWA toll free at:
1-800-866-2792

NUN SENSE

BENEFIT PERFORMANCE

Wednesday January 30, 1991

at

Portland Player's
Phyllis Baxter Theater
South Portland, ME

Limited Number of Tickets

Ticket Price \$13.00

Tickets are available at:
PWA Coalition of Maine
377 Cumberland Avenue
Portland, ME 04101
(207) 773-8500

for more information please call

The Coalition

or

Chuck Sawyer at 657-4252

SPECIAL GROUP

A special interest A.A. meeting has formed for People Living With AIDS which meets weekly on Tuesday, 8:00 PM at The PWA Coalition.

This meeting is designed to provide a safe space in which to discuss our HIV issues while living Positively Sober. For more information please feel free to call:

MAX at 871-9211

IN LOVING MEMORY

Tim McCue

1965 - 1988

*He flings his past behind him
like a robe worn thread bare.
But his new robe shall be
richer than the old.*

Love, Mom

FOOD PANTRY NEWS

(By: David Charity)

As many of you know, our food pantry at the Coalition was in great need. Over the past few weeks, my concern was for the up and coming winter months. It also made me wonder about what to do for our hungry brothers, sisters, and children. How are we going to be able to provide emergency food for these people when we are having trouble as it is now.

Begging, digging, and pleading with other food banks for information, applications, and policies I began addressing the problem. Filling out applications, going through orientations and meeting other people from other food banks, I began to see the bright light at the other end of a deep dark tunnel.

We are finally on our way. We have been approved to receive state surplus foods, as well as being able to draw surplus items from other food bank programs in the State of Maine as well as one in Boston, Mass.

This does not mean our battle is over with yet. We still need your support to help fund this important program. We also still need your food and other donations to keep up with the growing demands we now face.

Our case load is growing by the day and we are grateful to be able to help those individuals in need. Each can of food or other items you may have to donate will make the life of a Person Living With AIDS in Maine a little easier.

Donations can be dropped of at The PWA Coalition 377 Cumberland Ave, Portland, ME 04101 between the hours of 10AM-4PM. Weekend hours sometimes vary due to other activities going on, but in general someone is usually there on Saturday's from 11AM-4PM and the same on Sunday's. If possible canned goods should be in the 1-3 person serving size, but larger sizes will also be used. Let's hope that no person will ever be without food again. Thanks.

WISH LIST

Due to cold winter weather our needs have grown. There should never be a reason for a person to go without food or warm clothing. Please remember this as you go through closets full of clothing and other items in need to those without. You may have just one extra winter jacket you do not use that often. Think of what that jacket may mean to someone without even one.

In the spirit of Christmas, please remember this list, and see if you might have just one item that would make someone's Christmas even more merrier, and then think of the feeling you will be left with knowing you have help a needy person with AIDS keep warm and provided with food for their Christmas.

FOOD ITEMS NEEDED

Peanut Butter
Jelly
Tuna Fish
Juices of any kind
Beef Stew
Canned Fruits / Vegetables
Spaghetti Sauce
Ensure / Enrich
Dry Milk
Chunky Soups
Frozen Meals
Cheese

PAPER SHOPPING BAGS

OTHER NEEDS

Warm Winter Jackets (M/F)
Blankets
Boots
Floor Lamps
Paper Products
Cereal
Coffee
Toothpaste / Shampoo
Popcorn
Dish Towels/ Detergent
Carnation Breakfast

FRAN PEABODY

Fran Peabody, founder of The AIDS Project in Portland, Maine will be honored on World AIDS Day, December 1, 1990 at the First Parish Unitarian Church, 425 Congress Street Portland, ME at 3:00 PM.

Fran Peabody will also be honored on Friday, November 30, 1990 at a special dinner. The dinner will honor Fran and at the same time raise funds to help continue AIDS services in Maine.

It's especially appropriate to honor Fran this year since the theme of this year's World AIDS Day is women and children.

Fran has been a member of the board of The AIDS Project since it's inception in 1985. A major force in the life of nonprofit organizations in Maine for the past fourty years, the death of her grandson Peter was her drive for this particular involvement. Her daughter Barbara, Peter's mother, wrote *The Screaming Room*, a book about the experience of watching her son die that has become one of the major texts of the AIDS movement.

Other members of the Peabody family have also been involved in AIDS work across the country, in Texas, California, and as well in Maine.

Fran has met and spent time with many of the People Living With AIDS. I can only say that each and every person who has met Fran is grateful for everything she has done. She has been a special friend to many of us who work in the AIDS community.

OTHER NEEDS (continued)

Television
VCR
Stereo
Freezer
Refrigerator
Copy Machine
Folding Chairs
Apple Computer Supplies
Apple Laser Printer

RETURN TO SAN FRANCISCO

By: June Seamans

Where do I begin? There are so many places that I went and so many wonderful people that I met - renewed old friendships and made new ones. I left Portland in the freezing cold early one morning of October 30th headed for the city by the Bay. My intent was to touch base with groups that had formed since I was last there.

My first stop was at The NAMES Project headquarters on Market Street. Old friends were here. Marcel and Rebecca welcomed me with open arms and we talked for a long time about the direction that the AIDS quilt was to take for the coming year. Instant Quilt displays, the proposal for a new t-shirt design, more chapters forming nationwide....etc.,etc. The time just flew by. The workshop was the same...piles and piles of panels, with more coming in, lined the shelves and Gert moving everywhere making order out of a potential chaos.

The REST STOP was around the corner. A non-profit drop-in support center for people impacted by AIDS/ARC/HIV. This was Halloween day and decorations were everywhere. Bill was in the kitchen making the most delicious cookies from a recipe he had just created - yum! - and Paul was moving furniture around to accommodate the large group that was expected later that afternoon. Once again, it was nice to be back and see a place that I had visited a tear and a half ago, and to see the progress they had made in their programs.

Thom Bartsavage - what energy! The new director of the AIDS Food Bank on Duboce Street. The last time I saw the food bank it was run by The San Francisco AIDS Foundation but now under the direction of Thom and Open Hand there were numerous changes. An in-depth study of what a nutritional bag of food should contain had been made and each of the 600 plus bags that were distributed daily (not to mention the 150 - 200 bags delivered each day) reflected this new policy of the importance of a diet tailored specifically for the person with AIDS. What a store room and what a busy place. Thom and I visited for quite awhile and he left me with this thought:

"You can learn to live with a rhinoceros, but the ants will get you every time!"

This helps to put things in perspective.

It had been a long day and I was beginning to get tired, but I had been told to search out The Living Room, a new drop-in center very similar to ours. All volunteer,

making policies as they go along, learning through making mistakes...I could relate to this! So I headed down Castro Street to 18th Street and found this wonderful spot. After a tour of their space, I sat down with Mike and he started to explain the history of the Living Room and what new ideas they were working on. This place is so comfortable. A relaxed atmosphere where folks can sit and talk and share their feelings and experiences. A quiet area upstairs and a room with stereo, television and VCR - not to mention the outdoor courtyard and storage area out back - rounded out a very pleasant spot. Soon Will came in for lunch, and he and I traded stories of what can and will go wrong when you operate an all-volunteer program with expenses covered by fund-raising events. We laughed, we listened to each other, we shared the dreams of their living room and ours here in Portland....it was great!

Time to head back to the MUNI and change for the Halloween celebration that evening. I was exhausted, yet invigorated. The people I had met, the hopes and dreams that had been shared, the programs in place to offer direct support to people impacted by HIV - I remembered that we are all in this together and it is so important to support each other in our efforts. But most of all, I find that there are no words to express the love and admiration that I feel for these wonderful people on the west coast. They were so warm and open, they took time out of already busy schedules to sit and talk with me and make me feel at home...I miss them, but I know they are only a phone call or a letter away.

It was a terrific trip...I'm glad I went...but I missed our people here in Maine. So here I sit - the phone is ringing, people are coming through the door, David is down stairs getting the food pantry ready for winter, ladies are bringing food in for dinner tonight - it's really busy...but then again, that's the way we like it!!

June

CHRISTMAS 1990 FESTIVITIES

The PWA Coalition of Maine and The Names Project/Maine will have their annual Christmas Dinner Party on Wednesday, December 19th at 6:00 PM. Turkey and Ham will be provided. All other items will be pot luck. If you plan to attend, and are not sure what to bring, please call the coalition for a few suggestions.

Also, please don't forget our "TRIM THE TREE" night on Wednesday, December 5th at 6:00 PM. We encourage everyone to bring a decoration for the tree, but this is optional.

Everyone is welcome. Please join us for a joyous holiday season. Help us...

"Keep The Love Alive"

December 1990

PWA COALITION CALENDAR

SUNDAY

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY



HOLIDAY EVENTS		
December 5	6:00 PM	Trim The Tree Party
December 19	6:00 PM	Christmas Dinner
December 25	1:00 PM	Christmas Buffet

1
World AIDS Day



December 1, 1990

2QUILT WORKSHOP PORTLAND NAMES PROJECT	3	4 8:00 PM POSITIVLY SOBER AA MEETING	5 6:00 PM DINNER 6:00 PM TRIM THE TREE PARTY 7:00 PM EXECUTIVE BOARD OF DIRECTORS MEETING	6	7	8 OPEN 11 - 4
9 BRIDGES  6:30	10	11 8:00 PM POSITIVLY SOBER AA MEETING	12 6:00 PM POT LUCK DINNER 7:00 PM BOARD MEETING NEWSPAPER DEADLINE	13	14	15 TIM  TERRY
16QUILT WORKSHOP PORTLAND NAMES PROJECT	17	18 8:00 PM POSITIVLY SOBER AA MEETING	19 6:00 PM CHRISTMAS DINNER	20	21	22 OPEN 11 - 4
23	24	25 	26 6:00 PM DINNER	27	28	29 OPEN 11 - 4
30 Comedy  Can Can LimeLight	31 					



377 CUMBERLAND AVENUE
PORTLAND, ME 04101

ADDRESS CORRECTION REQUESTED

