

# THE AIDS PROJECT NEWSLETTER

A Publication of The AIDS Project, 22 Monument Square, Fifth Floor, Portland, Maine 04101

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**People stroll through the Portland Exposition Building, looking at the poignant messages on the AIDS Quilt on display there.**

Staff photo by Gordon Chibroski

## We Remember Their Names

The AIDS Project is proud to have hosted the display of the National Names Project AIDS Memorial Quilt over Memorial Day Weekend. The Quilt, which was displayed at the Portland Exposition Center on May 25-29, 1989 was visited by more than 9,500 people from Maine and New England, and received outstanding coverage by Maine media services.

Nominated for a Nobel Peace Prize and often compared with the Viet Nam Memorial, the Names Project Quilt powerfully gave a message of love, dignity and remembrance to all those who visited the display. Parents and loved ones, school children and government officials, lov-

ers and People With AIDS all came together to remember those who have died of AIDS, and to share their concern and hope for the future. To remember their names.

The Board of Directors and staff of The AIDS Project want to express deep appreciation and heartfelt thanks to the hundred of volunteers and dozens of organizations and business for helping to make the display of the Quilt possible. No one can visit the Quilt without being profoundly touched by its message and meaning, and all of you who participated in the display have, through your efforts, helped to touch the lives of others. Thank you for making a difference.



## THE AIDS PROJECT SERVICES UPDATE

By Perry Sutherland Program Director

As The Project grows, our services continually change in effort to meet the community's needs. The following is a current review of the agency's services.

The Project's Case Management Program is currently providing services to over 95 individuals. Among the services available to clients, their lovers, families and friends are general counseling and support, advocacy, information and referrals for people needing public assistance, housing and legal advice, medical and/or hospice care, or one of the many other needs that may arise for people affected by the human immunodeficiency virus. Our staff works closely with a wide range of community providers, including physicians, Portland Social Services, local and regional hospitals, home health care agencies, Hospice, mental health care providers, homemaker and transportation services, and a variety of others depending on client needs.

Recognizing the importance of a place where people can come together to share their concerns, their joys, and their hopes, The Project is currently offering 8 support groups. Groups are available for PWA's, people with HIV infection, their lovers, families, caregivers and friends. There is also a group specifically for women with HIV infection, as well as an AA-AIDS-related support group.

The Project's volunteer training program prepares volunteers to work in several of the agency's programs. Volunteer opportunities include working directly with clients, assisting with resource development and fundraising projects, providing information and referrals through the AIDS Information Hotline, as well as a variety of other possibilities.

The AIDS Information Hotline offers the latest information about AIDS and HIV infection. The Hotline received over 2,500 calls last year, providing callers with information on safer sex, risk reduction, information about the HIV antibody test, as well as referrals to local and statewide resources.

The Project has contracted with the Maine Office on Alcohol and Drug Abuse Prevention to provide AIDS street education to intravenous drug users in the Portland and Lewiston areas. The outreach staff of this innovative program will work to provide hard-to-reach individuals with risk reduction information, such as information about needle cleaning and safer sex.

The counseling and testing program offered anonymous HIV antibody testing to approximately 500 individuals in 1988, and continues to provide HIV antibody counseling services to the greater Portland area.

Two recently established program services for clients include the Lunch in the Lounge which is prepared on Tuesdays and Thursdays, and served in the PWA Lounge. Additionally, there is a regular series of seminars held on the 3rd Sunday of each month. Topics for Sunday seminars have included nutrition, acupuncture, and alternative therapies. As we continue to schedule future sessions, we welcome topic ideas from clients and those affected by HIV infection.

Please call The Project for additional information about any of the agency's programs.

## Statistics

### MAINE

As of April 30, 1989 there have been 122 diagnosed cases of AIDS in Maine. Of the total 122 people with AIDS, 61 have died. The numbers of people in Maine who have tested positive on the HIV-antibody test is 435.

### NATIONAL

National data as of April 30, 1989: Diagnosed cases of AIDS 90,990; deaths 52,435.

### The AIDS Project

To date, The AIDS Project has provided case management services to 151 people with AIDS, ARC and HIV+ individuals in Southern Maine.

## The AIDS Project Newsletter

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## Board of Directors

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The AIDS Project is a not-for-profit organization dedicated to providing and promoting services to people with AIDS and AIDS related illnesses, advocacy regarding AIDS related issues and concerns, and AIDS related health education and information to the citizens of Maine.



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## Executive Director's Message

By Robert Mitchell

The display of the Names Project AIDS Memorial Quilt in Portland touched the hearts of its thousands of visitors. With a quiet message of love and dignity, The Quilt evoked deep emotions and powerful remembrances of those who have died and are affected by AIDS. In the spirit of remembering, I want to share with you an article entitled "I Remember" which appeared in the January 10 issue of the *Village Voice*. These are the thoughts and feelings of one man affected by AIDS who simply signed the article, "John Doe"

### REMEMBERING AIDS

I remember when people called it "gay cancer."

I remember when everyone thought you got it from poppers.

I remember when the acronym hadn't yet been coined.

I remember when a friend, whose father ran a government health agency, had appendicitis and how his father wouldn't let the doctors give him a transfusion, and wondering what he knew that no one else knew.

I remember when some of the early ones got sick all the time and made jokes about being run-down, then died without knowing what hit them.

I remember wondering, much later, whether they'd been better off.

I remember seeing R. in a restaurant after he was diagnosed and being amazed at his healthy complexion.

I remember hearing that R. had enrolled in a drug test that involved a placebo.

I remember hearing that a week after the protocol ended R. came down with pneumocystis.

I remember keeping up with each generation of acronyms: GRID, AIDS, SIDA, HIV.

I remember running into B. one year on the subway and hearing his story about taking time off to help an ex-boyfriend die.

I remember running into R. another year at the Palladium and listening to his story about taking time to help his brother die.

I remember when the obits began to mention unrelated survivors as life partners or longtime companions.

I remember how it incensed me when journalists reported that the disease hadn't yet spread to the "general population".

I remember my surprise when women began to get it, even women who didn't use drugs.

I remember the syphilis theory, the swine-fever theory, the germ-warfare theory, and that guy who postered the city with paranoid screeds about the CIA.

I remember how relieved F. was when the thing on his face turned out to be an ordinary melanoma.

I remember how friends would casually palpate their glands as we talked.

I remember when N.'s shrink forbade him to do that.

I remember trying to remember that no matter what you thought you knew about people, you never truly knew what they did for sex.

I remember wild rumors about guys who went crazy when they found out and had sex with anyone they could pick up.

I remember thinking those stories must be untrue.

I remember attending a GMHC [Gay Men's Health Crisis] buddy meeting and feeling angry when the buddies criticized "clients" who went on having sex.

I remember when I stopped having sex.

I remember when I started censoring fantasies that involved unsafe practices.

I remember when I made a list of all my sex partners and tried to calculate the odds.

I remember thinking I was lucky they all fit on a list.

I remember realizing that it was much more of a crapshoot than I could figure.

I remember the first year the subject came up once in every conversation.

I remember thinking that I'd have to start considering junkies as human beings.

I remember when my friend began to report that it was "sweeping the rooms".

I remember when my former-drug-abuser friend told me she thought she was "ARC-ing".

I remember the whole year my officemate spent shouting at doctors on the phone while his life partner was dying.

I remember everyone around him pretending not to hear.

I remember the horror stories, the miracle cures, the crystal cures, the religious conversions, the radical diets.

I remember when I finally took the test, carrying a vial of my blood to Bellevue on the Second Avenue bus.

I remember my doctor's failure to warn me that using a fake name (like the one I'm using here) was best when you were tested for HIV.

I remember not being able to get life insurance later on.

I remember my doctor's attitude when he said I'd make a good candidate for AZT.

I remember bigots at the Washington march shouting "AIDS is the cure".

I remember the first time I recognized a KS [Kaposi's sarcoma] lesion.

I remember catching myself saying "victims" sometimes.

I remember thinking you were safe after five years, then seven, then ten, and then reading in the New York Times that the virus could escape detection.

I remember dealing with that.



## Compound Q Warning, and Update

Reprinted from *AIDS Treatment News*, May 5, 1989  
Issue Number 78

Compound Q, an experimental AIDS treatment extracted from the root tuber of a Chinese cucumber, has received wide publicity in the last month. On May 5 we heard the first report of a severe adverse reaction to a bogus "compound Q", apparently homemade from the root which was obtained from a health-food store, and injected. According to Martin Delaney of Project Inform, who is now warning buyers' clubs, the person almost died as a result, and was in intensive care for three days. This case occurred in Kansas City.

We have also heard that some health-food stores are exploiting the situation and promoting a dried root or extract by suggesting that it contains compound Q. People should know (1) that the root also contains lectins, which are poisonous when injected because they cause blood cells to clump together, which can cause heart attacks or strokes, and (2) that compound Q (which is a protein called trichosanthin) is almost certainly destroyed by drying, so the dried root used as an herbal medicine for other purposes does not contain the active ingredient.

It is generally believed that a good-quality equivalent of compound Q does exist in China, and has been used there for other purposes for several years (see *AIDS Treatment News* #77, pages 1-2 and page 5). However, this drug is tightly controlled and very difficult to obtain. We have heard from knowledgeable persons (but have not yet been able to confirm independently) that only a half a million doses a year are manufactured, all by one factory in or near Shanghai, and that some of it did reach a few persons with AIDS in the U.S. While extracting the active ingredient (trichosanthin) from the Chinese cucumber root is not too difficult for a protein chemist, there are practical problems, especially the need to obtain large quantities of the fresh or frozen root, as well as the usual

difficulties of setting up effective manufacturing and quality control for pharmaceutical.

Any credible, good-quality data which may develop from use of the Chinese compound-Q equivalent would be very important in speeding the authorized clinical trials. At this time, the only clinical trial planned anywhere in the world is a "phase I" study to take place at San Francisco General Hospital. This trial may be slowed by the current budget crisis of the City and County of San Francisco, since hospitalization is required for the study but there is not enough funding to staff the nursing support for the hospital beds.

The San Francisco trial will also be slow because it is designed primarily to test for toxicity and determine whether the drug can help patients. A tiny dose which no one believes could be effective will be tried first, followed by a wait to look for side effects. This process will be repeated several times, with a wait each time. This dose-escalation study could take as little as three to six months, or as long as a year. By contrast, "underground" users of the Chinese drug will test reasonable doses right away -- the same which have already been used in China -- so they can get results far ahead of the official trials. If such use should happen to produce credible evidence that the drug is useful in treating AIDS, then far more pressure would develop to speed the research and regulatory system and make compound Q available through authorized channels. If you have any information about anti-HIV use of the Chinese "crystallized" grade of trichosanthin, please send it to *AIDS Treatment News* at the address above, or call us at (415) 255-0588.

We have heard that a phase II trial is now being designed, and could be started before phase I is finished.

We will continue to report on compound Q as we learn more about it.

## THE AIDS PROJECT

### 3rd Sunday Workshop Series

#### "Legal Issues for People With HIV Infection"

Mary Bonauto, an attorney with the law firm of Mittel and Hefferan in Portland, will be giving a workshop on legal issues of concern for people living with and HIV-infection.

Mary has represented PWA's in cases involving employment discrimination, disputes with insurance companies regarding coverage for HIV-infected people and debt collection defenses. Mary has also assisted PWA's in drafting powers of attorney, wills and living wills.

This workshop is open to anyone interested in learning more about legal issues of concern for HIV-infected people.

DATE: June 18, 1989  
TIME: 1:00-3:00 P.M.  
PLACE: The AIDS Project Group Room  
FEE: \$15.00 - Scholarships available to people with HIV-Infection

Registration Deadline: June 14, 1989  
- Call 774-6877

For more information call Toby Simon at 774-6877

## Volunteers Needed

The AIDS Project needs volunteers for the following fund-raising events

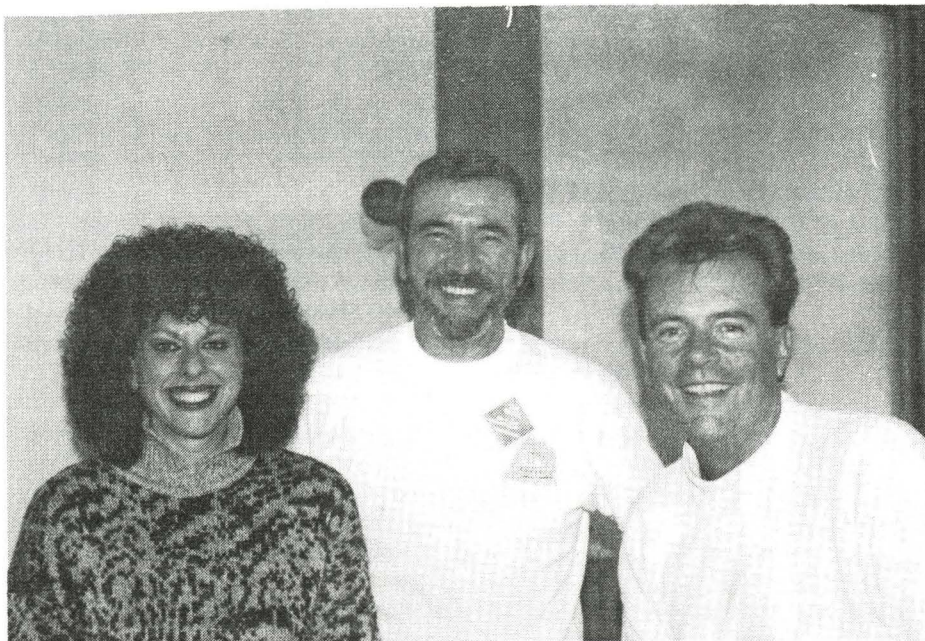
**Bike-For Hope Bike-a-Thon**  
Contact: David Ketchum

**All Singing, All Dancing, All Concerned. A concert fund-raiser.**

Contact: Jeannie Ross or Arne Hanson

For More Information Call:  
774-6877 Between 9 and 5.



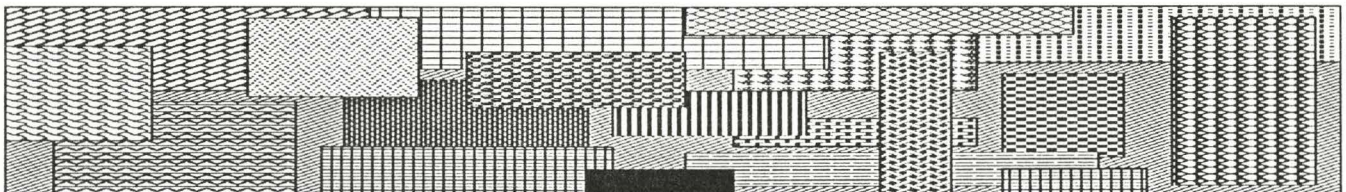


## Many Thanks

We wish to extend our heartfelt thanks to the hundreds of volunteers who were part of this tremendous event. There were 9,557 people who viewed the Quilt. In terms of education for AIDS, it was remarkable, not to mention a very positive event. We are also grateful to the countless volunteers from Boston, New Hampshire and Vermont who gave so much to help us. Maine and its neighbors have a lot to be proud of.

Also, a memory book of the Quilt is being put together. If you have pictures to share, contact Peggy Quinlan, volunteer coordinator at The AIDS Project 774-6877.

**From Left to Right** - Jeannie Ross, David Ketchum and Malcolm Mailloux - Co-Coordinates in Helping Bring The Names Project Quilt to Portland This Past Memorial Day Weekend.



**Pictured from Bottom Row Left** - Josiah Adams, Robert Mitchell-Executive Director, Stephanie Martyak-President, Frances Peabody, Kristen Kreamer. **Top Row Left** - B.J. Broder-Treasurer, Lydia Cohen, Laurel Thom-Vice President, Tom Antonik. **Not Pictured** - Zane Blair, Susan Cummings-Lawrence, Heidi Johnson, Martha Mickles and John Preston.

The AIDS Project is a community based non-profit organization governed by a thirteen member volunteer Board of Directors comprised of lawyers, health and social service professionals, representatives from the business community and persons with AIDS.





## Ongoing Calendar of Meetings

### MONDAY

AIDS Response of the Seacoast in Portsmouth, NH, runs a support group for PWA's and PWARC's and HIV+'s. The group is open to people from York County. A holistic healing model is used incorporating meditation, visualization, heart centering, music and touch in a supportive and loving environment. For more information and an intake interview, contact Suzanne Bowman at (207) 439-2136 or Peter Welch at (603) 436-5115.

Waterville Support Group for PWA's, PWARC's and HIV+'s and their families, friends and caregivers. Meets from 6:30-8:00 P.M. at St. Mark's Episcopal Church, Waterville. For more information call Dan Gardiner at 873-3904.

Support Group for PWA's, families, friends and significant others, every other Monday at Miles Conference Center, Damariscotta, 6:00-7:00 P.M. Contact Kandy Powell at 563-1709. Sponsored by AIDS Coalition for Lincoln County.

A Support Group for persons with AIDS, ARC and HIV infection meets in Auburn at the First Universalist Church. Meetings are the 2nd and 4th Monday from 1:00 to 3:30 p.m. in the Church Library. Call Tim Sutter (626-3435) or Cecilia Leland (289-5060) for more information.

Belfast Area AIDS Support in Waldo County. For PWA's, PWARC's, HIV+'s, firends, family and caregivers. Call 338-3736 (Family Planning) Mon-Thurs 9 a.m.-4:30 p.m. or Alan 548-2929 evenings/weekends for information.

### TUESDAY

Morning Support for PWA's, PWARC's, HIV+'s, their families, friends, and caregivers meets from 10:30-12:00 Noon. Location: The AIDS Project, 22 Monument Square, 5th Floor, Portland. Call 774-6877 or 1-800-851-2437 for more details.

Evening Support Group for lovers, friends, caregivers and family members only. Meets from 7:00-8:30 P.M. at 29

Cushman Street, Portland. Call Brooke Alexander at 772-1678 for details.

Merrymeeting AIDS Support Services (MASS) A support Group for families, partners & friends of persons with AIDS and HIV disease. Meets the 2nd and 4th Tuesday of each month at 7:00-8:30 P.M. at Parkview Hospital Library in Brunswick. Contact Cecilia Leland at 725-4955 for more information.

ACT-UP Boston meets every week at 7:30 P.M. Call (617) 49ACTUP (492-2887) for more information. ACT-UP: AIDS COALITION To UNLEASH POWER -- United in anger and committed to direct action to end the AIDS crisis.

AIDS-Line Staff Meeting at 6:00 P.M. the first Tuesday of each month. Location: The AIDS Project, 22 Monument Square, 5th Floor, Portland.

Downeast AIDS Network (DEAN) holds a support group for people affected by AIDS every Tuesday evening at 7:00 P.M. in Ellsworth. Call 326-8580 for the location.

AIDS Education & Support Group for Knox County, P.O. Box 1613, Rockland, Maine 04841. Public meeting are held at 7:00 P.M. on the 2nd Tuesday of each month at the University of Maine Augusta Thomaston Center. For more information call 354-6906 or 596-6979 or write.

Support Group for Parents and Friends of Lesbians and Gays meets the 4th Tuesday of each month at the Pilgrim House, 9 Cleveland Street, Brunswick. Call 729-9843 for more information.

### WEDNESDAY

Positively Sober Group, AA-AIDS-related meeting from 6:00-7:00 P.M. at The AIDS Project, 22 Monument Square, 5th Floor, Portland. Meeting is open to all PWA's, PWARC's and HIV+'s in recovery from substance abuse.

### THURSDAY

Women's AIDS, ARC & HIV+ sup-

port group. The group meets 10:30-12:00 at The AIDS Project, 22 Monument Square, 5th Floor, Portland. Facilitated by Diane Elze and Jan Carter. This group is for Women with AIDS, ARC or HIV+ only. Call 74-6877 or 1-800-851-2437 for more information.

Lewiston Area Support Group for PWA's, lovers, friends and family members meets in the afternoon at Clover House in Auburn. Call Evelyn Piper-Keene at 783-9095 for more information.

Bangor Area AIDS Support Group meets every Thursday evening. Contact the Eastern Maine AIDS Network (EMAN) at P.O. Box 2038, Bangor, ME 04401, or call 990-3626

HIV+ Support Group meets from 5:30-7:00 P.M. at The AIDS Project, 22 Monument Square, 5th Floor, Portland. This is an open group, no advance contact is needed. Call 774-6877 or 1-800-851-2437.

An AIDS Service Providers Support Group every 2nd Thursday of the month held at the AIDS Project, 22 Monument Square, 5th Floor, Portland, ME. For more information call Toby at 774-6877.

A Healing Circle for People affected by AIDS is held the 2nd and 4th Thursdays of each month in Hancock County. Sponsored by the Downeast AIDS Network (DEAN). For information and directions, call 326-8580.

### FRIDAY

PWA/PWARC Support Group meets every Friday from 6:00-7:30 P.M. at The AIDS Project, 22 Monument Square, 5th Floor, Portland. Drop-in group. This is for people with AIDS and ARC only. Call 774-6877 or 1-800-851-2437.

Support Group for persons with AIDS, ARC and HIV+, and their family members, friends and caregivers. The group meets every Friday, 7:30-9:30 p.m. at Portsmouth Hospital, Classroom I & II.



## OTHER

AIDS Coalition of Lincoln County is a group focusing on AIDS education in Maine. We welcome PWA's, PWARC's, HIV+'s and their lovers, friends and family members, as well as all concerned people to our meetings. For time and place, call Barbara Brampton at 563-3032.

**Lunch at the Lounge**-Tuesday & Thursday 12:00 to 1:30. Tuesday - Vegetarian, Thursday - Traditional Fare. **Open to all PWA's, PWARC's**

## Out-of-State Services/Hotlines

NH-AIDS Info Line:  
(603) 224-3341  
(800) 752-AIDS (24 hr. Hotline)

VT- AIDS Info Line:  
(802) 254-4444  
(800) 882-2437 (VT Only)

Mass.-AIDS Info Line:  
(617) 536-7733  
(800) 235-2331 (MA Only)

## Comemorative Poster For Sale

The Names Project Quilt Comemorative Poster of the "Quilted Heart" is currently available at a special price of \$20.00. It is heavy weight and suitable for framing.

Available at:

The AIDS Project  
22 Monument Square, 5th Floor  
Portland, Maine 04101  
774-6877

Greenhut Galleries  
146 Middle Street  
Portland, Maine 04101  
772-2693

Graphiti  
547A Congress Street  
Portland, Maine 04101  
774-7599

## The AIDS Project Wish List If you can help us with these items, please call us at:

**774-6877**

Air Conditioners  
Bookcases (for offices and reception area)  
Coat Rack  
Records  
Books  
Games  
Cassette Recorder

6 Burner Electric Stove  
Industrial Dishwasher  
IBM Compatible Wordprocessing System with Printer  
Typewriters  
Photocopier  
Telephone System  
Pots and Pans

## Two Ways You Can Help Us Help Others

### A General Donation

The AIDS Project relies on the support of its friends to provide services and to provide educational programs. Contributions to support our programs are welcome.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Donation ☐ \$15 ☐ \$25 ☐ \$100 other \$ \_\_\_\_\_

### A Memorial Contribution

To express condolences for the loss of loved ones, many friends choose to make a memorial gift to The AIDS Project. A letter will be sent to notify a surviving loved one or friend of your gift.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Donation \$ \_\_\_\_\_ In Memory Of: \_\_\_\_\_

### SUBSCRIBE

This Newsletter relies on subscriptions to exist. We are grateful to those who have subscribed, and to those who have not, please do so now. Rates: Individuals \$10/Low Income \$5/Institutions \$30/PWA's Free. Please make your check payable to: The AIDS Project, 22 Monument Square, Fifth Floor Portland, Me 04101. Thank You.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Henry  
2 Henry Beth Lane  
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