The AIDS Project Newsletter (April 1988)

David Ketchum

The AIDS Project

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EDITORIAL

This month's editorial is reprinted with permission from the Kennebec Journal of Augusta.

STILL STRUGGLING FOR JUSTICE
by Tom Hanrahan
Kennebec Journal City Editor

The Kennebec Journal won an award the other night from a very special group of people — Maine's lesbians and gays.

These are people for whom some segments of our society have created particularly vicious slurs — words like faggot and queer, dyke and homo. They are folks who have had to endure an especially potent form of prejudice, because they have chosen to love someone of the same sex.

In a world filled with injustice, lesbians and gays are struggling to free themselves from the oppression of the majority. They must also struggle with the deadly disease called AIDS.

In short, there is plenty to be unhappy about if you are a lesbian or gay.

But at the awards dinner held recently in Augusta, the mood was festive and upbeat.

Dale McCormick, the president of the Maine Lesbian/Gay Political Alliance, fairly radiated good feeling. I watched her throughout the program, smiling broadly as she supervised the award-giving. She is a good and kindly person and it makes me damned angry to think that anyone would wish her anything but well.

I heard person after person testify about the struggle to be a lesbian or gay in our homophobic society. It was very moving. I heard of the struggle to gain the acceptance and love of their parents, friends and co-workers. I heard of the agony of AIDS. I heard the cry for justice, as American a plea as I can think of.

The keynote speaker, a black radical feminist named Barbara Smith, championed the plight of black women and noted that if black women get a fair shake in our society, then that means just about everyone else will. It's an intriguing argument.

But as political dinners go, this was something different. Something real. Real political problems and real strategies. I found it infinitely more interesting than the Iowa caucuses or the travails of our local school board. And the joy I felt within the group was something never to be found at say, a Republican fundraiser.

Sadly, no senator attended, or governor, or congressman or congresswoman. Marge Clark, a Maine legislator, made it, and so did Trish Riley, who was recently given the heave-ho by Rollin Ives at Human Services. Bless them.

Because for most politicians, appearing with lesbians and gays is deadly. They fear the ignorant wrath of their most small-minded constituents. They fear the caning they might get from Jasper Wyman and the Christian Civic League, which practices homophobia like marching bands practice Sousa.

They fear that which they do not understand.

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STATISTICS

As of March 15, 1988, there have been 73 diagnosed cases of AIDS in Maine. Of the total 73 cases, 32 have died. People who have tested positive with the AIDS virus (in Maine) is now at 261. National Data as of March 14, 1988: diagnosed cases of AIDS 56,212. Deaths 31,420.
AIDS '88 -- AN EDITORIAL

By Max Navarre

Entering the eighth year of the health crisis, AIDS is not the same disease it was when I was diagnosed in the summer of 1985, either experientially, or in its official definition. As the crisis has expanded, so too has the disease itself: The CDC, by enlarging on the symptomatic boundaries of AIDS, has made a diagnosis of frank AIDS easier to achieve. Symptoms which didn't used to be AIDS now can be construed as such. While this broader definition has its uses, it makes for a much less clear conceptualization of what AIDS actually is.

It seems as if everything is now AIDS: AIDS is AIDS, ARC is AIDS, HIV seropositivity is AIDS. This interpretation can be maddening, particularly in the case of seropositivity. We now have hoards of people, asymptomatic but with antibodies to HIV, being treated willy nilly with AZT, acting, feeling and being perceived as people with AIDS. THEY AREN'T. AIDS is AIDS, ARC is ARC and HIV seropositivity is just that. In all this confusion it's almost as if people need to be sick, as if some herd instinct has emerged which has us rushing to the sea like lemmings. All over, alarms go off every four hours, and out comes the AZT. Lots of these people aren't sick, or are only sickish. Believe me, I now from sick, and if you've got a shortage of T-cells, or a few shingles, you ain't sick.

I don't get it. One would have thought that the race would be on to be as healthy as possible for as long as possible, not to crawl over each other to join the ranks of the ill.

Are doctors responsible for this? Is the only way of coping with the finer shades of illness to ignore them and treat everyone as life-threatened? For years some of us have been saying that the only way to cope with AIDS is to act as if everyone has it. But, that was by way of rousing compassion and generating responsible behavior, not sending people into the jaws of the dragon when they didn't need to go.

Certainly the current fashion of prescribing AZT to virtually anyone with a few symptoms has contributed greatly to the trend towards AIDS-itis. The medical love affair with AZT is particularly alarming to those of us who remain unconvinced that HIV is "the cause" of AIDS. Every time I hear HIV referred to as the "AIDS virus", my teeth start to grind.

I understand that it is convenient for HIV to be the villain for researchers, politicians and the manufacturers of drugs (particularly antivirals like AZT). And of course we have the media's deliberate obscurity about what constitutes AIDS because they are too stupid or too bored to actually find out anything for themselves. There are simply too many questions to be asked about HIV.

Is the AIDS industry prepared to be wrong about HIV? Is Burroughs Wellcome prepared to have their drug, AZT, blow up in their faces if it turns out that, not only does their product have limited effectiveness, but that their antiviral goes to work on a virus which may turn out to be, certainly not innocuous, but a great deal less to blame than is currently thought?

Obviously, HIV is something; but is it "the cause"? There are people who don't think so.

No doubt, AIDS has changed. PWAs have better chances to live longer, and people are finding that out. More and more "human interest" stories are appearing. Of course, thanks to the victim obsession of the media, PWAs are still often portrayed as the helpless recipients of kindness rather than fully enfranchised participants in a human exchange of caring. But that seems to be changing too.

More and more, PWAs are standing up for themselves and their interests. Look at the historic and brilliant emergence of self-empowerment that is the Community Research Initiative. Here we have PWAs working with private physicians and an impressive array of clinicians and health crisis powerhouses in a community setting to develop data and research protocols on promising AIDS drugs. Something that the government, with all its resources, has failed to achieve. Not only that, but CRI will be getting promising drugs to the people who need them the most. This is amazing and wonderful. Hope.

The health crisis has attracted such media stars as Joanne Woodward, Peter Allen, Calvin Klein, and Dionne Warwick. AIDS has developed all the cachet usually reserved for the latest Soviet emigre virtuoso. This is good for attracting funds to those agencies who are fleetfooted enough to grab them. Often though smaller agencies and service
providers get left out in the cold. It is hoped that the enormous efforts of such tire-
less workhorses as Judy Peabody, Nathan Kolodner, Mathilde Krim, and La Taylor will bal-
once out the fashionettes and maintain some kind of fundraising momentum so that every-
body gets a share of the pie.

And not the Presidential Commission is turning out to be less of a dud than it seemed,
one can afford to feel a little more hopeful. Their report wasn't too bad. Maybe, even
if individual members of the commission are not experts, they will continue to pay atten-
tion to people who are. Good.

AIDS is about everybody, but everybody doesn't have to have it.

I feel better, more hopeful, less grief-stricken. I would like it better if the
healthy would allow themselves to be healthy. I cherish my times of health. I would
like it if friends would stop getting sick, giving up, dying without celebration of having
lived. I would like that. Sick is sick and well is well. And there is still room for
joy. And hope. And wellness.

(The above is reprinted with permission from The PWA Coalition of N.Y.C.)

EDITOR'S NOTE

I have shared the following poem with two very special
people in my life, and I now share it with you.....

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It's Okay

It's okay to be afraid
of the things we don't understand.
It's okay to feel anxious
when things aren't working our way.
It's okay to feel lonely...
even when you're with other people.
It's okay to feel unfulfilled
because you know something is missing
(even if you're not sure what it is).
It's okay to think and worry and cry.

It's okay to do
whatever you have to do, but
just remember, too...
that eventually you're going to
adjust to the changes life brings your way,
and you'll realize that
it's okay to love again and laugh again,
and it's okay to get to the point where
the life you live
is full and satisfying and good to you...
and it will be that way
because you made it that way.

-Laine Parsons

HUGGING IS PRACTICALLY PERFECT: THERE ARE NO MOVABLE PARTS, NO BATTERIES
TO WEAR OUT, NO PERIODIC CHECKUPS, LOW ENERGY CONSUMPTION, HIGH ENERGY
YIELD, INFLATION-PROOF, NON-FATTENING, NO MONTHLY PAYMENTS, NO INSURANCE
REQUIREMENTS, THEFT-PROOF, NON-TAXABLE, NON-POLLUTING AND, OF COURSE,
FULLY RETURNABLE.
NEWS FROM MERRymeETING AIDS SUPPORT SERVICES
by Eunice Cox

Merrymeeting AIDS Support Services (M.A.S.S.) is accepting applications for Buddy training to be held in Brunswick in May. The training is for anyone who wants to become a Buddy through The AIDS Project and is a rich opportunity to learn together with others about helping someone with AIDS.

The training will be held Friday evening and all day Saturday May 6 and 7 plus May 20 and 21. To join you must complete an application by April 15 and be interviewed by representatives of M.A.S.S.

After the training, Buddies must attend a support group in Brunswick or Portland twice a month and must make a year's commitment to being a Buddy.

If you would like an application, please call The AIDS Project at 774-6877 or 1-800-851-2437 or Julie Zimmerman at 833-5016 who can also give you more information. I will be away on vacation until April 7, but would be happy to talk with you about the Buddy program after then. You can leave a message for me at The AIDS Project, or call me at home at 371-2541.

REQUEST FOR PROPOSALS
The Maine Health Foundation is seeking proposals statewide from organizations or individuals to deliver innovative AIDS prevention education and outreach to hard to reach gay and bisexual men in Maine, including gay youth.

The Maine Health Foundation, a charitable, non-profit, tax-exempt organization which provides funding for gay and lesbian health concerns, has been selected by the Office on AIDS, Bureau of Health, Department of Human Services, to distribute $13,000 for this purpose.

For application, contact by April 1, 1988:

Maine Health Foundation
P. O. Box 7329
Downtown Station
Portland, Maine 04112

PROPOSALS WILL BE DUE BY MAY 1, 1988.

NEEDED
If you have a 35mm Slide Carousel that you are not using or do not need, please contact The Aids Project at 774-6877, as we are in need of same. Thank you.

ON THE LIGHTER SIDE

"Son, you do mean 'merry and bright,' don't you?"
Office On AIDS Speakers Bureau
by Ann Wheeler

The Office on AIDS is in the process of developing a Speakers Bureau on AIDS in response to the many requests for educational AIDS presentations. A comprehensive referral list of health care providers and educators should be available within the next few months. Topics for presentations may include:

* Epidemiology of AIDS in Nation and Maine
* AIDS, AIDS Related Complex, and HIV Infection
* Transmission of the Disease
* Prevention
* HIV Counseling and Testing
* Social Issues
* and others

The Bureau of Health will provide technical assistance and current information on the above topics upon request. People who are interested in being listed in the Speakers Bureau will be sent a detailed questionnaire to fill out and return to us. In addition, we will ask organizations who utilize the Speakers Bureau to fill out and send us an evaluation of the speaker so that we can keep our listings as specific and current as possible.

For more information, or to submit your name to the Speakers Bureau, contact Ann Wheeler, Office On AIDS, State House Station # 11, Augusta, ME 04333, or call Ann at 289-3747 or 289-2046.

MATERIALS

Light Video Television, Inc. has produced a compelling videocassette to educate the public on the facts and myths about AIDS.

AIDS: CAN I GET IT?, unlike other documentaries on the subject, (1) is intended for a public ranging from chief executive officers to heads of households, (2) focuses on AIDS as a venereal disease, rather than as a mysterious "plague", and (3) emphasizes the benefits of early detection. The 48-minute videocassette examines common concerns about this life-threatening disease and emphasizes that AIDS cannot be spread through casual contact. Through interviews with twelve renowned medical experts, six FWAs (Friends With Aids), and numerous people on the street, the tape dispels the mistaken belief that AIDS only strikes homosexuals and drug addicts.

AIDS: CAN I GET IT? is narrated by Dr. Jay Keyworth, Scientist and former Presidential Science Advisor. It is being offered for $9.95, a price that is affordable for everyone.

People can order the videocassette by calling 1-800-LIGHT-VT. In Mass., collect calls are accepted at 617-449-7770. Or they can mail a check for $9.95 (add $2.00 for the first copy and .50 for each additional copy for shipping and handling -- Mass. residents add 5% sales tax) to: LIGHT VT, 21 HIGHLAND CIRCLE, NEEDHAM HEIGHTS, MASS. 02194. Closed caption available.

Orders will be shipped within 72 hours. Light Video Television, Inc. is a Leading Edge World Trade company.

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SPECIAL NOTE: There is a copy of the above tape available from The AIDS Project by appointment. Contact Gary Anderson at 774-6877.

Oh the comfort, the inexpressible comfort, of feeling safe with a person, having neither to weigh thoughts nor measure words, but to pour them all out, just as it is, chaff and grain together, knowing that a faithful friend will take and sift them, keeping what is worth keeping, and then, with the breath of kindness, blowing the rest away.

Mary Ann Evans (George Eliot)
Many people having heard of the People with AIDS Coalition of Maine have begun to ask not only what is the Coalition, but what is it that we are doing? There is no one answer to either of those questions. First of all because we are many people and we have no "members" or "clients". We are people with AIDS and ARC, HIV positive or concerned individual working to help our own community -- ourselves. And sometimes we have to answer the question of "what are we doing" with not only some of the projects we have begun to work on but also with "we don't know". Not just because we're a young organization and certainly not because we're without direction, but because as we grow and evolve we are constantly discovering just what our needs are in the ever changing face of this crisis and how best to direct our energies. But while determining what projects need immediate attention while supporting those already in existence, there is one idea that is constant -- that of self empowerment. That we have the power to improve the quality of our lives, that we have an active say in our own care, not only medically, but also socially, spiritually, and politically. That we have the power within ourselves individually and collectively to shape our own future. That we are not victims. 

One of my greatest educations since having been diagnosed has been my involvement with the PWA Coalition in New York City, and I'm fortunate to be able to bring in my experiences as a member of their board to this Coalition. And not only as an individual but also as a part of the Coalition we have also been very grateful for the support we have received from PWAC as well as from NAPWA (National Association of People with AIDS), NAN (National AIDS Network), TAP (The AIDS Project), and for the many experiences and familiarity of other organizations regional and national brought in by the many individuals involved with the Coalition. But by far the most important experience any of us contribute to the Coalition is that of being a PWA or PWArc, of being HIV positive, of having our lives deeply and irreveribly touched by AIDS not only by the horrors of the pain it has brought about but also with the great joys of self discovery and the miracles of love and support it has uncovered.

We have begun regular meetings with a small group that has already grown and changed as will any organization. We have begun to explore projects that include a meals program modelled on the "living room" program run by PWAC (NYC). Such a program would provide more than just free nutritious meals but also an environment in a relaxed setting to socialize, exchange information and of course, hugs. We also look forward to participating in expanding counselling services including groups as well as individual psychotherapists who will work with PWAs and their families either for free or for reduced rates. Gathering and strengthening other networks of services are also a high priority including legal services. There is also a need to develop and discover services that no less importantly contribute to the quality of our lives such as where can we go to get a free haircut or massage or help in preparing our taxes. Some of these projects are already in the planning stages through TAP and other organizations. We intend not to duplicate services, but to enhance and create support with all organizations dealing with PWAs. Where there are gaps in services we will initiate projects ourselves or encourage appropriate organizations to fill those gaps. We do face frustrations as well as excitement with our own budding organization as well as with those already established. Delays
in getting programs off the ground due to bureaucratic red tape and funding problems are inevitable. Our frustrations are further fueled in that as PWAs we know all too well how precious our time is while we deal with our own varying and unpredictable levels of energies in lending support to a myriad of wonderful programs on one front while on another trying to battle damaging legislation and policies. All while trying to take care of ourselves.

Perhaps as no crisis has ever so fully taught us, we are all in this inextricably together. Even if your involvement is just letting your needs be known, it is a valuable and important contribution as it will help bring light to the needs of others. One of the wonderful things about hugs both physical and metaphorical is that all involved benefit.

There is one thing however that a Coalition of people with AIDS can do that no other group can do as well, and that is to keep a face on AIDS. We are not statistics. We are not only important to ourselves and each other but to our parents, our brothers and sisters, our partners, and indeed to all those whose lives we touch. Nor are we only facing issues unique to AIDS -- we still have universal needs, to love, to laugh, to cry, to be accepted as individuals. We need to know that we're here for one another and that we have the power to heal ourselves -- to make our lives whole.

I strongly believe that it is not just PCP or KS or TB or a host of other opportunistic infections that has led to the deaths of so many we love, but just as deadly is the erosion of spirit caused by isolation, loneliness, fear, misinformation, and lack of support. And as limited or unlimited your support might be, we look forward to the sharing, that we all may learn and grow in the process.

Visual Aids Committee Donates Funds by Bert LeClair

On March 8th members of the PWA Coalition met with F.R. Vance of the Visual Aids Committee. Mutual areas of concern were discussed and possible future funding projects. During the course of the meeting a donation was given to the Coalition to administer to PWA's and PWArc's in need of funds to attend movies, go out to dinner, etc. etc. Any interested parties should contact Bert at the Coalition, phone 775-1259. The Coalition was also informed that the Visual Aids Committee donated an undisclosed amount of funds to The Aids Project in Portland for the same purpose for their clients. The PWA Coalition wishes to thank the Visual Aids Committee for once again greatly enhancing the quality of life for people with AIDS/ARC and their ongoing commitment to this population.

CONDOMS ARE EFFECTIVE!
**CALENDAR**

**APR. 7**  - "The Diagnosis and Management of HIV-Infected Patients" - Robert Schooley, MD - Dean Education Bldg. - Mid-Maine Medical Ctr. - Waterville, Me. - For information call 872-1320.

**APR. 8**  - First Maine Conference On Gay And Lesbian Youth: Creating A Brighter Tomorrow - Sheraton Tower - South Portland, Me. - For information call Augusta 622-7524.

**APR.15-16** - Dying Before Their Time: The Role of the Medical Humanities in Early Death From Genetic Diseases, Infectious Diseases and AIDS. A two-day conference at Ramada Hotel, 100 East River Drive, East Hartford, Ct. 06108. Call Cecile J. Volpi at 203-679-3340 for further information.

**APR. 19**  - "Structure Of The Immune System I: Cellular Immune Function" - Margaret Shipp, MD - Noyce Auditorium - Dana Health Education Ctr. - Maine Medical Center - Portland, Me. - For information call 871-2131.


**APR. 29** - MITCHELL'S CALENDAR**


**ONGOING CALENDAR**

The PWA Coalition of Maine will meet the first and third Monday of every month at 1:00 pm at 25 Parris Street, Portland. Call 775-1259 for further information.

Every Tuesday from 10:30am to 12noon at The Aids Project - 48 Deering St. - Portland - there is a group meeting for all PWA's, PWArC, caregivers, and family members, to share your thoughts and feelings relative to AIDS. The meeting is conducted by Jacob Watson, M.A. Jacob is a psychotherapist specializing in loss and transition and is a staff member of the Elizabeth Kubler-Ross Center.
ONGOING CALENDAR cont.

Every Tuesday evening 7:00pm to 8:30pm at 29 Cushman St. - Portland - there is a group meeting for all lovers, caregivers, friends, and family members only. The meeting will be conducted by Brooke Alexander, an Episcopal priest and pastoral counselor. Call Brooke at 772-1678 for further details.

ACT UP - Boston. 30,000 plus are dead from AIDS - haven't you been silent long enough? Join ACT UP - Aids Coalition To Unleash Power - United in anger and committed to direct action to end the AIDS crisis. Meetings every Tuesday at 7:30pm in Boston. Call 617-49ACTUP.

On the first Tuesday of every month at The Aids Project- 48 Deering St., Portland:
6:00 pm - A-Line Staff Meeting.
7:00 pm - HIV Counselor Staff Meeting.

Support Group for Parents of Adult Gay Children will meet the 2nd Tuesday of every month. Please call 774-HELP for time and place.

DEAN (Downeast AIDS Network) educational and business meeting the 2nd Tuesday of every month at Ellsworth City Hall Council Chambers at 7:30pm. DEAN now has a newsletter and a support group for PWA's, HIV+, family members, and lovers. Call Tracy or Lynnsey at 326-8546 for more information.

Support Group for Parents and Friends of Gays will meet the 4th Tuesday of every month at The Pilgrim House - 9 Cleaveland St. - Brunswick, Me. - call 729-9843 for further information.

There is now an AIDS support group in the Bangor area meeting every Thursday evening. Anyone interested in the group should call 469-7343 or write EMAN - P.O.Box 2038 - Bangor, Maine 04401.

Every Friday evening 6:00pm to 7:30pm at The Aids Project - 48 Deering St. - Portland - there is a support group meeting for PWA's and PWArc ONLY. Call 774-6877 for further information.

COMMENTS

We welcome your thoughts and suggestions to help the Newsletter meet your needs. If you have an event in your area that you would like to have published in the Aids Project Newsletter, please contact us at The Aids Project - 774-6877 - or by mail to the attention of: David Ketchum.

SUBSCRIBE

SUBSCRIBE NOW TO THE AIDS PROJECT NEWSLETTER

THIS NEWSLETTER RELIES TOTALLY ON SUBSCRIPTIONS TO EXIST. WE ARE GRATEFUL TO THOSE WHO HAVE SUBSCRIBED, AND TO THOSE WHO HAVE NOT. PLEASE DO SO NOW. $10.00 COVERS ONE YEAR (12 ISSUES). PLEASE MAKE YOUR CHECK OR MONEY ORDER PAYABLE TO "THE AIDS PROJECT", THANK YOU.

NAME
ADDRESS

LET'S HUG
THERE'S A HUG TO SAY
I LOVE YOU
AND A HUG TO SAY GOODBYE
THERE'S A HUG TO SAY HOW ARE YOU
AND A HUG TO SAY, WE TRIED
THERE'S A HUG TO BOND A FRIENDSHIP
AND A HUG WHEN THE DAY IS THROUGH
BUT THE HUG I LOVE IN ALL THE WORLD IS THE HUG I GET FROM YOU!

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