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Spring 1991

The AIDS Project Newsletter, Vol.4, No.1 (Spring 1991)

Jeffrey Levensaler

The AIDS Project

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THE AIDS PROJECT NEWSLETTER

Spring 1991
Volume 4 Number 1

A NIGHT TO REMEMBER

by Jim Bratton

From the moment the guests rose in thunderous applause as Frannie Peabody entered the ballroom on the arm of Governor John McKernan, everyone knew that November 30th was going to be a night to remember. Over 350 friends and fans of Frannie had gathered at the Sonesta Hotel Portland to celebrate the life and accomplishments of a truly remarkable woman. And celebrate they did.

Dinner charman Bettsanne Holmes, assisted by an energetic and dedicated committee, had spent months planning the evening, making sure that every detail, from the invitations to the flowers on the table, was perfect. No one was disappointed.

Lisa DiFranza, Associate Director of Portland Stage Company, coordinated a program, chronicling Frannie's life and many accomplishments, that was interesting, entertaining and emotion-packed. Portland Mayor Peter O'Donnell began the program by reading a proclamation declaring November 30th, Frannie Peabody Day. Reverend Fred Lipp, from the First Parish Unitarian Universalist Church, gave the invocation, and after dinner, Bettsanne Holmes introduced the master of ceremonies, Dr. Bob Arnot, Medical Correspondent for CBS This Morning.

With cameras from Channel 13 and Good Morning America taping the evening's activities, Dr. Arnot introduced Governor McKernan, who read a proclamation honoring Frannie. Other speakers included Earle Shettleworth, Director of the Maine Historic Preservation Commission who talked about Frannie's commitment to the preservation of historical and architectural resources, Barbara Peabody, who made candid and emotional remarks about Frannie's commitment to her family, John Preston, Board President of The AIDS Project, who, in a moving speech, told of Frannie's commitment to people with AIDS, and Fred Lipp, who talked of the honoree's spiritual journey.

The final speaker of the evening, United States Representative Olympia Snowe announced that Frannie had been named by President Bush as this country's 314th "Daily Point of Light," a recognition accorded those who have given unselfishly of

themselves so that others might have a better life. Another standing ovation.

Interspersed throughout the speakers were readings from Frannie's own oral history, highlighting important moments which gave the captivated audience insight into the life of this extraordinary person that everyone knew was truly a national treasure. Readings from Frannie's life story, in her own words, were beautifully performed by Kate Lippa and Rickey Wilson.

After Frannie humbly thanked all who participated, Honorary Dinner Chairman, Jean Gannett Hawley, Publisher and Chairman of Guy Gannett Publishing Company, presented John Preston with a check for \$35,000.00, representing proceeds from the dinner. To the delight of everyone involved with the dinner, when the final accounting was made, the Peabody Dinner raised nearly \$50,000.00 to establish the Frances W. Peabody Fund to benefit The AIDS Project, (Please see article on page 6). And everyone knew that an added and important benefit was that the dinner heightened the awareness of and sensitivity to issues surrounding AIDS and HIV infection in the greater Portland area.

The many volunteers and organizations who helped plan the dinner and contribute to the fund are too many to list here, but special mention and gratitude should be given to those who were intimately involved in planning the spectacular evening. In addition to Honorary Chairman, Jean Gannett Hawley, and Chairman Bettsanne Holmes, members of the planning committee included James T. Bratton, Madeleine G. Corson, Howard H. Dana, Jr., Liza DiFranza, Louise P. James, M.J. Larned, Barbara McInness, Wilma P. Redman, Anita C. Stickney, Marlise Swartz, Megan Thorn, John Walker, Katherine Woodman and Roger Woodman. Congratulations to all on a job well done!

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Executive Director's Message

by Marjorie Love, MSW

When I came to TAP last August, I joined an organization that continued to function in the face of enormous odds. TAP had just been through a year of deep financial hardship. Staff were working four-day weeks, at 80% of salaries, despite staggering workloads. Clients were growing frustrated with the limits to the services we could provide.

Yet despite the organizational pain, something very valuable was intact. After six months at reduced pay, not one staff member had abandoned ship. Despite the limits imposed by our overwhelming workloads, people with HIV and their families continued to look to us for guidance and support. TAP continued to have strong presence providing AIDS prevention education in the schools, on the streets, throughout the community, and via our statewide hotline. And while there was never quite enough, money continued to flow into our coffers in response to our board's and staff's efforts, and our community's response.

I inherited from Perry Sutherland (last year's Acting Executive Director) an organization somewhat shrunken and bruised. But Perry had seen the agency through its most difficult year, and in surviving that year, The AIDS Project had emerged lean and tough enough to take on whatever would come next.

Much of last year's financial crisis at TAP was caused by its long tradition of trying to do what was needed despite resources too small for the job. Most of our services are delivered under contracts with various government agencies. However, these contracts provide only 60-80% of the funds it costs to provide the service; in each case we

have promised to raise the balance. As TAP has grown, that balance has grown to enormous proportions, committing us to raising funds far beyond the means of our small organization. When fundraising fell short, financial crisis hit.

Last year's shrinkage helped to create expectations more in keeping with our actual resources. My work so far this year has focused on assuring financial stability for the size of organization we now are. I began by advocating with our contract agencies for more realistic assessment of the costs of the services we provide, and for those costs to be reimbursed in the contracts we sign. While the current human service funding situation limits what we can expect at this time, the message has been heard and small improvements have been made.

Meanwhile, our board has been busy planning a resource development strategy ambitious enough to fill the gaps left by our service contracts. Beyond our traditional reliance on fund raising events (which we plan to make fewer and more successful), this year we're gearing up for more direct mail, corporate, and foundation fundraising. We know the times are tough for non-profits, and we're staying conservative in our expectations, but we also know that there is a lot of support for our efforts in AIDS prevention, advocacy, and client support work, and we plan to tap it.

Our development plans were given a big boost by the enormous success of the dinner for Frannie Peabody. Frannie so deserved the appreciation! We were thrilled to see such attention given to her powerful message about the need for compassion for those now affected by AIDS and for prevention of the further spread of this infection. And substantial money was raised (see more elsewhere in this issue), enough to launch The

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The AIDS Project Newsletter

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The AIDS Project is a non-profit organization dedicated to providing and promoting services to people with AIDS and HIV-infection, advocacy regarding AIDS related issues and concerns, and AIDS related health education and information to the citizens of Maine

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Peabody Endowment Fund and also enable us to erase the remaining debts carried over from last year.

This combination of development planning, dinner, and contract negotiations brought enough security that priority #1--returning the staff to fulltime--has been achieved. You can see the importance of this most clearly in case management where 3 staff (2 in our Portland office, 1 based in Lewiston) provide support, information, and advocacy to more than 135 clients living with AIDS or HIV infection. This makes for enormous caseloads, even at full-time. When cut back to a four day work week, these staff still carried the same hefty responsibility, with 20% less time to carry it out. The pressure on our staff was immense, and our clients suffered as well from the corners that we inevitably cut. Similar dilemmas affected all our staff during the 8 months at 80%. I'm grateful that they hung in there!

Besides basic financial stability, another initial priority was TAP'S volunteer system. Volunteers have always been central at The AIDS Project, from our beginnings as an all volunteer organization to the enormous contributions in recent years of TAP volunteers in direct client support roles, hotline coverage, provision of meals, board and advisory board service, fundraising, etc. Last year's cut-backs meant the elimination of our Volunteer Coordinator staff position, and at a time when remaining staff had little time to fill the gap. The result was an under-utilization of volunteers that added to the overall organizational stress.

We still are not able to afford a paid Volunteer Coordinator. Proper attention to, and utilization of, volunteers continues to be difficult to provide. So, we have been working to set in place a totally volunteer-run system of volunteer coordination, featuring "team leaders" for each type of volunteer work, who will provide intake of new volunteers, matching of volunteers with jobs, and ongoing volunteer support. I am hopeful that this approach will allow TAP and our clients to profit from the enormous generosity and talent available to us, and will permit (at least) adequate attention to the coordination and support needs of volunteers working with us.

Financial stability, a full-time staff, and increased support feels like a good start. These necessities bring us to a place where we can carry on the critically important work of planning for our future. What follows are some of the issues that I believe will need our attention as we plan for TAP's future.

Until there is a cure, AIDS prevention work is our only hope. How do we best use the resources we now have--staff positions in community education and street (I.V. drug user) prevention, the statewide AIDS hotline, a counseling and testing program--to slow the spread of this disease? How do we break through a climate of apathy and denial and create behavior change. How do we convince people that AIDS prevention is important for them, not just the other guy? What more do we need to do, and how do we get the resources to do it?

People with HIV and AIDS--as well as their families and friends--throughout York, Cumberland, Androscoggin, and Oxford counties look to us for help in coping with the enormous emotional, financial, medical, and social consequences of this epidemic. Three case managers are not enough. What is the best model for expansion; what blend of staff, volunteers, and support groups? Where do we find the additional resources that will be needed?

To document what we are currently doing, and to make the case for additional resources, we need to be much more sophisticated than we currently are at measuring and reporting what we do. To take best advantage of the resources we now have, and to plan and advocate for the resources we will need in the future, we need program management resources far beyond our current scope. In last year's downsizing, we eliminated three middle management positions: business manager, director of client services, and (part-time) volunteer coordinator. What is the most efficient staffing model that still permits the functions that were eliminated with these positions?

These are the immediate pressing issues. There are other issues as well. How do we most effectively participate in the political process that governs law, policy, funding of AIDS issues? How do we broaden our focus to truly reflect the needs and abilities of all four counties that we intend to serve? How do we better involve people living with AIDS and HIV in planning for the services we'll provide?

How do we support our staff and volunteers as they do this incredibly difficult and important work? How do we make peace with the limits to our abilities, individually and organizationally, in the face of the enormity of human need that is the AIDS epidemic? How do we become, and remain, the best we can be?

In my first six months at The AIDS Project, my priority has been on stabilizing the financial and organizational base needed to support our work. While not finished, that work has been fruitful.

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I hope that the next six months will permit more journeys beyond the bottom line, into the networking, planning, and imagining that lies beyond.

Finally, I have to give some thanks where thanks are due. In joining TAP, I took on some sizable challenges. I also inherited a wealth of resources. A hard-working, enormously caring, impressively talented staff. A very supportive and committed board (Frannie is the jewel, but it's an amazing group led by a president, John Preston, who's a pleasure to work with). And people throughout the community whose giving makes all the difference--our volunteers, our Advisory Board, our donors, colleagues in the PWA and service provider community, and the many people who have reached out to me with advice, support, constructive criticism. There are so many key people that I have not yet met (having kept my nose a little too much to the grindstone), and I look forward to finally doing so.

It has been, and will be, a pleasure to work with you. Together, we can make such a difference.

EVERY PENNY REALLY COUNTS

by Amanda Coffin

"How much money can we possibly raise by collecting change in jars?" I asked, "and is it worth the work?". Eight months and over \$7,000.00 later, I have an answer: The Every Penny Counts campaign is a success.

Since May, volunteers have placed almost forty 1-gallon jars in businesses from Wells to Lewiston. The volunteers collect the contents of their adopted canisters periodically, keeping the funds from each jar separate and marked. Once the money is counted, The AIDS Project sends letters to both the volunteers and the business owners to keep everyone aware of each jar's progress. On each jar is a label to indicate how much money the jar has produced to date.

Since some jars have been in place longer than others, our "Top Five" listing is not altogether fair, but it seems appropriate to acknowledge the businesses that have hosted jars which produce a steady and unrestricted flow of income for The AIDS Project. As of mid-January, our Top Five are as follows:

Victory Deli	\$799.00
Mill Creek Bookland	\$635.00
Magic Muffin, Congress St.	\$618.00
Lisa's	\$451.00
Video Port	\$417.00

Volunteers placed all of these jars in May. Mark, the co-owner of Victory Deli, claims that the jar has profited from a lot of foot traffic and many small purchases that generate change. Mill Creek Bookland staff members concur, although they have found some larger bills. They nearly always thank customers who deposit change in the jar, but no one saw the generous customer who deposited a \$100.00 bill shortly before Christmas.

As we approach the one-year anniversary of the Every Penny Counts campaign, we are working on ways to expand and improve it. We need more 1-gallon glass jars and more volunteers to prepare and adopt the jars. If you are able to help and would like to become involved, please call Mark,

***The AIDS Project, Portland, Maine,
requests the pleasure of your company at
the 5th Annual***

**VISUAL
AID**

***An Art Auction For AIDS Education
And Direct Support Services***

***Friday, March 1, 1991
(Snow Date: Saturday, March 2, 1991)***

Sonesta Hotel

***Cumberland Hall
157 High Street
Portland, Maine***

***Preview: March 1, 1991
Noon to 7:30 PM
Auction: 7:30 to 9:30 PM***

Admission \$5.00

***Visa and MasterCard
Accepted***

**IN LOVING MEMORY
JOHN MOORE, III
June 14, 1956 - January 26, 1991**

BIKATHON RETURNS

by Bob McCormack

Over 70 Scarborough students participated in an autumn bikathon to raise money for The AIDS Project, resulting in a generous donation to TAP of \$3,408.00.

On Saturday, October 20 a bikathon was held in Scarborough to benefit The AIDS Project. The ride was organized by and for the students of Wentworth Middle School, and led by teacher Tom Griffin. The route covered twenty scenic miles, from Oak Hill in Scarborough to Kettle Cove in Cape Elizabeth and back. Participants in the ride were students in grades 6 to 8, with a few high school students who had been involved in previous years returning for the event. Faculty organizers and directors were Tom Griffin, Sharon Larando and Mike Currier.

Each participant paid a five dollar registration fee to cover administrative expenses and delivered a minimum of twenty dollars in pledges to benefit TAP. A yellow T-shirt with "1990 Scarborough Bikathon for AIDS" written across the front was presented to each rider as a remembrance of the day.

At 8:00 A.M. on the morning of the ride, the bicyclists gathered in the parking lot of the Scarborough Department of Public Works building on Black Point Road. Parents, students and teachers were volunteers for registration and refreshments. Tom Griffin gave instructions to the riders about safety precautions and road etiquette. Ed Wimert was introduced by Sharon Larando and spoke briefly to the riders about the previous bikathons and expressed his appreciation for their endeavor. Bob McCormack, Board Vice President of The AIDS Project, thanked the participants for their support. He also had the pleasure of being one of the few adults to participate in the actual ride.

The ride itself was over rolling terrain. Parents set up traffic cones to create special bike lanes at crowded points and acted as traffic coordinators at every turn. There were water/refreshment stops at Len Libby's Candy in Scarborough and at the halfway point at Kettle Cove. The event was non-competitive and most riders were clustered in small groups. A barbecue, prepared by the parents, was held at the end of the ride.

This was the fourth annual bikathon that the students have been involved in. The first ride was initiated and organized by the students under the direction of Sharon Larando as part of the

school's Project Quest. The next two years The AIDS Project organized a bikathon that the students participated in. When the students found out that The AIDS Project was pursuing other avenues for fundraising this year, they took it upon themselves to organize and administer the ride.

The benefit to The AIDS Project is substantial. In a brief ceremony at the Wentworth School on December 12, a certificate was presented to each student rider and a check for \$3,408.09 was presented to TAP. TAP was the beneficiary of an event that was entirely organized and sponsored by the community itself. TAP's resources weren't tied up in any way, guaranteeing that all monies raised can be spent on vitally needed client support services.

The students involved are to be applauded for their dedication to the fight against AIDS, for their initiative in raising needed funds for The AIDS Project, and for their contribution to the awareness that AIDS is a community concern. Their "Bikathon for AIDS" is a model of community responsibility for which The AIDS Project is very grateful.

The AIDS Project Advisory Board

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Roger Woodman**

THE PEABODY ENDOWMENT FUND

by John Preston, President of the Board

The Frannie Peabody Dinner certainly gave The AIDS Project a boost, and a much needed one. The proceeds from this one event helped us wipe out an onerous debt and also presented us with the foundation for The Frannie Peabody Fund, one of the dreams Frannie has had for years.

The Endowment Fund presents problems, though. How do we handle this money with the best stewardship? The board of directors had to wrestle with that question. We asked advice from community leaders and financial consultants. We could have simply spent the cash we received from the event, nearly \$50,000.00. Or, at the other end of the spectrum, we could have put all the money into a trust, taking only the income for annual expenses.

Neither one seemed to meet our needs, nor the expectations of the people who organized the dinner. Taking the entire sum and using it for this year's operating expenses would have meant that there wouldn't have been any lasting benefit from the dinner. Leaving the money in a trust and withdrawing only the seven per cent or so that would have been earned wouldn't have alleviated the desperate current needs of The AIDS Project. The people who held the dinner certainly wanted to honor Frannie Peabody, but they also wanted to help The AIDS Project in what they knew was a time of crucial need.

Members of our Community Advisory Board brought up still another consideration: We really don't want The AIDS Project to be an institution that exists perpetually. We should be ready, happily and willingly, to go out of business when a cure for AIDS is found. It doesn't seem appropriate to establish a trust Fund that would never be able to be liquidated.

Here's our board's solution, one that's met with enthusiastic endorsement from others we've talked to. The Frannie Peabody Endowment Fund exists as a separate entity from The AIDS Project. It is separately named and we will continue to fund-raise for it. Annually, one-quarter of the Fund's money will be distributed to The AIDS Project for its operating expenses. This will both insure a regular flow of income to The Project, and of a meaningful sum, while not depleting the Fund. The remaining money in the Fund will be kept in secure, conservative investment vehicles.

We do hope for a time when AIDS doesn't exist, when there

is a cure and a vaccination. Until that time, we have to plan, not only to maintain our organization, but also to grow. Tragically, we know that the case-load of The AIDS Project will only increase in the next few years. We'll need more staff, more education, more support for clients. All of this is going to happen just as both the state and federal government are operating under their own escalating financial constraints. We'll have to raise money, not just to deal with the expanding number of clients, but also to compensate for the loss of government support.

The AIDS Project is gearing up its own fund-raising efforts with a more rational and thought-out approach that will involve corporate fund-raising and increased use of direct mail appeals. The Frannie Peabody Endowment Fund will be able to offer large donors and those who wish to leave The AIDS Project bequests, for instance, with a way to ensure that their donations are carefully nurtured and well-protected, at the same time that their gifts go directly to support services for people who are living with AIDS.

What we need are people who understand the vital importance of both these strategies, people who will support The AIDS Project and help it meet its current heavy demands, as well as those who will give to the Frannie Peabody Endowment Fund and make our future secure.

A SPECIAL WELCOME

The AIDS Project Portland is pleased to announce the addition of Cathy Kidman to our Staff.

Cathy joins our staff as Community Education Coordinator, bringing with her extensive experience in community education and volunteer training in rape crisis and domestic violence programs.

Cathy reflects an enormous creative energy and commitment that will enable TAP to keep moving forward in the future.

Welcome Cathy!

IN HONOR OF WOMEN AND CHILDREN WITH AIDS

by Barbara Peabody

The following are excerpts from a speech by Barbara Peabody, presented on World AIDS Day, December 1, 1990:

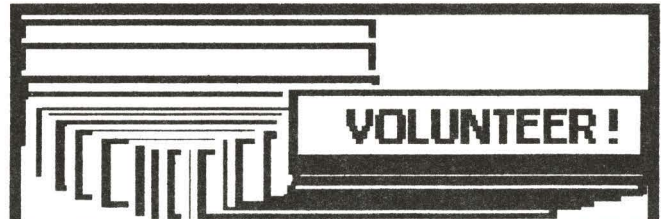
I want to thank you for inviting us to meet all of you here today, on World AIDS Day. Having to set aside a day for AIDS gives me many mixed emotions: sorrow and grief, for those who have already died; for those whose youth has been cut short by this crippling disease; and for all our families who have lost our children, spouses, parents, and siblings to this virus. Fear: fear that this disease is going to decimate the youth of the world. The World Health Organization estimates 20-30 million infected by the end of the century. And fear that there will never be a cure; this virus is always going to be with us even if it is controllable with early diagnosis. And anger: that we even need to have a World AIDS Day, need it because this virus is not getting the attention and respect it deserves as a viciouscrippler and killer of our young.

The anger started when my son, Peter, was diagnosed with AIDS in late 1983. I was angry at the two doctors who had failed to detect my son's infection for a year. One even told him he might have AIDS phobia--when actually he was already in the late ARC stage. They hadn't listened to him. My anger continued all through his last year, often against medical people who didn't listen; Peter would say, "They don't listen to me." I've heard the same complaint from hundreds of PWAs since then. Anger at callous treatment by Emergency Room staff; non-AIDS specialists he had to see; lab technicians; maintenance and food personnel who wouldn't come near him. But my greatest anger, then and now, is at public apathy, prejudice, and judgmentalism, extending even to the President who couldn't pronounce the word AIDS till well after it had killed my son. I'm still angry; that President's blind indifference retarded education, prevention, and treatment efforts so severely that it has caused the needless deaths of thousands of our sons and daughters. There was a brief flurry of compassion after Rock Hudson's death, with celebrities riding the crest of a wave they didn't care about personally; AIDS was the "cause of the year", and now, though there is more awareness, we've sunk back into apathy and indifference. Young people continue getting infected, being diagnosed, and dying, dying, dying, while the media gives falsely optimistic pictures of new treatments, possible cures, and film clips of brave people (a small, small group) living for years with the virus. But for every one who struggles

to survive an incredible five, six, or eight years, there are thousands who succumb after a few short months, a year, two years. AIDS has not been overcome. It's here to stay, and the lives of thousands--millions--of men, women, and children will be viciously crippled and obliterated.

Today is supposed to be dedicated to women and children with AIDS. In this country, we still don't realize--yet--the impact of this virus on women and children. In Africa and Latin America, women get AIDS as often as men. This is an equal opportunity virus. AIDS is a venereal disease, venereal diseases come from sex, and all human beings are sexual. Whole families--even villages--are wiped out by the uncontrolled assault of this virus in the Third World. The virus is making vast inroads on the youth of Brazil: it is estimated that 5-8 million Brazilians will be infected by 1995. They'll be men, women, and children. In this country, women are the last

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Many volunteer opportunities are currently available at The AIDS Project. If you would like to put your skills and caring to good use, call us at; 774-6877.

Some of the areas where volunteers are especially needed are:

- Adopting an Every Penny Counts Jar
- Cleaning and Maintaining TAP Offices
- * Client Visits/Transportation/Assistance
- * Cooking/Serving Meals Program
- Help with Fundraising Events
- Maintaining TAP Library
- * Receptionist for Counseling & Testing (Eves)
- * Staffing AIDS Hotline
- TAP Newsletter (Writers, Editors)
- * Telephone Coverage in Office (Days)

*** These roles require completion of TAP Volunteer Training. Next training will be Friday evening and Saturday, March 15-16 and 22-23. Hotline emphasis. Call TAP to register.**

to receive experimental drugs; the reason usually given is that women might become pregnant and the drugs might harm an unborn fetus. As if women were incorrigible breeders without the mental capacity to prevent conception. That makes me angry; men are also responsible for conception.

I knew this anger firsthand when a female PWA I knew well, Lina, was refused entry into the first AZT study in San Diego. This was a gutsy, little woman with multiple possible causes of infection: IV drugs; 30 blood transfusions when her despair over addiction made her try suicide; and sex. "They're afraid I might get pregnant!" she exclaimed angrily. "God, I'm too damned sick to even think of sex!" She was also refused pain medication for her severe neuropathy--they thought she might be faking it to get drugs--for fear that she'd get back into her habit, and she resented their lack of trust and assumption that she'd do wrong instead of right. She didn't get AZT until the study was opened up a year later, after being diagnosed with *Pneumocystis pneumonia*--and it was too late. It's only now, years into the epidemic, that the powers-that-be are finally acknowledging the existence of women with AIDS--which means, of course, that they are finally acknowledging that AIDS is not a gay disease, that women are being diagnosed at a higher rate than men now, and that their children, too, are often being born infected. Many of these women were infected through drug abuse; many were sexual partners of drug abusers; many were infected by a bisexual man; and many were infected by transfusion. It doesn't matter how they were infected. What does matter is that AIDS is the number 1 killer of women of child-bearing age in New York City, and that one out of every six babies born there is infected.

And when women get AIDS, it's not like it is in the gay community. The woman with AIDS presents multiple psychosocial problems: if she dies, she leaves orphaned or semi-orphaned children--if they, too, are not infected. It means elderly grandparents raising small children, or social workers desperately seeking foster homes who will accept these children. It means more daycare, household help, emotional support for husbands, children, and parents. Sometimes it means an abortion decision if the woman is pregnant. It means more complex medical care; AIDS attacks women differently. And it means the growing, overwhelming tragedy of warehoused infants with AIDS babies whose parents have died or are incapable of caring for them, and living their too-short lives in hospital cribs.

Lina was my first introduction to women with AIDS. I first met her when she came to my AIDS art class in San Diego, and knew her well for the three years she survived--as the only

AIDS patient in the city who never was hospitalized, partly through her own refusal and partly because she, as a woman, received inadequate care.

My first introduction to a family with AIDS came when, as bilingual counselor for the Visiting Nurse Association, I was sent to a Mexican Home. Mother and father, 26, a 2 year old and a 1 year old. Antonio, the two year old, had just been diagnosed with AIDS and subsequently the parents and younger child were tested. Mother and father tested positive, the baby negative. The mother, a sweet, pretty young woman who spoke no English, had no idea how they'd become infected. I was shaken when I left the apartment, realizing that some day three of this small family would be dead. Antonio lived two years, two years of constant testing and IV treatment, hospital cribs, chronic illness, wasting, mental retardation, and finally died four days after he was diagnosed with lymphoma of the liver. The parents, still healthy and working, still cannot believe they could sicken and die and have refused AZT. One day, they'll start the chronic ups and downs of AIDS, and one day they'll die. This story is repeated over and over in the AIDS clinics of New York, Miami, and Newark--and will be seen increasingly throughout the country just as it is now in Africa. Because of indifference and stupidity, too many young people and children will die. Why didn't we learn from Africa? We are not prepared for the new epidemic of the 90's, AIDS in women and children, and it's our own fault.

Women with AIDS are terribly isolated. The gay community has its own infrastructure of support and has done an incredible job of helping its own with support, aid, and fighting the medical and political establishments. But women, usually concerned with their families and children, feel out of place in male support groups, and even when there are women's groups they are unable to attend because of lack of babysitters (how do you ask someone to babysit in an AIDS home?), transportation, encouragement. They feel alone and abandoned; gay men are not the only ones whose families shun them. When you feel that no one cares, you don't make the effort to live. Sometimes, because of ignorance about AIDS effects in women, they are not diagnosed until it's too late to do much.

I've known several HIV-infected women:

Dora, a Mexican woman, left four children, one with muscular dystrophy. She was 28 at death, and the children are now scattered among four foster homes.

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Kara, infected by a hemophiliac fiance during high school, died at 25, leaving a bereft new husband.

Kathy died at 36, leaving 3 half-grown children and an incompetent husband.

Sherry is HIV positive. She has 3 children (none infected) and tries to maintain her sanity caring for them and a severely demented, 6' 4" husband with AIDS--while anticipating her own disease progress.

Gay, 40, was diagnosed with AIDS a month after it had killed her husband. She has two teenage sons and is unable to be the strong disciplinarian their father was.

The list goes on and on, these women in the shadows of AIDS, and these are only ones I've known personally. Don't tell me AIDS is a gay disease. I'm angry that it was considered such for so long in order not to deal with it. They could have looked at Africa.

The World Health Organization estimates 20-30 million infected worldwide by the year 2000. Many will be women, many will be children. Many will be entire families. And what are we doing? Not much, really, despite the dedicated efforts of small groups here and there. AIDS is already wiping out medical resources in New York City. HIV-infected persons in the Third World simply don't receive care; they don't have the money, they're going to die anyway, and AIDS care is expensive.

We need constant, nagging education at all levels of comprehension, tagetting everyone from the junior high school student to the elderly (they get transfusions). We need money for education and for care; people are living longer. People are sick of hearing about AIDS,

they'd rather not know about it any more. It's not stylish any more. But it's still here, it's still there, and it's still killing our young. Despite the hopeful faces of TV of the longtime survivors, this ugly, deceitful disease is still killing. And it's going to get worse before it gets better.

And I'm still angry. I'm angry that Peter died at 29. I'm angry that people are still dying at 25, 26, 35--or 3, 4, or 5. We have to keep this anger alive, we

have to keep educating, telling our personal experiences with AIDS, raising money, nudging public consciousness.

Because if we who have lost don't care, who will?

IF YOU WOULD LIKE TO SUBMIT AN ARTICLE, POEM, OR COMMENTS TO THE AIDS PROJECT NEWSLETTER, CONTACT MARK, TAPS ADMINISTRATIVE ASSISTANT: 774-6877

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: _____

Ongoing Calendar of Meetings

MONDAY

Support group for Seronegative lovers of Seropositive individuals, 5:15-6:45 P.M., at the PWA Coalition. Call 774-6877 or 1-800-851-2437 for more details.

AIDS Response of the Seacoast in Portsmouth, NH, runs a support group for PWA's, PWARC's and HIV+'s. The group is open to people from York County. This group is lead by professional facilitators utilizing holistic healing techniques, meditation, visualization, heart centering, music and touch in a supportive and loving environment. For more information and an intake interview, contact: Suzanne Bowman (207) 439-2136.

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.

Belfast Area AIDS Support in Waldo County. For PWA's, PWARC's, HIV+'s, friends, 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.

Rumford area C.A.A.P., (Community AIDS Awareness Project), Support Group. Contact Ron Ashworth, 364-2616 for further information on meeting time/place. For PWA's, Family members and/or friends. Monthly meeting open to the Public.

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.

Tuesday evenings, closed support group for people with HIV infection, 6:00-

8:00 P.M., The AIDS Project, 22 Monument Square, 5th floor, Portland. Contact Toby Simon at: 774-6877.

Support Group for Caregivers, every second and fourth Tuesdays, 7:30-9:00 P.M. at the Down East AIDS Network (Dean) office, 114 State St., Ellsworth. Doug Kimmel, Ph.D., facilitator. For more information contact Bobby Poulin, 667-3506 or Doug Kimmel, 422-3686.

Support group for PLWA's, PWARC's, HIV+'s their Partners, Families, and Friends - 7:30-9:30. Meets in the CDU Building, 2nd floor, Frisbie Memorial Hospital, Whitehall Road (Route 16), Rochester, NH.

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

WEDNESDAY

Augusta area HIV/AIDS Support group meets at the office of Dr. Karen Kalustian, 152 Dresden Ave. in Gardiner. The group is open to all on the second and fourth Wednesdays of each month, 6:30-8:00 P.M.. Contact: Cecilia Leland, 371-2147 or Steve Fleming, 777-1701.

THURSDAY

Women's AIDS, ARC & HIV+ support group. The group meets 10:30-12:00; 22 Monument Square, 5th Floor, Portland. Facilitated by Diane Elze. This group is for Women with AIDS, ARC or HIV+ only. Call 774-6877 or 1-800-851-2437 for more information.

Women's HIV Support Group every other Tuesday 7:00-8:30 P.M., facilitated by Roberta (Bobby) Poulin, M.S.. For information call: Bobby: 469-6405 or 667-3506 or call: Patty Miles: 947-0700.

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.

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

Thursday support group for seropositive people. Call Diana Carrigan at The AIDS Project's Lewiston office, 783-4301.

FRIDAY

Support group for PLWA's, PWARC's, HIV+'s their Partners, Families and Friends - 7:30-9:30. at Portsmouth Hospital, Classroom B, Near Main Entrance.

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.

***Please call 207-774-6877
with any corrections or
additions to our calendar.***

NOTICE

Persons interested in a Lewiston area group for families of People with HIV call Diana Carrigan at: 783-4301.

Hotlines

Maine AIDS Line:
1-800-851-AIDS
OR 775-1267

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)

National AIDS Hotline:
(800) 342-AIDS

VOLUNTEERS MEETING

The monthly meeting of TAP Volunteers will be Saturday, March 16, 1991, from 9:00-11:00 A.M., 22 Monument Square, 5th floor.

REGIONAL PWA CONFERENCE

Friday, May 17 - Sunday, May 19 is slated for the Regional PWA Conference in Portland. A public candlelight memorial service will be held on Sunday.

Hosted by People with AIDS Coalition of Maine. For more information, call 773-8500.

HIV/AIDS ACTION AGENDA FOR 1990'S

Richard Keeling, M.D. will speak on HIV/AIDS: Action Agenda for the 1990's in an engagement at the University of Southern Maine.

Dr. Keeling is the Chair of the American College Health Association HIV/AIDS Task Force, President of the International Society for AIDS Education, and the Past Chairman of the Board for the National AIDS Network.

The program is set for 7:00 P.M., Wednesday, March 20, 1991. The location is the University of Southern Maine Gymnasium. The admission is free. For further information call: 780-5370.

A HUNDRED LEGENDS

A Hundred Legends...A collection of art, poetry, prose, and music by over one hundred men, women, and children living with AIDS.

The show opens April 4, 1991, 5:00-7:00 P.M. at the Barridoff Gallery, 26 Free Street, Portland, and will continue through the weekend. For more information on A Hundred Legends, call Ellen Grant at: 829-3148 (evenings/weekends).

The University of Maine at
Farmington
**Gay and Straight People's
Political Alliance
Presents a 1-day conference**

AIDS ACTION AND ACTIVISM

**Saturday April 27, 1991
at U.M.F.**

Opening Programs by:

*** Fran Peabody, founder of
The Maine AIDS Project**

*** Toby Simon, of ACTUP/
Maine**

*** Teens in Theatre, of
K.V.C.A.P., Waterville**

Call: 207-453-4075

Or write:

**G.A.S.P.P.A.
5 South Street
Farmington, Me. 04438**

MORE PEACE, LOVE, AND HEALING WITH BERNIE SIEGEL

Monday, March 11 will mark the return of Bernie Siegel, M.D., to the Portland area.

Bernie is a physician and teacher at Yale Medical School, who believes in, and practices successfully, a combination

of Love, Medicine, and Miracles, and brings Peace, Love, and Healing to his patients.

Plan to attend Bernie's lecture on the evening of Monday, March 11 and his

all-day workshop on Tuesday, March 12. For registration information, call 874-6500. Scholarships are available to those in financial need.

PWA scholarships available through TAP

TAP
22 Monument Square, 5th Floor
Portland, ME 04101

ADDRESS CORRECTION REQUESTED

