The AIDS Project Newsletter (August 1987)

David Ketchum
The AIDS Project

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AUGUST 1987

SPECIAL EVENT

The Aids Project Annual Meeting and Pot Luck Picnic.
Date: August 29, 2:00 p.m. to 6:00 p.m. (Raindate - August 30)
Place: Home of Kristen Kreamer, 128 Gertrude Avenue, Portland.
Phone: 878-2722

All volunteers, clients, friends, supporters, and contributors are urged to attend. Please come and help us celebrate our first year, and let us express our gratitude for all of your support.

EDITOR'S NOTE

One big hug for Vickie Poulin!!!

Hello, my name is Vickie Poulin. I am a mother, wife, nurse and student. I am the oldest of a family of six, the youngest of which, my brother, Christopher, age 12, has died of AIDS.

I would like to say that throughout my brothers’ illness (lasting not quite one year) he received wonderful, compassionate care.

When it began to be apparent to me that there was something wrong with Christopher in the fall of 1985, AIDS came immediately to mind. My family and I were very aware of this disease, since both of my brothers, John and Christopher, have hemophilia. I would like to be quite honest, and say that I was scared, really scared!

But, as we loved Christopher, my family and I began to educate ourselves against this potentially crippling fear, so that we were able to support Christopher and each other with our love throughout this crisis.

When Christopher’s diagnosis was made, we then took steps to educate our friends and community as we had educated ourselves, against fear.

After his initial hospitalization, Christopher received schooling, at first, from a tutor at home. When he was strong enough, he returned to school without an uproar. The children knew about the hemophilia, and they took this new development into stride without difficulty.

Chris spent the last four months of his life on a respirator with many trials and tribulations. These were met with support from all hospital personnel at the Maine Medical Center - Special Care Units, who were our extended family, and from a great many community members. I am confident that the acceptance of his peers through cards, letters, photos, and pictures, made this time somewhat more bearable for a twelve year old fearing rejection from peers, and for us, the family needing support.

The classmates and their families continued to be supportive to us even after Christopher’s death, when we needed it most.

The thought that I would like to leave you with, is that if a small Maine community, such as Monmouth, can learn and be supportive, so can the vast majority. AIDS isn’t spread by hugs, pats on the back, or companionship. However, it is my experience, that all of these things are necessary, needed, and important to PWA’s and their families.

Thank you for coming! Thank you for listening! And most of all, for me, if you see someone with AIDS or their family, don’t be afraid----give them a hug. It won’t hurt, and I bet it will help! Thank you.

Aside from her regular job as a nurse, Vickie is busy talking to various groups across the state about Aids, about her brother Christopher, but most of all, she is talking about love and compassion for all mankind.
I want to talk tonight about the disease that has brought us all together. The poet W.H. Auden said that the true men of action in our times are not the politicians and statesmen, but the scientists. I believe that's especially true when it comes to the AIDS epidemic.

AIDS has been one of the fastest-growing parts of the budget, and, ladies and gentlemen, it deserves to be.

We are also tearing down the regulatory barriers so as to move AIDS drugs from the pharmaceutical laboratory to the marketplace as quickly as possible. It makes no sense—and, in fact, it's cruel—to keep the hope of new drugs from dying patients. And I don't blame those who were out marching and protesting to get AIDS drugs released before the T's were crossed and the I's were dotted. I sympathize with them, and we'll supply help—and hope—as quickly as we can.

It is absolutely essential that the American people understand the nature and the extent of the AIDS problem. And it's important that Federal and State governments do the same.

I recently announced my intention to create a national commission on AIDS, because of the consequences of this disease on our society. We need some comprehensive answers. What can we do to defend Americans not infected with the virus? How can we best care for those who are ill and dying? How do we deal with a disease that may swamp our health care system? The commission will help crystallize America's best ideas on how to deal with the AIDS crisis. We know some things already—the cold statistics. But I'm not going to read you gruesome facts on how many thousands have died or most certainly will die. I'm not going to break down the numbers and categories of those we've lost, because I don't want Americans to think AIDS simply affects only certain groups. AIDS affects all of us.

What our citizens must know is this: America faces a disease that is fatal and spreading. This calls for urgency, not panic. It calls for compassion, not blame. And it calls for understanding, not ignorance. It's also important that America not reject those who have the disease, but care for them with dignity and kindness. Final judgment is up to God; our part is to ease the suffering and to find a cure. This is a battle against disease, not against our fellow Americans.

We must not allow those with the AIDS virus to suffer discrimination. I was told of a situation in Florida where three young brothers—ages 10, 12, and 14—were all hemophiliacs carrying the AIDS virus. The pastor asked the entire family not to come back to their church. Ladies and gentlemen, this is old-fashioned fear and it has no place in the "home of the brave."

Education is critical to clearing up the fears. Education is also crucial to stopping the transmission of the disease. Since we don't yet have a cure or a vaccine, the only thing that can halt the spread of AIDS right now is a change in the behavior of those Americans who are at risk.

You know, it's been said that, when the night is darkest, we see the stars. And there have been some shining moments throughout this horrible AIDS epidemic. I'm talking about all those volunteers across the country who have ministered to the sick and the helpless.

For example, last year about 450 volunteers from the Shanti Project provided 120,000 hours of emotional and practical support for 87 percent of San Francisco's AIDS patients. That kind of compassion has been duplicated all over the country, and it symbolizes the best tradition of caring. And I encourage Americans to follow that example and volunteer to help their fellow citizens with AIDS.

I'm closing, let me read to you something I saw in the paper that also embodies the American spirit. It's something that a young man with AIDS recently said. He said, "While I do accept death, I think the fight for life is important, and I'm going to fight the disease with every breath I have."

**AIDS Prayer**

Blessed are you, Lord of all, giving new life and health to those who call upon you in all their troubles. Usher into your kingdom and manifest your power to heal those with AIDS.

Blessed are you, Lord of Wisdom, who push back borders of darkness and disease. Enlist those who search for a cure for AIDS and strengthen those who care for our suffering brothers and sisters.

Blessed are you, Lord of Love and Peace. Be with families of loved ones of those who live with this disease. Teach all who will with your love and make us instruments of your healing.

Blessed are you, Lord, in this Sacrament of bread and wine. Let us receive with joyful thanks this true and living bread from heaven, your reconciling light and life throughout the ages. Amen.
The greatest danger, however -- greater even than the danger of AIDS itself -- is that we will lose the battle because we fail to wage it with wisdom, reason, dignity, and common sense. We must not permit ourselves to risk defeat through errors born of fear, ignorance and prejudice that will divide America against itself, that will only make the catastrophe worse, and that will cause untold additional suffering and loss of life.

Those who seek a vaccine and a cure deserve resources commensurate with the challenge -- and they also deserve our gratitude for the extraordinarily rapid advances they have made so far.

People with AIDS and ARC need care and treatment. Those who are infected need compassion, counseling and support. Both groups need the hope of a cure -- and the commitment of society that their private crisis of sickness and suffering will not be compounded by a hue and cry of public castigation and discrimination.

Last month in the Senate, I proposed comprehensive legislation to accelerate and coordinate a sensible national response to this deepening public health disaster. Our purpose is fourfold:

-- To educate all Americans about AIDS and enable them to make informed choices to protect themselves;
-- To develop care and treatment facilities and networks for those with AIDS that are both effective and economical;
-- To accelerate the search for AIDS vaccines and cures by putting federal funds to work more rapidly;
-- And, finally to assure that all Americans have access to voluntary and confidential testing and counseling, under circumstances that guarantee full protection against discrimination in any form.

Unfortunately, the Federal Government has wasted precious time in launching an all-out campaign to conquer AIDS. We would not be facing a crisis of this magnitude today if Congress and the Administration had listened earlier to many of you in this room.

Almost singlehandedly, you have aroused a negligent nation to action, and we will need your leadership more than ever in the months ahead if we are to avoid the mistakes of ideology that threaten to destroy our resolve and divide our people.

Because the battle against AIDS is a national undertaking, the most important role of the Federal Government is to direct the effort so as to ensure that adequate national resources are available -- to allay and not inflame the fears and passions that could endanger all our other efforts.

Finally, let me close on a personal note. All of you who are here today are aware -- far more than most of us -- of the devastating impact of this epidemic. You know what AIDS has done to families and friendships, to shining young lives, to the most brilliant talents and the most innocent children. You have seen how AIDS tests the character and courage -- not only of those with the disease, but of our country as a whole.

You have been there when those who suffer have reached out. You have endured the insensitivity -- and, worse, the insults -- of a society that too often in the past has failed the test of character, of a nation that sought at first to turn its back and ignore your pleas for help and action.

But you kept the faith when others failed you. And today you are teaching us the most important lesson of all -- that we will never win the battle against AIDS if we permit ourselves to lose our humanity in the struggle.
AIDS IS MORE THAN STATISTICS
AIDS IS PROLONged PHYSICAL AND MENTAL TORMENT FOR MANY THOUSANDS OF HUMAN BEINGS. IT IS HEART-RENDING CONFUSION AND DESPAIR. IT IS THE CONFRONTATION OF ONE'S MORTALITY, MOST OFTEN IN THE PRIME OF LIFE. IT IS THE EXPERIENCE OF HOPE THAT IS OFTEN SHATTERED, AND REINAMED, ONLY TO BE SHATTERED AGAIN. FOR MANY, IT IS SHAME AND GUILT, WHICH RESULTS IN LIVING A LIFE OF REPRESSION, ISOLATION AND DECEPTION.

AIDS IS FEAR - DEVASTATING FEAR - FEAR OF DEATH; FEAR OF SUFFERING; FEAR OF THE PAIN THAT WILL BE EXPERIENCED BY LOVED ONES LEFT BEHIND; FEAR OF BEING FOUND OUT AND BEARING THE BRUNT OF THE SENSELESS STIGMA OF AIDS - DISCRIMINATION AND BLAME. FEAR THAT DESTROYS REASON. FEAR THAT DESTROYS CLOSE PERSONAL RELATIONSHIPS - AT A TIME WHEN THOSE RELATIONSHIPS ARE NEEDED MOST.

AIDS IS IRRATIONAL FEAR OF CONTAGION TO MANY OF THOSE WHO ARE NOT INFECTED - UNWARRANTED FEAR OF PERSONAL ASSOCIATION - AND FEAR OF WHAT IS PERCEIVED TO BE UNKNOWN.

TO THOSE WHO ARE NOT DIAGNOSED, YET ARE AWARE THAT THEY HAVE BEEN INFECTED WITH THE VIRUS, AIDS CAN BE EQUALLY, IF NOT MORE TORMENTING. THE CONSTANT THREAT - THE TERROR OF THE KNOWLEDGE THAT ANY DAY, AIDS MAY BECOME A PERSONAL REALITY. THE FEAR OF HAVING NO FUTURE ON EARTH. IMAGINE YOU WERE TOLD YOU HAVE AIDS.

EACH OF YOU IN THIS ROOM. TAKE A MOMENT AND JUST IMAGINE.
WHAT WOULD YOU SAY TO YOUR CHILDREN?Your HUSBAND ORwife?
YOU PARENTS? YOUR LOVER? YOUR FRIENDS?
WHAT WOULD YOU DO IF YOU WERE FIRED, REVICTED OR RIDICULOUS?
WOULD YOU RIGHt? WOULD YOU HAVE THE STRENGTH? THE COURAGE?
HOW WOULD YOU FACE THE PROBABILITY OF DEATH?
YES, AIDS AND THE FEAR OF IT ARE INDEED TERRIFYING. FEAR THAT THREATENS TO TEAR APART THE VERY FABRIC OF OUR SOCIETY.

AIDS REPRESENTS UNIQUE AND SERIOUS CHALLENGES UNPARALLELED IN RECENT MEMORY -
- CHALLENGES TO OUR ABILITY TO OVERCOME FEAR AND ACT RATIONALLY;
- CHALLENGES TO OUR ABILITY TO OVERCOME OUR OWN PREJUDICES AND TO UNITE TO DESTROY A COMMON ENEMY;
- TO OUR CREATIVITY AND RESOURCEFULNESS; TO OUR ATTEMPTS TO EDUCATE MULTICULTURAL AND MULTINATIONAL COMMUNITIES;
- CHALLENGES TO OUR GOVERNMENTS TO DESIGN, ASSESS AND IMPLEMENT TIMELY AND EFFECTIVE RESPONSES;
- TO OUR SCIENTIFIC CAPABILITY TO PREVENT AND CURE THE DISEASE;
- TO OUR MEDICAL COMMUNITY TO PROVIDE ADEQUATE AND COMPASSIONATE HEALTH CARE;
- CHALLENGES TO OUR BUSINESSES AND CORPORATIONS TO PROVIDE LEADERSHIP AND RESOURCES.

The following two articles are reprinted with the permission of PWA Coalition Newsline of New York City.

A SEXUAL BILL OF RIGHTS
From the GMUIC. The Study, 1986

1. You have the right to say no.
2. You have the right to judge your own actions, both in and out of bed, and to take responsibility for their initiation and consequences upon yourself.
3. You have the right to make a decision and not explain it to anyone.
4. You have the right to enjoy sex, free from anxiety and fear.
5. You have the right to change your mind.
6. You have the right not to have sex.
7. You have the right to be responsible only for your own orgasm.
8. You have the right to set limits.
9. You have the right to be hopeful.
There is a future, and it belongs to you as well as everybody else.
10. You have the right to camp it up (or butch it up, or clone it up, or fuck it up).
11. You have the right to be moody.
12. You have the right to be confused.
13. You have the right to love and be loved.
14. You have the right not to be enthusiastic about organized sports.
15. You have the right to be safe.
16. You have the right to watch Monday Night Football.
17. You have the right to be respected, pampered, hugged, sad, funny, moody, sexy, sleazy, proper, bitchy, Bette Davis, John Wayne, Diana Ross, Fay Emerson, anybody & anything you want to.
18. You have the right to BE YOURSELF WITHOUT FEELING GUILTY!

SO MANY MEN
by Kevin Imbusch

There are so many of us now Walking with feet of clay. A long and ever-lengthening line Growing longer by the day. And the Worried Well in alarm look As we go our silent way.

Some walk with slow and faltering step. Others on crutches drop. Limping from hospital to home, A sad, pathetic group. And those on the fence watch fearfully At this pitiful, feeble troop.

At first a single line were we, Unnoticed by the crowd. Now eight and nine abreast we plod Like a long and winding shroud. And no one seems to care or heed, Though we protest long and loud.

What we harbor in our bosom Is indeed an evil guest. Is there not a man among you Who can rid us of this pest? Now our number is legion And we're waiting for the rest.

We feel as if we have been robbed Of this, our time and place. Are we the losers and the lost In this dateless term in space? Are you the next to join us In this macabre race?
AIDS education efforts in a sample of nations

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MATERIALS

The Person With Aids - Nursing Perspectives - by Jerry D. Durham, R.N., Ph. D. and Felissa L. Cohen, R.N., Ph.D., F.A.A.N. - Springer Publishing Company - available through the Nursing Book Society - or special order from any Bookland.

Safe Sex - The Ultimate Erotic Guide, by John Preston & Glen Swam - available at The Aids Project office - $10.00. The ground breaking program that makes safe sex great for gay and bisexual men and the women who love them.

"Delivers the facts in a clear and specific manner." New York Times (3/1/87)

AIDS ALERT - UPDATED VERSION

This cartoon video answers the most frequently asked questions in a direct yet non-threatening way. Now used in over 4000 schools and hospitals from New York to Singapore.

Time: 20 minutes Pricing: 1/2" VHS, Beta - $125, 3/4" - $160

"An innovative way to teach about herpes." Sol Gordon, Ph.D.

HERPIE - UPDATED VERSION (Available 7/1/87)

This cartoon video dispels the myths with the facts and presents ways for management and prevention of genital herpes.

Time: 18 minutes Pricing: 1/2" VHS, Beta - $125, 3/4" - $160

CHLAMYDIA - The Invisible Disease

Our latest cartoon health video explores the current Chlamydia epidemic, the visible and invisible symptoms and ways of prevention.

Time: 18 minutes Pricing: 1/2" VHS, Beta - $125, 3/4" - $160

SPECIAL INTERVIEWS WITH:

Dr. Richard P. Keeling, Chairman AIDS Task Force, American College Health Association; Director of Student Health, University of Virginia.

Each video is introduced and concluded with remarks by Dr. Keeling regarding the specific venereal disease.

AUDIENCE LEVEL:

Grades (7-12), College, Hospital Patient Education and Military Personnel.

TO ORDER:
Send $125 for 1/2" VHS or Beta and $160 for 3/4" U-Matic plus $3 for shipping.

TO PREVIEW:
Send $15 and specify five-day preview period.

TO RENT:
Send $45 and specify one week rental period.

FOR IMMEDIATE ORDERS:
Call (804)296-6138.

HEALTH ALERT
CREATIVE MEDIA GROUP, INC.
123 Fourth Street, NW
Charlottesville, VA 22901

ACKNOWLEDGEMENTS

The Aids Project wishes to acknowledge all of you who have made donations in recent months. Secretarial support has been absent and so we have not always been able to respond to your kindness in a timely fashion. But we will respond. If you haven't already, you soon will receive a letter acknowledging your gift. We greatly value your support, and want you to know that. Our humblest apologies for not being more courteous to you.

A hearty thank you to Culinary Creations - 11 Bishop Street - Portland - for the great catering service at our recent open house. And a very special thank you to Tom's Twin City Florist - 232 Main Street - Saco - for their donation of flowers.

REMONDER

The Aids Project is requesting that all persons who have borrowed books or articles from the office, to please return them as soon as you have read them. We are especially interested in the return of the book "The Screaming Room" by Barbara Peabody.

STATISTICS

As of July 21, 1987, there have been 56 diagnosed cases of Aids in Maine. Southern Maine 37, Central Maine 13, Northern Maine 6. Of the total 56 cases, 23 have died.
HELP WANTED

The Aids Project is looking for individuals who receive daily newspapers, weekend editions, weekly and monthly magazines, who would be willing to clip articles from these periodicals to send to TAP. What we would like to do is find one person for each local newspaper (all over Maine), the New York Times, USA Today, Wall Street Journal, Time, Newsweek, Reader's Digest, Science, Discover, Atlantic Monthly, etc etc., who would make it their responsibility to send us clippings from these publications on a monthly basis. If you receive professional journals, we would also welcome clippings or copies of articles (especially covering mental health issues, volunteerism, home care, nursing care, housing options, longitudinal studies on behavioral issues, IV drug user issues, ethics, employment, legal and civil rights issues, etc. Help us stay informed. To volunteer, please contact TAP by mail (stating your publication of choice and how long you wish to contribute to this activity), or call Gary Anderson at 774-6877.

One of our PWA's has great need for an electric can opener. Please call or write to the Aids Project if you can help with this need. Phone 774-6877.

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One of our PWA's has great need for an electric can opener. Please call or write to the Aids Project if you can help with this need. Phone 774-6877.
Recently it has come to the attention of TAP that certain individuals in Maine who have AIDS or ARC are having some difficulty finding adequate financial assistance to provide them with AZT. The problem seems to be that these individuals either are eligible for Medicaid and haven't received their card yet, or they are covered by private or group insurance that will only pay 80% of the cost for AZT. Since AZT can cost over $800 per month, this can create quite a problem: the person who does not have Medicaid yet would need the full $800 per month to start on the drug; the person who has 80% coverage under their insurance still needs to come up with an additional $160 on their own.

The benefits of AZT are well known. Persons with AIDS or ARC find it very hard to accept the situation of needing AZT and not being able to afford it, especially knowing that it is the only proven treatment available. One person who has insurance through work said that he would rather keep his job and not go on AZT (since he couldn't afford the additional 20%) knowing full well what this could mean to his health; for him the thought of losing his job, spending down to be eligible for Medicaid, etc., was not acceptable.

We know that the State of Maine is working hard to address this problem. It will take time for the State's response to be readied and then implemented. In the meantime, people in Maine need help. Therefore, TAP is hoping to set up a "Sponsorship" program for people needing financial assistance with AZT. This is only a temporary approach, but it is an important one. As the following letter makes clear, this problem can be solved. If you would like to help us "sponsor" people who need AZT and can't afford it, please send your earmarked funds to TAP. Every little bit will mean a lot.

My name is Bert and about one month ago I was informed that I was in the advanced stages of ARC and would need to go on AZT. In the doctor's presentation to me it was made to sound like good news, "to avoid the further advancement of the disease," but as reality set in, quickly the negative element also set in. How do I afford this drug? Not being disabled, I do not qualify for medicaid or SSI. Anger quickly arose, which for me initiates action.

What started off as a lark on my part with a friend is now becoming a reality. "Sponsorship," for myself and other individuals in my predicament who cannot afford a drug they so desperately need.

I have always had difficulty in feeling helpless, thus my energies took over. I needed to search into myself for I knew that if I was going to help initiate a new concept I would have to be ready to suffer any ramifications that came my way. I chose to go public, newspaper, television and pray for the best. So far the outcome has had positive affects but a few negative ramifications have occurred which are mostly to people who are close to me, support me and love me. I thank God daily for placing them in my life and wish to thank each and every one of them. I sometimes do revert back to anger that myself and other individuals are placed in the position we are placed in but realize I need to let go of that.

The sponsorship program is now in it's initial planning stages. The Aids Project as myself are very optimistic. Already someone has come forward and is sponsoring my 20% of the cost of AZT for the next 12 months. I wish to thank this individual whoever he/she may be but realize that words cannot express my gratitude. His/her generosity only re-inforces my belief that there are some very good and compassionate individuals in our society.

I ask you all to reach into your hearts, locate your compassion and support the "Sponsorship" program. We will only get thru this unfortunate tragedy if we support one another.
ONGOING CALENDAR

Every Tuesday from 10:30 a.m. to 12 noon at the Aids Project - 48 Deering Street - 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 spiritual teacher and psychotherapist. A graduate of the University of Pennsylvania, Beacon College, and the Gestalt Institute of Cleveland, he has trained with the Elizabeth Kubler-Ross Center.

On the first Tuesday of every month at the Aids Project - 48 Deering Street - Portland:
- 6:00 p.m. - A-Line Staff meeting.
- 7:00 p.m. - HIV Counselor Staff meeting.

The regular calendar events for August are suspended due to vacations. Time to relax and to reflect. It will be full steam ahead for September.

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

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