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The AIDS Project Newsletter (December 1988)

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The AIDS Project

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Hemophilia, Aids, Gay Pride, and Unconditional Love

What an odd group of subjects you say? Well, I would have thought so a couple of months ago, but certainly not now. I have been through a unique experience that I feel I must share.

In mid September I was asked by a staff person at The AIDS Project if I could spare two or three hours one day a week to go to the home of a person with AIDS and help with the noon meal. Of course I knew I would and I adjusted my schedule to be available on Wednesdays.

I then got the details and whatever history was available on this PWA. His name was Tim. He was 22 years old. He was living with his mother, Jeri, stepfather, George, and brother, Michael. Tim was a hemophiliac who contracted AIDS through a blood transfusion.

I was not troubled with the hemophilia as much as I was concerned that this would be my first experience with AIDS in a heterosexual surrounding. Friends and family who know me well, know that I am immensely proud of my gay lifestyle. I lived a lie for almost half of my 47 years, and will never return to that way of life again. I will continue to be a fighter for gay rights etc., but I must also admit that my love and compassion for humanity, whether straight or gay, is my ultimate goal. I've always been able to detect when someone is negative or uncomfortable around the subject of gayness. I did not want that to be a problem in this new situation.

Well, to make a long story short, I need not have concerned myself at all. From day one when I entered that beautiful, loving, and warm log cabin on a mountaintop in western Maine, I was treated as part of the family. I first met Tim, his nurse Mary, and his mother Jeri; and for the next eight Wednesdays I witnessed and became a part of a truly beautiful experience of love and devotion.

Tim had been sick for a very long time. He had been through four bouts of pneumonia, as well as a number of other opportunistic infections that accompany AIDS. If this was not enough, he also had to contend with the hemophilia which was part of his life all along. Hemophilia is a hereditary plasma-coagulation disorder, principally affecting males but transmitted by females, and is characterized by excessive, and sometimes spontaneous bleeding. Tim also suffered from the various discrimination problems that come with AIDS. He did, however, have a very supportive family. His mother, stepfather, father, and stepmother were a loving and concerned unit that were with him constantly.

It would be safe to say that I met Tim during the final stages of his battle to live with AIDS. Aside from feeding Tim once in a while, I would help Mary to move him from side to side, help to change the bed and whatever I could do to help make Tim comfortable. During the times that Tim would sleep, I would answer as many questions as I could about AIDS that Jeri or Mary would ask. It also allowed Jeri time to come and go from work as the situation required. Thanks to both Jeri and Mary, I was able to learn a lot about hemophilia as well as to see first hand what hemophilia and AIDS working together can do to the human body. (I must interrupt my train of thought for a moment to give my utmost respect to Mary. If I am ever in need of home nursing care, I hope Mary is available. She is a credit to her profession, and it was a pleasure to watch her "strut her stuff" as they say!).
I guess just being there, someone objective to talk to, was the most help of all that I was able to give.

Timmy died peacefully at home just one day prior to his 23rd birthday. His death was not a shock for me, but it did come suddenly. I selfishly wanted more time to prepare for it. I do have one image, (though there were many), that will remain with me as long as I live. When the funeral was over, and the family was leaving the church, Jeri, herself overwhelmed with grief and barely able to walk, stopped near the entrance to the church when she saw me. She called my name with outstretched arms and said "Thank You"! I went to her. We hugged. We cried. I was grieving with her, but my heart was also busting with pride. This incredibly beautiful woman was able to stop at this moment in time and acknowledge those of us whom she met just a few short weeks before, with her unconditional love.

Jeri, may this gift of love return to you triple-fold.

I have not always believed that one person could make a difference in anything. But Tim and his family have certainly made a believer out of me. I did make a difference in their lives, and they have indicated that to me in many ways. In the process, I have gained the extra strength that I needed to continue my struggle with anxiety in helping to find a cure for this hideous thing called AIDS.

It is I who wants to "Thank You", Jeri, for allowing me to come into your lives and make a difference. My heart is with you all.

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!

PWA MEMORIAL BRACELET PROGRAM

The Public War on AIDS Memorial Bracelet Program was initiated in 1987 in cooperation with Mothers of AIDS Patients (MAP). The National Chair of this program is Mary Jane Edwards, co-founder and former President of the Mothers of AIDS Patients/Los Angeles and the National Director and creator of the bracelet is Mark Manning of Pride Media Relations.

Simply designed by POW/MIA bracelet designer Stephen Frank (whose Vietnam bracelets numbered in the millions), the silver or gold plated PWA bracelets bear the name, age, and death date of men, women and children struck down by AIDS. The bracelets not only symbolize our national family unity and commitment in the battle against AIDS, but clearly illustrate the devastating effect this vicious disease is having on our nation and the world. A donation of $10 or more is required for each PWA bracelet and proceeds have been benefiting the Mothers of AIDS Patients who provide support and assistance to people with AIDS and their families, and the PWA Endowment Fund, a nonprofit corporation whose purpose is to provide emergency funding to AIDS patients and their loved ones.

For more information, call 1-800-248-0465 (toll free) or 213-933-0093 or write PWA BRACELET ENDOEMNT FUND, c/o PRIDE Media Relations, 731 South Spaulding, Los Angeles, California 90036.
The following is a list of research studies that are available at the National Institutes of Health through the National Institute of Allergy and Infectious Diseases (NIAID) and the Clinical Center Intramural Program on the NIH Campus in Bethesda, Maryland. It will be updated periodically. For further information please contact the designated study coordinator listed after each protocol.

We currently have studies for the following patient groups:

**KAPOSI'S SARCOMA**
- **MTP -** Patients with KS who have less than 200 CD4 cells/mm³ are being screened for a phase I open trial of CGP 19835A (muramyl tripeptide), a monocyte activator. Study participants must be on AZT from their physicians. Contact: Margaret Easter, RN (301)496-7196

**HIV INFECTION**
- **Alpha Interferon/IL2 -** Patients with HIV infection and at least 200 CD4/mm³ are sought for a phase I trial of alpha interferon in combination with interleukin-2. Contact: Dianne Lee, RN, MS (301)496-7196
- **AZT/Interferon 3 Arm Study - AZT vs. AZT + Alpha interferon vs. Alpha interferon -** This 3-arm, randomized, unblinded study seeks HIV-infected persons with a CD4 count of at least 500/mm³ for a study comparing the efficacy of each of the 3 treatments. Contact: Victoria Davey, RN (301)496-7196
- **AZT/IL2 -** Patients with HIV infection and at least 200 CD4 cells/mm³ are sought for a phase I trial of AZT in combination with interleukin-2. Contact: Dianne Lee, RN (301)496-7196
- **GM-CSF/AZT/Alpha Interferon -** This study is designed to evaluate the safety, toxicity and efficacy of giving granulocyte-macrophage colony stimulating factor in combination with AZT and Interferon in HIV infected persons with CD4 Counts of 200-500/mm³. Contact: Victoria Davey, RN (301)496-7196
- **Bronchoscopy Study -** This is a diagnostic study to evaluate the lung tissue and pulmonary status of persons who are HIV infected who have less than 200 CD4/mm³, with no history of PCP nor PCP prophylaxis. Contact: Barbara Baird, RN (301)496-9565

**NORMAL VOLUNTEERS**
- **Vaccine (gp160) -** This is a phase I trial of an AIDS vaccine, recombinant HIV-envelope protein (gp 160). We are seeking healthy men who are HIV antibody negative to participate in this study. Contact: Margaret Easter, RN (301)496-7196

**PNEUMOCYSTIS PNEUMONIA**
- **Trimetrexate (TMTX) Combo -** Trimetrexate (TMTX) + Dapsone vs. Trimetrexate (TMTX) + Aerosolized Pentamidine - Patients with HIV infection and documented PCP untreated for their current episode. Contact: Debra Ogata-Arakaki, RN (301)496-9565

**CMV RETINITIS**
- **Foscarnet Study -** Foscarnet + AZT vs. Foscarnet vs. AZT - The National Eye Institute (NEI) in collaboration with the NIAID is conducting a 3 arm study for persons with non-sight threatening CMV retinitis. Contact: Judith Rubin, MD (301)496-1243

For NIAID Extramural Studies, please call (301)496-5717

Every forty-five minutes, someone in this country dies of AIDS ******
Every twenty minutes, another case is diagnosed ******
SPECIAL NOTE
A video tape is now available of All Singing, All Dancing, All Concerned, the benefit concert that was done at The Performing Arts Center this past September. The complete tape is $32.00. It is available for $25.00 if you supply your own blank tape. Contact Reggie Geoff at 774-6446 or Ed Wimert at The AIDS Project 774-6877. The tape was made by Video 4 Productions.

STATISTICS
As of November 16, 1988 there have been 89 diagnosed cases of AIDS in Maine. Of the total 89 cases, 44 have died. People who have tested positive with the AIDS virus (in Maine) is now at 349. National Data as of November 14, 1988: diagnosed cases of AIDS is 78,312. Total number of deaths is 44,071.

HOW TO PERSUADE YOUR LOVER TO USE A CONDOM...AND WHY YOU SHOULD
Patti Breitman, Kim Knutson and Paul Reed, foreword by John Money. Prima Publishing (St. Martin's, dist.); $4.95
Prompted by concern about the spread of AIDS, this book is written for sexually active people who “believe that a good sex life is [a] right and ...aren't willing to choose abstinence.” The authors recommend condoms for all these people—except those in ongoing monogamous relationships who have tested negative for AIDS infection—since condoms are the most effective means of preventing the spread of the disease. After discussing the advantages of condoms (they are also relatively effective as birth control), the authors give commonsensical advice on how to broach the topic of using condoms, giving examples for a variety of circumstances, be it during a one-night stand or in a long-term relationship. Typical advice: “Whatever you say, try to phrase it so that you leave the door open for discussion. You can do this by remembering to add a question such as, 'What do you think?'” They also have a series of suggested arguments to the usual negative responses toward condoms, and Money, a former professor of medical psychology and pediatrics at Johns Hopkins, provides a historical context for condoms and AIDS. This is a plain-talking, informative work.

MERRY CHRISTMAS

Heterosexuals who still view the growing epidemic as a distant tragedy, the medical equivalent of a typhoon in Bangladesh, had better change their attitudes—and fast.

SAFER SEX CAN BE SENSUOUS!

Anyone who is sexually active needs to practice safe sex.
TO THE FRIENDS I'VE NEVER MET
By Ramona McKenzie

For one reason or another people never seem to have the time, nor are they willing to take the time, to share love for those people that they are supposed to love, unless of course some terminal illness suddenly finds them at the side of that same person that they could scarcely find the time to be with before, i.e. unless that terrible illness be diagnosed as AIDS. It would seem that these unfortunate individuals are left out in the cold, without a sympathetic ear to hear them or an enduring shoulder to hold them up.

I simply cannot understand why cancer, heart disease or a severe car accident can tug at our heart strings with sympathetic emotion and interest, and a person with AIDS is looked upon as less than human. We all say a person with AIDS is responsible for what they acquire because of their lifestyle, and perhaps so! But what about the 3-pack-a-day smokers who deliberately keep smoking when the Surgeon General gives them the prognosis for their compulsion? Or how about the drinkers who wreak havoc with their cardiovascular systems and their liver, or when they drive to endanger their lives or the lives of others who may be with them? Or how about the person who contemplates suicide? These people would have our attention, have their needs met, and be given all the care, concern and love until they either got better or finally expired. Surely these same people are fully responsible for their actions too.

Could our apathy toward one and our empathy toward another be because we know we can't catch a heart attack or cancer, etc.? I mean how much do we really know about the AIDS virus, we all ask? What can we do, what can't we do, how close do we get, how far away should be enough to be safe, do we play together, do we work together, do we breathe, do we hold our breath, do we look at each other from across a crowded room? Yes of course all these questions might have some relevance to many of us, but what about those to whom the questions are about? You could be a friend, brother, sister, wife, husband or a mother of a person with AIDS. Just what do they do, and how do they cope with the unsympathetic complaints of the self-centered individuals? The answer is that most of them don't. From what I've seen, heard and read, many of these people spend their last months or years in solitude waiting for the inevitable with cries of loneliness, pain and utter despair.

Barbara Streisand once sang in a song, "People who need people are the luckiest people in the world". A nice tune, but not for people with AIDS. They are not lucky, for they need people, but people do not need them.

I am sorry and hurt for all the PWA's, but I feel more sorry for all of you out there who are ignoring your chances for giving support to your fellow man, lending a helping hand wherever you see the need, or just plain being there. After all, Jesus cried for the sick and ate with the downtrodden, and walked among the lepers. If it was good enough for Him, then who are we to do any less?

I am a mother of a person with AIDS, and I never told him that I approved or liked how he acquired his disease, but I also never told him he had to go through it alone. My son is my flesh; my son is my friend; my son is my love; and I'll always be there for him in whatsoever way that I am able.

To all of you out there who are people living with AIDS, may I offer you my prayers, my friendship and my support, and always remember that God loves you all and so do I!!!

Ramona McKenzie, P.O. Box 583, Old Orchard Beach, Maine 04064

SPECIAL EVENT

"IT'S A PWA CHRISTMAS"

To our friends and family, will you please be our guest this Christmas as we join together in celebration at this special time? There will be lots of fun for young and old alike. "It's A PWA Christmas" should definitely be written on your calendar.

The spirit of Christmas begins as we sing Christmas Carols in Monument Square on Saturday, December 17th at 10:00am; followed by hot chocolate with marshmallows and hot sugar cookies right out of the oven. At 5:00pm, we will decorate and light the tree at The AIDS Project. On Sunday, December 18th, a splendid Christmas dinner the likes you've never seen before will tempt your palate. Will Santa be here for all good girls and boys? You better believe he will!!!

For more information on how you can help or to confirm your dinner plans, please contact Pete at The AIDS Project before December 13th. 774-6877.
TIRED
by Gary Mackler

I am tired of being asked, How long do I think I'll be alive
I am tired of the fear, the awareness of the fear, being the object of the fear, of being afraid
I am tired of taking pills, keeping track of medicines, having my life reduced to survival
I cringe every time someone tells me that they will pray for me
I am tired of hanging in there
I am tired of people who assume I am gay, assume I still shoot dope, assume I feel fine when I'm not hospitalized
I am sick and tired of the idea that AIDS has made anyone a better person, tired of the notion that anyone is paying for their sins angry at this twisted "blaming the victim" thinking
I am tired of people who see AIDS as a political problem, the biological response to an industrial society gone mad
I am tired of the self-centered new age response of mediation, introversion and orchestrated denial of the horror show I am living every moment of every day
I am tired of all the people who believe that a cure lies around the corner, who think that everything will be ok just fine back to normal just as soon as that magic bullet arrives
I am bored with the healing powers of crystals
I am tired of hearing of the evils of AZT and the wonders of wheatgrass
I am sick and tired of the treatment of the month club: vitamin therapy, ozone, good attitude
I am really tired of AIDS activists who believe drug addiction is not their problem
I will puke if I hear one more time: just say no to drugs, as cocaine barons throw parties for orphans while holding whole countries hostage
I am tired of hearing all the reasonable arguments for testing and contact tracing
I am sick and tired of reading about AIDS in the style section of the Village Voice, of being a victim in the human interest section of the New York Times, of reading about innocent victims everywhere I turn
I am bewildered by all the people who believe our government is doing all it can do, that research is proceeding as quickly as it could be, who cannot see history repeating itself ("Holocaust II," playing at a hospital near you) and who do not realize that our government is at least guilty of murder, and that we are at war
I am tired of fighting and I am tired of hanging in there and the skin of my teeth is stretched very tight

"Taking time to explore myself for myself was not easy. I have always been an externally motivated person, responding to the world around me rather than the world inside me. In the ministry the work will always expand to more than fill the time you make available to it. Before my diagnosis, I filled my time working on other people's needs: this committee, that family, this person seeking counsel, that worship service. Activity was a game I played to avoid facing my illness. Soon it became clear that looking inward would have to become an activity itself if I was to understand at all what was happening to me, and if I could understand it from the inside, I would be of greater use to my congregation.

The scriptures remind us that Jesus broke through all the stigmas of his day and his culture. He touched, he walked with, he prayed with, he ate with, and he entered the homes of those who were stigmatized.

My faith tells me that just as Jesus was ever ready to identify completely with the suffering of those who were the outcasts and rejected of his day, Jesus is with those today. Today, in the midst of the AIDS crisis, Jesus identifies with persons who have AIDS and ARC, with persons who are HIV positive, with persons who are well and worried.

The Jesus of the scriptures is the self-same Jesus who would stand before us today wearing the purple blotches of Kaposi's sarcoma. And wouldn't he do this because his message is the same today as it was then? Would not this Jesus take on the most visible sign of AIDS in order to say: Be not afraid, be not ashamed. There is nothing—no blemish, no stigma, no reality, no form of being—that separates us from God's love and God's acceptance.

Cathie Lyons

When AIDS is discussed in public, the conversation always includes "risk behaviors" which expose people to the human immunodeficiency virus (HIV). Ironically, I have risked more since my diagnosis than before, i.e. risked in the important ways that open us up to growth. I have had to risk looking inward; risk letting myself be loved; and most of all, risk speaking publicly of my new growth and understanding. I have grown more in the last year and a half than I ever would have imagined possible.

My story has many heroes -- the members of my congregation. They have demonstrated through these years an integrity of religious purpose and action which makes me very proud. Just as they were willing to take the original risk in calling an openly gay minister, they have chosen to take the risk of remaining faithful in the face of death. They could have pensioned me off right away, removing me and the stigma of my disease from the church. They could even have done that in the name of compassion, claiming it was the best for me. But they stuck to their religious principles, and are showing the world that people with AIDS are not to be feared; people with AIDS are to be loved."

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Do not stand by my grave and weep
I am not there. I do not sleep
I am a thousand winds that blow
I am a diamond glint on snow
I am the sunlight on ripened grain
I am the gentle autumn rain.
When you awake in the morning hush
I am the swift uplifting rush
Of quiet birds in circling flight
I am the soft starshine at night
Do not stand by my grave and cry
I am not there ... I did not die.

—Anonymous

A smile is something nice to see
It doesn't cost a cent.
A smile is something all your own
It never can be spent.
A smile is welcome anywhere
It does away with frowns.
A smile is good for everyone
To ease life's ups & downs.
AIDS Response of the Seacoast in Portsmouth, N.H. has started a support group for persons with AIDS, ARC, or HIV+. The group meets on Monday evening and consists of wholistic healing incorporating meditation, visualization, heart centering, music, and touch, in a supportive and loving environment. Contact Suzanne Bowman, M.A., at AIDS Response at 439-2136 or Peter Welch, M.A., Wholistic Psychotherapist at 436-5115 for more information and intake interview. This applies to York County PWA's etc. of Maine.

Waterville Support Group for PWA's, PWArc, and HIV+ to meet the 1st and 3rd Monday of each month at 6:30pm to 8:00pm at St. Mark's Episcopal Church. For more information call Dan Gardiner at 873-3904.

Every Tuesday from 10:30am to 12noon at The AIDS Project - 22 Monument Square - Portland - there is a group meeting for all PWA's, PWArc, care-givers, 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.

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.

Merrymeeting AIDS Support Services (M.A.S.S.) is sponsoring a support group for anyone personally affected by AIDS. It will be held the 2nd and 4th Tuesdays of every month at 7pm at Parkview Hospital Library in Brunswick. The group is for family, friends, lovers, and persons with AIDS, and will be led by Cecelia Leland, M.S.W. Preregistration is not necessary. For more information, call 725-4955.

ACT UP - Boston. 40,000 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 - 22 Monument Square Portland - there is an A-Line Staff Meeting at 6pm.

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.

The AIDS Education and Support Group for Knox County meets the second Tuesday of every month at the University of Maine at Augusta. For more information call 354-6906 or 396-6979.

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

AA AIDS-related meeting - every Wednesday from 6-7pm at The AIDS Project - 22 Monument Square - Portland. This group is open to PWA's, PWArc's, HIV+'s in recovery from substance abuse. For further information call 774-6877.

There is an AIDS support group in the Lewiston area for PWA's, lovers, friends, and family members. It meets on Thursday afternoons at Clover House in Auburn. Call Evelyn Piper-Keene at 783-9095 for information.
There is 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.

There is a support group for people who are HIV+. It meets Thursday evenings from 5:30pm to 7:00pm at The AIDS Project - 22 Monument Square - Portland. The facilitator is Jacob Watson. No advance contact needs to be made to attend this group.

Every Friday evening 6:00pm to 7:30pm at The AIDS Project - 22 Monument Square - Portland - there is a support group meeting for PWA's and PWArc ONLY. Call 774-6877 for further information.

AIDS Coalition of Lincoln County is a group focusing on AIDS education in Maine. It welcomes PWA's, PWArc, HIV+, lovers, friends, families, and all concerned people to its meeting. For time and place of the meetings, and for further information, please contact Barbara Brampton at 563-3032.

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HOW CAN YOU HELP?

THERE ARE MANY WAYS YOU CAN HELP TAP. FOLLOWING ARE SEVERAL SUGGESTIONS. CHECK THOSE YOU CAN DO:

___ YES, I WANT TO HELP TAP. I WOULD LIKE TO BE A VOLUNTEER. SEND ME AN APPLICATION.
___ YES, I WANT TO HELP TAP. I AM ENCLOSING A CONTRIBUTION.
___ YES, I WANT TO HELP TAP. I CAN DONATE NEEDED ITEMS OF FOOD, CLOTHING, HOUSEHOLD GOODS, ETC. CALL ME AT:
___ YES, I WANT TO HELP TAP. SEND ME INFORMATION ON WHO I SHOULD CONTACT IN STATE AND FEDERAL GOVT. TO INCREASE FUNDING FOR AIDS EDUCATION & SUPPORT SERVICES.
___ YES, I WANT TO HELP TAP. I CAN'T DO SO RIGHT NOW, BUT ADD ME TO A MAILING LIST OF CONCERNED PEOPLE.

NAME: ___________________________  ADDRESS: ___________________________
TOWN: ___________________________  STATE: ___________________________  ZIP: _____________

SEND THIS FORM TO:
The AIDS Project
22 Monument Square
5th Floor
Portland, Maine 04101

WHEN YOU SEE SOMEONE WITHOUT A SMILE, GIVE THEM ONE OF YOURS.
TAP
22 MONUMENT SQUARE
5TH FLOOR
PORTLAND, MAINE 04101