

The Aids Project Newsletter

NOVEMBER 1988

22 Monument Square - 5th Floor
Portland, Maine 04101

Subscription - \$10.00 per year
Editor - David Ketchum

The AIDS Line: 1-800-851-AIDS
or
775-1267

AIDS Research
Intramural Program
National Institute of Allergy and Infectious Diseases
National Institutes of Health

The Laboratory of Immunoregulation of the NIAID is involved in basic and clinical research associated with the acquired immunodeficiency syndrome (AIDS). Over the past 6 years we have conducted clinical trials with anti-retroviral agents including suramin, HPA-23, foscarnet, AZT; biologic response modifiers including alpha interferon, interleukin-2, and gamma interferon; and we have evaluated the role of bone marrow transplantation in HIV infection. In 1985 an outpatient clinic was established at the NIH in Bethesda, Maryland to facilitate these trials.

With a focus on treatment of primary HIV infection and prevention of infection, 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.

HIV Infection

◆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.

◆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.

◆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 trial comparing the efficacy of each of the 3 treatments in prolonging the time to development of an opportunistic infection.

◆Gadolinium-enhanced MRI

This observational study will compare gadolinium-enhanced magnetic resonance imaging (MRI) to unenhanced MRI in detection of central nervous system disease in patients with HIV infection.

CMV colitis

◆DHPG

This is a multicenter, placebo-controlled, double-blinded study of intravenous DHPG for AIDS patients with documented CMV colitis.

Normal volunteers

◆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.

For further information call: Margaret Easter, RN, M.N., Dianne Lee, RN, M.S.,
or Victoria Davey, RN, M.P.H. (301) 496-7196

THE VALUE OF ONE LIFE
by Belinda Mason

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Because my HIV infection came from tainted blood and the hospital responsible for transfusing me with a whole new identity (as well as a political and social agenda) freely admits that its blood bank did not screen that unit for the presence of antibody, I am involved in litigation. By not testing for HIV, the hospital, I contend, fell shamelessly below acceptable standard of care.

The case, my high-priced Eastern-bred lawyers tell me, "looks good."

If they're right, then sometime in the next year my family and I stand to come into an obscene sum of money. I hate to seem coy, but I'd rather have won the lottery. For me, the lawyer is just an extra seat on the AIDS merry-go-round. Another reminder of what I resent most about this disease, not that it might kill me, but that it has stolen away the "normal" life I had forever.

My father-in-law, a Kentucky farmer and builder, who never wore a suit to work a day in his life, says this: "You've come to a bad out when you get tied up with doctors and lawyers."

My husband and I were country mice in the legal world. In our innocence and with a concept of justice honed in Sunday school and cowboy movies, we originally believed the young doctor who told us how "bad" everyone at the hospital felt about what had happened and how "eager" the administration was to make restitution.

Now, as the months crawl by and we're battered repeatedly by this system, I've been tempted more than once to call off the whole thing. This, my lawyer points out, is exactly what the hospital's insurance carrier wishes me to do.

Our initial faith in the inevitability of justice and the power of right to prevail was the first casualty in this battle. Right and wrong, we've learned, have no place in the world of medical malpractice, which measures itself by such fabricated concepts as "comparative negligence" and "failure to meet acceptable standard of care."

In what is surely a demonstration of an inborn sense of order, my five-year-old daughter asked me, "Why did the hospital give you the AIDS virus if they were trying to cure you?" But the system is not designed to respond to the obvious question. It's not "pertinent to the case."

Any hope of a hasty resolution was abandoned long ago. We've become accustomed to the delays in court dates, the hocus-pocus of motion filing and all the posturing, by both sides, as we live on borrowed money. (My husband left his job to care for our children and me. I'm not well enough to hold down a regular job, even if someone should be bold enough to hire me.)

The frustration of the endless delays and disappointments was overshadowed this week, though, when I came face to face to face with the nastiest aspect of the whole affair.

I was evaluated by a vocational rehabilitation expert who'll determine a "life-worth profile" for me. His associate, still new to her job and too eager, asked an exhausting list of questions and took an extensive work history which encompassed the first dollar I ever earned. (As a waitress and fry cook when I was 14.)

I went across the hall then to the expert's office and took a seat in a stylish leather chair across from him. The carpet was plush; the walls were neutral and the windows generous. The room

was, I noted, half as large as my grandmother's house. Above the desk were professionally framed pictures of his sons. He looked over my papers and asked half-a-dozen questions. "My job," he said, "is to provide an economic assessment for the case. You know, future earnings, that sort of thing."

"You want to know what I'm worthdead so the insurance company can buy me," I said.

He tittered nervously and looked away.

"What is it worth," I asked him, "that I'm a good friend? What is it worth if I have a big heart, I like country music, or that I'm good to old people? Is there a place on the form for that?"

In retrospect, I feel a little foolish, but not sorry about what I said. The immorality, or rather, the amorality of this process is too large to comprehend. But again, my daughter's clear eye and razor sharp instincts cut to the core of the matter. She asked: "What does money have to do with a mistake?" Indee.

On the way home, I thought about Max Navarre, who was known to me only by his writings in *Surviving and Thriving*. When I received my copy last summer, it became a good luck charm. People could live with AIDS. I had pictures to prove it and words to tell me how. I never knew Max Navarre, but I borrowed some of his courage. My copy of *Surviving and Thriving* is tattered and worn. Although parts of the advice was useless to me--an article about subway fares by David Summers was as remote from my life in Indiana as space travel--the important thing was that the authors were people who were living with, as opposed to dying from AIDS. I soon knew the faces in *S&T* by heart. When I heard Max Navarre dies, a little of my hope died with him. "In the media," he wrote, "everyone is a victim."

My lawyer once told me that his case would be easier had I lost a body part. "I can tell you what an eve goes for in Kentucky, I can tell you what insurance companies will pay for a leg, but this I don't know."

Human beings, though, are more than the sum of their parts. We know part of what the loss of the Max Navarres, the hundreds of them, is costing our society. The economic loss to the fashion and art world, only two of the communities touched by AIDS, is being documented every day. But that's not easy. As Michael Callen has written, we must be able to experience each death as an individually painful and unique loss. Perhaps we are numbed to inaction by the thousands of losses precisely because we've never truly appreciated the vastness of the one.

Sylvia on Sunday



Nicole Hollander



To Those of You Concerned

My name is Richard Brooks Jr. and I am a 26 year old single male living in West Newfield, Maine.

I have Acquired Immune Deficiency Syndrome (AIDS).

I am writing this letter to you in hopes that you will take the time to read it and please respond in some way.

This letter concerns a MAJOR problem with income guidelines in the Department of Human Services Medicaid Program. I feel that there has been an enormous oversight of these guidelines and there is an immediate need for attention to this matter.

In order to qualify for Medicaid the guidelines state that a person may receive up to a total of \$441.00 in unearned income (Social Security Benefits). Any income over this amount would put you on a so-called "spend down" figure before you would become eligible for Medicaid benefits.

Here is an actual example of my circumstances,

* I receive \$735.00 per month in Social Security Benefits.
(Based on my contributions over the last ten years)

* I am allowed to receive the following Income Allowance,

*Basic Allowance.....\$366.00

*State & Federal Disregard (\$55,\$20).....\$ 75.00

*****Total unearned Income Allowance.....\$441.00

By receiving \$735.00 per month from Social Security I am \$294.00 in unearned income over the guidelines to qualify for Medicaid benefits.

In order to qualify for Medicaid benefits, based on a six month period, I must "spend down" a total of \$1,764.00 from my social security income in medical expenses in order to receive Medicaid benefits for the remainder of the six month period, and then the six month cycle starts over again.

It is financially impossible to live on \$441.00 per month. I cannot do it and I am sure you could not do it. I cannot afford to spend \$294.00 of my Social Security for medical expenses and live on \$441.00. These guidelines do not realize that an AIDS patient incure MUCH more than this in expenses per month. In meeting the guidelines by SPENDING DOWN your income to qualify for Medicaid benefits you do not have enough money to live on.

For further information, contact, Richard directly at P.O. Box # 35, Springvale, Maine 04083 (207) 793-8194 or Diane Elze at The AIDS Project.

***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.***

**No one can ignore
AIDS.**

**The invisible time
bomb**

**SAFER
SEX**

CAN BE SENSUOUS!

Tired of cooking? Feel like you're not eating as well as you should because it's too much of a hassle to cook just for yourself? Well, the folks at First Congregational Church at Meetinghouse Hill in South Portland want to be of help.

Thanks to Richard Hughes, Associate Pastor, Betsy Parsons and the Mission Board, several members of the church have been cooking and freezing meals to distribute to PWA's and PWArc. The meals include meat and vegetarian casseroles, baked goods and soups, and can be delivered directly to your home by a volunteer. They are generally packed in one-meal containers, and are great when you want something good to eat but don't have the time or energy to cook yourself.

If you would like more information or would like to place an order for meals, please contact Diane or Toby at 774-6877. We are also looking into getting a freezer for the AIDS Project kitchen, along with a refrigerator and stove, so you can prepare meals when you are here.

AWARD-WINNING ARTICLE AVAILABLE

"AIDS in the Heartland", this year's Pulitzer Prize winning features article by Jacqui Banaszynski, is available in a special 20 page (newspaper size) edition. Banaszynski's poignant reporting on the lives of two gay men living with AIDS in the farming country of Minnesota, the effects AIDS has on them, their families, and their communities is moving, inspirational, and ultimately as tragic as it is redeeming. The text is accompanied by stunning photographs by Jean Pieri.

To order: Make check or money order payable to St. Paul Pioneer Press Dispatch. Single copies are \$1.25. Five copies are \$2.50, ten are \$3.50. Cost includes mailing and handling. For larger orders call (612) 228-5522. Include your name, address, city, state, and zip. Send your request to: Heartland, St. Paul Pioneer Press Dispatch, 345 Cedar St., St. Paul, Minn. 55101.

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!



***All any responsible
health advisor can say
is: Understand the
risks and make your
own decisions.***

Every forty-five minutes, someone in this country dies of AIDS *****
Every twenty minutes, another case is diagnosed *****

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

Mary Ann Evans (George Eliot)

AIDS UPDATE

AIDS Update articles are reprinted with permission from the National Association of Social Workers, 7981 Eastern Avenue, Silver Spring, Maryland 20910 (NASWNEWS). The following are AIDS-related news briefs, based on stories that appeared recently in the national press, to bring readers up-to-date on research and other developments concerning various aspects of the acquired immune deficiency syndrome epidemic:

Human Tests: A genetically engineered vaccine by Bristol Myers will soon be tested on volunteers at six U.S. medical centers to determine its safety and effectiveness in stimulating an immune response against the AIDS virus. Volunteers cannot contract the disease from the tests, which also are being conducted on a vaccine made by MicroGeneSys, Inc. The Bristol Myers vaccine is being tested at centers at several universities. A vaccine is not expected to be approved for general use before the mid-1990's.

Serious Problem: Americans consider AIDS the most serious problem facing the country, according to a survey of 5,000 households done for the Conference Board. Drug abuse was second, followed by medical costs. AIDS had ranked ninth in the 1987 survey.

Support for Care: A report by the Citizens Committee on Biomedical Ethics found that 79% of New Jersey residents say AIDS patients should receive free or government-assisted medical care. Only subsidized nursing home care for the terminally ill or those with Alzheimer's disease received more support than care for AIDS patients.

School Attendance: A federal district judge in Tampa, Florida ruled that Eliana Martinez, a six-year-old retarded girl with AIDS may attend school provided that she remains behind a glass partition separating her from other children in the classroom. Rosa Martinez said she would appeal the ruling so that her adopted daughter would not have to "sit in a cage". Eliana has been instructed at home for the past year. The judge ruled that she must stay inside the enclosure until she is toilet-trained and has stopped sucking her fingers. A full-time aide would be assigned to her. Eliana is thought to have contracted AIDS through infected blood transfusions after being born prematurely in Puerto Rico. She is one of 500 children receiving experimental AIDS drugs including AZT.

Estimate Raised: The World Health Organization raised its estimate of the number of world-wide AIDS cases from 150,000 to between 200,000 and 250,000. The official count by July 30 was 108,176.

International Barriers: Twenty countries have developed travel and immigration restrictions for people with HIV infection, and several have instituted compulsory screening of selected citizens for AIDS, according to a study released at the 10th National Lesbian and Gay Health Conference and AIDS Forum, Cuba; for instance, tests all returning citizens, including soldiers, and keeps 150 people in perpetual quarantine.

Semen Tests: Only 44% of the nation's 11,000 physicians who perform artificial insemination test the donated semen for the AIDS virus and even fewer test for other sexually transmitted diseases, according to a study conducted for Congress. About 65,000 babies were conceived through artificial insemination last year.

No Bleach, No Condoms: Los Angeles County supervisors have stopped plans to provide social workers with bleach kits and free condoms to hand out to drug addicts during on-the-street counseling sessions, despite pleas from the county's Commission on AIDS and the Dept. of Health and Human Services. Officials voted to consider other educational approaches to combat AIDS, which infects an estimated 5% of L.A. County's 125,000 IV drug users.

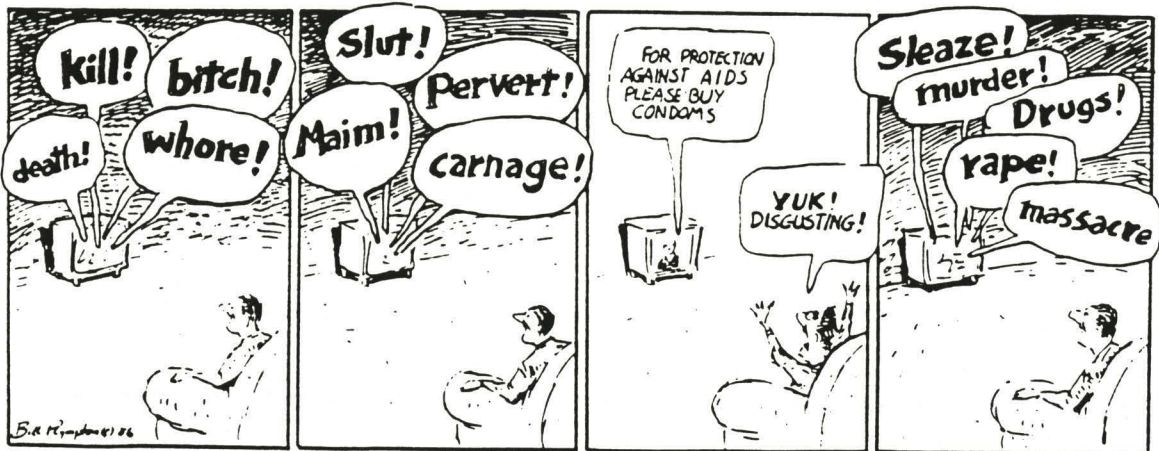
Increased Sampling: The Federal Government has begun an annual program that will anonymously test the blood of 1.6 million newborns as well as thousands of college students doctor's patients, prisoners, and emergency room patients. The surveys are expected to cost about \$40 million a year and will supplement continuing tests on blood donors and military personnel.

No Notification: House Democrats in mid-September shot down a Republican move to require physicians treating AIDS patients to notify a patient's spouse of the infection. Republicans were trying to attach the measure to a \$1.2 billion bill for AIDS testing, counseling and

AIDS UPDATE CONT:

education. Representative Ron Wyden (D-Ore.) said the required-notification measure would discourage patients from seeking the AIDS blood test. Wyden said the bill's supporters favored voluntary notification. The bill seeks to encourage testing and contains confidentiality protections. It allows notification of health workers engaged in high-risk work.

Bill Plympton



STATISTICS

As of Oct. 14, 1988 there have been 89 diagnosed cases of AIDS in Maine. Of the total 89 cases, 41 have died. People who have tested positive with the AIDS virus (in Maine) is now at 345. National Data as of Oct. 17, 1988: diagnosed cases of AIDS is 75,768. Total number of deaths is 42,653.

The following is the AIDS Project Wish List-----If any of you can help us out, please call us at 774-6877;

Bookcases (for offices and reception area)
Living room chair
Free standing storage unit
Lamps
Conference tables
vacuum cleaner
Coffee table
Coat rack
Set headphone
Records
Books
Puzzles
Games

***Anyone who is sexually
active needs to
practice safe sex.***



I am looking for copies of "Susie's Story" and "Tidy Endings." These are both AIDS related programs. The first is an Australian production featuring a woman who has AIDS. The second is a Harvey Fienstein production, I think. Both were shown on HBO in recent months. I want copies to show at the Nov. 16th and 17th :Living with AIDS in Maine" conference in Augusta. If you taped one or both of these or if you know someone who has a copy, please call Susan Cummings-Lawrence at 874-8452 or 775-0287.

SPECIAL EVENTS

November 16th & 17th - Third Annual Conference of LIVING WITH AIDS IN MAINE - Augusta Civic Center - a forum for health professionals, public health experts, educators, politicians and others to discuss how AIDS is influencing life in the State of Maine.

World AIDS Day - Dec. 1st 1988, the AIDS Project is planning activities to recognize this very special occasion. Participants will be meeting at Monument Square in downtown Portland at 12 o'clock noon to listen to the "Bells" which will be ringing throughout the Greater Portland area. Along with the bells will be a 21 gun salute and a small ceremony with guest speakers. Following the "vigil" there will be an interfaith service at the Chestnut St. Methodist Church. The AIDS Project is also presently making arrangements on bringing to Portland panels of the Names Project Quilt to be displayed on this day at the Chestnut St Methodist Church. Following the service the AIDS Project will be hosting an open house to the public from 1:00 to 3:00 pm at their office at 22 Monument Square. All are encouraged to attend and support this most "special" occasion.

ONGOING CALENDAR

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, caregivers, and family members, to share your thoughts and feelings relative to AIDS. The meeting is conducted by Jacob Watson, M.A. Jacob is a psychotherapist specializing in loss and transition and is a staff member of the Elizabeth Kubler-Ross Center.

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.

ONGOING CALENDAR cont.

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 596-6979.

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.

CONDOMS ARE EFFECTIVE!

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.....



TAP
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5TH FLOOR
PORTLAND, MAINE 04101

