

The AIDS PROJECT News

P.O. BOX 10723

AUGUST 1986

PORTLAND, ME 04104

AIDS-LINE TURNS ONE

Monday, August 18th, will mark the first anniversary of the AIDS-Line. In the past year, over 400 callers have had their needs addressed by the 17 volunteer operators (who amassed over 900 hours of public service work). The AIDS Project heartily commends each and every one of these volunteers for their invaluable contributions in the fight against AIDS in Maine.

AIDS PROJECT OPENING OFFICE

The COMMUNITY RESOURCE CENTER is the name for an office being opened by the AIDS Project. The purposes of the CRC are many: administrative office space for the AIDS Project; storage and distribution of educational materials; collection center for donated goods; meeting space for support groups, volunteers, etc.; walk-in educational and social services; space for volunteer training, public education classes, etc.; and space for HTLV-III pre/post test counseling. CRC Location: Room 209 of the Congress Square Building, 142 High St, Portland. Hours of operation will be announced in the next APNews. This office will have its own phone number 774-6877 (now in service). Anyone wishing to do business with the AIDS Project should use this number. An open house is being planned for September.

HTLV-III COUNSELORS TRAINED

On July 22 and 23, in Portland, the State Bureau of Health trained 13 people to be counselors to individuals expressing an interest in taking the HTLV-III antibody test. The trainees included city health workers; State STD clinic workers; a number of social workers; a nurse; and several AIDS Project volunteers. The counselors will be paid through grant monies from the CDC. The majority of these counselors will be operating out of York and Cumberland Counties (training of other counselors for other parts of the state are in the works).

TAP MEETS NAN

On Saturday, July 12, representatives of the AIDS Project (TAP) met with Jay Coburn of the National AIDS Network (NAN). Mr. Coburn was in Maine on other business and made himself available for consultation. NAN is set up to be a national resource center for people and organizations involved in the fight against AIDS. Mr. Coburn said that the AIDS Project had three major obstacles to face in its efforts to provide quality educational and social services: 1. growing without resources (which has been happening); 2. trying to do everything; and 3. isolating ourselves (i.e. keep regional and national contact with other AIDS services, educational, and political groups). Mr. Coburn praised the efforts of the AIDS Project to date and hopes that we can continue to do the work that we have undertaken.

VOLUNTEER

1-800-851-AIDS

TAP MEETS THE PRESS

The AIDS Project has been rather 'visible' of late. Channel 6, WCSH, the NBC affiliate in Portland, invited three members of TAP to express their (unfavorable) views of the recent Justice Dept.'s decision on employers and AIDS (we were part of the lead story); AIDS Project member Frannie Peabody was featured in a front page article in the Portland Evening Express; Fred Berger was interviewed on the AIDS Project's activities for a feature article on AIDS in Maine that appears in the first issue of the bimonthly National AIDS Network's newsletter called the Monitor; and Debbie Walsh, Support Services Coordinator, is interviewed in the August issue of Our Paper.

TAP GOES TO JAIL

The AIDS Project and the Bureau of Health are undertaking a new project to address AIDS in Maine. TAP wanted to educate prostitutes and the 'johns' who get arrested. In concert with Susan Cummings-Lawrence of the Portland STD clinic, a meeting was held in early July at the Cumberland County Jail with Sherrif Martin Joyce. Out of that meeting sprang a planning committee comprised of Gary Anderson of TAP, the aforementioned Cummings-Lawrence and Joyce, various jail personnel (including a nurse, social worker, transport person, and staff trainer), and a drug rehabilitation specialist. Plans now are for TAP and the STD Clinic to provide inmate and staff training on AIDS, to provide educational materials to people arrested who do not get jailed, and to do HTLV-III antibody test counseling. Target groups reached will include 'johns', male and female prostitutes, inmates, IV drug users, and families and friends of inmates. Other than education as a means of prevention, TAP and the STD clinic plan to provide 'johns', prostitutes, and inmates being released with condoms.

MALE HAIRDRESSERS SUFFER FROM MISINFORMATION

In the past month, the following accounts were relayed to the AIDS Project: 1. A hairdresser had a blister on his hand from doing some other work. A customer noticed the blister and asked the hairdresser if it was caused by AIDS. 2. Another hairdresser applied for a job with a shop in the Old Port. During the interview he was asked if he was gay. He asked the woman interviewing him why she wanted to know. Her response was "I want to know if you have AIDS." 3. Yet another hairdresser, who told his prospective employer he was gay, was told that as a condition of employment he would have to take "the AIDS test". The man involved in case # 1 did some educating with his customer and resolved the issue (the woman is still a customer). In case #s 2 and 3 the men refused to work for either employer. Both are now employed in a more enlightened environment.

STATISTICS

As of July 24, 1986: 24 cases of AIDS
16 South / 5 Central / 3 North
11 have expired
Ages range from 13-50.

REMEMBER: AT THE AIDS-Line (775-1267 or 1-800-851-AIDS)

Assistance - Information - Direction - Support

IS BUT A PHONE CALL AWAY.

-----Knut Ra, head of the Bureau of Health's Office on AIDS, will be leaving that post as of August 15. A replacement has not been named at this time. The AIDS Project wishes Mr. Ra good luck in whatever endeavors he undertakes in the future.

-----Members of the Advisory Committee to the Dept. of Human Services have been selected. They are being notified by mail of their appointment. The AIDS Project intends to list the names (and a brief bio) of all the appointees in the next issue of the News.

-----The Conference Center, Inc. (P.O. Box 1296, Bartlesville, OK 74005, (918) 337-0206), writes to tell us that they will be hosting a conference on "AIDS and Substance Abuse/Treatment, Counseling, and Prevention" in Boston, Sept. 11-13. The conference is designed for people working with individuals with AIDS. For more information contact Karen K. Maltby, Conference Coordinator.

-----Ohio State University Gallery of Fine Art (128 North Oval Mall, Columbus, Ohio 43210, (614) 422-0330, c/o J.Z. Grover) is asking people and organizations responding to AIDS to send "graphics, film, video, photographs, flyers, posters, brochures, illustrations, PSAs" for a touring exhibition and catalogue to be called "The AIDS Show". Contact Nancy Robinson, Public Programs Coordinator, if interested.

-----AIDS Action Council (729 Eighth St., Suite 200, Wash. D.C., 20003 (202) 547-3101), asks all of us to thank the members of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for voting to increase AIDS funding from \$224 million to \$337 million (a 48% increase). See the following information:

Contact Information

The best way to communicate your thanks is by personal letter. Mailgrams and telephone calls are also effective. You can send the same basic letter to all members of the Committee (see below). Letters don't have to be long; in fact the shorter the better. Avoid negative or accusatory remarks. Our problem is not with Congress, but with the administration.

An alternative to writing is to call the Congressional switchboard at (202) 224-3121 and ask to be connected to the legislator's office. Once connected, identify yourself and ask to speak to the staff member in charge of health, science, or education. When you reach the appropriate person, state your thanks simply and directly. Have your call returned if the person is unavailable.

If you have question or need additional information, call Miguel Gomez in our Washington office. Thank you.

HOUSE OF REPRESENTATIVES

Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Democrats

William H. Natcher (chair) KY
Neal Smith Iowa
David Obey WI
Edward R. Roybal CA
Louis Stokes OH
Joseph D. Early MA
Bernard J. Dwyer NJ
Steny H. Hoyer MD

Republicans

Silvo Conte Mass.
George M. O'Brien IL
Carl D. Pursell MI
John Edward Porter IL
C.W. Bill Young FL

Proper forms of address are as follows:

The Honorable (full name)
United States House of
Representatives
Washington, D.C. 20515

Dear Rep. (name):

SUBSCRIBE

SUBSCRIBE TO THE AIDS PROJECT NEWS.

IT COSTS US MONEY TO PRODUCE AND MAIL THIS NEWSLETTER. WORKING ON A SMALL BUDGET MEANS WE ARE RAPIDLY RUNNING OUT OF RESOURCES TO KEEP THE NEWSLETTER GOING, AND REQUESTS FOR COPIES ARE ON THE INCREASE. IF ONLY 1/10TH OF THE READERS OF THE NEWSLETTER WOULD SUBSCRIBE, OUR FINANCIAL CONCERNS WOULD BE ABETTED. PLEASE, IF YOU CAN, WHY NOT SUBSCRIBE TODAY. SIMPLY RETURN THE FORM BELOW. AND THANKS.

NAME (Please type or print): _____

ADDRESS (Include zip): _____

PAYMENT ENCLOSED (Circle your choice): \$5 \$10 \$15 \$20 \$25 \$50

Note: Subscriptions run for 1 year (12 issues).

THANKS.

CALENDAR

On-going meetings:

- Every Wednesday, Portland, support group for people with AIDS, ARC, and seropositivity. Call the AIDS-Line for referrals.
- TAP meetings: Aug. 4 and Aug. 18.
- AIDS-Line Staff meeting: Aug. 6 at 7 p.m.
- Support Services Group (Buddies): Aug. 13.

- "Parting Glances", a film about "gay love and friendship in New York" will be playing at the Movies on Exchange St. in Portland AUG. 6-9. One of the lead characters is a person with AIDS.
- The Mid-Coast AIDS Support Group will meet on AUG. 6 at 7 p.m. at New Leaf Books in Rockland.
- Excerpts from "The AIDS Show" (drama, comedy, and music) will be shown at Our Books, 4 Pine St., Portland on AUG. 14. Time 7 p.m. Admission is free, donations will be accepted.
- Hike for Like: A recreational day climb up Mount Washington. Participants will include members of TAP and the Chiltern MT. Club. Plans are to car pool as many people as possible from Portland. If you're interested in going, call the AIDS-Line and leave your name and phone number BEFORE August 13. Climbing date is Saturday AUG. 16.
- Maine Health Foundation is sponsoring the Second Annual Cruise For Life to benefit AIDS related projects in Maine. Cruise Casco Bay aboard the Longfellow with your friends and help benefit a good cause. Tickets cost \$12.00 each and are available at Our Books (773-5540), Entre Nous (Spring St.) and The Cafe (Spring St.), all located in Portland. Last year this event sold out fast. Get your tickets ASAP. The cruise date is Sunday, AUG. 17, from 5:15-7:30 p.m.
- The Annual Meeting of the AIDS Project will be part of an afternoon and early evening of fun and relaxation on Saturday, AUG. 23 (rain date AUG. 24). All AIDS Project members, volunteers, friends, etc. are invited. BYOF (i.e. food). For information on time and place, call the AIDS-Line or Fred at 773-5540.

MATERIALS

"MOBILIZING AGAINST AIDS: THE UNFINISHED STORY OF A VIRUS" has just been published by the Institute of Medicine and the National Academy of Sciences. The book is rather unique in that a writer was assigned to take presentations made at the annual meeting of the Institute of Medicine in Wash., D.C. in Dec. 1985 and put them together in book form. Thus you have contributions from national AIDS leaders speaking on the status of the disease, its history, the search for a vaccine, current treatments, public policy issues, individual and societal stress, brain infections, etc. The book has very clear diagrams, charts, lists, etc. It is easy to read and is the best book on AIDS yet seen for those new to the disease and for those who have been involved with it for many years. Highly recommended. Available from the Harvard University Press, Cambridge, MA. Price: \$7.95.

CONVERSATION WITH A PWA, PART II

by

Gary L. Anderson

(John was quick to become a patient advocate for himself. He took an active role in his care and treatment. He was scheduled for a colonoscopy the following day. He was told by his doctor that he would not be given breakfast in the morning. When morning came, a nurse brought a breakfast tray into his room. John told her he wasn't supposed to eat. He had her check to make sure he was correct. He was.)

- GA: It sounds like right from the beginning you took some control over what was happening with your care. Is that still the case?
- J: My doctors have been real good in letting me contribute to my own well-being.
- GA: Give some examples.
- J: After the colonoscopy a doctor wanted to put me on Flagel, an antibiotic to keep me from infecting myself. I told him I knew Flagel destroys the immune system and that I didn't want it.
- GA: How did you know that?
- J: When I was living in San Francisco some friends had to take Flagel for stomach ameobas. Back in '78-'79, Flagel was the drug of choice. But it was discovered to be immuno-suppressant. For that reason, there was a big flack as to whether or not it should still be used. So I suggested that my doctor recommend another drug. He instead prescribed Keflex and Kayopectate.
- GA: Did your doctors or nurses wear gloves when treating you?
- J: Some did, some didn't. There was a nurse who was to draw my blood and she wasn't wearing any gloves. I told her I was "blood and bodily fluids precautions" because I have AIDS and suggested she wear gloves. "I haven't worn gloves before and I've been doing this for twenty years and I'm not about to start now," she said. "If I get a needle stick, a glove isn't going to stop it." She also said that she wasn't afraid to get a little blood on her skin, and that made me feel good. But I did have to remind people to wear gloves at other times though. Since the KS was in my mouth, the doctor had to put his hands in there and I had to remind him to wear his finger cotts.
- GA: Sounds like the medical staff had few concerns about getting the AIDS virus from you. Any other examples of how your taking an interest in your illness had an effect?
- J: I had been scheduled for chemotherapy for my Kaposi's. When I showed up for my first treatment, my doctor said he had been thinking about what I had said to him earlier about keeping up my immune system. So, he had called some doctors in San Francisco to see what they would do for treatment of the KS. They suggested mild radiation therapy instead of chemotherapy. (That became John's course of treatment. He had radiation therapy five days a week for four weeks. It was apparently successful. The lesions in his mouth went away.)
- GA: Looking back, say two years ago to the present, did you have any of the common symptoms of AIDS?
- J: I've always had night sweats, for 20 years or so. So I ignored that. When AIDS started in San Francisco, and I learned that was a symptom, I said "I've got it" because I'd had sweats right along. I lost some weight in S.F., too, but that was on purpose.
- GA: Had you known any persons with AIDS prior to your diagnosis?
- J: (Pause, then quietly): Yes. Alot. I've lost...oh, God, 25-30 people, and I know a bunch more who have it.

HTLV-3 - ANTIBODY COUNSELING

6.

VOLUNTARY--ANONYMOUS--CONFIDENTIAL--FREE--DAYS OR EVENINGS

The AIDS Project now provides trained counselors to answer your questions and address your concerns about possible exposure to the AIDS virus. To schedule a counseling session call:

774-6877

For more information call:

AIDS-LINE 775-1267
1-800-851-AIDS

P.O. Box 10723
Portland, ME 04104

BULK RATE

THIRD CLASS MAIL

U.S. Postage PAID

Portland, Me. 04101

Permit #417