

Press Release

DATE: February 11, 1988

CONTACT: Robert Mitchell
Executive Director

PORTLAND PREMIERES MOVIE ON FAMILIES OF AIDS PATIENTS

PORTLAND - The Portland premiere of Too Little, Too Late, a powerful new video documentary about families of AIDS patients, will be held on Saturday, February 27, 1988, at the Luther Bonney Auditorium, University of Southern Maine campus, Portland. There will be two showings, one at 7PM and one at 8:30PM.

Too Little, Too Late was inspired by Barbara Peabody's highly acclaimed book, The Screaming Room, a moving account of the author's love, dedication and courage in caring for her 28 year old son during the last 10 months of his life. Barbara is the daughter of Francis Peabody, a resident of Portland and a member of the Board of Directors of The AIDS Project. Francis appears in the video and will attend the premiere to answer questions from the audience.

The 48 minute documentary explores the experiences of mothers and fathers, sisters and brothers, partners and friends who have lost or are losing someone to AIDS. These intimate interviews show that families, like AIDS patients themselves, risk rejection and isolation because of fear and ignorance about transmission of the disease, and experience prejudice due to its association with homosexuality.

Victor Neufeld, Executive Producer of ABC's 20/20 called this production "a powerful work of high professional quality . . . the victims of AIDS as I have never seen them portrayed before."

Too Little, Too Late was made by Boston producer/director Micki Dickoff and is being released nationally by Fanlight Productions, a Boston-based distributor of independent film and video programs. Major funding was provided by the American Foundation for AIDS research. Filmmaker Micki Dickoff will be present at the premiere, and a discussion with representatives of The AIDS Project will follow each showing.

"I wanted to show the human side of AIDS, beyond the statistics," Dickoff says. "My hope is that when people see this devastating disease through the eyes of families much like their own, they will be moved to replace fear and prejudice with compassion and understanding."

The Portland premiere of Too Little, Too Late is sponsored by The AIDS Project, a Portland-based organization providing services to persons with AIDS and their families. Proceeds from this event will benefit the work of The AIDS Project, and tickets will be available at the door or may be reserved by calling 774-6877. Tickets will be provided for a donation of from \$5.00 to \$25.00.

The Aids Project Newsletter

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Portland, Maine 04101

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Editor - David Ketchum

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

FEBRUARY 1988

PLEASE MAKE NOTE OF OUR NEW MAILING ADDRESS ABOVE.....

A NEW CHAPTER

by

Gary L. Anderson

A new chapter in the history of the AIDS Project begins this month.

As some of you may already know, I have voluntarily chosen to resign as Executive Director of the AIDS Project. I have made this decision after careful thought and consideration. Everything seemed to be just right for me to make this choice now; and so I have.

I will continue to be an active voice and presence in the fight against the spread of the AIDS virus in Maine and in the development of the services required by persons affected by AIDS virus infection.

I will continue my association with the AIDS Project, but in a different guise. Instead of acting in a largely administrative role, I intend to address my personal and professional skills to the areas of policy, advocacy, community organization, public relations, and education. As you are well aware, I have performed many of these functions over the past three years. As Executive Director, however, I was finding less and less time to do so. The responsibilities of the Executive Director go far beyond these tasks. Such responsibilities are no longer those I desire to have.

Robert Mitchell will be assuming the position of Executive Director effective February 1. I hope you will lend him the same kind of support that I have received from all of you.

SPECIAL NOTE

As featured in our January issue of this newsletter, there is an ongoing appeal to all PWA's and persons with ARC and HIV positive to please step forward and assist in the formation of a PWA Coalition in Maine. Please contact Bert at 775-1259 if you have any questions, comments and/or interest. Anonymity is assured.

LET'S HUG

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



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!

!

The following article is the last in a series of related subjects concerning various drugs used for the treatment of AIDS. It is reprinted with permission from the PWA Coalition of New York City.

EDITOR'S NOTE: CORRECTION. In the January issue of the Newsletter, R. C. Morse's report on Ampligen incorrectly states that there was a 2-5 fold increase in T4 cells in patients with AIDS in the study. There were only 3 people with AIDS in that study and "a transient 2.5 fold increase in T4 cells at 4 weeks" was claimed by the author of The Lancet article.

The data on changes on T4 cells on the 3 people with AIDS published in The Lancet is as follows: The first patient had 21 T4 cells at entry and 24 T4 cells after 18 weeks of treatment. The second patient had 54 T4 cells at entry and 90 after 6 weeks of treatment. The third patient started with 35 T4 cells and 18 weeks after treatment there were 31 T4 cells.

Mr. Morse states that his information came directly from Dupont, which manufactures Ampligen.

ddC

by R. C. Morse

Dideoxycytidine, or ddC, was first synthesized in 1964. In 1984 laboratory research begun by Dr. Samuel Broder, associate director of NCI's Clinical Oncology Program, and his colleague, Dr. Hiroki Mitsuya, discovered that ddC inhibits replication of the AIDS virus in cell cultures, and could be a possible treatment for AIDS.

The NCI started a pilot trial at the end of 1986 for individuals with ARC and AIDS. So far, this study has enrolled a total of 20 individuals who received treatment for up to 12 weeks. Although results from this study suggested antiviral activity, it is still too early to make conclusive results. In addition, side effects different from those caused by AZT were observed.

ddC is a chemical variation of an essential DNA component. The chemical is thought to work by inhibiting the normal function of "reverse transcriptase", a viral enzyme necessary for HIV replication, working at a critical step in the HIV replication cycle. Inhibiting this step may stop the spread of HIV from cell to cell. ddC seems to work in a manner similar to that of AZT.

While the Federal Government holds the patent on ddC, its National Technical Information Service, the licensing agent for the U. S. Dept. of Health & Human Services, accepted bids this year from a number of leading drug manufacturers for development of the antiviral. Of those bids submitted, that by Hoffmann-LaRoche, Inc. of Nutley, NJ was accepted. The agreement, announced on May 29th, gives Roche exclusive license to develop, and after approval, market ddC.

Scientists at Roche are now working closely with the NCI and NIAID in further clinical trials of ddC with PWAs. Roche has no plans at this time to test ddC against or concomitantly with AZT, although such a test may develop in the future. Roche does not expect to be in a position to make even a preliminary statement about ddC's efficacy until early next year.

NOTE: In a letter published in the September PWA Coalition Newslne, Dr. Barry Gingell writes: "In the vast majority of patients taking ddC for more than 8 weeks, a significant peripheral neuropathy occurred. In some patients, this has been mild; but in others, it has been severe and required morphine for pain relief.... Moreover, the damage done to the nerves has not reversed to date after discontinuing ddC.... Because of this toxicity, the future of ddC is bleak."

Naltrexone

Naltrexone is an oral opiate antagonist originally developed by the National Institute on Drug Abuse and FDA-approved for the treatment of narcotics addicts. At a high dosage of about 50 mg/day, Naltrexone works by blocking opiate receptors -- sites on cell membranes where opiates have their effect. If a person on Naltrexone later takes heroin or other opiate, the drug will not have the desired effect or expected high. Naltrexone has also been tried in very high doses, 200-300 mg/day, for treating obesity.

The thinking that brought Naltrexone into consideration as a treatment for AIDS is based on its relationship with the endorphin system. Endorphins are produced by the pituitary gland and elsewhere in the body and act as the body's own natural opiates. These natural opiates help the body respond to stress, and are also released into the body through various forms of exercise, accounting for what is commonly referred to as jogger's or runner's high.

What immunologists have since discovered is that endorphins are a major link in communication between the body's central nervous and immune systems. Every cell in the immune system has receptors that respond to endorphins. What initial research suggested was that endorphins seem to serve as a natural up-regulator for the entire immune system.

The blocking effect of low-dose Naltrexone wears off in a few hours, but at the same time the up-regulation of the immune system works during the blocking period and for the rest of the day as well. The drug is taken orally before sleep because the pituitary produces most endorphins in early morning.

The first application of Naltrexone for AIDS was a phase one, double blind trial started at Downstate Medical Center in Brooklyn, NY in mid-1985 by Dr. Bernard Bihari and colleagues. Of 30 individuals in the trial, 20 were given a placebo, while the other 10 were treated with 1.75 mg/day of Naltrexone. After three months, those on the placebo were switched to Naltrexone.

The key test of whether Naltrexone is working is not by T-cell counts, but rather a reduction in the abnormally high levels of alpha interferon found in PWAs. In abstracts delivered at last year's international conference on AIDS in Washington, Downstate reported that of the 39 individuals treated with Naltrexone, 23 (or 60%) showed a marked decrease in alpha interferon levels down to normal antiviral levels over a 12-month period, while the other 16 (40%) showed continued high levels of alpha interferon. Those who responded to Naltrexone treatment also showed a higher survival rate over the year than the nonresponding group (83% vs. 19%).

However, despite these encouraging preliminary results, Dr. Bihari warns against over-optimism. The data on Naltrexone is limited because the phase one trial involved so few individuals. But Dr. Bihari is hopeful that a phase two trial with more individuals participating will prove the efficacy of Naltrexone treatment.

Since the Naltrexone study began before approval of AZT, initially none of the individuals involved in the Downstate study were using AZT concomitantly with Naltrexone. Since FDA approval of AZT, a number of PWAs on Naltrexone have also started AZT therapy. No interactions or side effects have been as yet reported when the drugs are taken concomitantly. Naltrexone is administered by dozens of doctors in private practice since it is already FDA-approved, and it is also made available on a "compassionate use" basis for PWAs as approved by the FDA.

Pentamidine

Pentamidine is an antiviral that is an alternate therapy from sulphur-based drugs for the treatment of pneumocystis carinii pneumonia (PCP), the most common life-threatening opportunistic infection in PWAs. While it can be effective against PCP, when administered intravenously it causes severe side effects, such as diarrhea and vomiting, as it is absorbed through the body's organs -- especially the kidneys and liver.

The use of Pentamidine administered in aerosol form directly to the lungs as a prophylaxis against PCP has been the subject of a continuing study at New York City's Memorial Sloan-Kettering Cancer Center. Studies in animals first showed that aerosol Pentamidine can prevent PCP. At Sloan-Kettering, under Drs. Donald Armstrong, Ed Bernard, Laurel Pagel, and associates, an ongoing trial is already in phase two.

Results from phase one were published in June in "Clinical Research". The article makes the point that aerosol administration delivers Pentamidine direct to the desired site of action, the lungs, thereby eliminating its accumulation (and therefore its side effects) in other organs. At Sloan-Kettering, individuals are administered Pentamidine at bi-weekly doses of 30 mg. using a hand-held ultrasonic nebulizer.

60 PWAs were treated for 1-11 months in phase one. No participant in the study showed a significant decline in pulmonary function, abnormalities in biochemical or hematologic tests, or chest x-ray changes attributable to aerosol Pentamidine. Nor was any detectable systemic absorption detected.

Of the 60 individuals involved, two confirmed cases of PCP occurred; both PWAs had received 5 doses of aerosol Pentamidine. No one in the study who received 6 or more doses have developed proven or provable PCP. The researchers say they should have seen 12-18 cases of PCP if the regimen had been ineffective. Based on these preliminary results, the researchers conclude that "aerosol Pentamidine is a well-tolerated and promising new method for PCP prophylaxis".

A number of doctors in private practice are also administering aerosol Pentamidine as a prophylaxis against PCP.

STATISTICS

As of January 20, 1988, there have been 65 diagnosed cases of AIDS in Maine. Of the total 65 cases, 31 have died. People who have tested positive with the AIDS virus (in Maine) is now at 240. National Data as of January 4, 1988: diagnosed cases of AIDS 50,265. Deaths 28,149.

[EDITOR'S NOTE: The following letter has been sent to several gay publications. It is provided for information purposes only.]

To Whom It May Concern:

It has come to our attention that several gay publications, including the New York Native, The Advocate and the Village Voice, are accepting advertisements from companies offering "egg lipids" or "egg lecithin." As founding members of the People With AIDS Health Group—a group formed to make egg lipids available to those individuals who desired to purchase egg lipids—we believe we have developed a body of experience which we'd like to share with those of your readers wishing to purchase lipids.

The lipid "market" is changing rapidly. Smelling huge profits, a number of manufacturers and distributors of lipids are entering the market. As a result, within the next few months there is likely to be a "price war." To the extent that this competition lowers the price of lipids, it will benefit the consumer. However, there are a number of points which potential purchasers of lipids should consider:

1. Beware of Manipulative Advertising and False Claims. Although there are theoretical reasons to believe the egg lipids may be of some benefit to People with AIDS and ARC, there presently exists no data conclusively demonstrating a beneficial effect for lipids in AIDS. Beware of any company or individual who asserts or strongly implies with authority that lipids are a "cure" for AIDS.

2. Beware of any Company who Will not Tell You the Precise Chemical Analysis of the Lipids They are Selling: The interest in egg lipids as a potential treatment for AIDS and ARC is based on studies published in Israel on a substance called AL721. The name "AL721" stands for "Active Lipids in a Ratio of 7 to 2 to 1." AL721 is a trademarked name for egg lipids in roughly a ratio of 7 parts neutral lipids, 2 parts phosphatidylcholine and 1 part phosphitydaethanolamine.

Although no one knows for certain whether this ratio of 7:2:1 is critical, we believe that it is important to come as close as possible to this ratio when purchasing analogues of AL721. Our reasoning is this: we know a little bit about the effects of egg lipids in roughly a ratio of 7:2:1; at the current time, we know nothing about the effects of egg lipids in significantly different ratios.

Future research may someday prove that this 7:2:1 ratio isn't very important; that soy lecithin works just as well as egg; or that it's unimportant whether you take it on a fat-free stomach. But until such time as these questions are resolved by research, we urge purchasers of lipids to insist on products which conform as closely as possible to a ratio of 7:2:1.

3. Beware of Any Company Which Does Not Guarantee that Each Lot of Lecithin is Tested For Potential Bacterial, Fungal or Chemical Contaminants as Well as for Ratio of Lipids and Phospholipids: Several companies are claiming that their "egg Lipids" conform to a ratio of 7:2:1. Since batches of commercially produced egg lipids vary in composition, the only way that a company can know the precise ratio for a particular batch is if it runs several complicated and expensive tests. Consumers should insist upon seeing documentation for each batch purchased. We believe a number of companies are claiming that they test each batch when in fact they are not. Don't be fooled. Prior to purchasing, ask them to send you documentation—or have them send it to your doctor.

It's also important to make sure that your egg lipids are free from contaminants. This requires a series of tests and cultures which are time-consuming and expensive. But you must insist that they be done. Egg lipids can spoil if contaminated and/or not properly refrigerated. (Think of lipids as perishable, like mayonnaise.) Make sure that any lipids you purchase have been properly tested for chemical or other contaminants.

4. Beware of Companies Which Charge a Lot of Money for Lipids. The actual manufacturing cost of one kilo (1000 grams) of egg lipids—exclusive of packaging, importation and other handling costs—should be about \$100. If all the recommended bacterial and compositional tests are performed, the price per kilo will of course be higher to recover these costs. But if the price is significantly more than \$200, then something's wrong. Beware of anyone charging thousands of dollars for egg lipids.

CONDOMS ARE EFFECTIVE!

The PWA Health Group has publicly stated that it is our goal to get out of the business of "selling" lipids as soon as possible. Having delivered over a ton of egg lipids to PWAs and PWArCs has been a logistic nightmare. It has been time consuming and expensive to perform the requisite tests on each and every lot which we've delivered. We sincerely hope that the companies currently entering the market make it possible for us to go out of business. But before we get out of the lipid business, we feel obligated to insure that the companies are behaving ethically and delivering the best product—one which has been analyzed and tested—at the lowest cost.

It is to be expected that increased competition among various suppliers of lipids will occasion wild charges back and forth between the various suppliers. In all likelihood, various suppliers will attempt to discredit the products of other suppliers while making claims for their own. The key is for consumers to become educated enough to sort through the claims and counterclaims of competitors.

What will be required in the next few months is that consumers of egg lipids will have to become educated about what to demand from companies selling lipids. We hope that the information contained here is helpful towards that goal.

"I swear, Ronnie - I don't know why some cute little girl hasn't caught you yet!"



Very truly yours,
Michael L. Callen and
J. A. Sonnabend, M.D.
Manhattan

SAFER SEX

CAN BE SENSUOUS!

Cartoon by Michael Willhoite
from his book of cartoons
"Now For My Next Trick" -
Available from Alyson Publications,
Inc. - 40 Plympton Street - Boston,
Mass. 02118

THE OFFICE ON AIDS CLEARINGHOUSE

The Maine Bureau of Health AIDS clearinghouse contains a variety of information for a diversity of audiences on HIV-infection and the Acquired Immune Deficiency Syndrome. Materials include the following issues: blood donations, banks, and transfusions; counseling and testing; education; epidemiology; financial issues; health care and infection control; insurance, legislation, and law; prisons; public health; psychosocial issues; patient care; policy and law; persons; public health; risk reduction; school issues; sex and sexuality; sexually transmitted diseases; therapy and treatment; women, children and AIDS; AIDS in the work place; and general information.

Material are available in the form of brochures, booklets, books, video cassettes and audio cassettes. A catalog will be available in the Spring of 1988 which will indicate the exact publications, a brief description of the contents, and the quantity or time period in which it is available.

By working closely with the Department of Human Services Library, we have been able to establish a small collection of books and videos that are available on loan, on a first come basis.

The catalog will include materials available from both the Library and the Office on AIDS.

The Office on AIDS welcomes requests for materials. For more information, contact the Office at 289-3747.

CALENDAR

- FEB. 6 - Maine Lesbian/Gay Political Alliance Annual Meeting - Senator Inn Western Avenue, Augusta - 12 noon to 4pm - cocktails at 5pm - dinner at 6:30pm - speeches, awards, and dancing after dinner - contact Barb Wood at 871-1555 for prices and reservations - PWA's admitted free but reservations must still be made.
- FEB. 12- Learn To Teach About AIDS - An Instructional Symposium - Maine Medical Center - contact Larry Johnson at 623-8411 x5622 for further information.
- FEB.18-20-AMSAODD'S 2nd Annual Forum On AIDS and Chemical Dependency - The Hyatt Regency - Phoenix, Arizona - for registration, prices, and additional information, please contact area 404-458-3382.
- FEB.22-26-There will be a nightly report on AIDS on WGME channel 13, with a "live " call in show on Friday the 26th. Please refer to your local TV listings for that week for proper times to be aired.
- MAR.4-6- AIDS Medicine and Miracles - What Holds Promise - Boulder, Colorado - please call area 303-447-8777 for further information.
- MAR.10-11-Developing AIDS Community Education Program for Family Planning programs - call Karen Brenner of the John Snow Institute at area 617-482-9485 for further information.
- MAR.21-22-Interfaith Conference on AIDS and ARC - for detailed information contact: AIDS/ARC Conference Proceedings - c/o Shanti Project - 525 Howard Street - San Francisco, California 94105.
- SPRING - Aids Prevention Education Conference Follow-Up - Maine Medical
1988 Center - call 871-2131 for further information.
- JUL.20-26-The Second International Lesbian and Gay Health Conference and AIDS Forum - Call For Participation - Boston Park Plaza Hotel and Towers - To submit a proposal and for registration information contact NLGHF/AAPHR Programming Committee - P.O. Box 65472 - Washington, D.C. 20035 or contact Michael Weeks at 202-797-3708 or Greg Thomas at 202-994-4285.

ONGOING CALENDAR

Every Tuesday from 10:30am to 12noon 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 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 Street - 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 or Lucy Marbach at The Aids Project 774-6877 for further information.

On the first Tuesday of every month at The Aids Project - 48 Deering St. - Portland:

6:00 p.m. - A-Line Staff Meeting.

7:00 p.m. - HIV Counselor Staff Meeting.

Support Group for Parents of Adult Gay Children will meet the 2nd Tuesday of every month. Please call 774-HELP for time and place.

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

There is now 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

Every Friday evening 6:00pm to 7:30pm at The Aids Project - 48 Deering St. - Portland - there is a support group meeting for PWA's and PWArc ONLY. Call 774-6877 for further information.

SPECIAL

"I wish...oh forget it" he said, the smile fading. "You know, I regret more than anything else, that all the things I want to do for my son I can never do. I don't know how much more time I have; no one really knows. I just wish I could do something special for my son."

"He always wanted to go to Disneyland with me. I wish I could take him. He could have a memory connected to his **father** that was happy and fun."

The above remarks were part of a lengthy conversation between Bill (not his real name) and Lucy Marbach of our Aids Project office.

Bill is a 42 year old man living in Maine, who has Aids. He contracted the virus sharing needles during IV drug use. When Lucy and Bill met over six months ago, he was very ill and very scared. Scared of dying and scared of being out of control because of drugs and alcohol. He knew that his use of drugs and his having Aids was a lethal combination.

One day last summer he completely stopped using drugs and alcohol. That was no easy task for a man who had been addicted for 30 years! His control of the drug problem has dramatically improved the quality of his life.

Today, Bill is a changed man who has learned to explore the calm, gentle peaceful side of himself. He owes a great deal to the support and encouragement he has found in AA in combination with his discovery of a higher power that works hand in hand with his inner strength.

Bill describes his past drug use as "chasing a dream." Today, Bill has a new dream. A dream of being able to share a time of laughter and love with his 8 year old son. He has an income of \$350. per month in disability benefits; barely enough to survive on.

So many good people are now asking; "What can I do to help someone with Aids?" This is an opportunity for you to make a difference in the quality of one person's life. If you would like to help with Bill's dream, please send a contribution to The Aids Project at P.O. Box 4096, Portland, Maine 04101. Please make a note on the check or attach a note that specifies this donation to "Disney Dream." Thank you.

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 _____

TAP
P.O. BOX 4096
PORTLAND, MAINE 04101

