

The Aids Project Newsletter

48 Deering Street
Portland, Maine 04101

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Editor - David Ketchum

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

JANUARY 1988

EDITORIAL

In the September issue of this newsletter, we printed the following:
"Volunteers are needed for a special Aids vaccine program. You must have a negative HIV antibodies test reading to qualify. The program will be held in Bethesda, Maryland with travel expenses paid. Please call 301-496-7196 for further information."

Well, before the newsletter even hit the mails, I had called that number, and was on my way to being a volunteer for the program. I knew immediately that I had to do this, or at least try. I finally made an appointment for October 21st for the initial examination. The program is conducted at The National Institutes of Health in Bethesda, Maryland. It is technically called "A toxicity/immunogenicity study of a recombinant HIV-envelope protein (gp160)." This manufactured protein is identical to the outer coating of the Aids virus. However, it contains no live or killed virus, so you will not get Aids.

I was notified in early December that I passed my initial exam with flying colors, so to speak. I returned to Bethesda on December 29th and 30th for a complete physical exam plus more blood work, and an extensive question and answer period. After indicating my desire to continue on with the program, I was given the vaccine!!!!!! I was given 20ug (units) of gp160 by injection in the upper arm muscle. I will return to Bethesda once a week for the next four weeks for blood work and observation. On the fourth week, I will be given a booster shot of 20ug units more of gp160. I will then return to Bethesda once a month for one year. I will periodically give a progress report in this newsletter.

In the meantime, they are still in need of more volunteers for this program. If you are interested in participating in this fantastic opportunity, please call Margaret Megill, R.N. or Victoria Davey, R.N. at 301-496-7196. I would also be happy to relate any information I can to interested parties - call me (David Ketchum) at 934-4997 - leave a message, and I will return all calls.

I have nothing but praise for the staff at The National Institutes of Health. Their dedication, concern, and caring is quite obvious. It is an uplifting experience that I feel very positive about. It may not be a cure, but it is certainly a step in the right direction. We must have HOPE. Please volunteer NOW.

HUGGING
(THE MIRACLE DRUG)

*IT HELPS THE BODY'S IMMUNE SYSTEM *IT KEEPS YOU HEALTHIER *IT CURES
DEPRESSION *IT REDUCES STRESS *IT INDUCES SLEEP *IT'S INVIGORATING
*IT'S REJUVENATING *IT HAS NO UNPLEASANT SIDE EFFECTS.....

PWA COALITION

I am appealing to every PWA, persons with ARC and HIV positive to please step forward and assist me in forming a PWA coalition in Maine.

I have been a board member of the Maine Health Foundation, worked on joint ventures with the AIDS Project and listened to a great deal of dialogue of what is best and can be done for PWAs, persons with ARC and HIV positive. I have been to Washington and other political activities and also listened. Although very well intentioned by a body of wonderfully concerned individuals with alot of love and compassion, who knows better of the needs of this population than the "silent population" itself? I feel we can better voice our needs, concerns, and offer a support system that is unsurpassed by any other present group. I feel we are a group who needs to empower ourselves to help ourselves in various aspects.

I am not asking anyone to break their anonymity, become politically active or join any present program. I'm asking for people to get together to dialogue needs, concerns and how they can best be met. Needs may vary and be as simple as to get together with other people with a common disease who understand and dialogue in an informal setting. I have seen this work in other communities and work well. We have brothers and sisters not getting the assistance they desperately need for various reasons, let's give them or us that "safe" place to come together. A place that is not connected to any program but is an entity unto itself, to help individuals they understand due to being part of that population. A place to have a united and consistent voice.

A new year is approaching, let's get together, discuss our needs and concerns in the upcoming year and get to know one another. Society at large wishes to keep us silent and in our "closets", let's not feed into this and do it ourselves.

On a personal note, I wish to meet others in my situation to come together and^I think there are others out there who feel the same.

Please contact me, Bert, at 775-1259, or Zane or Vincent if you have any questions, comments and/or interest.

We need your help.

Anonymity assured.

*EDITOR'S NOTE: Persons interested in the formation of a PWA Coalition in Maine, can also contact David Ketchum at 934-4997. Bert will be in New York during the beginning of January, therefore, I will pass on all pertinent information to him when he returns.

From The Office on AIDS

The Community AIDS Education Project

Over the past year, interest in AIDS and the need for local AIDS education and information programs have dramatically increased. In response, many local communities throughout Maine have developed AIDS education and support services. Many of these community-based groups are beginning to feel the overwhelming pressure of providing AIDS education to religious groups, civic organizations, local businesses, professionals, schools, townspeople, social services agencies, health care institutions, etc.

Some groups have discovered that, even in small communities, it's very difficult to provide AIDS education with limited financial and human resources. For groups that are staffed by volunteers, there are problems finding the time and energy to accomplish basic tasks. The expenses associated with obtaining and distributing brochures; publicizing meetings and conferences; and phone, postage, and travel are also limiting the activities of these groups.

In order to begin addressing these concerns, the state legislature has appropriated funds to help promote AIDS education efforts at the community level. The Office on AIDS will be spearheading this project and is actively seeking comments from all community-based organizations who are offering AIDS education. Our initial plans include locating your groups and identifying the areas in Maine where AIDS education is not being addressed, sponsoring a statewide "get-acquainted" meeting of representatives of your groups, and conducting a needs assessment to establish how to best apply our limited funds to this seemingly limitless project. For more information, or to express your interest in this project, please contact Peaches Bass, Office on AIDS, State House Station 11, Augusta, 04333, 289-3747.

AIDS Conference Documentary

Through the help of a \$6400 grant from Blue Cross/Blue Shield of Maine, the MHC will be able to make a one hour video documentary of its conference, "AIDS: Plague, Panic and the Test of Human Values," which took place this May at the Augusta Civic Center. Held before an audience of over 500 concerned citizens, the aim of the conference was to examine our responses to AIDS in light of the history of other epidemic diseases and the patterns of social, sexual, and cultural conflict that they produced.

Keynoted by Susan Sontag, the day featured presentations by medievalist David Herlihy of Brown, social historian of medicine Allan Brandt of Harvard, and theologian Tom Driver of the Union Theological Seminary; Maine scholars from Bowdoin and the University of Maine conducted workshops on philosophical, literary, and artistic representations of disease in Europe and America. The day ended with a series of hard questions for those currently shaping public policy about AIDS in Maine. Using excerpts from all of these talks, the Council hopes to capture in this video the dominant sense of the conference: that human reason and discourse can generate hope even in the face of horrifying and real threats to life. The video will be available from the Council.



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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!

CONDOMS ARE EFFECTIVE!

The following article is part two 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.

ACYCLOVIR

by R. C. Morse

Acyclovir, or ACV, is an antiviral that was initially developed for treatment of herpes simplex. It is manufactured under the brand name Zovirax by Burroughs Wellcome. Its antiviral action became of interest to AIDS researchers at the National Cancer Institute (NCI) in Bethesda, Maryland, where it was postulated from cell culture studies that ACV might work synergistically with AZT.

An NCI phase one trial began in December 1986 and ended in July 1987 (results are expected to be published this fall in a medical journal). Eight individuals with symptoms ranging from ARC to AIDS (KS/PCP) were treated with both AZT and ACV. AZT was administered at slightly lower dosages than the regimen calls for to lessen its side effects and toxicity. By administering the two antivirals simultaneously, NCI researchers are attempting to derive empirical evidence that AZT works better in blocking HIV in tandem with ACV.

Other similar trials are being conducted under the auspices of the National Institute of Allergy & Infectious Diseases (NIAID), also in Bethesda. Of all government agencies, NIAID seems to be taking the most aggressive approach to AIDS research. NIAID has established or is establishing Clinical Studies Groups, National Drug Discovery Groups, National Cooperative Vaccine Development Groups, Vaccine Evaluation Units, AIDS Treatment & Evaluation Units (ATEUs), as well as a national computerized genetic database for use by medical professionals.

Some 19 ATEUs were established in 1986 in 11 states, affiliated with some 35 leading medical and university research centers. As of July 31st, there were 20 active studies with 1,072 individuals participating at 16 of the centers. Also by the end of July, in addition to ACV, ATEUs were also evaluating six other AIDS-related drugs. (NIAID is also planning a trial for ribavirin, as well as a phase one study for AL-721.)

One of the ATEUs is specifically testing a protocol including both AZT and ACV. This placebo controlled trial is evaluating the pharmacokinetics and pharmacodynamics of AZT and ACV when administered concomitantly. Individuals are divided into six distinct groups: a) gets a small dose of AZT and no ACV, while b) gets the same small dose of AZT, but with 800 mg. of ACV; c) do the same with larger doses of AZT; and e) and f) the same with regimen levels of AZT. As of the end of July, nine individuals were enrolled in what is expected to be a 12-week study. Once toxicity levels are established, the trial will attempt to determine if achievable concentration of AZT and ACV have a synergistic activity against HIV infection.

AMPLIGEN

Ampligen was developed by HEM Research, Inc. of Rockville, MD. HEM is a privately held company formed in 1966 to analyze and develop mammalian cell culture and growth media. It later developed compounds to stimulate or amplify the immune system. HEM was the first company to commercially produce beta interferon.

Its newest product, Ampligen, is a patented, mismatched, double stranded RNA molecule that may be a therapeutic antiviral for HIV+/ARC/AIDS. The first in vitro trial (an independent study by HEM) ran in 1986 through early 1987 with 10 individuals at George Washington University and Hahnemann University. The results proved impressive.

In a nutshell, Ampligen may prove to be more powerful than AZT, with no toxic side effects, and may also help to increase the all-critical T4 cell count. According to the study's authors, their report published in "The Lancet" on June 6th states: Ampligen seems to have the dual ability to restore immunological function and to control HIV replication."

Inside an individual's body, Ampligen acts like an artificial virus. The immune system recognizes Ampligen not as an artificial agent, however, but as the real thing. This subsequently stimulates the body's own natural interferon production. Interferon, in turn, stimulates the growth and development of healthy red and white blood cells. Ampligen has also been demonstrated to inhibit HIV virus replication.

The 10 individuals in the study covered the range of infection from ARC to KS/PCP. They received 200-250 mg. of Ampligen intravenously twice a week for the duration. According to results published in "The Lancet", no side effects or toxicity were observed in any of the individuals involved. After 2-8 doses, seven subjects reported increased energy levels, improved performance status, and lymph node shrinkage. In individuals that were removed from

treatment after more than a dozen doses, symptoms did not appear again for 2-3 weeks, but then fatigue and other symptoms began reappearing. When treatment was resumed, the symptoms again abated.

As an antiviral, Ampligen showed a significant effect in reduction of HIV expression in 9 of the 10 individuals involved in the study, with greatest changes occurring in individuals with ARC. Acting as a well-tolerated antiviral, Ampligen also seems to have potential as an immune system modulator. In those individuals with ARC, T4/T8 white cell ratios improved in as soon as 2-4 weeks of treatment. In those individuals with full-blown AIDS, a 2-5 fold increase in T4 cells occurred at 4 weeks. In total, T4 cell counts rose in 8 of the 10 individuals enrolled in the study.

The authors of the report suggest that Ampligen may have two theoretical advantages over AZT: no side effects or toxicity. The authors also suggest that Ampligen may be most efficacious in the early stages of HIV infection, rather than at the state of full-blown AIDS. They also believe it may work synergistically with AZT, so that a combination of the two (with lower, less toxic doses of AZT) may act better on those individuals with fully developed AIDS. Ampligen is also believed to have the ability to cross the blood-brain barrier treatment AIDS-related neurological disorders.

The potential seen from this preliminary study was enough for Delaware-based DuPont to acquire a minority equity position in HEM, an action that was announced on May 28th. With DuPont's manufacturing and clinical capabilities, as well as its previous experience in development and marketing AIDS diagnostics, Ampligen is now being tested further. A clinical trial with some 200 individuals participating began this summer in New York, Philadelphia, and Washington, D.C. This is a double-blind, placebo-controlled study. At this time, there are no plans to test Ampligen concomitantly with AZT. Results from this phase two trial are expected to be released by the end of the year once the data have been collected and analyzed.




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TRIBUTE TO MICHAEL HANSEN
by Tom Cunningham

Michael Hansen died of AIDS on June 27th at age 31. Michael was a gifted actor, singer/songwriter, and teacher, who touched all that he met with warm, unconditional love. He will be remembered by this love, his humor, his beauty, and his music. He will be missed by many forever. The following is a song of love and great hope he wrote and recorded after his diagnosis:

WE'VE GOT TODAY

We got problems, kid
and the rent is barely paid
They turned the phone off
my bed is never made
They're talking deadlines
they're talking hard times ahead
They're printing headlines
that keep the fatalistics fed
They're cutting lifelines instead

But we've got today
no matter what they say, we've got today
and that's time enough to say
how much you mean to me
Pastures are green to me
when I know you care

There's so many would've run
there's so many would condemn
but here you are
just loving me again
We're sharing secrets
we're laughing harder than we did
We're staying up late
acting like we're kids
We're trading teardrops we've hid...

So it's love over everything
with laughter as my friend
My tears are crystals
that help me start again
It's a teddy bear to take the place
of dragons that I slay
It's a light that shines so simply
even if it's night or day

We've got today
No matter what they say, we've got today
and that's time enough to say
how much you mean to me
pastures are green to me
when I know you care

We've got today...

(Copyright 1986 by Michael Hansen)

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from the PWA Coalition
of New York City.

ON THE LIGHTER SIDE



"I'm sorry, sir, but this survey does not allow
for that opinion."

"It was awful! Wife, kids, dog - even the house was straight!"



DIRECTLY SPEAKING

by
Gary L. Anderson

It was just about this time three years ago that I first became active in the AIDS arena. That may not seem like a very long time ago, but then there was no such thing as the AIDS Project. It has taken alot of work by alot of dedicated people to get us where we are today.

But the work that needs doing has just begun. The epidemic of HIV disease in this state is still nascent and it will be years before its full impact is felt. Compared to the future, these past few years have been the easy ones.

The AIDS Project has made many contributions in the fight against the spread of HIV disease in Maine and in providing support services to those Maine people who have HIV disease. The AIDS Project has grown and changed along the way. A grassroots organization meeting in churches and a bookstore has become a corporate entity, an agency. And it will continue to grow and change as the epidemic spreads.

1988 will be a hard year for the people of Maine. More and more people in our lives will be touched by HIV disease. The role of the AIDS Project will become ever more crucial.

As the AIDS Project struggles to expand and improve the caliber of its services, some important changes will take place. We will count on your support during these periods of transition. It has been your support and encouragement over the past three years that has kept us going. But, your support will never be needed more than it will be in the year we've just begun. So bear with us. Or, better yet, help bear us along on our way to becoming a better agency.

The real work is still ahead.

SAFER SEX

CAN BE SENSUOUS!

Safety Tips for Vacation Trips



AIDS Project Hosts Holiday Dinner

On Sunday, Dec. 20th, the AIDS Project Board of Directors hosted a Christmas dinner at Boone's in Portland. Twenty-one persons with HIV disease and their special guests were in attendance. A surprise visit from Santina (Santa was busy elsewhere) heightened the good will and good cheer of the evening.

Thanks go to Robert Mitchell, Board President, and Lucy Marbach, Client Services Coordinator, for thier hard work in pulling this off (and Lucy especially for finding all the right gifts). Thanks to Kristen Kreamer for her Jocular ad-libbing performance as Santina.

SOME THOUGHTS ON AIDS ISSUES

By Mike Ossias

I have a few thoughts on AIDS and AZT that might help the newly diagnosed, and figured it was about time I wrote something for your Newsline. Credentials first: I presented with PCP in November 1985. I'd been ARC for a year or so, but my friendly (ex) GP basically fudged, and I was too ignorant and unwilling to look at what was going on to question him fully. This leads to my first point. It's really important for you to get as much information as possible on not just the major aspects of the disease, but also on all sorts of smaller annoyances that can crop up. You can do this in a mammoth library session, or by asking other PWAs, and definitely by asking your doctor to explain things. A lot of doctors are very casual in their explanations, but it's important to press them.

Have a dialogue with your doctor. The only way you can do this successfully is to become at least passingly familiar with the pertinent medical terms and with the body's workings. We differ in our capacities to absorb medical information, but we can achieve a certain degree of medical literacy, especially about AIDS and ARC, and that's vital. I've heard too many horror stories in the past two years to believe that all the doctors treating AIDS actually know what they're doing. The more you know, the less you might suffer.

On to AZT. Yeah, another opinion, but based on a lot more experience than most. I participated in the Phase II trials that began in April 1986 and led to release of the drug. In fact, I was the first person in the New York City trials to get AZT (as opposed to placebo). That was in April '86, and I'm still on AZT. I can tell you that it created a significant improvement in the quality of my day-to-day existence with AIDS. No, AZT does not prevent PCP -- I found that out the hard way. No, AZT has not prevented the emergence of KS in my body, though it may have slowed it down. And yes, I've been affected by the toxicity, put on half dose, and been given innumerable transfusions (well, at least 15; I've lost count). Apparently I had the dubious distinction of being one of the most sensitive in the study to the bone marrow suppressive qualities of the drug. So much for negatives. The fact is, AZT is doing a lot of good for a lot of people, and I've personally seen some miraculous results of going on it.

That's why I get irritated when people criticize AZT for not doing more. It's not a panacea and no one said, ever, that it was a cure. But to refer to it, as Michael Callen did recently, as "that poison" is simply irresponsible. Some of us know better, but someone newly diagnosed is still feeling his or her way, and deserves not to be terrorized.

To those trying to decide whether or not to go on AZT, I'd say, try to find out about others' actual experience with the drug and weigh the symptoms you hear about against the acknowledged benefits. Transfusions are really not so bad; neither are minor headaches. The fact is, as Donna Mildvan of Beth Israel said in a response to a question about AZT's toxicity, "AZT is not as toxic as AIDS". And there's nothing else yet available that addresses the virus itself successfully. Think about it. You can always go off AZT if you really feel you're suffering being on it.

A couple of last comments. I agree fully with Michael Callen that no one should have to give up PCP prophylaxis to participate in a study. I came through my second bout of PCP easily enough, but I wasn't happy about it. For what it's worth, and without urging "unethical" behavior, let me just say that the blood work done for the AZT study did not detect Bactrim. But it's a tricky game to play, trying to be on prophylaxis and stay in a study. We shouldn't have to make such a choice.

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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 _____

*NOTE: The article on page 8 entitled "Some Thoughts On Aids Issues", was reprinted with permission from the PWA Coalition of New York City.

CALENDAR

- JAN.15-17-Conference On Aids Ministry - Westin Oaks Galleria Hotel - Houston Texas - Designed by gay/lesbian people specifically for the gay/lesbian community - Sponsored by Samaritan College and The UFMCC Board of Elders - Call 1-800-642-4386 for further information.
- JAN. 16 - "The Emotions of AIDS" - a one day workshop conducted by Jacob Watson, M.A. and Kristine Myers, M.A. - University of Southern Maine Portland - 9am - 4pm - contact Jacob at 761-2522 or Kristine at 775-0366 for further information.
- JAN. 23 - The Merrymeeting Aids Support Services group will be conducting a "Buddy" training session - 9:00 am to 5:00 pm - location to be announced - call 729-8727 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.

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

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