3-1988

The AIDS Project Newsletter (March 1988)

David Ketchum

The AIDS Project

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In the January issue of this newsletter, I reported on my involvement in an AIDS Vaccine Study program at NIH (National Institutes of Health) in Bethesda, Maryland.

Briefly, the vaccine study is designed to test an AIDS vaccine called gp160. This gp160 is a protein produced through recombinant DNA technology, and thus does not contain live or killed AIDS virus. You will not get AIDS. The gp160 protein is similar to the protein coat of the AIDS virus, and corresponds to the part of the virus responsible for allowing the AIDS virus to infect cells. It is hoped that by developing an immune response to this outer protein of the virus one could in effect "neutralize" the AIDS virus if exposed to it in the future.

This vaccine has been tested in mice, guinea pigs, rabbits, Rhesus monkeys and in chimpanzees and has been shown to induce the production of antibodies that in the test tube neutralize the AIDS virus. Such antibodies theoretically would make the virus incapable of infecting a cell.

The purposes of this study are to determine the ability of the vaccine to produce antibodies in humans, to evaluate side effects and toxicity of the vaccine, and to test various dosage levels.

Volunteers for the vaccine study should be healthy gay males between the ages of 18 and 60, who have had a negative HIV antibody test. NIH is looking for approximately 96 volunteers for phase 1 of this study. As of this writing, there are about 55 volunteers currently involved in the study. More are needed. Travel expenses are paid by NIH.

After my initial screening in October, I received the first injection of 20mg units of gp160 on this past December 29th. I returned to NIH once a week for four weeks after the injection for blood work and observation. On the fourth week (January 27th) I received a booster shot of 20mg units of gp160. I am now returning to NIH once a month for one year. It is what I refer to as a waiting game now. I have had no adverse side effects at all, except for anxiety, waiting for reactions to the vaccine.

All interested volunteers should contact Margaret Megill, R.N. or Victoria Davey, R.N. at the National Institutes of Health. Call area 301-496-7196. Also, I would be delighted to answer any questions from interested volunteers. Call me, David Ketchum, at 934-4997. Leave a message, and I will return all calls.

I cannot speak highly enough for the dedicated staff at NIH. My overall reaction to this study has been one of tremendous excitement and pride. It is a very positive feeling. We may not have a cure for AIDS, but it is sure as hell a step in the right direction.

Please volunteer; the rewards are endless......

"The journey of a thousand miles begins with the first step."

Chinese proverb
As of February 9, 1988, there have been 70 diagnosed cases of AIDS in Maine. Of the total 70 cases, 32 have died. People who have tested positive with the AIDS virus (in Maine) is now at 252. National Data as of February 15, 1988: diagnosed cases of AIDS 53,814. Deaths 30,158.

THE AIDS LODGING HOUSE, INC.

The AIDS Lodging House project is alive and well and living in Portland!

The AIDS Lodging House, Inc. began last spring, seeking appropriate housing with a supportive, home-like environment for people with AIDS or ARC. Our goal is to provide an affordable independent-living situation. No in-house medical care or supervision will be offered. The house will be for those who are able to care for themselves, but want the mutual support, financial advantages, and/or conveniences of group living.

Last fall, a Hanover Street location was announced, but the Board of Directors and the donor were unable to reach mutually agreeable terms, so we have renewed our search for a location. It should be noted, however, that the Hanover Street neighborhood gave its full support to the project.

Community response has been wonderful. Our board members constitute a spectrum of health, business, religious and social service backgrounds. Over $25,000 in cash donations has been received from corporations, churches and caring individuals state-wide. Donations of furnishings and volunteer time continue to come in. Most of the necessary resources are in place, once a suitable location is found.

I have recently been hired as house manager, and would welcome any questions or input you may have. This has, and continues to be, a community effort.

Bob Cameron, 233 Oxford Street, Portland, Maine, 04101 874-1000

Report says AIDS surfaced in 1969

CHICAGO - Doctors believe a 16-year-old St. Louis teenager who died in 1969 was infected with the same virus that causes AIDS 10 years before the first AIDS cases appeared in male homosexuals in New York City, a newspaper has reported. Doctors were so perplexed by the death of the 16-year-old patient, identified only as Robert R., that some of them saved samples of his body fluids and tissues for nearly two decades, hoping to find the reasons for his death. The Chicago Tribune reported today. Tests on the samples by Dr. Robert Garry of Tulane University showed with virtual certainty that the AIDS virus was present, said a colleague at Tulane, Dr. Arthur Gottlieb. (AP)

ON THE LIGHTER SIDE

"Miss Hatton - A hairy chest is not a certificate of heterosexuality!"

MODIFIED CDC CLASSIFICATION OF HIV INFECTION

Group I: Initial Infection
Subgroup I-A: Asymptomatic seroconversion (may occur with or without hematologic abnormalities such as anemia, leukopenia, lymphopenia, decreased T-helper lymphocyte count and thrombocytopenia.)

Subgroup I-B: Symptomatic seroconversion (may include a mononucleosis-like syndrome, aseptic meningitis, rash, musculoskeletal complaints and hematologic abnormalities as well as other clinical and additional laboratory findings such as hypergammaglobulinemia and cutaneous energy.)

Group II: Chronic Asymptomatic Infection
Patients in this group may or may not have abnormal laboratory findings.

Group III: Persistent Generalized Lymphadenopathy
Patients in this group may be designated on the basis of laboratory evaluation in the same manner as those in Group I.

Group IV: Other Diseases
(Medical evaluation must exclude the presence of other intercurrent illnesses that could explain the symptoms.)

Subgroup IV-A: Constitutional Disease
Patients in this group may be designated as having fever for more than one month, involuntary weight loss greater than 10% of baseline body weight, diarrhea lasting more than one month, or any combination of these.

Subgroup IV-B: Neurologic Disease
Category 1: CNS disorders: Includes (a) dementia, (b) acute atypical meningitis (occurring after initial infection), and (c) myelopathy.
Category 2: Peripheral NS disorders: Includes (a) painful sensory neuropathy and (b) inflammatory demyelinating polyneuropathy.

Subgroup IV-C: Secondary Infectious Diseases
Category 1: Patients in this group may be designated as having one or more of the following: Pneumocystis carinii pneumonia, chronic cryptosporidiosis, toxoplasmosis, extra-intestinal strongylidiasis, isoporiasis, candidiasis (esophageal, bronchial or pulmonary), cryptococcosis, disseminated histoplasmosis, mycobacterial infection with M. avium complex or M. Kansasii, disseminated cytomegalovirus infection, chronic mucocutaneous or disseminated herpes simplex virus infection and progressive multifocal leukoencephalopathy.
Category 2: Patients in this group may be designated as having one or more of the following: oral hairy leukoplakia, multifocal herpes zoster, recurrent Salmonella bacteremia, nocardiosis, tuberculosis or oral candidiasis (thrush).

Subgroup IV-D: Secondary Cancers
Patients in this group may be designated as having one or more of the following: Kaposi's sarcoma, non-Hodgkin's lymphoma, (small, noncleaved lymphoma or immunoblastic sarcoma), or primary lymphoma of the brain.

Subgroup IV-E: Other Conditions
Includes patients with clinical findings or diseases, not classifiable above which may be attributed to HIV infection and/or which may be indicative of a defect in cell-mediated immunity. Patients in this group may be designated on the basis of the types of clinical findings or disease diagnosed, eg, chronic lymphoid interstitial pneumonitis.

CONDOMS ARE EFFECTIVE!
Dear NAN Member:

As an additional service to physicians who care for AIDS and ARC patients, GMHC is offering a clinically-oriented quarterly publication -- AIDS Clinical Update. If you are in contact with AIDS physicians, please forward this letter to them. Thanks.

Dear Doctor:

It's difficult for the busy clinician to keep up on the volumes of literature on AIDS. Because of the diversity of HIV-associated disease, important articles appear in a broad range of journals that the primary-care clinician might not read on a regular basis.

Yet keeping up-to-date on the information in these articles can make a big difference in patient care. Particularly useful are the clinically-oriented review articles on the ever-changing management of AIDS patients.

GMHC is proud to announce a new publication for clinicians who provide primary care for people with AIDS and ARC. Called AIDS Clinical Update, it will be a collection of important review articles on clinical aspects of AIDS. A comprehensive literature search by A.T.I.N. (AIDS Targeted Information Newsletter) looks at over 100 journals monthly; from this search key clinical articles are selected. AIDS Clinical Update will be published quarterly and distributed free of charge to physicians.

Because the information is technical and somewhat voluminous, AIDS Clinical Update will be reserved for physicians only. If you or any of your colleagues are interested in receiving AIDS Clinical Update regularly, please fill out and return the form below. Make any additional copies you need.

Included in the first volume of AIDS Clinical Update are:


Barry D. Gingell, M.D.

Please put me on the mailing list for AIDS Clinical Update:

Name

Address

City State Zip

Send to:
Gay Men's Health Crisis Medical Information Box 274 132 West 24th St. New York, NY 10011
212-807-7035
AIDS PLAN
By Lani Graham M.D., M.P.H.
Director, Division of Disease Control
Maine Department of Human Services
Bureau of Health

Governor McKernan established the Department of Human Services as his lead agency in formulating a response to the AIDS epidemic. Within the Department, the Bureau of Health developed the first draft of the AIDS Plan. This draft was evaluated by the State AIDS Interdepartmental Committee, a 25 member group representing every Department/Agency in State Government. After the initial work by the Interdepartmental Committee, the Plan was submitted to the Committee to Advise the Commissioner of Human Services on AIDS. With input from that Committee, the Plan was revised again and submitted again to the Interdepartmental Committee. Finally the Governor's Cabinet Council on AIDS, a nine member group of Commissioners representing key government agencies evaluated the plan. These Commissioners met on three separate occasions for periods of 5 - 9 hours to discuss the plan. One greatest strengths of the Plan can therefore be seen in the process of its development.

Governor McKernan and his Commissioners have committed themselves to regular re-evaluations of the policy decisions made. The Plan is expected to be updated at least every six months based on new information and citizen input. The resource persons listed in the Plan can serve to initiate change or strengthen the current direction of the Plan. These professional resources include persons both inside and outside of State government.

The title of the document is expected to be, AIDS in Maine: Background and Policy. As the title suggests, this is not a State plan in the classic sense of identifying unchanging goals and objectives to be achieved over specific time periods. Rather, this plan is expected to serve as the foundation for a coordinated statewide approach to AIDS.

The plan addresses key policy issues which need to be resolved to advance the State's current capacity to deal comprehensively, compassionately and effectively with AIDS. It identifies the persons and agencies within, and outside of, State government who will help. The plan is an educational tool and will serve as a catalyst for drawing further creative approaches from Maine citizens. Although many parts of this plan are written specifically as State government policies or for State employees, it is hoped that these parts may be useful as models for private organizations in need of policies and recommendations. Commitment of resources and implementation of specific parts will depend on citizen interest and/or involvement. As the plan offers the opportunity for change it must of course be strongly supported by those who are concerned, for its strengths, in addition to committing energy to altering its weakness. Such is the nature of the best education. As someone once said, any jack-ass can kick a barn door down, but it takes a carpenter to build one.

SAFER SEX CAN BE SENSUOUS!

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!
The following is reprinted with permission from the PWA Coalition of New York City.

EDITORIAL
by Max Navarre, Editor

I'm about to put my head on the chopping block. I want to put my two cents in about the latest in a long line of wonder treatments, AL721, or egg lecithin, lipids, call it what you will.

I'm not prepared to make a judgment about the effectiveness of lipids, but I am concerned about their legend. I'm concerned about the abandon with which some of our community have embraced lipids. I'm concerned about the power some of us have ascribed to them. Lipids may be useful, but, lest we forget, lipids are not manna from heaven.

Recently a New York gay newspaper profiled a man with AIDS. He was a local businessman who had been very ill for sometime. He started taking lipids and improved markedly. There was much ballyhoo in this newspaper about how wonderful lipids are, and how miraculous this man's recovery.

Well, shortly after this piece appeared, the man in question unfortunately died.

There was much shock in the community, almost a sense of betrayal. How could he have died if he was taking lipids? How could this have happened? We all know lipids aren't a cure, but gosh, aren't they?

One of the good things about lipids is that their popularization is totally grass roots. They became available because PWAs made them available: self-empowerment at its best. No mega drug companies, no FDA, no price gouging; just a need being filled.

But I think because of this home grown quality, egg lipids have themselves emerged as a symbol of self-empowerment. We have confused the product with the motivation behind the product's availability. And how shocking when self-empowerment fails. When the home grown treatment is as fallible as that offered by the big boys, then where does one turn?

Where indeed. We are all so desperate for something to believe in, something that works, that we are constantly in danger of disappointment or worse.

Where is the evidence about lipids? There isn't any. Am I supposed to believe that a bunch of PWAs who "feel better" is evidence? What does that mean? Maybe they feel better because they're doing something to help themselves. I feel better when I have acupuncture, but maybe that's because I roused myself to go and do something about my health. Is acupuncture going to keep me alive? Beats me.

I don't hold with the prevailing attitude that says: if it can't hurt and might help, why not? One could say the same thing about Cod Liver oil.

And who knows it can't hurt? Where's the evidence? Who's to say that ingesting large quantities of highly concentrated animal products won't prove harmful?

I'm just asking. I don't want a ton of letters from satisfied lipid users whose undies are in a bunch because I'm criticizing their baby. I am just saying what I always say about everything: WATCH OUT! We must be careful how much faith we put in anything. These are perilous times.

We have all been through this before with a variety of drugs, substances and treatments. Whether you get your treatment products from another PWA or from the local drugstore, they deserve to be treated with the same respect and skepticism.

Remember, it's your body.

ON THE LIGHTER SIDE

"Oh, God. He's going into his 'In some countries, men aren't afraid to touch each other, embrace each other, even kiss each other' routine."
TOGETHER FOREVER
by "Wizard"

LOVE
The two of us,
SHINING.
Seemed like forever.
SIX YEARS pass,
LOVE together,
together forever.
THEN AIDS
A VIRUS.
So many things change
except our LOVE grows stronger.
Two more years pass, Eight years of LOVE,
SHINING,
with added fears and fighting.
Then the last shot.
He goes on, He's healed,
Is the battle over? NO.
Just a smaller troop,
same beliefs, same love,
same fears,
same fight.
Two as one, now stronger than ever,
LOVE WILL WIN IT OVER.

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of New York City.

AIDS
LESBIAN
Risk Study

There is a research study of HIV transmission being conducted in NYC at NYU Medical Center which would like to include Lesbians. The research involves pre-test counseling with a Lesbian counselor, risk reduction for Lesbians, an explanation of the HIV antibody test, and a discussion of your personal pros and cons about taking the test. If you decide to take the test, it can be done at that appointment. You will then be asked to complete the research questionnaire. Three Visibilities staff members were invited to have input into the development of the questionnaire. All information is confidential and can be anonymous. Follow-up counseling is available. Lesbians who feel they have no risk, but would like to participate in the study because someone cares enough to study us, are most welcome. For more information or appointment, contact Denise Ribble at (212) 675-3559.

Whether or not you have been tested, and whether you live in NYC or elsewhere: If you are interested in participating in this study, and are tested where you live, you can receive a copy of the research questionnaire to complete by writing to Visibilities, Dept. LRS, P.O. Box 1258, Peter Stuyvesant Station, New York, NY 10009-1258. The questionnaire is completely anonymous and Visibilities will release NO IDENTIFYING INFORMATION TO THE RESEARCHERS. Inquiries about risk reduction, testing and counseling can be obtained by sending an SASE to Visibilities, Dept. TC, at the above address. We will try to put you in touch with a group or organization in your area which can help.

NEW NATIONAL LESBIAN MAGAZINE, VISIBILITIES, INITIATES FIRST LESBIAN RISK STUDY FOR AIDS

"In order to believe that lesbians are not at risk for AIDS, or that those who have already been infected are merely incidental victims, I would have to know and agree with the standards by which we are judged to be safe. Meaning, I would have to believe...that lesbians, unlike straight women, can get seven years worth of honest answers from their lovers about forgotten past lives." So states author Lee Chiaramonte in the January 1988 issue of VISIBILITIES, a new national magazine for lesbians. Chiaramonte's article, entitled "Lesbian Safety and AIDS: The Very Last Fairy Tale," is the culmination of a six-month investigation of media and medical community assurances that lesbians, as a group, are at almost no risk for the fatal disease.

The article casts doubts upon prevailing medical wisdom: after extensive interviews with AIDS foundations in San Francisco and New York and discussions with virologists at the Centers for Disease Control in Atlanta, Chiaramonte discovered that claims of lesbian safety from AIDS are based upon no clinical data whatsoever.

Susan T. Chasin, Publisher and Editor-in-Chief of VISIBILITIES, together with Chiaramonte, and health educator Denise Ribble, sought the cooperation of epidemiological researcher Michael Marmor in order to create the first scientific lesbian risk study of AIDS. VISIBILITIES readers will be able to participate in the confidential study and be tested for sero-positivity anonymously. The magazine's concern for Lesbian safety has resulted in this landmark study. For information contact: Susan T. Chasin at (212) 473-4635.
CALENDAR


MAR. 10-11 - Developing AIDS Community Education Programs, for family planning programs - call Karen Brenner of the John Snow Institute at area 617-482-9485 for further information.

MAR. 10-13 - AIDS In Perinatal Medicine and Nursing, Marco Island, Florida. For more information contact Symposia Medicus, 2815 Mitchell Drive, Suite 128, Walnut Creek, California 94598-1622.

MAR. 13 - RHYTHMS OF HOPE - An evening of creative dance to benefit The AIDS Action Committee of Boston. Dancers from 30 professional companies have come together to perform a program that will include 5 world premieres. John Hancock Hall - Berkeley Street - Boston. Tickets on sale at Ticketron.

MAR. 19 - Maine Health Foundation Benefit Ball - Eastland Ballroom - Sonesta Hotel - Portland. $50.00 per person - "Black Tie" - Dr. Owen Pickus, Honorary Chairman. 7:00 pm Cocktail Hour with Charles Grindle, pianist - 8:00 pm Dinner - 9:30 pm Dancing with Red Light Review. To benefit AIDS related projects. For tickets please call 773-1409. PWA's will be admitted free by calling Bert LeClair at 775-1259 for arrangements.


APR. 8 - First Maine Conference On Gay And Lesbian Youth: Creating A Brighter Tomorrow - Portland - contact Joni Foster at Department of Educational and Cultural Services at 289-5925.

APR. 15-16 - Dying Before Their Time: The Role of the Medical Humanities in Early Death From Genetic Diseases, Infectious Diseases and AIDS. A two-day conference at Ramada Hotel, 100 East River Drive, East Hartford, Ct. 06108. Call Cecile J. Volpi at 203-679-3340 for further information.


CALENDAR cont.


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 for further details.

On the first Tuesday of every month at The Aids Project - 48 Deering Street 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.

DEAN (DownEast AIDS Network) educational and business meeting the 2nd Tuesday of every month at Ellsworth City Hall Council Chambers at 7:30pm.

DEAN also has a support group for PWA's, HIV+, family members, and lovers; call Tracy or Lynnsey at 326-8546 for further information.

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.

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. .......