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THE SCOOP

PUBLISHED BY THE PEOPLE WITH AIDS COALITION OF MAINE

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VOL 5 NO 5

Living Longer

What are the variables of long-term survivorship?

In a session on long-term survivorship offered at the ninth international conference on AIDS, Dr. Jay Levy, head of the Cancer Research Institute of the University of California, San Francisco, said that healthy long-term survivors have at least two things in common: they have a small amount of virus in their body (called a "low viral load") and they're infected with weak strains of HIV.

This may not be just good luck, Levy says. He presented evidence that the immune system of long-term survivors are able to control HIV replication and prevent the virus from mutating into more powerful strains.

Levy says the secret weapon is strong, consistent, "cell-mediated" suppression of HIV replication by the CD8 T-lymphocyte, a relative of the CD4 cell.

An increase in the number of CD8 cells is typical of people with HIV infection. The difference in long-term survivors, Levy says, is not CD8 *count* but CD8 *strength*.

Levy's lab has shown that in long-term survivors, virus replication in 20 infected CD4 cells can be controlled by just one CD8 cell. In people with AIDS, however, 20 CD8 cells may be needed to control HIV production in a single CD4 cell.

CD8 cells control HIV replication indirectly, through secretion of a type of chemical called "cytokine." Levy has not been able to isolate the specific cytokine that suppresses viral activity, but his researchers have ruled out many cytokines, including all the known interleukins and interferons.

"(Therapeutic) approaches that can maintain CD8 cell anti-HIV activity should keep the virus in check," Levy says. "Efforts directed at these cell-mediated immune processes and attention to the CD8 cell could lead to long-term survival for all HIV-infected individuals."

Levy's data about the role of CD8 cell strength in long-term survivorship and in controlling HIV replication is backed up by several other presentations at the conference.

CD8 activity is probably not the only factor in determining long-term survivorship. For example, Susan Buchbinder

of the San Francisco Department of Health has identified certain genes that occur in significantly higher frequency among long-term survivors with more than 500 CD4 cells. Buchbinder says that such research could lead to treatments that mimic the role of important genes.

But many persons living with a long-term diagnosis want to ensure that the potential psychological and lifestyle-related factors of long-term survivorship are also studied. Many believe that there are other factors that keep them healthy. Personality, diet, exercise, stress reduction, and outlook on life are all important variables.

AIDS activist Aldyn McKean, himself a long-term survivor says, "Most long-term survivors I know have good, solid relationships in their lives."

Modifiable lifestyle factors such as sex, diet and social support may play an important role in determining survivorship. But research by I.P.M. Keet of the Municipal Health Service, Amsterdam, suggests that lifestyle choices *before HIV infection* may not have any bearing on survivorship. In other words, he found that these men began their battle against HIV on a level playing field,

Keet compared questionnaires answered by gay men at the beginning of their enrollment in the Amsterdam Cohort Study. Questions concerned the men's psychological copy mechanisms, recreational use of various drugs, and number of sexual partners. After dividing these questionnaires into two groups - those who became long-term survivors and those who progressed to symptomatic disease - Keet found no significant differences.

What lifestyle changes the men made *after infection*, however, remains unknown and probably significant.

(Article reprinted in part from "Living Longer" by David Thomas. AWAKE: The Monthly Journal of Test Positive Aware Network: 7/93)

UP TO DATE HIV/AIDS Medical News

Dapsone, pyrimethamine combination effective against PCP, toxo

Studies continue to validate a dapsone-pyrimethamine combination therapy as a therapy equal in effectiveness to aerosolized pentamidine (AP), and a new study indicates that dapsone is more effective than AP in preventing toxoplasmosis, according to a report in the New England Journal of Medicine. The study compared results in almost 350 patients who received either 300 mg AP once per month or a combination of 50mg of dapsone daily plus 50mg of pyrimethamine per week. All participants had HIV-related symptoms and CD4 counts of less than 200 with no previous history of pneumocystis carinii pneumonia or toxoplasmosis.

Survival rates were similar among both groups and an equal number (10) went on to develop PCP during the 18-month course of the study. However, only 11% of those on the dapsone and pyrimethamine combination developed toxoplasmosis, compared to 18% in the AP group.

Intramuscular pentamidine prevents PCP

STEP also reports on a study which showed that monthly intramuscular injections of pentamidine worked well in preventing new PCP episodes among those who could not tolerate Bactrim (TMP-SMX), dapsone or aerosolized pentamidine. Only three of 96 participants in the study developed PCP while receiving the injections, the group said. STEP says that the advantage of using intramuscular injections is that the drug is then distributed through the entire body, whereas aerosolized pentamidine only works in the lungs.

AIDS cases among women, heterosexuals soar in new CDC study

While the total number of new AIDS diagnoses rose only 3.5% between 1992 and 1991, reflecting over 47,000 new cases, the most startling element of a new CDC analysis of AIDS case reports in 1992 is a major increase in new heterosexual cases over those occurring among gay men and injection drug users.

Between 1991 and 1992, new diagnoses among gay and bisexual men dropped by one percent and increased among intravenous drug users by one percent. But the numbers of heterosexual cases increased by 17% with cases involving mother-to-child transmission increasing by 13 per cent.

New cases among men = who still accounted for over 40,000 of the 47,000 diagnosed in 1992 - increased by 2.5 percent. New cases among women in 1992 increased by almost 10 percent, according to the study, with sexual transmission surpassing needle sharing as the leading cause of infection for the first time since the epidemic began. Most of the women infected sexually were non-white and most of the sexual partners were IV drug using men, according to the CDC.

Non-latex condom expected soon

A British company expects to gain approval for the sale for a transparent condom designed to allow better sexual sensation than latex condoms within the next year, according to the Associated Press.

The newly developed polyurethane condom is made of thinned material than latex condoms and tests with users showed greater sensitivity, the company said. Another advantage of the new condom is that it can be used with oil based lubricants such as petroleum jelly and mineral oil, which are not recommended for latex condoms since they may erode the condoms membrane and reduce its viability.

The new condom is expected to be more expensive than American-made latex condoms, the company said.

AIDS phobia alive and well, study says

University of California researchers say that at least one-third of Americans are "very or somewhat" afraid of people with AIDS, while a similar number believe that people with AIDS "should be legally separated from others to protect the public health."

The study published in the American Journal of Public Health in April was conducted by researchers at the University of California at Davis, and reported on a national telephone survey of 538 adults in 1990 and 1991. In the study, 35.7 percent of the respondents favored quarantine of known people with AIDS and almost half - 47.1 percent - said that would stop shopping at their local grocery store if they knew the owner had AIDS. One in five respondents said that would quit their jobs if they found out they were working alongside a person with AIDS.

20.5 percent of those answering the survey felt that people with AIDS deserved their illness because of their sexual or drug behavior.

Another result of the survey was that nearly 20 percent of those responding felt that HIV infection was likely to result from two men having sex while using condoms - even when neither was infected with HIV.

gp160 vaccine trial crosses final hurdle

The U.S. Army and MicroGeneSys Inc. have reached an agreement to begin the first large-scale study of an experimental AIDS vaccine in the United States. The vaccine, called gp160, was approved six years ago by the U.S. Food and Drug Administration for testing in humans.

MicroGeneSys has agreed to donate enough gp160 for clinical testing involving 10,000 HIV+ civilian volunteers. The trial involves the U.S. Army because objections raised by researchers at the National Institutes of Health, which declined to participate because of concerns about the value of the vaccine being tested and the political influence which was exerted to get the trial funded. Unlike other publicly-funded AIDS clinical trials, which are funded through and supervised by NIH, MicroGeneSys allegedly used its political connections to get the study directly funded by the U.S. Congress to the tune of \$20 million.

Many scientists have criticized the trial, claiming that earlier trials have not indicated that the vaccine is ready for a large scale trial.

Actual implementation of the trial of the vaccine - known as gp160 - was delayed for many months after congressional authorization, first by NIH objections and later when the Army said it could not afford to pay for vaccine needed for the trial. MicroGeneSys' agreement to provide the vaccine at no charge has removed the last remaining obstacle to a large-scale trial, which is expected to begin sometime later this year.

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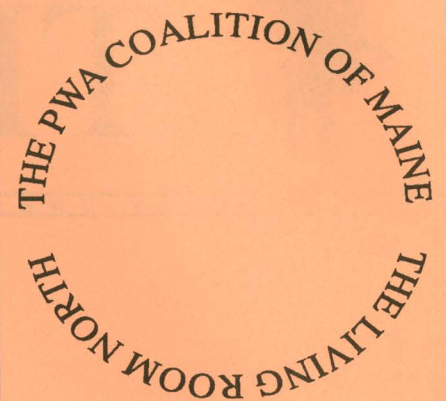
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Till 11:00 PM
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Dinner Nightly
6:00 PM

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The appearance of any person's name or image in this publication does not imply anything about their health status or sexual orientation. Views expressed herein are those of the author and do not necessarily express the views of of other authors, the PWA Coalition or any other organization.

IMPORTANT NOTICE

The SCOOP is updating its mailing list. If you are interested in a subscription **or have changed your address**, please fill out the coupon above and mail it to us.

READ THIS !!!

The PWA Coalition is looking at moving to a new site that would be handicapped accessible. But we will need some people to help paint, remodel and move. Are you interested? Call Roxanne at 773-8500 and put your name on the list.

Available to work on the
Halloween Ball
(Raise \$\$\$ for PWAC)

Let Us Know!
Call 773-8500



Reflections On Camp Chrysalis

(Camp Chrysalis, a camp for children and families with HIV sponsored by Waldo-Knox AIDS Coalition, was held again this summer bringing together 22 young people (ranging from ages of 4 to 16 years of age) and 15 adults, including parents and care givers.)

The weeklong event offered many camp-like activities for both children and adults, such as swimming, nature hikes, a trip to a llama farm, outdoor games and crafts. I can still see the clothesline festooned by tie-dyed t-shirts, towels and even some socks ! Amidst the laughter and shouts of successful frog catches (note the photo of the all-around champion frog catcher), there were many touching moments when the quiet was broken only by the haunting cry of the loons.

A writing and poetry workshop inspired many moving words that reminds us of how deeply our souls are touched by HIV, no matter what our age.

For many families this was another courageous step in a long journey of courage. Waldo-Knox AIDS

Coalition should be applauded for their continued sponsorship. My heart was touched not only by the children and families that I got to know; I also need to express my utmost admiration of Meredith and Donna who directed the camp, and to all of the staff and visiting volunteers. Such a week with many diverse people with diverse needs inevitably invites unanticipated problems, all of which were responded to with great compassion, caring, and wisdom. I am honored that I was invited to be a part of that staff, It was an extraordinary week, blending emotional challenges, exuberant celebrations, quiet reflection and, hopefully for all attendees, a safe and caring respite.

Sponsored by Waldo-Knox AIDS Coalition, Camp Chrysalis provides a weeklong camp experience for children and their families who are affected by HIV/AIDS in their hearts and/or their bodies. For more information , contact Waldo-Knox AIDS Coalition at (207) 338 - 1427.

FROM KITTERY TO CALAIS : THE MAINE SCENE

A Brief Look At HIV/AIDS Related News Across The State

Youth and Down East AIDS Network Team Up To Fight HIV

Working with the staff at Down East AIDS Network, a youth advisory council representing seven area schools in Washington and Hancock counties is preparing to form AIDS teams in their respective high schools. Focused on peer to peer education, these groups will form an area network that will share information school to school. Twice a year meetings of student representatives from all participating schools will provide important feedback and support for ongoing education and prevention programs in each school district.

Mt. Desert High School, the first high school in Maine to offer free condom distribution to the student body, is again in the forefront of AIDS education for youth. Students and school personnel are working on a video that will describe the steps to be taken to provide a program of HIV education and condom distribution in a public school setting. Copies of this video will be available for communities and school boards to wish to pursue a program of their own. This video will be available through the DEAN office in late October.

An interactive theatre presentation around HIV prevention and education by The Reach School in Bucksport, Maine is being offered to schools across Maine. Another youth - to - youth program !

For more information about any of the above programs, call (207) 667 - 3506 or write : DEAN
114 State Street, Ellsworth, ME 04605.

HIV/AIDS Program Offered Through Adult Education

M.S.A.D.#40 in Waldoboro is hosting the first comprehensive HIV/AIDS program offered in Maine through adult education. Facilitated by the People With AIDS Coalition of Maine, this five week series is designed to reach rural people who would not ordinarily have access to information on HIV disease. The offerings include: AIDS 101 - a general overview of the virus, transmission and generally accepted therapies; first hand accounts from those infected with and affected by HIV, including local persons from the midcoast area and school personnel who have dealt with HIV students; local support organizations from Belfast through Brunswick and including the Augusta-Waterville area; The NAMES Project AIDS Memorial Quilt; and finally AIDS 2000 - a look at infection statistics for the state, the nation and the world, plus prevention and education programs in place for Maine. This program brings together Waldo-Knox AIDS Coalition, Lincoln County AIDS Coalition, Merrymeeting AIDS Support services, Dayspring, Maine Medical Center AIDS Consultation Team, The NAMES Project, the state Office on AIDS, and the People With AIDS Coalition in a joint effort to reach out to rural Maine. The first meeting is October 19th at Medomak Valley High School from 7:00PM to 9:00 PM. For more information on these programs, call the adult education office at 832-5205.

AIDS Memorial Quilt Update

December 1 through December 4, 1993 - Portland YWCA
Volunteers are always needed !!!! Call David at 934-4997.

The P.W.A. Coalition Of Me.



Great Pumpkin Ball



Co-Host Underground

Sunday, October 31st.

Holiday Inn By The Bay

Spring St. Portland



8:00 pm. till 12: Midnight
Costume Contest at 9:30

Cash Prizes / Three Categories

1st. \$250.00 2nd. \$50.00

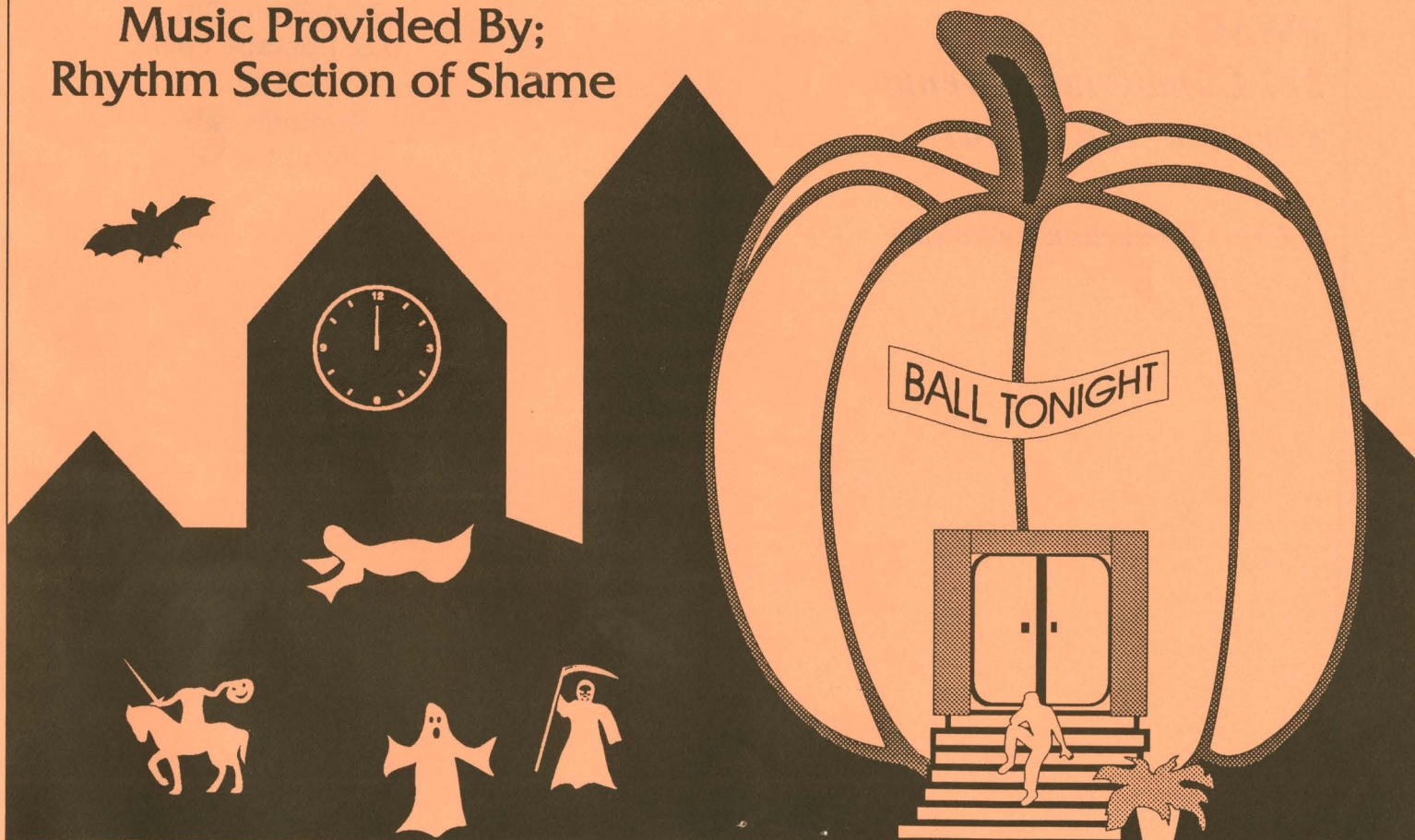
3rd. Dinner for two at Katahdin Rest.



Tickets: \$10.00 ea. or \$15.00 per couple

Tickets available at: Drop Me A Line, P.W.A. Coalition,
Blackstones, Underground, Chart Room and Out Post

Music Provided By;
Rhythm Section of Shame



SUPPORT GROUPS

The AIDS Project

MONDAYS - Support group for HIV-negative partners of HIV-positive persons. 6:30-7:30 p.m.

TUESDAYS - People living with HIV disease and all friends, families, lovers and caregivers, 10:30 - 12:00 noon at the AIDS Project.

Living Well - Focusing on quality of life and empowerment, 2nd and 4th Tuesdays at the AIDS Project.

THURSDAYS - Women Living with HIV, 1:15 - 2:45 PM at The Aids Project.

Men Living with HIV, 5:30 - 7:00 PM at The AIDS Project.

All the above support groups meet at 22 Monument Square, 5th Floor. Call Sandy Titus at 774-6877 or 1-800-851-2437 for further information

ALTERNATE WEDNESDAYS - Support group for mothers, sisters and loved ones of people with HIV disease at 7:30 p.m. Call Sandy (774-6877) for location.

The AIDS Project can be reached at 774-6844 or 1-800-851-2437.

Lunch is served at 12:15 each Thursday at TAP. Support group participants and clients welcome.

The Women's HIV/AIDS Support Group meets 2nd and 4th Tuesdays of each month in the Lewiston/Auburn area. Call Diana Carrigan at the TAP-Lewiston office: 783-4301

Merrymeeting AIDS Support Services

MASS is currently sponsoring three support groups relating to AIDS and HIV. These groups are anonymous and confidential, providing a safety environment to share feeling and problems concerning HIV infection.

TUESDAYS - MASS offers a group for family members and friends of people who are HIV-positive. 7:00-8:30 p.m.

FIRST & THIRD WEDNESDAYS - Group for people who are HIV-positive. 7:00-8:30 p.m.

Call MASS at 725-4955 for more information.

Waldo-Knox AIDS Coalition

Groups for anyone affected by HIV/AIDS on the third Monday of each month in Belfast. Call 338-1427 or 338-3135 for information.

Every other Thursday mother's group for mothers of persons living with HIV/AIDS or who have died of AIDS in Belfast. 338-1427.

THURSDAYS - PWA/HIV support group in the Rockland

Androscoggin Valley AIDS Coalition Support group for people with HIV and their loved ones. Come any time or call 786-4697 FMI.. Thursday 7PM at the American Red Cross, 70 Court St. 2nd fl., Auburn. (743-7451)

Southern Maine Medical Center, Biddeford Wednesday, Support group for Family and Friends Who Care 7 p.m. Cafeteria #3, 2nd floor.

WISH LIST

- someone who knows the PageMaker program on a Mac
- people to fold the newsletter Monday and Tuesday of the fourth week of the month
- food items
- personal hygiene items
- lamps, rugs, curtains, blinds, drapes, pots and pans, dishes
- blankets, full sized fitted sheets, pillows, comforters
- boots, gloves, winter clothing
- plants
- a new copy machine; fax machine
- stereo equipment, VCR's, CDs, records
- exercise equipment, bicycles
- new dish washer

From My Corner of the Office

The office is a mess! I mean it! Papers to be filed, stuff that people have dropped off, newsletter proofs everywhere...the phone is ringing and I know I smell something absolutely delicious cooking in the kitchen. It's good to be back! Last month I said I was going to change the name of this column but I got busy doing other stuff, so the name stays the same. A new board has been elected to take over for the interim board. Thanks should definitely go to those who served the past six months. Their dedication made it possible for the Coalition to continue through some rocky times. Now a new board will face the task of establishing a working budget, review programs, meet with clients to listen to their needs and chart a new and aggressive course for this organization.* Did you get a chance to see the HBO special "And The Band Played On"? I haven't seen it yet, but I was listening to a friend describe it to me and she kept saying "And I can't believe no one did anything!" And I kept thinking that that story covers events that happened over 10 years ago....and still we have trouble getting people to do just a little bit..you know, like come in and fold newsletters, or drop of a few cookies, or help decorate for a party. This isn't rocket science..it just takes an hour or two here and there. Think about it..ten years from now, when someone looks at you and says "I can't believe no one did anything!", what will your response be????

JUNE

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