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The Scoop ([November? 1993])

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Full 1993

UP TO DATE HIV/AIDS Medical News

Switching From AP to TMP/SMX

A study reported in *The Journal of Infectious Diseases* (1993;168: 314-7) found that two-thirds of 130 HIV+patients taking aerosolized pentamidine(AP) could be successfully switched to Bactrim or Septra(TMP/SMX) without allergic reactions or hematological toxicity. TMP/SMX is the most effective preventative treatment for *pneumocystis carinii pneumonia* (PCP), a common life-threatening infection in people with HIV. TMP/SMX is also less expensive and easier to administer than AP. Those who could not be switched developed fever and rash within the first two weeks, which resolved when the drug was discontinued. Significantly, patients with CD4 cell counts under 200 did not tolerate the crossover as well as those with higher CD4 cell counts. Fifty-seven percent of the lower CD4 group developed skin reactions to TMP/SMX compared with twenty-seven percent in the higher CD4 group.

HIV Hides in Lymph System

In the symptom-free stages of HIV infection the virus reproduces and accumulates in large quantities in the lymphoid organs, according to two reports in the March 25,1993 *Nature*. The lymphoid organs - such as the tonsils, lymph nodes, spleen and adenoids - serve as important components in the body's immune defense system.

Researchers at the National Institutes of Allergy and Infectious Diseases(NIAID) believe that this finding helps explain why HIV+ individuals lose CD4 cells, even when levels of the virus in the bloodstream are low.

In the first study, 12 HIV+ individuals at various stages of HIV disease were examined. Researchers compared the amount of HIV in the lymphoid organs and in the bloodstream. In symptom-free patients, the levels of HIV and the rate of HIV reproduction were low in the bloodstream, but the were higher in the lymphoid organs.

In the second study of lymphoid tissues of four HIV+ individuals, researchers found widespread HIV infection of CD4 and other cells during both the early and late stages of infection.

"This information may prompt a rethinking of the optimal time to initiate treatment of HIV infected patients," said Anthony Fauci,M.D.,NIAID director. Fauci said that the findings clearly demonstrate that a

latent stage of early HIV infection does not exist, and treatment intervention much earlier in the course of the infection may be necessary.

In a related story, researchers recently discovered that HIV was detectable in the blood plasma of 66 HIV infected individuals at all stages of HIV disease, according to a March 19,1993 Science report. The researchers suggest that their diagnostic-method, the quantitative competitive polymerase chain reaction test (QC-PCR), also may be useful in determining the effectiveness of antiretroviral drugs in early HIV disease, when conventional surrogate markers are negative.

TB Recommendations Issued by CDC

In an effort to control the growing tuberculosis (TB) epidemic, the CDC and the American Lung Association have issued new recommendations for healthcare professionals treating TB infected patients. The recommendations include the following:

- * People with HIV should be tested for TB
- * Close contacts of TB patients should be tested for TB
- * Healthcare workers should directly observe TB patients taking their TB medications
- * Cough producing medical procedures such as aerosolized pentamidine should be performed in isolation rooms or booths occupied only by the patient
- * Hospitalized TB patients should be kept in negative-pressure rooms
- * Health care workers should wear disposable particulate respirators instead of surgical masks when treating TB patients

Appetite Stimulant Gets FDA OK

The U.S. Food and Drug Administration has approved the use of dronabinol (brand name Marinol) to stimulate appetite and to alleviate nausea in people with AIDS who suffer sever weight loss. The drug is a synthetic form of THC, the chemical in marijuana that produces euphoria.

Dronabinol may not be appropriate for all people with AIDS, especially those with mental impairments. It can also cause hallucinations in high doses.

The FDA's Antiviral Drugs Advisory Committee has recommended Megace, another appetite stimulant, for licensing.

Approximately \$18,000 in federal funds are used to support services benefitting children affected by HIV, their families and their caregivers. These services include networking and support groups for women with HIV, a respite camp for children and their families, and other programs addressing women and families. Once again, the government is covering about half of the cost of these programs.

Community-based HIV organizations are very active in raising funds at the grass roots level. We know that at least 50% of their support must be generated within our cities and towns. This is, in essence, what defines a community-based program. It's not just staffed by, or run by, local people, but it's also paid for by local people. This gives us a great deal of say-so in developing and designing programs. A recent example was the flak we took over safer sex education programs funded primarily by non-government funds, supplemented by a miniscule amount of state money. Without state support, we would've been freer to design innovative, effective programs, so we have to take government support with a grain of salt.

Government money isn't just restrictive and inadequate; it's notoriously unreliable, too. It depends on politics and bureaucracy. While government funding is essential to our organizations, it is not a blessing so much as a necessary evil.

The corporate community and major funders in Maine haven't mobilized to the degree that we need them to. While there are efforts under way to see a greater level of consistent support from major companies and foundations in the state, for the time being, community-based HIV services are not well-funded by these entities.

Community-based organizations need YOU, the community, in order to thrive. A community-based HIV organization is only as good as the community that supports it. The next time you think about writing a letter to your legislator in support of HIV funding, think again, and write a check to your local HIV organization, or volunteer your time and services, instead. That's where the resources really come from.

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A Special Request From The NAMES Project Quilt

For the upcoming December display, our Logistics Committee needs volunteers. If you are interested in the actual mechanics of the display, or have expertise in electrical and/or sound equipment, this is the right committee for you.

This committee will handle the actual Quilt set-up and breakdown, including the actual hanging of the panels. The 12' by 12' Quilt panels are often heavy and awkward. Most of the panels will be hung from the YWCA gym rafters. Ladders and scissor lifts will be utilized.

If this is an area of interest to you, please contact: Wayne Trombley at 772 - 4321 after 5pm

Wish List

- volunteers
- \$\$\$\$\$
- 12 8ft tables or 20 6ft folding tables (loan)
- 100 folding chairs (loan)
- 6 stanchions w/ rope (loan)
- 30 pieces 1' galvanized piping 12 1/2 to 13 ft lengths (loan)
- compassionate fathers
- facial tissues (2 cases)
- food donations for volunteers over four days plus -
- coffee, juices, soft drinks, water, tea, etc.
- several rolls of picture wire, depending on the length of the roll
- \$\$\$ for various printing costs or Printer to sponsor
- video equipment (loan)
- lots and lots of HUGS

FROM KITTERY TO CALAIS: THE MAINE SCENE

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

Where Does The Money Come From?

by Peaches Bass, Director
Maine AIDS Alliance

In case you haven't heard, state funding for HIV services has been cut in the area of prevention, and the funding for case management has been held level. This is not good news; while prevention services are cost effective, developing targeted programs that give us the biggest bang for our buck require an initial investment that state funds simply can't provide. Meanwhile, case management case-loads continue to increase in a service that is already labor intensive. When funding stays level while the need for services grows, we end up with a budget cut. Yet, in the face of shrinking government support, the services of community based HIV organizations are still being provided to those who need them.

The reason we can continue to provide services, though some of us are just treading water, is that we have a diversified funding base. To put it another way, Maine's HIV organizations don't depend solely on one type of income. Instead, we rely on private donations, major fundraisers, foundation grants, support from local businesses, volunteer labor, in-kind donations, and government funds.

In 1994, the state will provide \$180,000 for HIV prevention and related support services. Because of stricter criteria, a smaller number of Maine AIDS Alliance organizations than in the past will receive those funds. That figure is 20% less than 1993's funding. In every case, the organizations are increasing their fundraising and grant writing efforts to make up the difference. Most of them end up matching the state funds dollar for dollar in order to provide prevention services. That means that about half of the resources needed will come from the Maine AIDS Walk, auctions, casino nights, benefits, boat cruises, fees charged for certain programs and other donations.

Almost half of the community-based HIV organizations receive no state funding, or very small, one-time grants under \$1500. These groups, while generally smaller and more limited in focus, must struggle to raise local dollars through the Walk, local businesses and small fundraisers like the ones listed above.

So, in truth, the state government is providing less than half of the funding for community HIV prevention. Expect this share to continue to decrease.

Case management services are provided by five Maine AIDS Alliance organizations. The state provides a total of \$257,000 for 1994's case management, using \$136,000 in state funds and \$121,000 in federal funds. That is a whopping 30% cut from 1993's funding ! Bear in mind that the case-load from '92 to '93 increased by 12%.

The case management providers raise 40% of the funds needed to maintain that service. Case management also relies heavily on in-kind support and, unfortunately, the uncompensated overtime of paid staff. Once again, the government is providing no more than, and probably a little less than, half of the needed funding.

The state provides \$35,000 for the AIDS Lodging House. Since the total cost of the Lodging House is around \$68,000, the government is only funding 50% of this program, with the rest of the support coming from rental incomes, housing subsidies, donations and volunteers.

These are just the most visible community services funded through government and private sources. The AIDS Project manages a street based prevention program that will receive \$38,000 from the state. The street program costs at least \$6,000 more than that, however.

Three other services provided by The AIDS Project - the Hotline, counseling and testing, and prevention for men who have sex with men, cost \$132,000. The state provides \$63,000, which leaves \$69,000 that The AIDS Project must raise from other sources. \$20,000 alone is volunteer labor!

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

The AIDS Project can be reached at 774-6877 or 1-800-851-2437.

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

Lewiston-Auburn Area
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

EMAN

Call 990-3626 for info.

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.

Kennebec Valley Regional Health Agency

TUESDAYS-Support group for family & friends. 5:30PM
8 Highwood St., Waterville
873-1127 or 626-3430 for further information.

Waldo-Knox AIDS Coalition

Groups for anyone infected with or affected by HIV/AIDS on the first Monday of the month at 2:00 PM and third Monday of the month at 7:00 PM in Belfast. Call 338-1427 for information.

Androscoggin Valley AIDS Coalition Support group for people with HIV and their loved ones. Come any time or call 786-4697 FMI.. Thursday, 7:30 PM 4 Lafayette St., 1st floor, Lewiston.

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

WISH LIST

- people to bake pies for Thanksgiving dinner
- blankets, full-sized fitted sheets, gloves, winter coats
- lamps, rugs, curtains
- plants
- a snow shovel
- turkeys to cook for Thanksgiving dinner
- an electrician to hook up our clothes dryer
- hand held weights

From My Corner of the Office:

I was sitting here wondering what the score was in the baseball game, listening to the rain outside my window, when it occurred to me that I was very thankful for so many people who make this Coalition happen. It was five years ago this month when a group of people got together and decided that they wanted to make a difference in the lives of people with HIV. And so, with a dream and some energy and no money, they began the People With AIDS Coalition of Maine. And because of the continued dreams and energy and, now, money, of others, the dream continues. I think of, and thank, all those who walked in the rain on October 3rd in the Maine AIDS Walk. I think of **David K.** and **Jeri** and **Carl** who began our first Bike-A-Thon. I thank **Rick** and **Ralph** who got us started on Boat Cruises. I thank **David C.** who has worked so hard getting our Halloween Balls up and going. I thank **Thom** who gave endless hours of time and expertise to make our New England Conference for People With AIDS such an incredible success. I thank **Tom** and **Max** for their leadership and vision during these five years. Thank you to **Chuck Sawyer** for all the meals he arranged on Wednesday nights and for special occasions. Thanks to **Brian** who streamlined our food pantry program. Thanks so very much to **Gretchen Straub** who worked so long and hard keeping our books the past few years. Thanks to those persons who served on the interim board this past year and kept us open and moving. Thanks to those persons newly elected to serve on the 1993 - 1994 board of directors. They have a lot ahead of them! And I thank those persons listed below who join a growing list of people who make the Coalition possible. I guess the ball game will have to wait a few minutes longer, 'cause after all, that's just a game, and this place is real life!!

THANK YOU! THANK YOU!

To the area businesses that sponsored the Halloween Ball (Complete listing in the December Scoop)

To the PWAs who make delicious dinners every evening - that's you **Wayne** and **Tom** and **Stephen**

To **Roxanne** who does everything well and with a smile

To the people who called and volunteered their computer skills and their time to fold the newsletter

To the folks who drop off delicious meals and desserts

To all of you who take the time and effort to give a little of yourselves to make the Coalition a special place for persons living with HIV -

Happy Thanksgiving !!!!!

June