

## Maine AIDS Alliance

P.O. Box 973

Camden, Maine 04843

(207) 236-8561

# Newsletter

October 1990

## AIDS Walk Names Honorary Chairperson

Dr. Lani Graham, Maine Bureau of Health Director, has been named Honorary Chairperson of **MAINE WALK '90**, a fundraising walk-a-thon slated for October 7 to benefit the fourteen community-based AIDS service and support organizations across the state. As a representative of the department of Human Services AIDS Advisory Committee and former Director of Disease Control, Dr. Graham's professional and personal efforts in the fight against AIDS have been evident. "I believe it is very important to support efforts like this one that serves to focus public attention on a serious problem, while at the same time strengthening local community organizations as they work to respond to that problem," stated Graham. "Through my work as Director of Disease Control, I became completely convinced that strong community efforts are the key not only to the control of HIV infection, but in fact, to improved health in all areas."

In this effort to generate community support, increase AIDS awareness, and benefit the fourteen community-based AIDS services organizations in Maine, **MAINE WALK '90** is being held at seven locations across the state. Dennis Hatch, **MAINE WALK** coordinator, strongly encourages "any person or group interested in sponsorship, pledges, volunteer and/or walker information to contact the organization sponsoring a **WALK** in their area." Hatch further stated, "**MAINE WALK** promises to be a celebration of Maine's commitment to the fight against AIDS—as well as each participant's commitment to make a difference, one step at a time."

Intent on creating a festive atmosphere surrounding the **WALK** event, local groups have plans for speakers, refreshments, AIDS Quilt panel displays, decorations, and in some areas, entertainment as part of the day's activities. For further information, contact the community-based organization in your area. For your convenience, a pledge sheet is enclosed in this newsletter.



### MAINE WALK '90 Locations

<b>Portland</b>	People With AIDS Coalition	773-8500
	The AIDS Project	774-6877
	The Names Project	774-2198
<b>Belfast</b>	Waldo County AIDS Coalition	338-1427
<b>Ellsworth</b>	Down East AIDS Network	667-3506
<b>Rumford</b>	Community AIDS Awareness Program	369-0259
<b>Bangor</b>	Eastern Maine AIDS Network	990-3626
<b>Bridgton</b>	Community Task Force on AIDS Education	787-3266

# Maine AIDS Alliance

P.O. Box 973 • Camden, ME 04843 • 207-236-8561

## Profile

The Maine AIDS Alliance is a consortium of fourteen community-based AIDS service organizations. The Alliance was formed in 1988 to provide a cooperative approach to meeting the needs of local organizations by consolidating resources and efforts while retaining local program autonomy.

The major functions of the Maine AIDS Alliance are to assess AIDS-related needs in Maine, to recommend policies and programs to meet those needs, to present a unified voice on AIDS issues in the state, to coordinate and support community-based services and education through sharing of resources and skills, to assist local organizations and communities in AIDS-related program development, to acquire and distribute funds, and to provide a forum for the exchange of support, technical resources, and professional skills among the member organizations.

The Maine AIDS Alliance also works closely with other state-wide organizations on issues related to health care, public health, health education, professional training and education, social services, and public policy.

The Maine AIDS Alliance was incorporated as a non-profit corporation in 1988 and in 1989 was successful in its efforts to secure funds from the state legislature to support the member organizations' local work in AIDS prevention and support services. Also in 1989, the Alliance received its federal 501(c)3 tax exempt status and hired a director to implement and coordinate its activities. In addition to the director, the Alliance has a Board of Directors and five standing committees: Executive, Resource Development, Program, Public Policy, and Communications and Public Relations. The Board of Directors meets monthly; committees meet as needed and report directly to the Board.

The Alliance member organizations meet bi-monthly in locations that rotate throughout the state. This location rotation has increased attendance at these general meetings; in addition, the Alliance has recently been awarded a grant to utilize a state-wide interactive television system to hold special technical assistance workshops while minimizing travel for the participants.

In April of 1990, the Maine AIDS Alliance began publishing a newsletter to keep member organizations informed of Alliance activities and news, as well as to provide general information on resources, conferences, and related activities.

The bulk of funding for the Maine AIDS Alliance is provided by state funds appropriated by the Maine Legislature for the support of community-based AIDS services. This funding is supplemented by federal funds, grants from foundations, and fundraising events. The Alliance membership decides on an allocation formula and process to insure fair, non-competitive access to these funds.

In its two years of existence, the Maine AIDS Alliance has been recognized by the state government, statewide and community organizations, and many national agencies as a strong and authoritative voice of AIDS leadership in Maine and New England. The Alliance's consortium approach to resource utilization and development is recognized as a model for service provision, and has helped to strengthen the work of AIDS service providers throughout Maine.

# AIDS in Maine: A Serious Problem with Room for Hope

by Peaches Bass

Human Immunodeficiency Virus, or HIV, has changed Maine's landscape forever. In some places, the change is subtle, almost unnoticeable. Tourists still crowd coastal towns; bigger cities and towns still have their big city characteristics; Joe Brennan and John McKernan are still sniping at each other about the state budget. It can be pretty easy to forget that HIV and AIDS are much of a problem here in Vacationland, but if you ask the right people and hang out in the right places, you'll hear a different story.

As of July 31, Maine has recorded 196 full-blown AIDS diagnoses, a small number compared to the over 140,000 cases reported nationwide, perhaps, but enough to have taxed AIDS service organizations beyond their capacities. In addition to these individuals, there are people living with AIDS here who were diagnosed elsewhere, and those people require our services, too. And not only are there people who've been diagnosed with AIDS, but there are those people who have tested positive for HIV antibodies, indicating that they are infected with the virus. Most of these people are not experiencing any physical problems, but many of them have symptoms associated with their HIV infection.

Even those who are not symptomatic have pressing needs related to their HIV status — the need for medical evaluation and routine monitoring of their immune systems, the need for education and counseling, the need for support for themselves and their loved ones, the need to prepare for the future and the possibility that they will, at some point, become ill. According to the Office On AIDS, nearly 600 people have tested positive for HIV antibodies, but as many as several thousand people in Maine are actually infected but unaware of their infection. The majority of these people will eventually need care.

Even though many organizations in the state are providing services (see below for profiles of some of these organizations), there are other factors contributing to the AIDS situation in Maine. State and federal funding has been barely adequate. The state funds case management services, but not at a level that meets our needs. In southern Maine, the case load is overwhelming; in central, eastern, and northern Maine, the service territories are so immense that many people fall through the cracks. State and federal funds also support prevention, education, training, and support services, but again, these funds do not approach adequate levels.

To make matters worse, federal money that funds prevention education will be drastically reduced in 1991; a new formula will cut Maine's federal AIDS prevention budget from \$500,000 to \$200,000. This comes at a time when prevention programs are most needed; prevention is the only thing that stands between our problem now and a much larger problem in the future. AIDS service organizations are taking on more and more prevention work at a greater financial cost. This cost will have to be assumed by private sources and the state government at a time when Maine's economy is suffering serious setbacks.

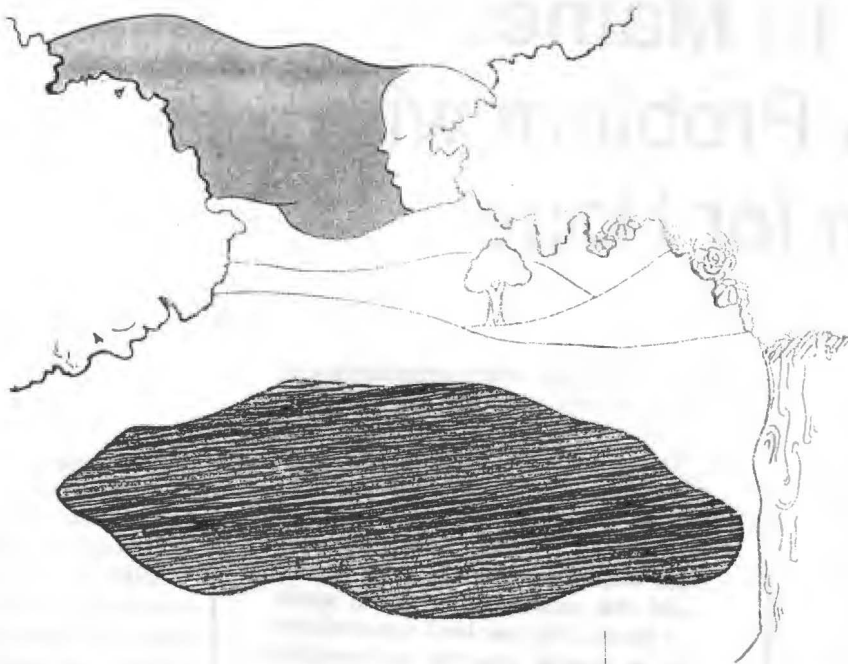
Various legislative initiatives to deal with HIV and AIDS are under consideration, including an increase in funds for prevention programs and case management and an amendment to legislation that would afford AIDS service organizations official representation on the Committee to Advise the Department Of Human Services On AIDS. Federal legislation has just been passed to provide some assistance for care and treatment of people with HIV/AIDS, although Maine will not receive a great deal of funding through this legislation.

In addition to funding problems, other serious concerns exist. People with HIV and AIDS still experience

discrimination on the job, in housing, and on the streets, despite being protected by the Maine Human Rights Act. Many people with HIV/AIDS find it difficult to obtain affordable or competent medical care. Some physicians no longer accept patients without private insurance; many health care providers refer, or "dump" their indigent and Medicaid-covered patients on out-patient clinics, where staff are hard-pressed to provide appropriate care. People with HIV/AIDS who also have substance abuse problems have difficulty obtaining needed treatment, and many are not willing to seek treatment, which complicates prevention efforts and compromises their health.

There are relatively few women and children with HIV/AIDS in Maine, but their treatment and care is not meeting their basic needs, mostly because physicians are just not well-informed in the areas of pediatric and female AIDS care. Even people who have access to care find the price of many medications to be prohibitive, in spite of a state-administered program to assist individuals with the cost of medications and treatments.

Of course, there remains hope and opportunity, but any improvement in the situation depends heavily on our ability to recognize that Maine has a very serious AIDS problem. AIDS service organizations are the vanguard of this commitment and action, and as you read on, you will see that there is a body of people and agencies who are working feverishly to attach the problem.



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# AIDS TREATMENT

*This column is a compilation of reports from a wide variety of sources. It is not intended as an endorsement. Consult your physician before embarking on any alternative treatments. At this time there is no cure for AIDS. It would be cruel to insinuate otherwise. However, there is growing optimism within the community that this disease can be better managed and possibly controlled, greatly improving the patient's quality of life!*

## Understanding the Terminology

People often tell me they become very frustrated whenever they try to read about AIDS in the medical journals or clinical trial reports. They say they have a difficult time deciphering and remembering all the different terms used to describe HIV and its treatment. Indeed, it is not only the "civilians" who get confused; even war-weary PWAs are often stymied by reports on their own blood tests and drug treatments. Therefore, I thought it might be a good idea to devote this month's column to an explanation of some of the most commonly used terms. I will try to be as clear and concise as possible...

### I. BLOOD TESTS

Some of the terms you will come across when reading about blood work are: the Complete Blood Count (CBC), the T-Cell levels, P24 Antigens and P24 Antibodies, Liver Function, and Beta 2 (B2M).

**COMPLETE BLOOD COUNT (CBC):** The CBC test will show you your number of Red Blood Cells (RBC), White Blood Cells (WBC) and Platelets. The job of the Red Blood Cells is to bring oxygen to all parts of your body. HEMOGLOBIN is the actual protein within the Red Blood Cell that is responsible for oxygen transportation. Anemia occurs when there are not enough Red Blood Cells. A person with a low RBC count will also have a low hemoglobin level. (One of the drawbacks of AZT, is that it can cause anemia in some people). The term HEMATOCRIT refers to the percentage of Red Blood Cells found in a sample of blood. Healthy adult males usually will have about 43-49% Red Blood Cells, and adult females will usually have between 37-43%. (The rest of the blood sample would consist of different types of cells and serum - the fluid in which the cells travel). The hematocrit value is usually about three times the hemoglobin value. Unfortunately, some physicians and medical reports will use the terms HEMATOCRIT and HEMOGLOBIN almost interchangeably, which can be very confusing to the patient or reader!

The White Blood Cells (WBC) - also known as "leukocytes" - are an important part of the immune system. Their job is to fight off infection. A White Blood Cell Count is the number of white blood cells per cubic millimeter of blood. A normal count can range anywhere between 4,500 to 10,500. Several drugs used to fight HIV can be toxic to the white cells. However, many people with HIV infection will have a low WBC count even if they are not on any medication. There are several different kinds of White Blood Cells: Neutrophils, Monocytes, Eosinophils, and Lymphocytes. The Neutrophils fight bacterial infections. "Neutropenia" is a depletion of these types of cells. A person is said to be "neutropenic" if their Neutrophil count falls below 1000. If you have a low count, you have a greater risk of getting a bacterial infection. As with other blood cells, the neutrophils are produced in the bone

marrow. Anything that affects the bone marrow, will affect the blood cell count. Certain drugs - including AZT, Ganciclovir (DHPG), and Bactrim - can be toxic to the bone marrow and therefore suppress production of these cells.

Monocytes are a type of White Blood Cell that will circulate through the blood stream and then settle into various tissues of the body where they become "macrophages". Macrophages are "garbage collector" cells which ingest dead cells and organisms during an infection. Macrophages are reservoirs for HIV, and it is believed that the virus is spread throughout the central nervous system and brain via these cells.

Eosinophils are WBCs that are believed to be involved in allergies and parasitic infections. People with these conditions will often have an elevated Eosinophil count.

Lymphocytes are WBCs that are responsible for normal immune function. Usually, 25-45% of the White Blood Cells are made up of Lymphocytes. Lymphocytes consist of T-Cells and B-Cells. The B-Cells are responsible for producing antibodies to fight infection. There are two different kinds of T-Cells: the "T4" cells and the "T8" cells. The T4 cells are thought of as "helper" cells because they help to activate the immune system's response to an infection. In other words, the T4 cells are very important because they "help" to "turn-on" your body's immune system. (T4 cells are often referred to as "T-Helper" cells).

T8 cells, on the other hand, do just the opposite. The T8 cells are known as the "suppressor" lymphocytes because it is their job to "turn-off" the immune system. If your immune system was allowed to constantly be on the attack, excessive damage would be done to healthy, uninfected tissues. Therefore, the T8 (suppressor) cells act as a safety valve, turning off the immune system when there is no longer a threat of infection. Obviously, a normal immune system has a balance between the T4 cells which "turn it on" and the T8 cells which "turn it off".

**NOTE:** The Complete Blood Count test (CBC) does NOT distinguish between these different types of lymphocytes. Just because your White Blood Cell (WBC) count goes up or down, does NOT mean that your T4 count is rising or falling. A CBC test showing a WBC count does not tell you anything about your T4 levels.

**T-CELL LEVELS:** There are three things that a T-Cell Test can tell you. 1) The **RATIO** of your T4 to T8 cells, 2) what **PERCENTAGE** of your total T-cell count is made up of T4 cells, and 3) how **MANY** T4 cells you actually have.

A healthy immune system will have a 2 to 1 ratio of T4 to T8 cells (about twice as many T4 cells as T8 cells, although in some healthy people there is a 1 to 1 ratio, or just about an equal number of T4 to T8 cells). People with HIV infection usually have a much lower ratio due to the destruction of T4 cells. Most of us are very interested in knowing just how **MANY** T4 cells we have. An absolute T4 count above 500 is considered normal and indicates that the immune system is probably in pretty good shape. Over time, however, the T4 count of someone with HIV will usually decrease. A T4 count below 200 is often associated with the development of opportunistic infections such as Pneumocystis Carinii Pneumonia (PCP) - see **OPTIONS** Oct/Nov. '88. Preventive steps can be taken to avoid PCP by using the drugs Bactrim,

continued on page 6

## Maine HIV-Education & Preventions Funds Cut by More Than 60% by HOPE

Maine's HIV Prevention and Education Programs are about to be dismantled. We need everyone to write and call Maine's Congressional delegation, and Senator Robert Byrd (D-West Virginia) who chairs the Appropriations Committee.

The Health Omnibus Programs Extensions Act (HOPE), passed in 1988, shifted the funding of federally-supported AIDS Prevention Programs from a competitive basis to a formula basis. In addition, funding will be merged for State health and education departments into one grant. The HOPE formula (can you believe that name, given effects of this policy?) is based, in part, on the number of AIDS cases reported from a State and the size of the State's population.

The funding formula was recently finalized and Maine is losing 60.19% of our prevention and education money.

AIDS preventions programs throughout the United States were notified of this July 9, 1990, by the Centers for Disease Control (CDC).

Maine programs affected by these cuts include education efforts aimed at the public, education targeting people engaged in risky behavior, education for people of color, outreach to substance users and their sexual partners, and education for school-aged children.

We need to strongly urge our Senators and Representatives to insure that Maine will receive no less than level funding through federal Fiscal Year 1991 for AIDS prevention activities. Ideally, our goal is for CDC to abandon these changes in the allocation formula. At a minimum, cuts need to be delayed for a year to allow states to make plans to deal

with the loss of funding. This cuts will undo years of work. And, without money going into prevention and education, we can expect the cases of HIV disease to rise in Maine.

The names and address for Robert Byrd and Maine's Congressional delegation:

**Senator Robert Byrd**  
United States Senate  
Washington, DC 20510

**Representative Joseph Brennan**  
1428 Longworth Building  
Washington, DC 20515

**Representative Olympia Snowe**  
2464 Rayburn Building  
Washington, DC 20515

**Senator George Mitchell**  
176 Russell Office Building  
Washington, DC 20510

**Senator William Cohen**  
322 Hart Senate Office Building  
Washington, DC 20510

### **AIDS Treatment *continued***

Dapsone, or better yet, Aerosol Pentamidine. However, just because someone has a low T4 count, does not always mean that they are about to become ill. I recently spoke to a volunteer at the PWA Coalition Hotline in NYC who has had a T4 count of "zero" for months. He tells me that although he has had no measurable T4 cells for some time, he is doing quite well, thank you! (He is on AZT and has not had many problems with it).

Conversely, you can have a relatively HIGH T4 count and still develop Kaposi's sarcoma. For some reason, KS does not seem to be directly related to the T4 level. Infants and children can also develop opportunistic infections at much higher levels. NOTE: Many HIV infected adults will start AZT when their count falls below 200. These standards should not be applied to children. Many children have been unable to meet the criteria set for obtaining life-saving drugs. Also, there is the growing opinion within the community that

people who are asymptomatic with T4 counts well above 200 should begin AZT early to stall the progression of the HIV. (More on this in a future issue!)

It is very important to understand that a T-Cell test can have varying results. Sometimes these variations are a real reflection of what a person's immune system is doing. However, no single T4 test can give you a complete picture. T4 testing should be done at least every 3 months for people who have counts of 500 or below. The count should be taken at least every 6 months for people with higher levels. The T4 level can go up and down so it is important to look at the overall trend, rather than rely on 1 or 2 test results. Naturally, some people become upset if they think their T4 count has dropped, but there are other factors that can cause a change in the test results: 1) Always get tested at the same time of the day. There are always fewer T4 cells early in the morning. Later in the day, and after you have eaten, the number are

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greater. By always testing at the same time of the day, the numbers from one test to the next will be more accurate. 2) Use the same lab for each test. Different labs use different machines which can produce different results. 3) Try to take the test when you are free from infection. Even a minor infection will affect the count. 4) Extreme stress, "recreational" drugs, and lack of sleep will also lower your T4 level.

**THE P24 ANTIGEN & P24 ANTIBODY TESTS:** An antibody is a protein produced by the B-Cell lymphocytes (one of the types of white blood cells that we just discussed) and is the part of your immune system responsible for attacking invading viruses. An antigen is a protein produced by the enemy virus. Antibodies are made to attack antigens. In other words, the antibodies are the good guys and the antigens are the bad guys. "P24" is just the label for those antibodies and antigens that are specifically involved in the HIV battle. If you have a high level of P24 antibodies, that is good news; it means your immune system is fighting. If you have a high level of P24 antigens, that is bad news; it means your immune system may be breaking down and is unable to cope with the invading virus. People with a high P24 antigen level are more likely to develop "full-blown" AIDS in the next few years, even if their T4 counts look good. (P24 antigen results are sometime reported as positive or negative. A negative result is any count below 40 or 50. A positive count is any number above 50. A typical positive count is between 100 and 400. How high the number goes does not seem to be that important; unfortunately, ALL positive results seem to indicate the same risk. A positive count — no matter what the number — is a serious warning). Physicians use the P24 antigen test to evaluate how well anti-viral medications are working. For more about P24 Antigens and Antibodies, see OPTIONS Feb/March '89.

**THE BETA-2 MICROGLOBULIN TEST:** B2M is a term you will see often. This is a small protein present in most cells. As the cells die, B2M is released into the bloodstream. As the HIV destroys increasing amounts of cells, the B2M level will rise. People with a high level of B2M are also more likely to develop AIDS. Many researchers believe that the B2M test is the most accurate predictor of the progression of HIV.

**LIVER FUNCTION TESTS (LFTs)** show the levels of special enzymes (proteins) in liver cells. If the liver is inflamed, or if liver cells are dying, there will be an increase in these enzyme levels. Several viruses associated with HIV can attack the liver and many medications - such as AZT and Bactrim - can be toxic to the liver. The liver function tests help to monitor the situation.

**PLATELET COUNT:** The Platelets are blood cells which help the blood to clot properly. A normal count can range from 140,000 to 350,000. HIV infection often causes a lowering of the platelet count. This can happen at any stage of the infection — even the very early stages. If the count gets down to 40,000 or below, you are at risk for bleeding and bruising. The tongue-twisting term "thrombocytopenia" simply means a low platelet count.

## II. DRUG TERMINOLOGY

Several terms are used to describe the various medications used to fight HIV. They are: 1) Antivirals, 2) Cytokines, 3) Immunomodulators and 4) Anti-infectives.

An antiviral is a drug which stops or suppresses a virus. Because HIV is referred to as a retrovirus, anti-HIV drugs are sometimes called "antiretrovirals." An example of an antiviral would be Ganciclovir (also known as DHPG) which can be used to fight CMV. An example of an antiretroviral would be AZT, which acts on the HIV. A Cytokine is a drug which regulates specific types of cells. One example of a cytokine would be Alpha Interferon, which is used in the treatment of Kaposi's sarcoma. An Immunomodulator is a drug which alters the immune system. Lentinan is an experimental drug which is being used to strengthen the immune system. An Anti-infective is a drug that fights fungal or bacterial infections. Fluconazole is a newly released drug which is effective against thrush and meningitis. Many medications can fall into several of these categories.

In summary, I will repeat Project Inform's basic message: If you are HIV positive, talk to your doctor about anti-viral treatment. Monitor your T4 count and keep track of the trend. If the trend is downward, or if your T4 cells are below 500, consider both anti-viral and immune boosting therapy. If your T4 cells fall below 200, use a preventive treatment against PCP - preferably aerosol pentamidine.

With love and hope for us all,  
Thayer T. Dietrick

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## OCTOBER GENERAL MEETING

The Maine AIDS Alliance General Meeting scheduled for October 27th has been moved from Fort Kent to a location to be announced in Augusta. The tentative agenda is:

Member Reports	
Walkathon Report	
Elitism/Jargon in MAA	
State Funding and Allocation Formula	
Update on Federal Funding	
State Legislation	
Advisory Committee Meeting Report	
Other	

## ANNOUNCEMENTS

### QUILT PANELS

The Names Project/Maine has seven Quilt panels available for showings around the state. These panels are available to MAA member organizations for display. The Names Project would like to encourage you to display the panels, especially as part of your AIDS Awareness activities and educational efforts. Contact the Names Project, PO Box 4319, Portland, ME 04101, Telephone 774-2918.

### MEDICAL SUPPLIES & CLOTHING AVAILABLE...

The People With AIDS Coalition has received a generous donation of walkers, crutches, and lots of clothing which persons with HIV/AIDS may need. If you have any clients, or know of anyone in your community who needs these items or clothes, call the PWA Coalition at 773-8500.

### HEALTH CARE FOR ALL

Wednesday, October 3rd is Health Care Action Day sponsored by the AFL-CIO, Jobs for Justice, and, in Maine, Consumers for Affordable Health Care. Write a letter to your local newspaper; or contact a legislator; or speak to your employer, friends, and co-workers about the need for the U.S. to develop a system that guarantees access to affordable health care for all citizens. For more information, contact Consumers for Affordable Health Care at 622-4740.

### TESTING & INSURANCE COMPANIES

If you have been tested for HIV by an insurance company without being offered pre- and post-test counseling, or if the insurance company failed to obtain your written permission to be tested before testing you, call the State Bureau of Insurance at 582-8707 to register a complaint. Two insurance companies doing business in Maine have already been fined for violating these legal requirements.

### TAP OPENS LEWISTON OFFICE

The AIDS Project is pleased to announce the opening of their Lewiston office to serve residents of Androscoggin and Oxford counties. Diana Carrigan, a case manager with the AIDS Project will be staffing the office, which is located with Family Planning, 239 Main Street, Lewiston, ME 04240. The phone number is 783-4301. The AIDS Project can also be reached at 774-6877 in case of emergencies.

### NEW SUPPORT GROUP BEING FORMED

A support group for persons with HIV disease will begin on October 10, 1990. The meeting will be held at the offices of Dr. Karen Kalustian of the Gardiner Family Physicians, 152 Dresden Avenue., Gardiner from 6:30 - 8:00 p.m. every other Wednesday. For more information about these meetings call either Steve Fleming or Cecelia Leland at 289-3747.



The AIDS Coalition for Lincoln County and the Round Top Center for the Arts invite amateur and professional artists alike to participate in the AIDS, ART and HORS D'OEUVRES Show to be held October 21 in Damariscotta. This juried art show is open to artists of all ages and capabilities.

"This is a unique opportunity," states Barbara Brampton, Chairperson for the AIDS Coalition for Lincoln County, "it offers people a forum to express through art how they feel about AIDS and the issues surrounding it." Artists are invited to start now and create a piece of art in a medium of their choice.

"AIDS has touched many lives in many ways." Brampton continues, "Through the process of creating art, individuals are often able to draw on their inner artist and begin to heal, understand or explore new feelings in themselves and others." The Art Show is seeking to increase community awareness, education and compassion around the complex issue of AIDS.

For more information contact the AIDS Coalition for Lincoln County, PO Box 421, Damariscotta, ME 04543, or call Barbara Brampton at 563-4040.

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## ACT UP/Maine

We will not be silent.

This August a small band of frustrated and furious Faeries and Friends brought ACT UP to life in Maine. We are yours and you are us.

ACT UP/Maine wants to be a loose cannon for the AIDS community. We will fight when necessary to bring about changes that will save lives.

We do not seek to provide direct care or services for PWAs. We praise, respect and support the heroic and invaluable efforts of our brothers and sisters in the AIDS Project, the PWA Coalition, the Maine AIDS Alliance and all of its member organizations. To fulfill their programs, all of these groups must interact daily with both government and community. They must also maintain good relations with these resources; they can't bite the hands that feed them.

But we can bare our teeth and shriek at bigotry, hypocrisy, inaction and sloth wherever they may be. We hope to assist the AIDS community by standing a bit outside of it and badgering the community-at-large to do more. We are a combination of political street theater and non-violent guerilla warfare. Here are some examples of our actions:

August 20th -- We marched on Maine Medical Center in Portland. We held a DIE IN entitled Where's the Care? Many of us "bled" and "died" right there on the sidewalk. We outlined these "bodies" with chalk. We gave them the names of loved ones who have left us. We asked: "Where is the AIDS Resource Center?" We asked: "Why are doctors dumping PWAs on Medicaid?"

August 27th -- We awakened the candidates to our anger and impatience at the Health Care Forum (TV/Photo op) held at the Woodfords Congregational Church. We asked Jock: Where are we in your platform? Where is our money budgeted? We told all of Maine that ACT UP is Alive! We made the evening news reports -- print, radio, and TV.

September 9th -- Jock brought Louis Sullivan (Secretary, Health & Human Services) to Maine for some free TV-news bites and to raise funds at the Portland Club. We surprised both with a zap over the HOPE Act. We asked him why the Health Omnibus Program Extension Act is *reducing* AIDS funds to more rural states so that states like Maine will get even less money for AIDS prevention and education.

October ? -- We cannot publicize our next Action in advance. After all, we want it to be a surprise! But we want and need you there with us.

Although our objectives are, unfortunately, deadly serious, there is a certain pleasure in exploding our outrage in other people's faces. In other words we believe in exuberance and exhibitionism in getting our message across. Our hearts have not become faint from our oppression, but stronger for it. We are not an establishment-type organization, at least not at present. We have no office, no staff, no rules or requirements, and absolutely no money! Decisions are made by the consensus of all who attend our meetings. Anyone can speak; the meetings are an open forum; and everyone concerned may attend.

**ACT UP/MAINE meets at 7:00 PM every Monday night  
at the People's Building, 155 Brackett Street, Portland**

Becoming an ACT UP member is not a process -- you don't really "join," but ... We can't invite you to ACT UP if we don't know who and where you are.

We need volunteers and people with many different skills. People with graphic arts skills to help us win the battle of images. Fundraisers, so that in the near future we will be able to sell ACT UP T-shirts, buttons, stickers, posters, hats, etc. Money raised will be used for our political actions, ZAPS and for keeping ACT UP alive!

ACT UP meets with government officials, health policy makers, medical personnel, researchers, pharmaceutical manufacturers, and others to bring about concrete, crucial changes to meet the demands of the AIDS crisis.

We would like to organize a phone chain to announce demonstrations and actions. You know, one person calls five people and each of them calls five people ... you can get yourself on the list by doing one of the following: attend a Monday night meeting; drop a line to ACT UP/Maine, P.O.B 5267, Portland, Maine 04101; or call either Jim (774-5082) or Michael (775-3305). Leave a message if you miss them.

You can help even if you can't attend a demo.

We are organizing a Kondom Kween Brigade to spread a rubber message of safe sex to everyone. We hope to hold forth at bars and discos, street fairs, high schools, churches, anywhere we please.

We also plan to work with the national ACT UP data bank on AIDS treatment protocols and research activities. We want to make this invaluable information more readily available in Maine.



MAINE CONSORTIUM FOR HEALTH PROFESSIONS EDUCATION

AIDS Satellite Television Network  
Schedule of Programs

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The following programs can be viewed live at the VAM & ROC at Togus. Also, each program will be video taped and the tapes will be available for loan.

Please call Learning Resources at the VA Togus (623-5773) to reserve a viewing site or to borrow a tape.

If you want CEU credits, please complete the form that you will receive and return to:

Melda Page  
Learning Resources Service  
VAM & ROC  
Togus, ME 04330

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The following information is subject to change.

<u>DATE</u>	<u>TIME</u>	<u>TITLE</u>
8/17/90	1 - 4PM	°Kaposi's Sarcoma °Speciality HIV Care Issues °Highlights of the 6th International Conference on AIDS, Parts II & III
9/11/90	1 - 3PM	°Management of AIDS Dementia
9/26/90	1 - 3PM	°Burnout in Caregivers °HIV Nutrition Workshop I
10/10/90	1 - 3PM	°AIDS in the Black Community °Management of Pneumocystis Carinii Pneumonia
10/23/90	1 - 3PM	°Case Management Workshop II °Hospice Care of Persons with HIV Infections
10/24/90	1 - 3PM	°Investigational Drug Update °Management of Dedicated AIDS Units
11/9/90	1 - 3PM	°Management of HIV Infection in Hemophiliacs °Complimentary Therapies

<u>DATE</u>	<u>TIME</u>	<u>TITLE</u>
11/16/90	1 - 3PM	°Management of IVDU/HIV Patients
12/14/90	1 - 3PM	°International AIDS Update
1/9/91	1 - 3PM	°AIDS in the Hispanic Community °Management of Cryptosporidium
2/1/91	1 - 3PM	°Management of Hairy Leukoplakia °First Responders
3/6/91	1 - 3PM	°Role of Pastoral Care in the Management of PWA's °Pain Management in the HIV Patient
4/3/91	1 - 3PM	°AIDS in the Prison Population
4/19/91	1 - 3PM	°Pediatric HIV Infection
4/24/91	1 - 3PM	°Case Management Workshop III °AIDS-Related Lymphoma
5/22/91	1 - 3PM	°Management of IV Drug Users with HIV Infection °HIV Nutrition Workshop II
6/17/91	1 - 3PM	°Highlights from the 7 <sup>th</sup> International Conference on AIDS
6/18/91	1 - 3PM	°Highlights from the 7 <sup>th</sup> International Conference on AIDS
6/19/91	1 - 3PM	°Highlights from the 7 <sup>th</sup> International Conference on AIDS
6/20/91	1 - 3PM	°Highlights from the 7 <sup>th</sup> International Conference on AIDS

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#### **MAINE HEALTH PROGRAM**

Need health insurance but can't afford it? The Maine Health Program makes health care coverage available to individuals and families like you.

The Maine Health Program is a new health care coverage program operated by the Department of Human Services' Division of Health Insurance. People living in Maine whose income and assets meet the program guidelines are eligible.

The Maine Health Program covers a wide variety of services, including doctor visits, hospital and health center services, prescription drugs, family planning services, and laboratory and X-ray services.

You may apply for the Program at a Department of Human Services Regional Office.

## ...from St. John Valley AIDS Task Force

September 11, 1990

Dear Friends,

Like many of you, we in Northern Maine have been experiencing organizational difficulties over the past year. This has led to a drastic decrease in membership which sometimes leads to a drop in productivity. We are in the process of brainstorming and restructuring. We have not yet given up hope!!! As of September 6, however, the St. John Valley AIDS Task Force shifted into neutral gear. We still plan to follow through with the Valley wide needs assessment and will continue to provide AIDS education upon request. The Speaker's Bureau will remain active.

As for the Maine AIDS Alliance and committees, I regret that we have not been more active. Hopefully, this will improve, but it will not occur overnight. Many obstacles must be overcome first.

As you have probably guessed by the tone of this letter, we will be unable to participate in the upcoming **MAINE WALK '90**. Pledge sheets, however, will be distributed to members to solicit support. Maybe next year! Good luck to those of you that were able to pull together to accomplish such a worthy project! We will be thinking of you on October 7th.

Finally, I would like to thank all of the people who have kept in contact with me and have made me feel that Northern Maine is indeed part of Maine. I've appreciated your interest and enjoyed our communications. I look forward to seeing all of you at the Maine AIDS Alliance meeting on October 27th.

Thanks for listening.

Joanne M. Fortin, RN

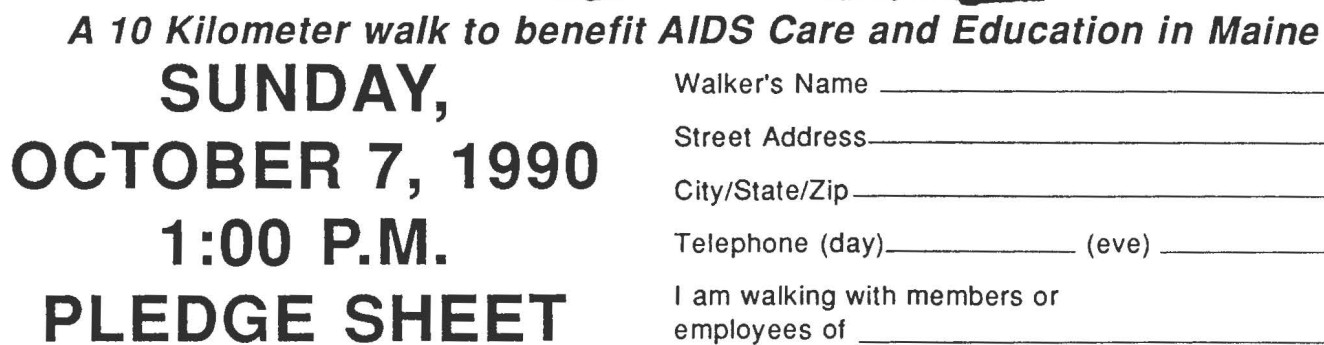
The MAA Newsletter reports on events and issues of interest to it's readership. This does not mean that the Alliance necessarily agrees with opinions expressed or participates in events listed.

## Calendar

### October is AIDS Awareness Month

- October 6**      **Putting Your Organization in the Limelight**  
Jewett Hall, University of Maine at Augusta.  
Sponsored by MaineShare, PO Box 2095, Augusta, ME 04438 (207) 622-0105. This workshop will focus on promotion and working with the media.
- October 7**      **MAINE WALK '90.** See cover story.
- October 12 - 14**      **Caring for Caregivers** A weekend retreat in Litchfield, Maine for caregivers of AIDS patients throughout New England. Sponsored by Hospice of Maine, 175 Lancaster Street, Portland 04101.
- October 19 - 20**      **Persons With AIDS/HIV Speakers Training** with Christian Haren. For information, contact Tom Antonik, Cindy Bouman, The AIDS Project, 774-6877; Laura Neal, EMAN 990-3626; or Brian Allen, MASS 725-4977
- October 30**      **Health Conference: How AIDS Affects Service Providers** Sponsored by Down East AIDS Network. For more information call DEAN at 114 State Street, Ellsworth, ME 04605 (207) 667-3506
- November 16**      **Fifth Annual Living With AIDS in Maine Conference** Sheraton Tara Hotel, South Portland, ME  
Maine AIDS Alliance is cosponsoring this event. For more information and application, contact: Lori Kiel, JSI Research and Training, 210 Lincoln Street, Boston, MA 02116 (617) 482-9485
- November 17**      **Women and AIDS Conference** Bangor. Cosponsored by the Mabel Wadsworth Women's Health Center and the Maine AIDS Alliance. For information, contact Ruth Lockhart, Mabel Wadsworth Women's Health Center, PO Box 20, Bangor, ME 04401 (207) 947-5337

ACT UP/Maine meets every Monday evening at 7:00 pm at the People's Building, 155 Brackett Street, Portland, Second Floor.



I am walking with members or employees of \_\_\_\_\_

Suggested minimum pledge: \$1.00 per kilometer. Contributions are tax-deductible.  
PLEASE PRE-PAY. Make checks payable to: MAINE WALK

# MAINE WALK '90

## GENERAL INFORMATION

A ten kilometer pledge walk to benefit AIDS education and care in Maine coordinated by Maine AIDS Alliance. Money raised will be returned directly to the community.

## BEFORE THE WALK

Sign up as many sponsors as you can - friends, relatives, co-workers, maybe even strangers. Set yourself a goal of raising at least \$100. Suggest that sponsors pledge as much money as they can per kilometer, a minimum of a dollar per kilometer is recommended.

Ask your sponsors to **PAY WHEN THEY PLEDGE**. Collecting your pledge money in advance saves us time and administrative expense, allowing us to distribute the proceeds as soon as possible.

Ask your sponsors to pay with a check, payable to **MAINE WALK**. **TRY TO AVOID COLLECTING CASH.**

## DAY OF THE WALK

12:00 Registration begins

1:00 Opening ceremonies and Walk

In case of rain or for further  
information contact:

## TO THANK YOU

– Each person who registers to walk will receive a commemorative MAINE WALK button.

– commemorative MAINE WALK t-shirt for those who turn in \$100.00 or more.

## FOR MORE INFORMATION

If you are unable to attend the MAINE WALK but would like to make a donation, or if you would like any additional information, contact:

**MAINE AIDS ALLIANCE**  
**P.O. BOX 973 • CAMDEN, MAINE 04843**  
**236-8561**

Portland	People with AIDS Coalition	773-8500
	The AIDS Project	774-6877
	The Names Project	774-2198
Belfast	Waldo County AIDS Coalition	338-1427
Ellsworth	Down East AIDS Network	667-3506
Rumford	Community AIDS Awareness Program	369-0259
Bangor	Eastern Maine AIDS Network	990-3626
Bridgeton	Community Task Force on AIDS Education	787-3266



## Maine AIDS Alliance Members

AIDS Coalition for Lincoln County  
PO Box 421  
Damariscotta, ME 04543

Contact: Barbara Brampton  
563-4040

The Names Project/Maine  
PO Box 4319  
Portland ME 04101

Contact: Debb Freedman  
774-2198

Androscoggin Valley AIDS Coalition  
PO Box 7977  
Lewiston, ME 04243-7977

Contact: Lewiston STD Clinic  
795-4357

Community Task Force on AIDS Education  
PO Box 941  
Naples, ME 04055

Contact: Peter Allen  
787-3266

Dayspring c/o KVRHA  
Eight Highwood Street  
Waterville, ME 04901

Contact: Toni Ervin  
873-1127

Eastern Maine AIDS Network Services  
PO Box 2038 263 State Street  
Bangor, ME 04401

Contact: John Silvernail  
990-3626

Merrymeeting AIDS Support Services  
PO Box 57  
Brunswick, ME 04011-0057

Contact: Brian Allen  
725-4955

Community AIDS Awareness Program  
PO Box 431  
Rumford, ME 04276

Contact: Jackie Kilbreth  
364-4581 (M-F, 9am-4pm)

AIDS Lodging House  
c/o United Way 233 Oxford Street  
Portland, ME 04101

Contact: Steve Pinkham  
874-1000

Down East AIDS Network  
114 State Street  
Ellsworth, ME 04605

Contact: Roberta Poulin  
667-3506

People With AIDS (PWA) Coalition of Maine  
377 Cumberland Avenue  
Portland, ME 04101

Contact: Tom Antonik  
773-8500

Waldo County AIDS Coalition  
PO Box 956  
Belfast, ME 04915

Contact: Nan Stone  
338-1427

The AIDS Project  
22 Monument Sq. 5th Floor  
Portland, ME 04101

Contact: Perry Sutherland  
774-6877

St. John Valley AIDS Task Force  
c/o NMMC 143 East Main Street  
Fort Kent, ME 04743

Contact: Joanne Fortin  
834-3155 x194

First Class Mail

Maine AIDS Alliance  
P.O. Box 973  
Camden, ME 04843



First Class Mail