THE AIDS PROJECT

IN THE AFFIRMATIVE

A NEWSLETTER FOR MAINE'S HIV/AIDS COMMUNITY

Mid-October to Mid-November Volume V Number IX

Women's Leadership Luncheon Grows More Successful Every Year

by Mike Martin

The 4th Annual Women's Leadership Luncheon to benefit The AIDS Project was held on October 6th at the Marriot at Sable Oaks in South Portland. This year's event was co-chaired by Donna Mundy and Terry Cohen of the UNUM Corporation, which was the Gold Ribbon sponsor of the event. Mary J. Herman, the first lady of the State of Maine, was the honorary chair.

Receiving the Kerry A. Carson Memorial Awards were Cathy Kidman, Executive Director of Outright (an organization serving gay, lesbian, bisexual, and transgendered young people ages 22 and under), and Mary Ruchinskas, Community Services Director of New Beginnings in Lewiston (an organization serving youth who are runaways, homeless, or in high risk situations). Both recipients spoke to the need of reaching out to youth to prevent the further spread of HIV, which already disproportionately affects people under the age of 25.

The Kerry A. Carson Memorial Awards pays tribute to Kerry Anne Carson of York, Maine, who contracted HIV at the age of 15 and later died of AIDS. Past recipients of the award include Kerry (posthumously), Frannie Peabody, Lani Graham, and Elizabeth Watson.

Also participating was George Friou, TAP's Executive Director, who thanked all the sponsors, volunteers, and attendees for their support of people with HIV/AIDS. Stacy Bachelder from Telstar High School spoke to the crowd about her school's efforts to raise AIDS awareness and about her school's yearly fundraising benefit for a deserving AIDS organization. Mary Crothers and Bart Giamatti from Waynefleet School Students for Safer Sexuality performed an enlightening, yet humorous sketch concerning safer sex. A sketch they would normally be presenting to their peers.

Karla McGowan was singled out for all her hard work on the luncheon. Karla is a member of TAP's Board of Directors and chair of its Fundraising & Public Relations Committee

It was announced at the sold-out luncheon that the event had raised $18,000 for The AIDS Project. All in all, the Women's Leadership Luncheon has become an important annual area event to raise awareness of HIV/AIDS.

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We welcome David Swander to TAP as an Administrative / Development Assistant. And we wish a fond farewell to Rodney Mondor, formerly TAP's Volunteer Services Coordinator, who has left TAP for a job at USM.

HIV News

Teenagers in Turmoil

USA Today (10/05/98)

Many teenage deaths each year are avoidable, with approximately 10,000 of the 37,000 deaths among young people related to murder, suicide, or AIDS complications. HIV is increasingly becoming a problem among young people in the United States. The CDC says around 50% of the 40,000 new HIV cases in the U.S. occur in people under the age of 25. The CDC Youth Risk Behavior Surveillance Survey recently concluded that many teens were engaging in risky behaviors. Steve Small, a professor at the University of Michigan, also notes, "They [adolescents] do things like drink and smoke and become sexually active".

Despite widespread behavioral risks taken by teens, a CDC study indicates that sexual activity has declined among high school students for the first time in 20 years and that fewer students report having sex with a series of partners. The study of more than 10,000 students also shows that sexually active students were using condoms more often. Even though there has been a decline, one-tenth of all adolescents are sexually active before age 13, according to Janet Collins of the CDC. Suggestions from students at a recent CDC-sponsored meeting in Atlanta included increased positive role-modeling by parents and additional education initiatives.

The Need for Improved Data on HIV Is Critical

Boston Globe (10/03/98)

Dr. Helene Gayle, of the CDC, asserts that some people have misinterpreted recent data on the HIV/AIDS epidemic. In a letter to the Boston Globe, Gayle notes that while the number of AIDS cases and deaths have declined, there is an increasing number of people living with HIV due to new treatments that slow disease progression. She points out that statistics on AIDS cases and deaths are important indicators of the epidemic among some groups of people for whom treatment is unavailable, yet the data does not indicate the number of new HIV infections, nor does it show how and where these infections are occurring. According to Gayle, "In order to get a clearer picture of the HIV/AIDS epidemic in Massachusetts and across the country, there is a need for improved data on HIV". She warns that people should be careful not to be misled by the decreasing number of AIDS cases and stresses the critical need for HIV prevention.

Holding AIDS at Bay, Only to Face 'Lazarus Syndrome'

New York Times (10/06/98)

Protease inhibitor therapy has helped to increase the lifespans of many HIV-infected people, only to leave them attempting to adjust to what is--for many--life after death. A number of patients have seen their friends die from AIDS, and they face a harder life with the virus. Patients may face financial difficulties due to the cost of treatment or anxiety over the end of romantic relationships; some even become suicidal. Researchers have dubbed this anxiety the Lazarus Syndrome, named after the biblical figure who was raised from the dead by Christ.

Dr. Judith Rabkin, a professor of clinical psychology at Columbia University, estimates that tens of thousands of HIV-infected people may have the syndrome. While the rigid medical regimen of protease inhibitor treatment may not directly cause the syndrome, it can contribute to the anxiety. Researchers note that the syndrome is unique to AIDS, but liken it to feelings of trauma suffered by Holocaust survivors. Both groups have seen their friends and families die and expected that they too would die, but were saved instead. Some advocacy groups are offering counseling to help patients deal with their emotions.

BY THE WAY Change

by MIKE **MARTIN**

Fall is a season of change. The leaves are changing colors to magnificent shades of red and yellow and orange. Some wag once said that "change is the only constant." Well, I guess that's just about right.

There have been a couple of staff changes at The AIDS Project. On the plus side, David Swander has joined the staff...now I mentioned this last month, but I want to make sure he feels really welcome. David has taken on the additional duty of making sure this newsletter gets distributed. Thanks, David! And on the not-so-plus side, Rodney Mondor has left the Project for a job with the University of Southern Maine. Rodney brought a lot of energy and heart to his work as the Volunteer Services Coordinator. And he recently completed the Boston to New York AIDS Ride, for the second year in a row. Anyway, we'll miss his cheerful attitude and can-do enthusiasm. Good luck, Rodney!

When you visit the Portland office of TAP, you will notice some changes in the lobby area. The changes are designed to provide even more professional service to clients and to improve on clients' comfort levels around confidentiality.

On page five, I've reprinted TAP's Client Rights and Grievance Procedures. They haven't changed much over the years. Whoever wrote them did a pretty good job. Still, a refresher dose never hurts.

On page six, I've reproduced a chart outlining anti-HIV drugs' dosages from Project Inform. I do so as a little service to clients because a client recently told me about how his doctor had underprescribed one of his drugs and how the client had built up a drug resistant because of this under-dosing. Of course, I recommend to all clients that they carefully consult and question their doctors when it comes to taking meds. One thing we know for sure, if you aren't taking the right amount of these drugs, you can build up a resistance pretty quickly. The treatments for HIV are constantly changing, with more options than ever before. But they won't do you any good, if you don't get them right.

For those of you who participated in the Reconstruction programs this summer, I talked with Randy Norcross of the Maine AIDS Alliance and he tells me that followup from those sessions is in the thinking stages. In particular, the issues of going back to work and dating are on the list of things clients would like further workshops to address.

A pleasant change was not that this year's Women's Leadership Luncheon was a big success (previous ones have been successful), but that the amount raised to benefit TAP in its work with people with HIV/AIDS was significantly higher than last year. It was a grand event, and very moving. My congratulations to all who made it such a wonderful experience.

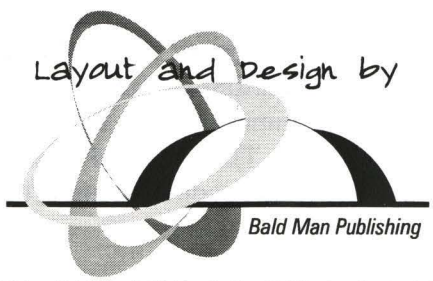
Speaking of change, TAP will pick up a nice piece of change ($$$) through the sale of WCLZ 98.9's "Homegrown, Volume 3" CD of local musical talent. Two dollars from each CD sold will be donated to TAP. They are available at Bull Moose Music stores. Thanks to WCLZ and Bull Moose Music for choosing TAP to be this year's recipient of their largesse.

Change can be a good thing. Sometimes a very good thing.

Sources for some of the material in this newsletter include:

The CDC Daily AIDS Update /Prevention News
Project Inform, San Francisco, CA

The next issue of In The Affirmative:
Mid-November 1998



More HIV News

Reporting HIV Cases Discussed

Augusta Chronicle Online (09/23/98)

Health officials in Georgia met in September to discuss the use of HIV reporting in the state. A decision on the matter is expected to be ready by summer 1999. Georgia is one of 11 states that does not currently report HIV cases. The state does report AIDS cases, but David Johnson, of the STD/HIV section of the Division of Public Health, said, "AIDS cases tell us what may have occurred 8-10 years ago, not what's occurring recently." Johnson also noted that the lack of HIV reporting could give people the false sense that the HIV epidemic is declining, since AIDS cases and AIDS deaths are falling. Some people voiced concerns that name- or code-based HIV reporting would keep people from getting tested for HIV. There are an estimated 25,000 to 30,000 HIV-infected individuals in Georgia, according to state officials.

Reporting HIV Cases Is Urged at Hearing

Boston Globe Online (09/23/98)

Several AIDS activists spoke in favor of non-name based reporting of HIV cases at a hearing in September in Massachusetts. The measure discussed would require the reporting of HIV cases to the state Department of Public Health using a 17-digit identifier code that would encode information relating gender, age, and residence of the infected patient. Physicians would also be required to submit similarly coded information on patients already diagnosed with HIV. Bennett Klein, AIDS law project director for Gay and Lesbian Advocates and Defenders, asserts that "a non-name-based HIV reporting system responsibly balances the goal of obtaining more accurate and complete information about the HIV epidemic with the critical need to encourage HIV testing." Some fear that the system, which would go into effect on January 1, would result in the duplication of case reports, while others opposed the plan completely, arguing that name-based reporting is necessary in order to conduct partner notification.

AIDS Deaths in U.S. Drop by Nearly Half

New York Times (10/08/98)

The AIDS mortality rate in the United States decreased by 46.4 percent in 1997, according to new data from the National Center for Health Statistics. There were 16,865 deaths due to AIDS in 1997, as compared to 31,130 deaths in 1996. The mortality rate decreased by a much greater margin than the previous record decrease, which measured 29 percent from 1995 to 1996. The death rate fell to the lowest level since 1987--the first year AIDS deaths were tracked. AIDS ranked as the eighth leading cause of death in the United States in 1996, but fell to the 14th leading cause in 1997.

However, the number of new HIV infections remained stable at about 40,000, indicating that there is a larger population of people living with the virus. The longer lifespan of infected people also means that there is an increased risk of the spread of the virus. Furthermore, some experts worry that the good news about the decrease in AIDS mortality will cause complacency. Health and Human Services Secretary Donna E. Shalala said the decline "reflects the tremendous power of the new combination therapies, the enormous effort to get the drugs to people and the huge Federal effort to pay for these drugs. What this also tells us is that we have serious problems when we have not brought down the rate of new infections." Some researchers note that they are particularly concerned that while the decline in AIDS mortality shows great strides forward in treatment, prevention efforts have not been similarly successful because the number of new infections has remained level.

Wave of Laws Aimed at People With HIV

New York Times (09/25/98)

Nationwide, laws that affect people with HIV are being passed following public fears about the spread of the disease. For example, at least 29 states now have laws making it a criminal offense to knowingly transmit HIV; one-third of the states adopted those laws within the last two years, and 16 states introduced such measures this year. Many states are also requiring HIV testing of certain populations, most notably prisoners and pregnant women.

Four states recently passed laws allowing good Samaritans and non-medical personnel the right to inquire about the HIV status of the people they assist. Other states are increasing partner notification systems. According to some experts, the new laws result from a change in attitudes toward infected people; they also stem from growing publicity concerning specific cases of HIV transmission, such as the case of Nushawn Williams, who is accused of knowingly infected over a dozen girls and young women in New York. Lawrence O. Gostin, a director of the Georgetown University-Johns Hopkins University Program on Law and Public Health and a member of the Centers for Disease Control and Prevention's advisory committee, said, "Legislators believe we have been soft on the epidemic, that we haven't treated AIDS like other infectious diseases, and the way they interpret it is a need to get tough on people with AIDS."

The shift in public opinion is also tied to the change in prognosis for HIV-infected people. Protease inhibitor treatment has changed the perception of HIV infection from what was viewed as a fatal condition to a seemingly chronic disease. Additionally, a recent national phone survey of over 1,700 people found that the public has become more suspicious of infected people, with 55 percent of respondents in 1997 believing that they can contract HIV by sharing a glass with an infected person and 41 percent saying the virus might be acquired through the use of public toilets. Comparatively, 48 percent of respondents in 1991 believed they could get HIV through the sharing of a glass, while 34 percent thought they could get HIV from using public toilets.

One of the authors of the study, social psychologist Dr. Gregory M. Herek, noted that the erosion of information could indicate that recent public health efforts have not underscored the fact that HIV is transmitted via sexual contact, contaminated hypodermic needles, or blood. Many public health officials are worried about the new criminalization laws and believe that the trend could result in HIV-infected people shying away from help.

Maine Mother Is Allowed to Withhold AIDS Drug

Washington Post (09/15/98)

Recently, a Maine judge ruled that Valerie Emerson of Bangor, Maine has the right to refuse drug treatment for her HIV-infected four-year-old son, Nikolas. Emerson denied her son treatment, fearing that the powerful treatment would kill her child.

The judge also ruled that Emerson could keep custody of the child, instead of turning the boy over to the state Department of Human Services. Emerson -- who is HIV-positive and does not take medication either -- said her decision stemmed from the death of her three-year-old daughter while on AZT, noting that she did not want Nikolas to go through the same process.

State Agency Backs Off HIV Names Proposal

Chicago Tribune Online (09/25/98)

The Illinois Public Health Department has reversed a decision to require the names of HIV-positive people and will instead track HIV cases using non-name-based identifier codes. The decision came after months of public hearings and discussions with AIDS advocacy groups. AIDS advocates had expressed concern that the confidentiality of the reported individuals may be at risk. The health department said that it wanted to reach a compromise between activist concerns and surveillance needs. Officials noted that the new plan could be changed to name-reporting if it does not succeed; the pilot program will be launched on July 1, 1999, and evaluated in mid-2001.

Chet Kelly, chief of the HIV/AIDS section for the Department of Public Health, said, "There's no way to predict how it will work. If we didn't think it had any opportunity for success, we wouldn't propose it."

DuPont Gets FDA Clearance For AIDS Drug

Wall Street Journal (09/21/98)

DuPont's pharmaceuticals division received FDA approval Friday to market its once-daily AIDS drug Sustiva, which the company says is as effective as the protease class of medicines when used with AZT and 3TC. The drug, which some analysts believe could generate $700 million in revenue a year, is the third non-nucleoside reverse transcriptase inhibitor (NNRTI) approved by the agency and is priced at about $11 a day in order to compete with protease drugs. Because the drug only needs to be taken once a day, DuPont believes Sustiva, a brand of efavirenz, will improve patient compliance and create a new standard of care.

AIDS Group Protests DuPont's Pricing of New Drug

Boston Globe Online (09/25/98)

AIDS activists are protesting DuPont's decision to price its new AIDS drug, Sustiva, between $4,000 and $5,000, which some say could push individual drug therapy costs to about $30,000 per year. Members of ACT UP Philadelphia rallied outside DuPont's Wilmington, Del., headquarters, dumping empty pill bottles from a black coffin to underline its point. DuPont maintains that the drug is priced in the middle of the range for HIV/AIDS antivirals, and said it tried to price the drug so that the cost would not hinder access. In addition, the company said it would expand its therapy assistance program for the poor.

Sustiva, which studies showed is as effective as Crixivan when taken in combination with AZT and 3TC, can lower the number of drugs patients take daily.

Huge Gains and Huge Worries on AIDS

New York Times (10/09/98)

The medical advances that led to a 47 percent decline in the AIDS mortality rate last year are remarkable, yet there are still many HIV-infected individuals, according to an editorial in the New York Times. As many as 900,000 people in the United States carry the virus, with the rate of new infections steady at about 40,000 cases a year. With infected individuals living longer, the author argues that "there is an increasing danger that they will pass the virus on to others." The author also notes that HIV is spreading at alarming rates in parts of the developing world, where treatment access is very limited and financially restricted. Until a vaccine against the virus is created, the author contends that the HIV epidemic will continue to spread.

Notice: Dignity/New England is sponsoring "A Time Apart - A Day for Caregivers."

This event is free and open to anyone involved in the care of a person with AIDS, and will be held on Saturday, October 31, 1998 from 9 am to 5 pm at St. Luke's Cathedral at 143 State Street in Portland. Lunch and a massage therapist will be available. Call 646-2820 to register.

More HIV News

African Growth Slows as Deaths Multiply

Philadelphia Inquirer (09/27/98)

United Nations demographers report that the effect of the AIDS epidemic on the population in some areas of Africa will be "unbelievable," according to one. Revised UN estimates for population growth will be released at the end of October, and some population experts believe that several countries in the region will reach zero population growth in a few years due to a combination of AIDS, food shortages, water depletion, social chaos, and ecological collapse.

Zimbabwe is expected to be the hardest hit by the AIDS epidemic, with one-quarter of the population believed to be infected with HIV. Botswana also reportedly has a 25 percent infection rate, while Namibia has a 20 percent rate, Zambia has a 19 percent rate, Swaziland has an 18.5 percent rate, and several other African nations have rates over 10 percent. However, the spread of HIV is apparently slowing in some other countries, such as the United States, Brazil, Thailand, and Uganda.

Worldwide population growth is expected to continue, with the population expected to reach 6 billion by mid-1999.

AIDS on Rise Among 50-and-Overs

Miami Herald (09/27/98)

According to the Florida Department of Elder Affairs, 10 percent of all AIDS cases in the United States occur in people over the age of 50 years, with rates reaching 12 percent to 14 percent in Florida. Of 67,282 AIDS cases in Florida, 8,400 patients are age 50 or over. Despite these numbers, older people are often not considered at risk for HIV.

Sue Saunders -- a 65-year-old Fort Lauderdale woman with AIDS -- started the AIDS activist group Senior HIV Intervention Project in response to this risk, receiving $170,000 from the Department of Elder Affairs to run a prevention group focusing on older people. Following the success of the initial program, the project spun off and a second group was formed in the Tampa Bay area. Saunders notes, "You're never too old [to contract HIV]. And all it takes is one partner--if he or she is infected."

Lower-Dose Regimen Works for Protease Inhibitor

Reuters (09/25/98)

Patients with AIDS may soon be able to take two doses of the protease inhibitor Viracept instead of three, Agouron said recently. The drug maker said 80 percent of 238 patients taking a higher, twice-daily dosage of Viracept as part of a drug cocktail were able to lower the levels of the virus to a level that was almost undetectable. The response was similar to that achieved by patients taking the drug three times a day in a lower dosage. If the drug is approved, it may erode market share now held by Merck's Crixivan.

Postexposure Treatment Not Easy to Swallow

AIDS Alert (09/98)

According to research by the Centers for Disease Control and Prevention, approximately one-third of health care workers who undergo HIV postexposure prophylaxis treatment (PEP) do not complete their regimen. Seventy-five percent of the workers who halted treatment cited side effects as the determining factor. Side effects were also an issue with exposed workers who decided not to receive the treatment; only 58 of 114 exposed workers opted to receive PEP in the study.

Research presented at the 12th World AIDS Conference in Geneva indicated that at least half of 100 occupational exposures to HIV investigated could have been prevented through proper work practices.

U.S. House of Representatives' AIDS Notification Measure Praised, and Attacked by Prominent Groups

Washington Times (09/30/98)

At a House hearing in late September, the HIV Partner Protection Act -- which would require HIV-infected people to be reported confidentially by name instead of anonymous codes -- was both praised and criticized.

The bill, co-sponsored by Rep. Tom Coburn (R-Okla.) and Gary L. Ackerman (D-N.Y.), would also require doctors to supply the names of sexual partners named by the infected person to public health professionals, who could then notify those individuals. Ackerman told the House Commerce subcommittee on health and environment that the bill was particularly important for women, because many women with HIV were infected by partners who engage in high-risk behavior. However, Dr. Helene D. Gayle, head of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention, asserted that the bill may cause people to avoid testing altogether due to confidentiality concerns. Gayle also noted that partner notification must be dealt with carefully, because it could result in domestic violence.

Critics of the bill included the American Civil Liberties Union, AIDS Action, and the Association of State and Territorial Health Offices. The measure's supporters include the American Academy of Family Physicians; and directors of AIDS outreach programs in Florida, Brooklyn, New York, and Los Angeles.

Patient Participation in HIV Treatment Plans Recommended to Improve Adherence

Reuters Health Information Services (10/08/98)

Dr. Barron H. Lerner, of Columbia University College of Physicians and Surgeons in New York City, and fellow researchers report in the October 1st issue of the Annals of Internal Medicine that anti-HIV drug regimen adherence may be increased by personalizing patient medication plans. The researchers recommend that patients first receive educational materials on the drugs, then the doctors should determine what patient lifestyle habits could affect adherence, and finally the patients should undergo a test regimen with dummy pills.

The authors discourage strict categorization of patients as either adherent or non-adherent. They note that more flexible labeling and active participation by the patient in the regimen can prevent judgmental and inaccurate behavioral assessment and could increase treatment adherence.

People Must Prove Exposure to HIV Before Suing, Supreme Court Says

Postnet Online (10/02/98)

The Illinois Supreme Court has ruled that patients who groundlessly feel they were put at risk for HIV due to medical care are not entitled to monetary damages. The court ruled against a woman who was cut by a scalpel in the office of an HIV-infected podiatrist. The woman, who worked as an aide in the office and cut herself while emptying a used sharps container, sued the two doctors at the office over fears that she may have been infected. The court also ruled against six patients who were treated by an HIV-positive dental student at Northwestern University.

The judges said that proof of exposure is necessary to warrant damages and that fear of exposure was insufficient for compensation. David Holmes, one of the lawyers who represented one the defendants, said, "It's important that the justices draw the line. There's a lot of hysteria about AIDS." None of the plaintiffs contracted HIV, the virus that causes AIDS.

Citing Privacy Rules, California Governor Wilson Vetoes Bill on HIV Reporting System

San Francisco Examiner Online (10/01/98)

California Gov. Pete Wilson has vetoed legislation that would require the creation of a statewide HIV reporting system. San Francisco AIDS activists and public health officials expressed dismay at Wilson's action, asserting that the system would have been beneficial to public health. Wilson contends that the measure was flawed since the system would not be name-based and that "concerns over confidentiality and discrimination should not be used to justify an inadequate reporting system."

California is one of nine states that does not require HIV-reporting. Wilson, who is ending his final term this year, also signed a number of related bills this week, including a bill that mandates prison time for people convicted of knowingly transmitting HIV, a measure that requires emergency regulations for health care workers who sustain needlestick injuries, and a plan to institute a new red-ribbon license plate to raise money for AIDS research at the University of California.

THE AIDS PROJECT

Support Groups Looking for New Members

Both the Tuesday morning and Thursday evening support groups sponsored by The AIDS Project are looking for new members. Both groups offer a safe and supportive space to share, listen, and connect with others. Please contact Susan Parr, TAP Case Manager, at 774-6877 for more info.

The Tuesday morning group is open to anyone who is infected or affected by HIV/AIDS. The group serves family members, partners, relatives, and friends of those living with HIV/AIDS, along with persons lving with HIV/AIDS. Meetings are every Tuesday from 10:30 a.m. to 12:00 noon in Suite 632 (TAP's Meeting Place) at 142 High Street in Portland. Joan Murray and Frannie Peabody facilitate the group.

The Thursday evening support group is open to people living with HIV/AIDS. The group meets every Thursday from 5:30 p.m. to 7:00 p.m. in Suite 632 (TAP's Meeting Place) at 142 High Street in Portland. Audni Miller facilitates this group.

Reviewing Client Rights and the Client Grievance Procedures

Editor's note: *From time to time I try to resubmit information in this newsletter that directly pertains to client needs. Basic to the relationship of clients to The AIDS Project is how clients are treated and what rights they have concerning the policies and services of The AIDS Project. So, for your information, here is information I think all clients should have at their disposal.*

Client Rights

As a client of The AIDS Project you have certain rights. They include:

1. Considerate and respectful care. The right to receive considerate, dignified, and respectful treatment and care regardless of your physical or emotional condition, by all AIDS Project staff, interns, and volunteers.

2. To be informed. The right to be informed of what services the agency provides, the method for obtaining those services, and the reasons why a service is not being provided.

3. A reasonable and timely response. A response by a staff member in a reasonable and timely manner to your request(s) for services.

4. Nondiscrimination. The right to quality services without discrimination as to race, color, age, disability, homelessness, religion, sex, national origin, economic status, or sexual orientation.

5. Confidentiality. The right to expect that The AIDS Project will maintain the confidentiality of charts and records pertaining to the services you receive(d), except for otherwise provided by law. Any exceptions of confidentiality shall require you or your designee to sign a release of information. This does not apply to statistical data, which is required by funding agencies where the client's identity is not made known.

6. Accessibility to your file. The right to request to review your file at a mutually agreed upon time with your case manager. Clients also have the right to request a photocopy of their records.

7. Grievance. The right to a formal grievance procedure in the event that you feel your rights as a client have been violated.

Grievance Procedures

The AIDS Project recognizes the importance of client rights with regard to the delivery of services which affect them. In keeping with this view, The AIDS Project has established grievance procedures through which clients may voice their concerns should an issue of dispute arise concerning policy or service delivery.

1. The first step in any grievance procedure is to address the issue directly with the person(s) involved, [such as client and case manager].

2. If the parties directly involved cannot resolve the dispute within 5 working days, the matter will be described in writing* by the grieving party to the program coordinator, [such as the Director of Support Services]. The coordinator shall attempt to achieve resolution with the parties involved.

3. If, within 5 working days, the dispute still exists, the coordinator shall notify the Executive Director in writing. The Executive Director shall decide all matters related to the dispute within 15 days and provide the client written notification.

4. If the grievance is not resolved to the satisfaction of the client, he or she may submit a written request to the President of the Board of Directors. A final binding decision will be made within 30 days of receipt of this request.

*Persons voicing grievances regarding anonymous testing may do so using their client number, in order to protect their anonymity.

Standard Dosing Schedule for Anti-HIV Drugs (from Project Inform)

Name	Brand Name	Class	Standard Daily Dose	Comments
Indinavir	Crixivan®	Protease Inhibitor	Two 400-mg capsules three times a day	Take on empty stomach, at least 1 hour before or 2 hours after a meal; do not take at same time as ddI, take indinavir at least 1 hour before or 2 hours after ddI; to reduce risk of kidney stones, drink 8 glasses of water a day; must be taken every 8 hours.
Nelfinavir	Viracept®	Protease Inhibitor	Three 250-mg tablets three times a day	Should take with food; diarrhea is a common side effect that is usually controlled with over-the counter medication.
Ritonavir	Norvir®	Protease Inhibitor	Six 100-mg capsules twice a day	Diarrhea and nausea may appear, is worse in first few weeks; needs to be refrigerated, consult doctor for initial dosing schedule (start at 300-mg twice a day for 2 days and increase 100-mg every 2 days until you reach 600-mg).
Saquinavir	Fortovase®, Invirase®	Protease Inhibitor	Fortovase - Six 200-mg capsules three times a day Invirase - Three 200-mg capsules three times a day	Take with food, within 2 hours of high fat meal; diarrhea and nausea are rare side effects.
Delavirdine	Rescriptor®	NNRTI	Four 100-mg tablets three times a day	Take with or without food; can be dissolved in water or other liquids if drank immediately; a severe rash could develop (usually within first 3 weeks) and require hospitalization or milder rash which can be controlled by antihistamines or topical agents.
Nevirapine	Viramune®	NNRTI	1 200-mg tablet twice a day	Dose usually starts at one 200-mg tablet and then increased to two 200-mg tablets after 14 days; take with or without food; a severe rash could develop (usually within first 3 weeks) and require hospitalization or milder rash which can be controlled by antihistamines or topical agents.
AZT	Retrovir®, zidovudine	NARTI	Two 100-mg capsules twice a day or 1 300-mg tablet twice a day	Take with or without food; common side effects (which diminish after 6 to 8 weeks) include headache, nausea, and a general sense of feeling ill; most serious side effect is anemia, if caught early can be treated with erythropoietin (EPO).
AZT + 3TC	Combivir®	NARTI	1 tablet (with 150-mg 3TC, 300-mg AZT) twice a day	Take with or without food; see comments in AZT and 3TC sections.
ddC	Hivid®, zalcitabine	NARTI	Three 0.75-mg tablets three times a day	Take with or without food; side effects can include pain or tingling in hands and/or feet, low platelets, and mouth sores; the most serious side effect is pancreatitis, which has been fatal in some people -- symptoms include sharp pain in upper abdomen, nausea, and vomiting, stop drug immediately and consult your doctor. Alcohol use increases risk of pancreatitis.
ddI	Videx®, didanosine	NARTI	Two 100-mg tablets twice a day	Take without food and on an empty stomach; do not take within 2 hours of drugs that require an acidic stomach environment, including many protease inhibitors and drugs such as dapsone; side effects could include increased uric acid levels (kidney function), headaches, sleeplessness, diarrhea, and pain and/or tingling in hands and/or feet; the most serious side effect is pancreatitis, which has been fatal in some people -- symptoms include sharp pain in upper abdomen, nausea, and vomiting, stop drug immediately and consult your doctor. Alcohol use increases risk of pancreatitis.
d4T	Zerit®, stavudine	NARTI	Two 40-mg capsules twice a day	Take with or without food; common side effects are pain and/or tingling in hands and/or feet and anemia; a rare, but serious side effect is pancreatitis, which has been fatal in some people -- symptoms include sharp pain in upper abdomen, nausea, and vomiting, stop drug immediately and consult your doctor. Alcohol use increases risk of pancreatitis.
3TC	Epivir®, lamivudine	NARTI	Two 150-mg tablets twice a day	Take with or without food; side effects are rare, but may include headaches, nausea, general sense of feeling ill, diarrhea, anemia, and hair loss.

NNRTI = Non-nucleoside reverse transcriptase inhibitor NARTI = Nucleoside analogue reverse transcriptase inhibitor
For more info, call the National HIV/AIDS Treatment Hotline at 1-800-822-7422

CLIENT SERVICES

MEDICAL ASSISTANT **FUNDS**

An important reminder to clients:
There are funds available to TAP clients with financial need for the following items: Routine Dental Care, Routine Eye Care and Eyeglasses, Vitamin Supplements, Non-Prescription Skin Care Products, and Non-Medicaid Medication Co-pays.
There is a dollar limit to how much a client can receive in any fiscal year. Contact your case manager for assistance.

FREE **LUNCH**

Enjoy a free lunch at The AIDS Project every Thursday at noon. Join other clients and TAP staff for a great meal, good conversation, and very good company. Drop on by Thursdays at noon!

IMMEDIATE **SEATING**

For free tickets to area events as they become available, sign up for "Immediate Seating." Call TAP at 774-6877 for more information.

I.V. **LEAGUE**

Meetings of the I.V. League support group are held on Wednesdays at 11:00 a.m. at the Parkside Community Center, 94 Mellen Street, in Portland.
For more information, call 874-8775.

THE MEETING **PLACE**

This room is used by TAP in Portland for support groups, counseling and testing, and some client/case manager meetings. Located in Suite 632, it provides more privacy for people served by TAP. Enter from the High Street side of the building.

FOR YOUR **INFORMATION**

HIV **WEBSITES**

Check out these websites:
www.hivpositive.com
www.thebody.com
www.projinf.org
for info on HIV and AIDS.

TAP **ON-LINE**

Visit our web address at:
"www.aidsproject.org"
To e-mail The AIDS Project, send your message along to "tap@aidsproject.org"

AIDS **HOTLINES**

Questions about HIV/AIDS?
Call toll-free
National AIDS Hotline:
1-800-342-2437
Maine AIDSline:
1-800-851-2437
Maine Teen Hotline:
1-800-851-2437

TAP's **MAILING ADDRESS**

When writing to TAP in Portland, please send your mail to our post office box. It really rushes mail delivery if letters are not addressed to our street address,
so write us at: P. O. Box 5305,
Portland, ME 04101

SUPPORT **GROUPS**
FOR PEOPLE INFECTED AND AFFECTED BY HIV/AIDS

TUES**DAYS**

Time: 10:30 a.m. to noon
Group: HIV Infected/Affected Drop-In Support Group
A meeting for people living with and affected by the virus.
Location: Portland, TAP, The Meeting Place, Suite 632.
Contact Randy May at TAP at 774-6877 for more information.

Time: 1:30 p.m. to 3:00 p.m.
Dates: Starts September 22nd, Meets every other Tuesday
Group: Women with HIV
A bi-weekly meeting of women living with HIV.
Sponsored by The AIDS Project (TAP)
and The AIDS Consultation Service (ACS)
at Maine Medical Center.
Location: Portland, ACS, 52 Gilman Street.
Contact Janine Collins at TAP at 774-6877
or Cindy Luce at ACS at 871-2991 for more information.

Time: 1:30 p.m. to 3:00 p.m.
Group: People Living with HIV
An ongoing drop-in support group for people living with HIV.
Location: Auburn, TAP, One Auburn Center.
Contact Diana Carrigan at TAP at 783-4301 for more info.

THURS**DAYS**

Time: 10:00 a.m. to 11:30 a.m.
Group: HIV Infected/Affected Drop-in Group
A TAP-sponsored meeting for people living with and affected by HIV/AIDS in southern Maine.
Location: Sanford, Unitarian Church, located at the corner of Main St. (Rte. 109) and Lebanon St. (Rte. 202).
Contact Getty Payson at TAP at 985-8199 for more info.

Time: 12 noon
Group: Open Lunch for TAP Clients/Staff
An informal luncheon gathering of TAP staff and clients.
Location: Portland, TAP, Conference Room.
Contact Randy May at TAP at 774-6877 for more information.

Time: 5:30 p.m. to 7:00 p.m.
Group: People Living with HIV/AIDS
A drop-in support group for anyone with HIV/AIDS.
Location: Portland, TAP, The Meeting Place, Suite 632.
Contact Randy May at TAP at 774-6877 for more information.

The AIDS Project
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P.O. Box 5305
Portland, Maine 04101
Phone: 774-6877 Fax: 879-0761
E-mail: tap@aidsproject.org
Website: www.aidsproject.org
AIDS Hotline: 775-1267
or 1-800-851-2437

Oxford/Androscoggin Cty. Office
One Auburn Center/Box 14L
Auburn, ME 04210
Phone: 783-4301 Fax: 795-4084

York County Office
Lafayette Center - 4th Floor
Kennebunk, ME 04043
Phone: 985-8199 Fax: 985-8646 *51

INTHEAFFIRMATIVE

In The Affirmative is a monthly newsletter published by The AIDS Project for people living with and affected by HIV/AIDS. Letters, articles, or other submissions should be sent to: *In The Affirmative*, c/o The AIDS Project, P.O. Box 5305, Portland, ME 04101, or call (207) 774-6877. Submissions can be printed anonymously as long as the person submitting the material includes his or her name and phone number for verification.

News, information, and features are as up-to-date as possible prior to publication. Any medical information included in this newsletter is submitted for the reader's information only, to be used as the reader so chooses.

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