10-15-1996

In the Affirmative, Vol.3, No.7 (Mid-October / Mid-November 1996)

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The AIDS Project

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Recommended Citation
Martin, Mick and The AIDS Project, "In the Affirmative, Vol.3, No.7 (Mid-October / Mid-November 1996)" (1996). In the Affirmative. 9.
http://digitalcommons.usm.maine.edu/affirmative/9

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Protease inhibitors: what's the price on life? This is a question that people, ranging from the President of the United States to clients here in Maine, have been asking themselves over the last six months. The standard of care for HIV infection has changed so dramatically that it's almost impossible to keep up, either intellectually or financially. With the discovery of these miracle drugs has come a wave of hope into what has thus far seemed to be a spiral downward in the laboratory battle against HIV and AIDS. At the International Conference on AIDS in Vancouver, protease inhibitors were even linked to the "C" word - cure. Most people, however, although optimistic, are staying realistic, and while a cure is always on the horizon, how far and how difficult the journey to that horizon is has not been determined.

One of the biggest obstacles thus far in the journey has been consistency. Once a client begins treatment with protease inhibitors, they should, in most cases, never stop taking them. HIV has a mutation rate like no other, and the second a client stops taking protease inhibitors, the virus is believed to mutate itself into drug immunity. If the client resumes protease inhibitor treatment, it may not be effective. More importantly, if a client who has stopped taking the drug transmits the virus to another person, the virus transmitted is the mutated, drug-resistant strain. Consistency is the key, but with consistency comes an entourage of dynamic difficulties.

A client in a protease inhibitor drug treatment program is spending on average $15,000 to $18,000 per year. Once in a program, the client should never go off. The wonder drugs which are allowing people to live longer and more productive lives are also prolonging the years of financial burden. A worthy swap? Yes. But who will pay for the drugs? Some clients who have received financial assistance through disability for the purchase of protease inhibitors are finding that the drugs have had such a positive effect on their health that they are no longer considered disabled -- no longer disabled, and no longer able to afford the medications which have given them back their lives. There is a gully looming between those who have private insurance and those who have Medicaid. The gully is filled with those who can't afford treatment, but aren't financially poor enough to be eligible for Medicaid. And then what happens when a client can get Medicaid, goes on a protease inhibitor, improves the quality of his life, gets a job, and is then no longer eligible for Medicaid? Shouldn't go off the drugs, remember.

So what does one do when dancing with a rock in a hard place? The answer is finding creative outlets for money and drug treatment. One of these outlets is the federally funded AIDS Drug Assistance Program (ADAP). The Maine ADAP "has been instituted to ensure equitable access to and efficient disbursement of federal and state funds for prescription drugs for HIV infection for qualifying individuals with HIV."

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**STAFF CHANGES AT TAP**

Steve Moskey, TAP's Executive Director, announced the following changes at The AIDS Project.

The HIV Prevention Department has been renamed The Policy and Program Department. John Holverson's title is now Director, Policy and Program.

The Support Services Department has been renamed The Social Services Department. Carol LeBlanc's title is now Director, Social Services.

The Business Office has been renamed the Finance and Administration Department. Steve Reevy's title is now Manager, Finance and Administration.

Tamara Harvey has accepted the new position of Development Associate. Jill Tacy has accepted the new position of Executive Assistant.

David Young, the MSM outreach worker for York County, has left to accept a job in Rhode Island. His position is being filled by both Gerry Scoppettuolo and Declan Buckley on a shared basis through December 31, 1996.

Simon Bogan, outreach worker, has left TAP to pursue other opportunities.

These are organizational changes within the agency and do not affect the actual case management of client services directly. They do better define staff functions.

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**SOMETIMES YOU GOTTA LET GO**

**Sometimes you just gotta let the past go and move forward.** I say this because The AIDS Project is in the process of moving forward with a new Executive Director and newly named and redefined departments. What with the new people on the staff and the changes being made in how the agency functions, I can't help thinking it's time to stop talking about past mistakes and grievances at TAP and really take a good look at the future. I know this is hard for some clients (myself included, at times), but it really is a brand new time in the life of The AIDS Project.

The mission of The AIDS Project is still the same: To provide care and compassion to people infected and affected by HIV/AIDS and to help stop the spread of HIV through education and prevention. But there are new realities in the evolution of HIV/AIDS: in the way funds are allocated and in the need to prioritize services to clients. One of the greatest challenges now and in the future is for all AIDS agencies, not just TAP, to learn how to allocate limited resources to a growing population of people with HIV/AIDS.

I think the future is going to mean that clients will need to rethink two questions. 1.) What do I want from The AIDS Project? 2.) And what do I really need from The AIDS Project? Nowhere is this so evident as in the disbursement of Ryan White Client Assistance funds. The reality is that there is a limited amount of money in this fund and a long list of client requests. In the past, The Project tried very hard to fill requests as they came in, ending up with no money left 8 or 9 months into the fiscal year. With the increased wants and needs of clients, it will be impossible for TAP to meet all the requests it receives for RW Client Assistance funds in the coming fiscal year. Serving on the Board of Directors and the Client Services Committee has made this fact all too evident to me.

Sometimes you just gotta let the past go.
ADVANCES IN THINKING ABOUT HIV

Fifteen years after the first reported AIDS cases, research has yielded a remarkable amount of progress in the fight against HIV. Three areas have shown promising results. The Food and Drug Administration has approved five new drugs that when taken in various combinations with AZT (this combination is frequently referred to as a "cocktail"), have helped some HIV-positive patients fight the virus with varying degrees of success. This past summer, a gene was isolated which appears to protect some people against HIV, even after repeated exposure to the virus. This has led researchers to expand their efforts with genetic therapies. In addition, researchers at the Aaron Diamond AIDS Research Center are working on new treatment therapies which concentrate on the early stages of HIV infection in the lymph nodes. While there is still much work to be done, HIV treatment will be radically affected by these researchers' results.

Since 1990, Dr. David Ho of the Aaron Diamond AIDS Research Center in New York City has worked with his colleagues in an attempt to learn what happens in the initial stages of HIV infection. The popular theory was that when a person became infected with HIV, the virus essentially remained dormant for seven to ten years. At that time, the HIV-infected cells would begin to seek out and destroy healthy T-cells. Ho and his associates have proven that theory false. They have shown that from the initial infection, HIV begins replicating itself with a billion copies, all aimed at destroying T-cells. This causes the infected person's immune system to create billions of new immune cells to fight HIV. Eventually, the immunological reserves are depleted, which is when full blown AIDS occurs. Ho's work has shown that this initial battle takes place in the lymph nodes and not in the circulatory system as previously thought. With the new drugs available, it is hoped that the drug cocktails will prevent the virus from copying itself and the patient's immune system will not become depleted.

On December 6, 1995, the Food and Drug Administration approved a new medicine called saquinavir. This protease inhibitor and others target the virus during the reproductive stage. Using a cocktail made up of this protease inhibitor, AZT and 3TC (a chemical cousin of AZT), doctors treated some of the sickest patients. While it did not work for everyone (some could not even tolerate this combination of strong drugs), this drug therapy and other similar therapies using newer and stronger protease inhibitors appear to have actually forced HIV into remission. Using a variety of sophisticated HIV tests, no trace of the virus was found in the patients' blood. This fall, Ho plans to biopsy lymph nodes in patients whose blood has shown no traces of HIV for the past year to see if HIV is present there. Researchers are now trying these treatments on patients in the initial stages of HIV infection.

This past summer, scientists from the U.S. and Belgium discovered that some people have their own genetic shield against HIV. Despite repeated exposure to the virus, they remained virus free. These people were found to have a double dose of a defective CKR-5 gene. HIV's critical weakness is that it needs to utilize our cellular structure to duplicate itself. However, to do this, it needs access to cells. It uses CKR-5 to "land" onto the healthy cells. Because the people studied were healthy despite exposure to HIV, it has led researchers to theorize that we don't require a "typical" CKR-5 gene to maintain health. Essentially, CKR-5 is dispensable to us, but it is indispensable to HIV. This recent discovery has spurred a wave of research on genetic prevention of HIV infection.

While a "cure" for HIV is unlikely in the next several years, dramatic success on varying fronts show much promise for the management and, perhaps, the eventual prevention of HIV.

Bethany Roma is a volunteer contributor to In The Affirmative. Her articles are well-written and informative, and her contributions are greatly appreciated.

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AIDS PROJECT TO STAY IN ANDROSCOGGIN AND OXFORD COUNTIES

The AIDS Project has decided to keep doing case management in Androscoggin and Oxford counties after the State increased its share of funding for that service. The State will pay $39,000 with TAP contributing $6,000. The money will fund case management for about 40 people in those two counties.

Case management includes referring clients to various social services, advocating for clients' rights and other support.

This summer, the State refused TAP's request for full funding for the program and offered only $22,000. TAP subsequently decided that it could no longer afford to subsidize the program, as it had done for the entire six years it had run the program under a State contract. News of this decision caused affected clients to call the State to complain, according to Jeannette Talbot of the Department of Human Services. Talbot said the State responded by speeding up its timetable for allocating federal AIDS grant money budgeted for Maine this year. Those grants are bigger than last year's, which allowed the State to spend more money on the case management program run by The AIDS Project in those two counties.

Steve Moskey was pleased with the State's new funding, but said TAP will withdraw from Androscoggin and Oxford counties next year and let another, more local agency seek the contract for that service. TAP is based in Portland and is most active in York and Cumberland counties.

Talbot said that by retaining TAP till October 1997, the State can avoid any problems caused by switching too quickly to a different organization. ACLA of Lewiston/Auburn is expected to apply next year and TAP will help them to do so.

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Currently, the program has 52 clients enrolled: 43 men, 8 women, and 1 female infant. Through increased Ryan White Title II funding, the program will be able to pick up 12 more clients in December of this year. What? Only 12? Yes, it's true, but at least it's more and not less. And don't forget to take into consideration the average price of keeping one client outfitted with protease inhibitors for a year. The standard of care for HIV infection is no longer mono-drug therapy. The inclusion of protease inhibitors has caused the average costs for the drug assistance program to almost double over the last six months.

The program is designed to pick up some of those people hanging out in the non-Medicaid-non-private-insurance gully. Criteria for being eligible for the program read like this:

A. AIDS Drug Assistance Program payments for HIV treatment shall be limited to those individuals who: 1.) Have documented HIV infection and a CD4 cell count of less than 400, or a documented viral load of greater than 20,000 copies AND 2.) Are low income individuals not eligible for the State Medicaid program, compassionate use programs, or any other third party payor system.

Anyone who wants to submit an application to ADAP must get a form from the Department of Human Services (DHS) and submit it through their case manager, hospital social worker, or physician. Authorization of payment for HIV treatment drugs with ADAP funds for eligible individuals will be made in the following ways:

1.) Authorization for payment will be made to eligible individuals in the order in which the applications are received by the Department. 2.) ADAP payments will be made on a per patient basis. The number of patients authorized to receive such treatment will be limited by the grant amount. 3.) The ADAP Coordinator shall maintain a waiting list of individuals who meet ADAP eligibility criteria once all grant funds have been authorized.

Placement of waiting list enrollees will be dependent on such things as change in financial eligibility for currently enrolled clients, enrollment in a manufacturer's program, or enrollment in other drug protocols. The following drugs will be covered under the program:

Nucleoside Analogs: Zidovudine/AZT (retrovir)
Didanosine/ddI (videx)
Zalcitabine/ddC (hivid)
Stavudine/d4T (zerit)
Lamivudine/3TC (epivir)

Protease Inhibitors: Crixivan
Invirase
Norvir

Other Anti-Microbials: Trimethoprim/sulfa (bactrim, septra, sulphamethoxazole)
Dapsone
Itraconazole (sporanox)
Fluconazole (diflucan)
Pentamidine
Acyclovir (zovirax)

Sources for some of the material in this newsletter include:

The Associated Press
The NAMES Project
The Portland Press Herald
Project Inform
TIME Magazine
USA Today

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Additional drugs can be approved on a case-by-case basis.

And if you apply and aren't one of the lucky twelve? Yes, there are still options. In December of this year, the DHS will be sending out a letter to all those currently enrolled in ADAP. The form will have a tear-off bottom which the client has to fill out in regards to current Medicaid and protease inhibitor status. The purpose behind the mailing is many fold. What the DHS needs to know is who might now be eligible for Medicaid, who's coming off Medicaid, who might be eligible for a manufacturer's program, who's coming out of a manufacturer's program, and so on. The goal is to get as many people as possible into some kind of drug treatment program. DHS is also hoping to work out some kind of deal with some of the pharmaceutical manufacturers. They hope that if someone is coming out of a program, and ADAP picks them up, then the manufacturer will pick up someone else. (Shouldn't go off the drugs, remember.) They will also be creating and distributing a monthly newsletter starting in December which will keep clients up-to-date with information about ADAP.

Other experimental drug protocols are also in progress around the state. Some of the drug trials target anti-HIV therapy, some opportunistic infections, and some target other complications of the disease. Trials usually include free medications and laboratory services for clients. Some pharmaceutical companies offer drugs on a "compassionate use" basis. Access to "compassionate use" drug protocols is for people with HIV who are unable to enroll in other drug trials and can often be obtained through a client's physician. The AIDS Consultation Service at Maine Medical in Portland can provide information on a number of drug trials available throughout the state and New England.

While financial dilemmas seem to be suffocating the wallets of clients needing drug treatment assistance, there are outlets for treatment available throughout the state, and more are on the horizon. It often feels like there should be someone or something to blame, but finger pointing doesn't change the problem, not to mention the fact that problems faced stem from so many different places within the system that no one would have enough fingers to point. Take encouragement in the fact that people like the DHS are doing what they can with the resources at hand while keeping in perspective the numerous dilemmas faced by the drug assistance program. Knowledge is power, and the only advice offerable is to find out what treatment outlets are available and then push every button possible to use them.

Information Sources:

Department of Human Services
1-800-821-5821
1-207-287-2046
1-207-287-2899
1-207-287-6865 Fax

Works cited:

Department of Human Services, Chapter 100, AIDS Drug Assistance Program - Draft Statement.


For information on trials in Maine and New England and access to experimental protocols, these places can help:

AIDS Consultation Service at Maine Medical Center in Portland:
871-2099
871-2701

Owen Pickus, D.O.:
878-0017

In Boston, Community Research Initiative:
617-566-4004

In New Hampshire, Dartmouth-Hitchcock AIDS Clinic:
603-650-6060

Amanda Sewall is a volunteer contributor to In The Affirmative and an HIV Educator with the Maine Red Cross. Her superb writing for this newsletter has been and is greatly appreciated. Amanda is moving on soon and we wish her the best of luck in the future and thank her for all her good works.
The New Client Advisory Group at the AIDS Project

The AIDS Project is looking for interested clients to join in the formation of a new client advisory group.

The AIDS Project will be putting together a group of clients who represent the different populations served by the project, as in gay, straight, women, men, youth, people of color, etc.

This new advisory group will be associated with the board of directors' client services committee.

The AIDS Project is looking for clients who will be able to look beyond their own individual needs and work for the good of all clients and the agency.

Contact Carol Leblanc at Tap
Call 774-6877 right away

The Arts

The Department of Theatre at the University of Southern Maine in collaboration with the Department of Social Work presents the compelling drama about AIDS...

As Is

by William Hoffman
Directed by Will Kilroy

Written in 1985, "As Is" explores the inner worlds of Rich, a man living with AIDS, and of the people touched by his life. Rich is living with Chet, his lover, in New York City when he discovers he is HIV-positive. Everyone around him turns their backs on him, except Soul - a former lover and his best friend. Soul is the only one who accepts and loves Rich..."As Is."

Director Will Kilroy and the cast did workshops with crisis hotline volunteers and the Merrymeeting AIDS Support Services, and have worked with The AIDS Project, the Red Cross and people living and dealing with HIV/AIDS to better understand the realities of the disease called AIDS.

After each performance, members of The AIDS Project or the Red Cross, Kilroy and cast will take part in a post-show discussion with the audience.

Kilroy says of the play, "We're getting a glimpse of society as a whole. Members of a support group, a pregnant mother who has AIDS and is afraid for her baby, or someone whose son has contracted the disease. That's what is important to me - it shows that the disease doesn't discriminate. The story is tragic, but it's also filled with humor. Our research has revealed that people with AIDS try to hang on to their sense of humor."

Francesca Jellison as Lily (top left) and Burke Brimmer as Soul (far right) comfort Patrick Davis as Rich, who is HIV-positive.

The play runs Friday, November 8, through Sunday, November 17, at the Gorham Campus of USM on the main stage in Russell Hall. Curtain is at 7:30 p.m. Wednesday through Saturday, with a 5 p.m. matinee on Sundays, November 10 and 17.

Tickets are $5 for the general public, $6 for seniors and USM faculty/staff, and $4 for students.

For more information, call the Theatre Box Office at 780-5483. The hearing impaired can call USM's Tels/TTY number at 780-5646.

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**TAKE NOTE**

Enjoy a free lunch every Thursday at noon at TAP. Join other clients and staff for a good meal and good company, so drop on by.

**CALL 774-6877 FOR INFORMATION**

For free tickets to area events as they become available, sign up with Steve Zimmerman for "Immediate Seating" at TAP. Steve is in on Thursdays, or you can just leave a message.

**Check TAP out on the World Wide Web at www.neis.net/aidsproject or E-mail us at aidsproject@neis.net**

**FOR YOUR INFO**

**TAP'S EXECUTIVE DIRECTOR TO GET TOGETHER WITH CLIENTS**

Steve Moskey is planning to visit TAP's offices in York and Androscoggin counties during November. During his visits, he will host a get-together with TAP clients to give him a chance to talk directly with those served by the agency. He will also host a similar meeting at TAP for clients in the Portland area in December. Watch for details!

**NEWS BRIEF**

**THE AIDS MEMORIAL QUILT IN ITS GLORY IN D.C.**

The AIDS Quilt was in our nation's capital from October 11th to the 13th. The President and First Lady were honorary co-chairs.

In a story in USA Today, Mike Smith, founder of the NAMES Project along with Cleve Jones, was profiled.

Smith, 35, said the panels started out as "spray paint on a sheet, and then something happened along the way. It became art." Almost 40,000 panels covered 24 acres, spread from the U.S. Capitol to the Washington Monument. The first D.C. display in 1987 had 1,920 panels. Smith expected that as many as 4,000 new panels would be brought in person for the 1996 display.

For almost a decade the Quilt has been Mike Smith's life. There are few who know it better. He can recite the names of the early panelmakers and their loved ones who died from AIDS. Over three hundred thousand people have died from AIDS in the U.S. since 1981.

"I know there is going to be that moment when I see the Quilt for as far as the eye can see, and it's going to tear me apart," Smith said last week. It may well be that this is the last display of the entire Quilt anywhere, he said. He worried that, with the Quilt being 20 times larger than the original display, some of the intimacy will be lost. Still, he feels the whole display is important.

70,000 names of people who died from AIDS were represented by the 40,000 panels. Those names were to be read aloud during the weekend display by celebrities, politicians and the friends and families of people who have died from AIDS.


Mondays
5:30 p.m.-7:00 p.m. - HIV and Substance Abuse Recovery
A safe space for people living with HIV and in the process of recovery from alcohol and drug addiction. Small Group Room, TAP.

Tuesdays
10:30 a.m.-Noon - HIV Infected and Affected Drop-in Support Group
A place for both persons infected and affected to express feelings, share experiences and receive support. Large Group Room, TAP.

Thursdays
Noon - Open Client Lunch
Informal gathering of TAP staff and clients. Large Group Room, TAP.

HIV and IDU Recovery
Discovery House and The AIDS Project are co-sponsoring a safe and supportive place for people living with HIV, who are also in recovery from intravenous drug abuse. It is not necessary to be a client of either agency.
Contact Randy May at TAP 774-6877 or Willy Willette at Discovery House 774-7111 for more information about the group.

5:30 p.m.-7:00 p.m. - People Living with HIV
Drop-in support group open to anyone with HIV/AIDS. Large Group Room, TAP.

Other Support Groups
Androscoggin/Oxford Counties
Tuesdays, 1:30 p.m.-3:00 p.m. - People Living with HIV
Drop-in support group. 3rd Tuesday of the month, also open to partners. Group Room at TAP Office at 1 Auburn Center, Auburn.
For more information contact Diana Carrigan at 783-4301.

Groups Resuming at TAP in the Fall:
Mixed HIV Status Gay Male Couples
A closed, time-limited support group that provides a space for both positive and negative partners to explore issues specific to their relationships. This group is limited to five couples, so please contact Victor Rash at TAP 774-6877 to sign up. Because of the success of this group, if we have enough interested couples, we will run a second group.

Heterosexual Couples Group
A closed, time-limited support group for couples with one or both partners living with HIV. This group is limited to five couples, so please contact Randy May at TAP 774-6877 to sign up.

Polarity Yoga
An open drop-in morning support group for anyone living with HIV. "Polarity yoga is based on the premise that the least amount of effort can produce the greatest results. Using movement, sound and breath, Polarity Yoga exercises the body, mind and spirit, allowing our vital energies to flow freely, bringing harmony, balance, and insight into our own truths."

Videos and Safer Sex for Men
An open discussion group for gay, bisexual and questioning men of all ages. This safe and confidential educational group will focus on safer sex today, barriers to safer activity, and skills development for healthier choices. Contact John Holverson at 774-6877 for more information.

New Groups Starting at TAP in the Fall:
Heterosexuals Living with HIV
A drop-in support group for straight men and women who are living with HIV.

HIV Negative Partners
A time-limited closed group for HIV-negative gay male partners, offering a time and place to share experiences, clarify feelings and needs, and gain strength and hope toward living and loving someone infected with the virus.

Any suggestions or questions about support groups, contact Randy May, LMSW, Case Manager, at The AIDS Project - (207) 774-6877.