

this
edition

Mid-August to Mid-September, 1996
Volume III Number V

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All this and more in this month's edition of In The Affirmative, a newsletter for Maine's HIV community.

in the **Affirmative**

THE
AIDS
PROJECT

A NEWSLETTER FOR MAINE'S HIV/AIDS COMMUNITY

our cover story

AN INTERVIEW WITH CAROL LEBLANC, TAP's DIRECTOR OF SUPPORT SERVICES by Amanda Sewall

(Editor's note: This interview was done before the change in Case Management that has Chris Monahan leaving for Toth House and Janine Collins stepping in as a new Case Manager.)

Let's set the scene...it was a dark and stormy night, wait, that's all wrong...it was another day at Coffee By Design (a place that probably thanks the lord of revenue every time they figure out their books since TAP moved across the street) between a coffee grande and a ginger peach tea. Carol LeBlanc had in front of her some notes she'd made on the questions I had faxed to her previously. I had a blank legal pad. It started something like this...

TANGENT !!! Before we start, I'd like to put in a little disclaimer. Not being as interview proficient then, as I might be now, I didn't use a tape recorder during the interview. Exact wording and phrases were difficult to

recreate, so to ensure honesty, the lovely Carol LeBlanc has proofread this article herself. Thank you and carry on.

As I was saying, it all started something like this...

Amanda: What exactly is your title at TAP?

Carol: Director of Support Services.

Amanda: Who and/or what does Support Services consist of?

Carol: Well, I supervise the Case Management Program, the Housing Program and the Student Program. We have five Case Managers on the staff: Getty Payson in York County, Diana Carrigan in Oxford and Androscoggin Counties, Steve Addario takes care of outer Cumberland County, Portland itself is taken care of by Chris Monahan, and Randy May is the Mental Health and Substance Abuse Case Manager.

(continued on page 6)

DRAPER, TREMBLAY, AND MONAHAN MOVING ON by Mike Martin

Three people who have been with The AIDS Project for several years have resigned to take on new jobs elsewhere.

Paul Draper, Director of Development for TAP, will leave at the end of August to take a new job with the Spurwink Schools. Paul was Acting Executive Director following the resignation of Deborah Shields up to the hiring of Steve Moskey. Paul has an extensive background working in the field of education and we wish him all the best in his new job.

Susan Tremblay, Associate Director of Development, is leaving by the end of August to take on the role of Executive Director at the Children's Theater of Maine. Susan came to TAP after doing development work for an AIDS organization in Atlanta. Susan is well-known for her work in theater here in the Portland area,

having recently played the female lead in the Portland Players' production of *Cabaret*. We're sure that she'll do a great job at the Children's Theater, bringing her enormous energy and talent to this new endeavor.

Chris Monahan has been a Case Manager at TAP for some time now. Chris will continue to serve the AIDS community as the new Executive Director of Toth House, formerly known as the AIDS Lodging House. It won't be too strenuous a move as Toth House's office is next door on the same floor of 615 Congress Street, where The AIDS Project is located. We wish Chris good luck in his new job.

All three of these talented people provided much needed energy, intelligence and commitment to people with HIV and AIDS during their years of service at TAP.

NEWSBRIEFS

LINK BETWEEN HERPES AND KAPOSI'S

Two research groups have gathered the best evidence yet that Kaposi's sarcoma, a cancer common among AIDS patients, is caused by a sexually transmitted herpes virus distinct from HIV. Such a connection would mean there's hope that the herpes virus can be blocked by a vaccine, even while AIDS remains incurable.

Kaposi's sarcoma, or KS, is a disease that is fairly common in homosexual men with AIDS, but rare in other populations. Two studies published in *Nature Medicine* implicate a virus known as human herpes type 8 as the cause of Kaposi's sarcoma.

TEEN SEX IN U.S.

U.S. high school students were just as likely to have sex in 1995 as in 1990, despite widespread messages about the value of abstinence.

The CDC, reporting at the 11th International Conference on AIDS, says that another message, concerning condom use, appears to have reached increasing numbers of teens.

According to the National Youth Risk Behavior Survey, 53% of the 12,000 students in the survey reported having sex in 1995, the same percentage reported in 1990. Condom use rose from 46% to 53% over the same period, with young women and blacks having bigger increases. However, condom use seems to decline as teens get older, with two-thirds of ninth-graders and just one-half of twelve-graders taking the precaution.

The survey found that students having sex started at an average age of fourteen, suggesting the need to get to teens early with information.

CONDOM USE HALVES HIV INFECTION IN MEN OF THAILAND

A condom campaign aimed at prostitutes in Thailand has proved a dramatic success, cutting HIV infections in young men in half over a five year period. Doctors at Johns Hopkins University, who have been tracking the Thai epidemic, say they hope "people making public health decisions in the world will profit from this remarkable success."

AIDS appeared in Thailand in 1988 and spread rapidly among the country's prostitutes. These women infected their male clients, who took the virus home to their wives.

By 1993, about 750,000 Thais were infected. This is about the same number as in the United States, which has four times as many people and where the epidemic has been going on for twice as long.

The Thai government began a campaign in 1990-91 to provide condoms to brothels and to educate men about the dangers of unprotected sex with prostitutes.

by the way

NOT AS CAUTIOUS AS I THOUGHT

by Mike Martin

It seems that I was none too cautious in the last newsletter. In fact, I was "Caustious", which isn't even a word. Now one can be "caustic" or one can be "cautious", but one can't be "caustious". Lucky for me my mistake was in bold headline at the top of the column last month for all to see. A dear friend pointed out my error, as only a dear friend can.

I was a bit more cautious when it came to having my picture taken for my driver's license. You see, I've been growing a little moustache/goatee combo of late, which has brought forth comments from friends like, "Oh, that interesting!" or "It's nice to experiment once and in a while." Anyway, I had to renew my license this week and decided that I couldn't live with six years of comments like those, which is the term life of a new license, so I shaved it off, smooth as butter. It's nice to be cautious once and in a while.

Not that I have too much idle time on my hands, but it occurred to me that there are no national holidays in the month of August (excluding my birthday, that is). If you don't believe me, check a calendar or an almanac. It's a crime, I tell you, but not as big a crime as say a beard/goatee combo on a 42-year old.

In this issue of the newsletter we have a terrific interview with Carol LeBlanc, TAP's Director of Support Services. Amanda Sewall did a great job with it, and I understand they both had a great time doing the interview. Carol is one of the recent changes at TAP, along with others announced in this newsletter. The theme of the interview seemed to be about change. And The AIDS Project is certainly going through some changes. New people coming on board, others leaving. Still, it is the hope of all involved that change will be a good thing, that The Project can grow to become an even better agency.

Next month, Steve Moskey, TAP's new Executive Director, will be the featured interviewee and I'll take a crack at being the interviewer.

Also next month, Amanda Sewall will write an article on Maine's Drug Reimbursement Program, a timely topic in light of the news that other states are facing huge financial strains under the weight of the costs of the new drugs, protease inhibitors, and the use of triple combination drug therapies for people with HIV/AIDS. The good news is that there are greater options in the treatment of HIV; the bad news is that they are really expensive. Still, there's hope here in our part of the world, while many countries are so underdeveloped that they spend as little as \$10 a year per person for health care on average. There are articles in this newsletter on the whole topic of drugs, treatments, new findings and the worldwide situation in the area of HIV and AIDS.

Back here at *In The Affirmative*, an interesting thing happened. Something we've not faced previously. A

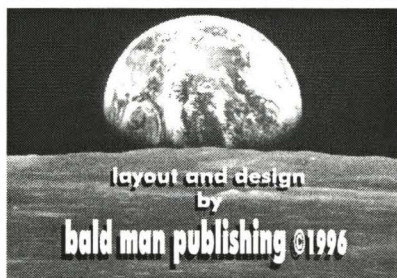
company called to offer financial support in the cost of this month's newsletter if we would include information about their company in the newsletter. It has always been the policy of this newsletter not to accept paid advertising or to endorse or appear to endorse any for-profit company. We have, in the past, done stories on organizations, other than TAP, that are non-profit; organizations such as Project Inform, Peabody House, Alpha One and Hospice of Maine to name a few. These are organizations which we have felt our readers might benefit by knowing about and which we felt were providing valuable services. However, we did those stories of our own initiative, unsolicited by anyone, and only on non-profit groups.

The company that contacted us was a viatical company, a business that does try to make a profit by hooking up people with terminal illnesses with other people willing to give them cash for their insurance policies. Of course, the person with HIV, say, does not get the full face value of his or her policy and the person buying the policy is hoping the person dies sooner rather than later to get a better return on the investment. I can understand terminally ill persons needing cash now, rather than after they're dead, but it's a moral quagmire to think about the people who invest in the hope someone else dies, and dies soon.

Still, that moral dilemma aside, it strikes me that, as much as I'd like to see this newsletter self-supporting, taking money from companies that clearly want to drum up business with the clients of The AIDS Project is not the way to go. And I was supported in this by the new Executive Director at the Project. Thank you. There are other ways to ease the cost of this newsletter, ways that are more palatable. In the meantime, we carry on every month trying to bring a good mix of news, information, announcements and interesting tidbits to our readers.

Finally, I draw attention to the little mini-bios we've been doing the past few months on the people at TAP. I must say I enjoy reading them and it is a nice way to get to know some of the people that make up Maine's largest AIDS service organization. The people who have, and will in the future, participate in this have taken a fair amount of time to sit down and answer the questionnaires sent to them. I appreciate their time and energy and their wonderful senses of humor. It's so easy to think of an organization as just an organization, but it truly is the people involved that define what it is and how it is greeted in the community. Thanks to all those participants.

Anyway, enjoy the balmy weather of August and, if you're like me, look forward to the best time of the year as fall is just around the corner.



In The Affirmative is a monthly newsletter published by the clients and staff of 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.

Contributors to this edition of *In The Affirmative* include:

Tamara Harvey, JoAnne Peterson, Steve Moskey, Victor Rash, Bethany Roma, Amanda Sewall and Jill Tacy.
Mike Martin, Copy Writer and Editor.

DEMAND FOR NEW AIDS DRUGS STRAINING RESOURCES from an AP article

The following article was recently published by the Associated Press on the demands for AIDS drugs assistance funds in other parts of the country. Next month in this newsletter, Amanda Sewall will report on the situation here in the State of Maine with its Drug Reimbursement Program.

State after state is running low on money to buy the newest, most potent AIDS drugs for thousands of low-income Americans, leaving many patients facing a possible rationing of medicine.

Washington last month became the latest state, following Illinois and Kansas, to dramatically cut its AIDS Drug Assistance Program (ADAP) as it tried to avert almost certain bankruptcy.

More cutbacks are pending as states scramble to cover the unexpected bills for today's patients, not counting the thousands suddenly demanding treatment because of headlines promising unprecedented new hope for AIDS.

And as many as 20 states haven't begun offering the newest drugs as they grapple with the costs.

"For all the folks drowning in the sea of HIV disease, all of a sudden there's a lifeboat...and when they swim to it, it's full," said Washington AIDS Director Mariella Cummings. She temporarily shut down that state's ADAP after a 76% jump in AIDS patients between January and June pushed her bills from \$53,000 a month to \$144,000. "That's the image I wake up with and go to sleep with," she said. "How are we going to get some more lifeboats in the water."

At issue are state ADAPs that buy medicine for uninsured HIV-infected people who don't qualify for Medicaid because they're not quite poor enough or sick enough. This fiscal year, ADAPs will spend \$145 million buying drugs for 65,000 Americans. That includes an extra \$52 million in emergency funds President Clinton allotted this spring in anticipation of the crisis, money many states say is all that's keeping them afloat.

ADAPs are in trouble mainly because of the new drugs called protease inhibitors that, when combined with two older drugs, are so potent that AIDS patients have their first hope of truly longer and healthier lives.

But these three-drug cocktails cost \$10,000 to \$16,000 per person per year. That doesn't count the myriad other drugs taken to fight pneumonia and other deadly illnesses that stalk AIDS patients.

And protease inhibitors have a unique problem: stopping taking them for even a month because the ADAP temporarily ran out of money can allow HIV to rapidly mutate into a virtually untreatable strain.

When protease inhibitors began selling in December, ADAPs faced a triple threat: how to afford at least one and give it to only the number of patients as they could

guarantee a constant supply, even as patients who had shunned treatment until the proteases made headlines this spring suddenly started lining up at their doors.

Twenty-nine states now offer at least one protease, and twenty-one offer all three, according to the National Alliance of State and Territorial AIDS Directors. This month, Virginia will begin offering one and Texas hopes to offer all three.

But most of the states told a NASTAD meeting last week they fear their money won't last until April 1st, when they're due to receive federal funding for fiscal 1997. President Clinton has asked Congress to appropriate \$195 million for ADAP's next year, and the states would be required to add \$65 million then.

Washington alone has \$980,000 to last until April 1, but at \$144,000 a month, won't make it, said Cummings, who is searching for a solution.

"A lot of people...were gasping" at the financial reports, said NASTAD Deputy Director Joseph Kelly.

The irony is that protease inhibitor treatment is expected to save millions of dollars in the long run as very sick patients bounce back. One preliminary study found protease treatment saved \$6,000 in other medical bills, said Richard Jeffreys of the ADAP Working Group, an AIDS activist coalition.

"Someone's got to pay," said Mike Shriver of the National Association of People With AIDS. The message to government is "you have underfunded our ability to stay alive."

Already several AIDS Drug Assistance Programs have made deep cuts. Washington's partially reopened last month, but restricts proteases to patients who were taking them before the crisis and gives new enrollees only antibiotics and certain other medicines for AIDS symptoms, not any drugs that directly attack HIV. Illinois now offers one protease, but cut 82 of the 112 other drugs that patients had been able to take, including almost every antibiotic. The ADAP is anxiously awaiting an \$800,000 from Chicago to help. In Kansas, people there can no longer enroll in the ADAP unless other patients leave the program.

NEW CASE MANAGER HIRED AT TAP

With Chris Monahan leaving for Toth House, TAP has hired Janine Collins as a Case Manager. Janine has been working at The AIDS Project for a few months through a work study program. Carol LeBlanc, Director of Support Services, said a letter would be going out to Chris's clients with this news.

Sources for some of the articles in this newsletter:

Associated Press
Portland Press Herald
USA Today
Los Angeles Times
The NAMES Project
Positively Social
Project Inform

NEWSBRIEFS

FDA APPROVES URINE TEST FOR AIDS VIRUS

The Food and Drug Administration approved the first urine test to detect the AIDS virus earlier this month. A California biomedical company developed the test which detects antibodies to HIV present in simple plastic-cup specimens.

The urine test is safer, easier and more accessible than traditional HIV blood tests, because it doesn't require needles or specially trained health-care providers to administer it, and because urine, unlike blood, poses no risk of infection.

However, urine testing is not as accurate as blood testing and anyone who tests positive must then undergo standard HIV blood testing to confirm whether he or she really has HIV, said the FDA.

MARIJUANA BUST

California state drug agents burst into the San Francisco headquarters of a controversial group that sells marijuana to AIDS, cancer and other terminally ill patients and closed the operation.

Armed with a search warrant, the agents raided the Cannabis Buyer's Club at about 7:45 a.m. on a Sunday morning earlier this month. The agents spent four hours hauling away computers, marijuana and a cabinet full of customer information. Records of some volunteers with Proposition 215, a statewide ballot to legalize medicinal use of marijuana, were also seized.

A State Justice Department spokesman said the agents had been investigating the Cannabis Buyer's Club for at least two years. Officials later said that they suspected the club was being used for distribution of large quantities of marijuana under the guise of medical treatment.

The Buyer's Club had been featured in a story on CBS's Sixty Minutes last year. The club opened again the day after the raid, albeit without any marijuana to sell.

PROTEASE COMBINATION THERAPY STUDIED

The first study to combine two of the new protease inhibitors used to fight the AIDS virus showed impressive early results, according to reports from the 11th International Conference on AIDS.

A mix of the drugs zalcitabine and didanosine reduced viral levels to a median of 99.6% in 48 patients after six weeks and caused no more side effects than either drug taken alone.

Studies reported at the conference have shown that combining a protease inhibitor with older drugs like AZT, 3TC, ddI, ddC, and d4T can be highly effective for up to a year. It is hoped that by combining protease inhibitors with one another the results will be even more effective. Used alone, zalcitabine is less potent than other protease inhibitors.

in the next issue of in the affirmative

An Interview with Steve Moskey, TAP's new Executive Director,
by Mike Martin.

A Look at Maine's AIDS Drugs Reimbursement Program,
by Amanda Sewall.

What is this volunteer group called the Maine Time Dollar Network?
by Bethany Roma.

plus more news and information for people with HIV/AIDS.

NEWSBRIEFS

HOW SOON TO TREAT HIV INFECTION ?

Scientists are taking the idea of early treatment for the AIDS virus to further extremes, even talking about treating some people within hours of their having sex with an infected person.

"We are on the speculative edge here," says Dr. Martin Schechter, co-chair of the 11th International Conference on AIDS, where extremely early treatment is being widely discussed for the first time.

Researchers reported the first results from studies in which people got anti-HIV drugs during or within a few months of a flu-like illness that marks HIV's onset. The patients saw dramatic drops of virus in their blood, scientists from Canada, the United State and Switzerland report. In some, the virus declined to undetectable levels.

Dr. Martin Markowitz of the Aaron Diamond Research Center in New York reported on 12 newly infected men treated with a potent three-drug cocktail. Of the 12, 3 dropped out of the study, and all 9 remaining in the study are free of detectable levels of the virus after four to ten months.

The audacious goal: to learn if HIV can be eradicated. After a year, doctors will run more extensive tests. If they can't find any HIV, they might stop treatment. Final answers could take years, but the latest findings about how HIV progresses "speak strongly to early intervention," Dr. Markowitz said.

Still, few get to a doctor so early. And "bringing out the big guns too early" could lead to drug resistance and unforeseen toxicities," said Gregg Gonslaves of the Treatment Action Group of New York.

Some doctors at the conference said they'll offer anti-HIV drugs to people who don't have symptoms, but know they have just been exposed to the virus. In the case of rape or a broken condom, for example. That's already done for health workers exposed to HIV.

"I'm not sure it's ethical for us not to," offer this option said Dr. Paul Volberding of San Francisco. But, he added, it's entirely unproven and "this is not a 'morning-after pill'...These are difficult therapies." Exposed health workers take the drugs several times a day for four to six weeks.

people ST TAP

A reader suggested that it would be interesting to learn a bit about the people on the staff and the board of directors of TAP. So, we asked the staff and board to fill in a little questionnaire that asks them to tell our readers a little something about themselves. Some of the questions are serious and some are just for fun, and each staff or board member was encouraged to skip any questions that didn't cause an answer to flow from brain to pencil easily. There are 20 board members and 17 staff persons at TAP, and we'll publish four responses each month.

STEVE MOSKEY, EXECUTIVE DIRECTOR

Steve is the new Executive Director at The AIDS Project and lives in Cape Elizabeth with his partner. Steve has two children, a daughter age 19 and a son age 16. Steve has a B.S., M.S. and Ph.D. from Georgetown University and did public health coursework at Harvard.

Steve says he sees his work at TAP as "bringing people, ideas, information and issues together to find and create responses to the challenges of HIV/AIDS in Maine." He says that "HIV brings people of diverse backgrounds together in a way that no other issue does." He has previously worked in non-profit academic publishing, as a public affairs officer and as a cook at a girl scout camp. He enjoys spending time with his children whenever he can, running, cooking (especially Indonesian Rijstafel), attending musical theater and surfing the Net.

His favorites include: book, *Jude The Obscure* by Thomas Hardy; movies, *It's A Wonderful Life*, *Wizard of Oz*, and *Breakfast At Tiffany's*; magazine, *The New Yorker*; TV shows, *E R*, *Seinfeld*, and any cop show; play, *Sunset Boulevard* (saw it once with Glenn and once with Betty in the lead role); color, blue; singers, Barbra and Judy; actor and actress, Bruce Willis and Susan Sarandon.

His fantasy vacation would be 2 weeks in the fall at an old country farmhouse with no electricity, only candles, oil lamps and a wood burning stove; spending the days hiking, biking, reading and cooking. The best trip he ever took was hitchhiking alone through Ireland for 2 weeks when he was 37 years old. His best meal is fried clams at the Two Lights Lobster Shack in Cape Elizabeth.

Steve's philosophy is to "recognize and respect the inherent worth and dignity of each person." He most admires B.J. Stiles, President of the National AIDS Fund, and Esta Soler, Founder of The Family Violence Prevention Fund in San Francisco. Asked who he'd choose as the 3 people he'd like for roommates and why, Steve answered, "My partner, Bob. Who else? Julia Child, so we could cook together. And Bob Villa, so all those handyman jobs I have to do would get done."

JILL TACY, ADMINISTRATIVE ASSISTANT

Jill Tacy has been at TAP about 6 months. She lives in Portland with her kitty, Cleo. Jill's goal is "to be the best darn support to case management possible." Jill, however, does a lot more, providing administrative support throughout TAP, being the Volunteer Coordinator and a big help with this newsletter. She enjoys travelling, reading and going to concerts.

Favorites include: book, *Catcher In The Rye*; TV shows, *Friends*, *E R*, and *X-Files*; color, purple. Her best trip was to Paris in 1994 and her fantasy trip would be a world tour. Her best meal was a baguette on top of the Eiffel Tower. She most admires her mother.

Her philosophy is "do what you can, but know that you can't do it all."

JOANNE PETERSON, BOARD MEMBER

JoAnne has been on the board about a year. She lives in South Portland with her husband and has 4 grown children. She hopes to "improve TAP's leadership and development of our organization, increase collaboration with other AIDS service organizations, prevention of HIV/AIDS and client services" as her goal as a board member. She's interested in HIV/AIDS because of the public health, education and medical issues involved. JoAnne serves on the Development Committee and was co-chair of the Executive Director Search Committee.

JoAnne studied Sociology at the University of Michigan and the Master's program at Fairleigh Dickinson University. She likes reading, music, family and enjoying Maine. She does a lot of volunteer work with non-profit organizations and provides consultation to non-profits. She has her own business that helps develop the effectiveness of non-profits.

Her favorites: books, *A Prayer For Owen Meany* and *Cry The Beloved Country*; movies, *Inherit The Wind* and *Gone With The Wind*; magazines, *The New Yorker* and *Architectural Digest*; TV shows, *Murphy Brown*, *Home Improvement* and *A&E*; plays, *Oklahoma* and *Streetcar Named Desire*; color, red; singers, Kathleen Battle and Pavarotti; actor and actress, Paul Newman and Meryl Streep.

She most admires Eleanor Roosevelt, Katherine Hepburn and Margaret Sanger. Her fantasy trip is a 6 to 12 month world tour. Her best trip was to St. Croix. Her best meal is either at The Osprey, Robinhood Marina or steak at Peter Luger's in NYC.

She believes "to thine own self be true." She also says that "people are our most important and valuable asset."

VICTOR RASH, COMMUNITY EDUCATOR

Victor has been with TAP about 9 months. He lives in Portland with his great dalmatian, Blaze. He has a B.S.W. from Temple University and an L.M.S.W. from Rutgers University. His goal at TAP is to expand the education and the outreach programs. He believes his work with HIV/AIDS is "challenging and rewarding. It's exciting to finally see some hope in treatments." Victor enjoys travelling, theater and reading. He says his friends "are very important family and I spend time cultivating those relationships."

Favorites include: books, *A Prayer For Owen Meany*, *100 Years Of Solitude*, and anything by Christopher Isherwood; poetry, the works of Walt Whitman, John Donne, Emily Dickinson, and A.E. Housman; singer, Joni Mitchell; actor, Richard Gere. His fantasy vacation would be anywhere with Richard Gere. His best trip so far was a European vacation. Best meal, dinner at the Grand Hotel in Paris.

He most admires his best friend, Jim Derham. Victor's philosophy is "now is all the time we have." The three people he'd choose for roommates are Jesus, for spiritual guidance and historical truth, Julia Child, for her great cooking, and Richard Gere.

take

note

ANNOUNCEMENTS

NEWSBRIEFS

HIV HOME TEST SLOW GO IN TEXAS

Texas pharmacists are wondering if the recently approved for sale home HIV kits are a dud. So far it has been for them, the first retailers to stock the highly publicized kits.

Experts say it's far too early to assess demand for the kits, which allow people to obtain and mail their own blood samples, then get results by phone.

And neither Johnson & Johnson Direct Access Diagnostics, which makes the Confide kit, or Home Access Health Corp., which just launched a similar kit, will say how they're selling through 800 phone lines.

An informal survey of Texas pharmacists, who've had the Confide kits for up to six weeks, suggests there's no drugstore stampede for a product supporters hope will boost the numbers of people tested for HIV.

"We had them for a month and did not sell even one," said Richard McClain, a pharmacist in Houston.

"We have not had anybody ask for it," said Eddie Klein, a Dallas pharmacist who, like most, advertises the kits with a store aisle display but keeps them behind a counter.

Pharmacist Anne Ballard said she sold "two or three" at the student pharmacy of the University of Texas in Austin. "We haven't heard a whole lot of interest," she said. At a nearby pharmacy, Shannon Zucca reported selling six, about one a week. She openly displays the \$38 kits.

The Confide kit is also available by phone in every state except California and New York. Call 800-843-8378. Home Access is sold nationwide at 800-448-8378. Store sales could begin beyond Texas in some chain stores nationwide by the fall.

FDA ORDERS HALT TO ADS FOR ZOLOFT

The FDA has ordered Pfizer Inc. to halt what it called the "false and misleading" promotion of the antidepressant drug Zoloft. Ads said Zoloft was recommended for depression after heart attacks, premenstrual depression and other unapproved uses. The FDA approved Zoloft in 1992 only as a short-term treatment for depression.

positive-ly social



POSITIVELY SOCIAL OF MAINE PRESENTS

THE FALL RETREAT

FOR ANYONE WITH HIV/AIDS

OCTOBER 18-19-20, 1996

FRIDAY THRU SUNDAY

\$40 (IF REGISTERED BY SEPTEMBER 15, 1996)

\$50 (AFTER SEPTEMBER 15, 1996)

INCLUDES ALL MEALS

The Fall Retreat is open to anyone with HIV/AIDS. The 3-day retreat will be held at Pilgrim Lodge in Litchfield, Maine from Friday, October 18th, to Sunday, October 20th. The Fall Retreat will be filled with fun, good company, interesting workshops, discussion groups and games. Pilgrim Lodge offers a beautiful setting on a lake, a warm fireplace and a relaxing atmosphere.

TO RECEIVE AN APPLICATION AND MORE INFORMATION CALL:

(207) 499-0166 OR

(207) 774-7630

Positively Social is a group by and for people with HIV/AIDS located in southern Maine, where members can socialize and enjoy the company of others with HIV/AIDS. Correspondence to and membership in Positively Social is strictly confidential.

REGULAR SOCIAL MEETINGS ARE HELD THE 2ND FRIDAY OF EACH MONTH AT WILLISTON WEST CHURCH, 32 THOMAS ST., PORTLAND AT 7 P.M.

LUNCH

As always, people with HIV/AIDS are invited to share a free lunch at The AIDS Project every Thursday at noon. Come and enjoy the company of others with HIV/AIDS and the staff of the The AIDS Project. Sylvia and her group of volunteers provide a healthy, nutritious, and filling lunch. It's a great meal and a great deal, so come on over.

TICKETS

Tickets to area events are often available at no cost to clients of The AIDS Project. Steve Zimmerman is in charge of handling these free tickets, so call Steve at The AIDS Project at 774-6877 for information. If he's not in, leave a message and he'll get back to you.

SOCIAL SECURITY UPDATE

Due to legally mandated changes in Social Security, persons receiving SSI or SSDI payments due to alcoholism or drug addiction will no longer be eligible for these payments. Benefits will be terminated in January of 1997, as will the benefits of Medicare and Medicaid. If you are receiving these benefits because of alcoholism or drug addiction, or if you are unsure, contact your case manager immediately. The AIDS Project will work with its clients to do all that is possible to help. Call your case manager at TAP at 774-6877.

!!! VOLUNTEERS NEEDED !!!

The AIDS Project and Peabody House are putting together a combined volunteer training to provide Direct Services to people with HIV/AIDS. Direct Services means things like helping with housecleaning, grocery shopping and other helpful chores for people with HIV/AIDS.

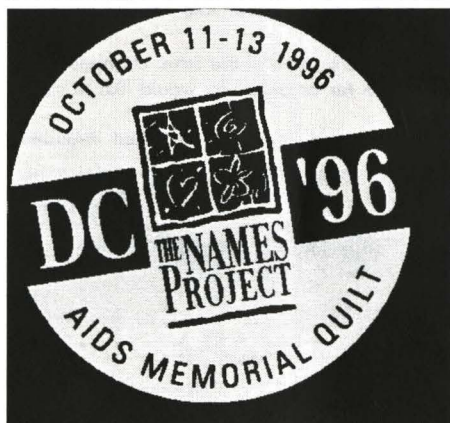
Jill Tacy, Volunteer Coordinator at The AIDS Project, and Gloria Vetro, Volunteer Coordinator at Peabody House, have set this three-day training for October 18, 19, and 26.

If you are interested in becoming a volunteer, contact:

**Jill Tacy, The AIDS Project
(207) 774-6877**

or

**Gloria Vetro, Peabody House
(207) 774-6281
for more information.**



The AIDS Quilt Goes to Washington, D.C.

October 11-13, 1996

Quilt on Display, Open to the Public, 8 am to 5 pm.

For more information contact:

The NAMES Project at 415-882-5500

or

The NAMES Project/Maine

(207) 774-2198

P.O. Box 10248

Portland, ME 04104

NEWSBRIEFS

GENETIC DEFECT MAY BLOCK HIV

Two studies have identified the gene, that if inherited from both parents, appears to render people resistant to the AIDS virus. Perhaps 1 in every 100 whites is genetically resistant, according to these studies. The findings not only explain why some people repeatedly exposed to the virus don't get it, but also offers some hope of developing an effective way to block the spread of HIV.

Earlier this summer, researchers identified a so-called cofactor, called CCR5, that is crucial to infection of human cells by HIV. Now, in studies of more than 1,400 people, teams from New York and Pennsylvania have independently found that cells from individuals who receive a copy of the defective CCR5 gene from each parent are completely resistant to HIV infection. The studies also show that those who receive a defective copy from only one parent, about 20% of the white population, appear to be more resistant to infection than others, but not completely immune.

Because the defective CCR5 gene apparently causes no adverse effects, researchers hope that a drug can be developed to block the CCR5 receptor and markedly slow the AIDS epidemic.

Originally, scientist thought people with defective genes from both parents would be about 1 in a million, but it appears to be more like 1 in 100 among Western European whites. The defect is much rarer in people from Central Africa and Japan, so rare neither team has observed it yet.

Two gay men who had been repeatedly exposed to the virus but had not been infected were studied, both were found to have inherited two mutant copies of the CCR5 gene. In test-tube studies, the men's white blood cells, a common target for HIV, were completely resistant to infection by the most commonly transmitted strains of the virus.

In these studies, whites without HIV infection were found to have the defective genes, while none of the people studied who had HIV had the two defective genes.

Scientists caution, however, that much more work will be required to absolutely verify these findings.

our cover story continued

THE INTERVIEW WITH CAROL LEBLANC

by Amanda Sewall

(continued from page 1)

Carol: The Housing Program Coordinator is Paul Lavin, and we also have a student summer work-study person named Janine Collins.

Amanda: How long have you been at The AIDS Project?

Carol: I started in April.

Amanda: Are you from Maine?

Carol: No, I'm from Massachusetts. I moved to Maine about three years ago and love it here.

Amanda: How about your background? What were you doing before you came to TAP? (A question that was really answered in bits and pieces throughout the interview, but for summation and non-confusion purposes has been collected here.)

Carol: I have an MSW from Boston College and worked for four years as a research associate for UMASS at Worcester. I did a two-year internship working with children, adolescents and families at the Eliot Clinic in Concord, Massachusetts. I worked as part of a team under an NIMH grant exploring aspects of dual diagnosis (mental health and substance abuse). I also worked for a residential program for adults with mental illness called the Wellmet Project. Also I worked at a methadone clinic for about 2 years, where I first came in contact with people with HIV. Currently, I'm working toward my Ph.D. in Clinical Psychology through the Fielding Institute. I hope to be done with that by next July.

Amanda: I can see why TAP would be attracted to you, but let's hear about what attracted you to TAP?

Carol: Well, I was really impressed with my first interview and the extent of the interview process. By the time it was all said and done, I'd gone through three interviews. Everytime I got the sense that they were looking for someone for the organization, not just someone to fill an opening. The Committee asked good questions - asked hard questions - and when I left, I felt invigorated, not drained by one more interview. I always left really hoping they'd call me back.

Amanda: Was there any particular attraction to the issues of HIV and AIDS?

Carol: Not specifically. I have a long history of education and work experience in and around health services. It wasn't HIV so much as it was working with people and working within an environment where I felt I could use my experience creatively. I wanted to work hard and do good work and also have the opportunity to progress in my field, as well as further my managerial and program development skills. The AIDS Project seemed to be a place where this could be accomplished.

Amanda: What are some of the skills you've learned in the past that you bring to TAP or you feel are essential to your role here at TAP?

Carol: I bring a lot of experience from working at the Wellmet Project, a residential program for adults with mental illness. This was a grass roots organization that started in the 60's, predating the Kennedy Mental Health bill. I started as a volunteer in the 80's and then moved into a managerial position. At that time, the entire program needed to be revamped. We developed what I believe were creative ways of planning for and executing change in a small agency. It seems to me we were doing focus groups before anyone had come up with the term "focus groups". The entire program had to be re-evaluated, especially material that fell under the category "this is the way we do this because this is the way we've always done this". This required a lot of buy-in from the residents.

Amanda: What do you mean "buy-in"?

Carol: Change is hard; it's hard for everyone. If people are going to change, they have to understand and believe in the rationale behind the change. This means they may need to have a vested interest in the outcome. We really had to listen to the residents and revamp the program around what they were saying.

Amanda: How has this helped you at TAP?

Carol: TAP appears to be in a state of transition, shedding its skin. A new Executive Director has just started and the agency's strength seems to be growing internally. There's fear that seems to stem from the anxiety around change. But if you're open and honest, really talk to those who have to go through the changes, then that anxiety can be shifted into energy to build programs which are both comprehensive and supportive.

Amanda: What are some examples of things you've changed so far?

Carol: Establishing a centralized filing system was one of the very first things the team did. This seems like a such a simple thing really, but so necessary in allowing for clear, swift communication to be available if there ever is an emergency situation with a client. Before, if a Case Manager wasn't available, and that Case Manager had a client's file, then it made handling an emergency or urgent situation very difficult. Now, because of the centralized filing system, services to a client can be much more complete.

Amanda: What are some of the other changes you've put into place so far or ones you would like to see in place?

Carol: We've been piloting new intake and disposition



The National AIDS Hotline
1-800-342-2437
The Maine AIDSline
1-800-851-2437
Teen AIDSline (Wednesdays 6-9 pm)
1-800-851-2437



which are working well. It's a way of bringing a new client immediately into the system so that they can have timely care, i.e. referrals to doctors, therapists, housing, or whatever the immediate needs are. With this new system, we hope that the immediate needs can be taken care of at the intake. The client then can be followed until their case is brought to a weekly disposition meeting at which a Case Manager will be assigned.

Amanda: It seems that, although it's the Case Managers who actually have to implement the changes, that the changes really reflect bettering services to the client?

Carol: We're all a team: administration, the providers and those who need services. I mean, it could have been dicey coming in and just changing things, but everyone's willingness to experiment and support each other has really bonded us.

Amanda: So what's next?

Carol: I hope to begin creating a stronger collaborative relationship with some of the other service providers, so that we can implement policies, procedures and referrals in the best and clearest way possible. Service provisions need to be more thorough and less repetitious. There is a need to clarify roles and referral sources. Defining boundaries would clarify responsibilities to the different needs people with HIV will have as the HIV/AIDS population becomes more diverse.

Amanda: Collaboration and networking certainly are the buzzwords of the 90's. How do you see those fitting into your organization?

Carol: The Student Program is going to provide a great opportunity for all of TAP's departments to work together. Weekly meetings with all the student interns will ensure cross-pollination of departments. It's good business for the Education Department to know what Case Management is up to and vice versa. A Case Management student can have an opportunity to work with the Education Department if they want to, maybe doing some work for the hotline or some outreach. The Education students can also work with Case Managers. It's good for all departments to know about other departments. So collaboration and networking within TAP itself will help create more cohesion within the organization.

Amanda: How do you plan to collaborate with the Counseling and Testing Department?

Carol: Doug Eaton and I have begun talking about having someone there from Case Management to meet with individuals who are receiving a positive HIV result in their post-testing session. People can react strongly and it would be helpful to have a Case Manager there who can make immediate referrals or just to provide support. (Doug Eaton is the Coordinator of Testing/Counseling and the Hotlines for TAP.)

Amanda: You certainly seem to be an intra-agency kind of woman...

Carol: I like to see the structure in place that anticipates situations, before situations happen.

Amanda: That's putting the horse before the cart! But enough about programs. I want to hear more about Carol LeBlanc and how she stays sane? What do you think your sanity ticket has been so far?

Carol: My sanity ticket is that it's all still so new. Everything's still fresh and exciting. I haven't run into that mundane dullness of doing something over and over. That's one of the reasons I came to TAP. I wanted to work somewhere that gave me the opportunity to learn new things.

Amanda: What do you think has been your biggest obstacle so far?

Carol: Change has been the biggest obstacle so far. I came into an organization at a time of change and it's hard to get a feel for an organization that's experiencing so much fluctuation. I've also been more cautious than normal when implementing changes in an already shifting organization. And, of course, funding. But all non-profits are struggling with raising needed revenues.

Amanda: What do you feel has been your saving grace so far?

Carol: That has to be the support of the team. They've all been really honest and upfront about their apprehensions around change. They know that the program is ready for change, but getting out of the "we've always done it this way" groove is difficult. No one knows what change will bring; that's the problem. But they also have a willingness to experiment with change. They give me feedback honestly and freely. The Case Managers have really just been so professional, supportive and encouraging.

Carol and I went on to chat about a number of things. Over all, what impressed me most about Carol was that she listens. Good listeners are hard to find, and those who seek out opinions of others so that they may act accordingly, are true gems. I was also impressed by how well she spoke of everyone. I don't think I heard a derogatory or judgmental word come out of her mouth for the whole hour and a half that we talked. All in all, I had a lovely afternoon, and have every confidence that this is the woman who can do wondrous things for and with The AIDS Project's Support Services department, as well as with the entire agency.

Amanda Sewall is an HIV Educator with the Red Cross and our ace reporter here at In The Affirmative.

If you have comments, suggestions or questions for and about In The Affirmative, write us at

**In The Affirmative
c/o The AIDS Project
P.O. Box 5305
Portland, ME 04101
or call (207) 774-6877**

TWO WORLDS, TWO REALITIES

News from the 11th International Conference on AIDS painted a picture of two worlds when it comes to AIDS treatment. Although the theme of the conference was "One World, One Hope", the reality of AIDS in the world is not so cohesive.

In the Western world, there's ample reason for hope as potent new drug therapies become available and dramatically suppress the virus in many people. Not everyone benefits from these drugs, and there is no cure, but there is hope.

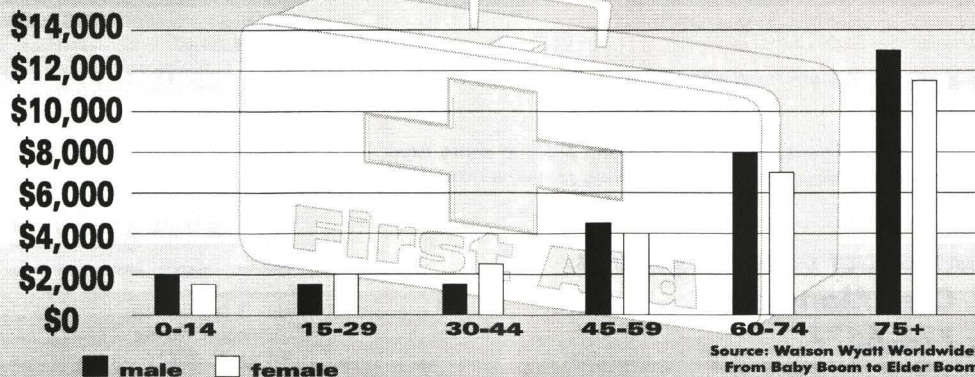
In the rest of the world, where more than 90% of infected people live, \$16,000-a-year drug regimens are unthinkable and prevention efforts are only beginning to make a dent in this expanding epidemic. A vaccine remains the best hope for this worldwide epidemic and remains a distant scientific goal.

Katherine Nyirenda of Zambia spoke to the conference. She is 24 years old and has AIDS. She said, "I will return home to be with my two young sons in a country where only a tiny few can dream of ddI and AZT. My impression is that the North is sick of poverty and death in Africa. Many may think that suffering is normal for us, but it isn't. We hurt and grieve and hunger as much as you would, and we hate disease."

The reality is that treatments so far are really out of reach for most people with HIV. Even in the world of developed nations, doctors are seeing many people who are failing on the new treatments and they don't always agree on the best treatment. Many doctors feel it's best to treat early and with the strongest drugs possible. Others worry this aggressive approach could prove to be toxic over time, or that patients will develop resistances to the drugs leaving no future options.

Some statistics concerning rates of HIV infection from UNAIDS and the CDC report 22 million infected worldwide, between 650,000 to 900,000 in the U.S.. Yearly infections are about 3 million worldwide and 40,000 in the U.S.; daily infections 8,500 worldwide and 111 in the U.S.. There are now 9 licensed anti-HIV drugs and the yearly cost of anti-HIV drug therapy runs up to \$16,000. There is no vaccine available for HIV.

Annual Health Care Costs in the United States: By Age and Sex.



support groups

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 is cosponsoring 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 Willie 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 Tuesdays 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. This group will begin the second week of September.

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. This group will also begin the second week of September.

Polarity Yoga

An open morning drop-in 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.

THE AIDS PROJECT

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