

in this issue

► page one

Our cover story: The importance of being earnest about taking HIV drugs.

► page two

By The Way: Editor Mike Martin's monthly meanderings.

► page three

Short takes: HIV News in Review.

► page four

TAP Support Groups.
The TAP List of People.

All here in this April edition of
In The Affirmative.



The good folks at Peabody House are sponsoring a celebration of Frannie Peabody's 95th birthday. The public is invited to join the celebration, which will be held on Sunday, April 19, 1998, at the Portland Museum of Art from 7:00 to 9:00 p.m.

Cake, ice cream, a tribute to Frannie, and a performance by the Maine Gay Men's Chorus will be served up in honor of this great lady's birthday.

Come and join the fun and help make this a spectacular evening.

Contact Peabody House at 774-6281 for more info.

a in the affirmative

THE AIDS PROJECT

a newsletter for Maine's HIV/AIDS community



Volume V Number IV

Mid-April to Mid-May 1998

cover story

The Importance of Being Earnest About Taking HIV Drugs

Editor's note: The following article appeared in the newsletter Maine AIDS Care, published by the AIDS Consultation Service (ACS) of Maine Medical Center. It is written for physicians caring for people with HIV/AIDS and talks about the importance of patients taking their HIV medicines as prescribed, meaning taking the right doses at the right time all the time. This is an issue of great importance to people with HIV; also, it is interesting to read the advice given to physicians who care for people with HIV/AIDS by the ACS, one of whose jobs it is to stay on top of HIV treatment issues.

The level of compliance with antiretroviral drug regimens can have a dramatic effect on the success of the treatment. Patients who are compliant with at least 90% of their antiviral medications had the best chance of achieving dramatic and long-term viral suppression, while those who missed more than 10% of their medications clearly had less success. There are few other illnesses that have such dramatic consequences in terms of taking medications correctly or incorrectly.

The safest way to use antiretroviral drugs is to take all doses or, if there are any problems, to stop taking the drugs completely. Intermittent dosing, or missing one or two doses per day, is the worst approach and is associated with a high risk of causing resistance to treatment.

Several factors influence compliance. The simplicity of the treatment regimen has a major impact. Compliance increases when treatments are given once or twice instead of three or four times daily. The patient's perception of the severity of their illness is another important factor. People who understand that HIV is a serious illness with serious consequences may be more likely to be compliant than those who in their denial view their illness less seriously. The side effects of the regimens are also important. People taking these regimens must understand that many side effects are transient and can be managed. Also, people who have contact with peers who are taking the regimens successfully may be more likely to adhere to their own regimens.

Consistency of dosing is important. The emergence of resistance is much more likely in a person who takes less-than-adequate amounts of drugs than in a person who stops

taking the drugs entirely. Without the presence of the drugs, there is little reason for the virus to develop resistance.

Once resistance to a particular protease inhibitor occurs, it is very difficult to overcome that resistance by increasing the drug dosage. It appears that once the effectiveness of a drug is gone, it is gone for good. The other issue is cross resistance to other protease inhibitors. Patients who develop resistance to one protease are less likely to respond fully to others.

There are some ways to try and maximize compliance. Have several discussions with the patient before starting medications. This helps both the doctor and the patient assess the likelihood that they can stay on the necessary schedule and dosage. Go through a typical day, hour by hour, and tell the patient exactly which meds to take at what time each day. Write it down for them so that they can see the details. Make the schedule personalized to the times they wake up, go to sleep, eat their meals, go to work, etc.

Also spend time discussing the risk for side effects, and what to expect regarding them lasting, diminishing, or being managed; and talk about how to manage them.

Ongoing reinforcement is also essential. Do follow up calls, provide coaching, and monitor their compliance by having them keep a log, do pill counts, etc.

Finally, it is important to tailor treatment recommendations to the patient's likelihood of compliance. It might be better to use a less taxing regimen, rather than risk resistance to the regimen that technically might hit the virus the hardest. Discuss all options with the patient and make the decision collaboratively. This will bring you a better chance for success. ■

medical assistance 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 an individual client can receive in any fiscal year. Contact your case manager for assistance by calling TAP.

i. v. league support group update

Meetings for the I. V. League support group are:

Wednesdays, 8:00 to 9:30 a.m.,
Discovery House, Portland.

Wednesdays, 6:30 to 8:00 p.m.,
Community Resource Center, Portland.

Contact the City of Portland Public Health Division at 756-8257.

the AIDS project's mailing address

When writing to The AIDS Project 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

by the way by Mike Martin

The clocks have been turned back and the snow is gone. It feels a lot like spring to me. It is a new season of hope. (And I am hoping we don't have one last surprise snow storm!)

Ten years ago this month I tested positive for HIV. It seems a long time ago, yet not so very long ago that I can't remember the details. I remember my doctor having a couple of tears in his eyes when he told me the results. I remember my doctor setting up an appointment for me with Dr. Michael Bach. I remember the shock of it all, but not being surprised. I remember thinking I would die in the not-too-distant future, probably of some horrible opportunistic infection. I remember the determination on my mother's face when she told me she didn't think I would die from AIDS. She had a sense of hope that was hard for me to relate to, yet here I am ten years later.

Along the way from there to here, I've met a lot of great people. People with HIV/AIDS, and people who care about people with HIV/AIDS. I'd just like to talk about two of them.

First is Steve Schuit. Steve was on the Nominating Committee when I interviewed to be on the Board of The AIDS Project two and a half years ago. Due to his family, business, and volunteer work, Steve just resigned from TAP's Board. I'll miss his presence on the Board because he is an exceptional person. He is the kind of guy who sees a problem or a conflict and immediately starts thinking of ways to resolve it. He has served TAP well through his work on different committees of the Board, such as Personnel and Search. His ability to really listen and then brainstorm solutions is something I try to emulate. We'll miss him at Board meetings. Thanks, Steve, for all your good work.

Second, but not least, I'd like to talk about Tamara Harvey. She is leaving TAP this month. Tamara has been an administrative assistant/development assistant during her time at TAP. She, too, is an exceptional person. She has a kind heart, a sweet voice, an agile mind, and she gives great hugs. She came to TAP in a time of need and has fulfilled that need admirably.

Tamara has proofread every issue of In The Affirmative since she arrived. We share the knowledge that no matter how careful we both are in putting the newsletter together, we always end up with at

least one mistake. The world is not perfect and neither are we. I've always appreciated the time and effort she has put into this newsletter. It won't be the same without her.

And she has done phenomenal work in the Development Office. The success of TAP's fundraising is very much a reflection of the countless hours she has put in. The recent success of the Art Auction is a tribute to her fine work.

As she proofreads this last newsletter, let me just say to her, "Love ya, darling."

On the front page of this month's newsletter is an article on the importance of people with HIV/AIDS to take their drugs compliantly. It is an issue so very important because of the virus' ability to develop resistance to the various drugs if they are not taken correctly. And drug resistance is not good.

Recently, I spoke at Southern Maine Technical College with Sandy Putnam of the ACS and two other folks like myself with HIV. We spoke to a nursing class about the treatments for HIV and our own experiences being HIV-positive. In the first part of the morning, Sandy spoke alone and I listened intently as she told the nursing students about the risks of drug resistance if patients are not compliant in taking their meds. In particular, she spoke of the knowledge that resistance to one protease inhibitor could well mean resistance to all other protease inhibitors. Compliance in taking these meds, and other HIV drugs, Sandy said, is very, very important.

As you will read in the article on the front page, it is now accepted that it is better not to take these drugs than to take them improperly. While just a short while ago protease inhibitors were being handed out like candy (my words, not Sandy's), doctors are more carefully assessing who should take them, based in part on a person's ability to follow the schedule and dosing requirements. It truly is a case of "if you're going to do something, do it right!"

We all want to live a long life. Perhaps as long as Frannie Peabody, who turns 95 this month. The folks at Peabody House are throwing her a very public birthday party, the details of which appear elsewhere in this newsletter. So, happy birthday to you, Frannie. We love you very much. And thanks for all you do for people with HIV/AIDS. ■

next issue

a *in the* **affirmative**
a newsletter for Maine's HIV/AIDS community

mid-may 1998

short takes: HIV/AIDS news in review

The first case to involve HIV/AIDS has been heard by the U.S. Supreme Court. It involves a Bangor dentist who refused to fill a HIV-positive woman's tooth cavity in his office, saying he would only do the procedure in a hospital. The woman sued for discrimination under the American With Disabilities Act. The justices could rule anytime before the court's term ends in late June or early August.

The government has recommended using a new HIV test that gives results instantly rather than a week later. Under current testing, nearly 700,000 of the 2 million people in the U.S. who get tested each year do not return for their results. The new test takes about ten minutes and, it is hoped, will eliminate the loss of those 700,000 non-returnees. Since it is estimated that there would be about 8,000 people who receive false-positive results, (meaning the test says they are HIV infected, but they really are not) the more traditional blood test will be done on anyone testing HIV-positive to verify the diagnosis.

A majority of blacks consider AIDS the nation's most pressing health problem. AIDS is the leading cause of death in black men and women between the ages of 25 and 44. Forty percent of all new AIDS cases are among blacks, while they make up only 12 percent of the population. Annual AIDS cases in black men is 6 times higher than in white men.

You can take some foods with the drug Crixivan, so says Merck, the company that makes the drug. However, the food cannot exceed 65 grams of carbohydrates, 5.7 grams of protein, 2 grams of fat, or 301 calories. Some suggested snacks for folks who don't tolerate Crixivan well without food are:

- 2 fig bars and 1 cup of juice;
- or 1/2 cup of dry cereal with 1/2 cup of skim milk and a 1/2 of a banana;
- or 1 English muffin or toast and 1 tablespoon of jam (no butter!), 1 cup tea or coffee with 2 tsp. of sugar;
- or 1 corn tortilla, 1/2 cup of steamed rice, and 3 tablespoons of salsa.

Global health experts are trying to work out a strategy for giving AZT to HIV-infected mothers-to-be in the developing world. Last month the U.N. reported that giving the drug to HIV-infected pregnant women for the last month of their pregnancy and during birth can cut virus transmission by 51%. It is estimated that 2 million women carrying the virus will become pregnant this year in the developing world. Without AZT treatment, it is estimated that 400,000 HIV-positive infants will be born. With AZT treatment, half (or 200,000) of the babies would be spared infection.

Early tracking of HIV aimed at identifying people in the earliest stages of infection is being debated across the country. The CDC may make recommendations on tracking individuals who

are HIV-positive in the next few months, possibly tying tracking compliance to federal funding. Currently, most states only require reporting of people who have an AIDS diagnosis.

Most AIDS groups and the ACLU are on record as opposing name-based tracking while some AIDS groups endorse tracking by either numbers or codes. Part of the emphasis on early reporting is the change in treatment options for HIV. It is now recommended that treatment begin as early as possible; and health officials want to reach the newly diagnosed to make sure they are aware of treatment options.

There is great concern over the confidentiality of any tracking system, and some argue that any HIV tracking would be low because as many as half of the people in this country who are infected with HIV haven't been tested or don't know their status.

The York County AIDS Network (YCAN) announced it has abandoned its goal to create rotating anonymous HIV testing sites in York County. YCAN is a collaborative team of people from many York County agencies, and they will continue to provide services and care for people with HIV and AIDS. There are currently only two anonymous testing sites in York County. They are at the University of New England in Biddeford Pool and Planned Parenthood in Sanford.

The Vermont People with HIV/AIDS Coalition with sponsor a retreat for people with HIV/AIDS in Plainfield, Vermont from Thursday, June 4, to Sunday, June 7. It will be their 8th annual gathering.

Workshops on Social Security, Insurance, Acupuncture, Tai Chi, and many other topics will take place during the retreat, which is entitled "Turning Hope Into Action."

For more information contact the VTPWA Coalition at P.O. Box 11, Montpelier, VT 05601-0011 or call them (in Vermont only) at 1-800-698-8792 or (elsewhere) at 1-800-229-5754. The cost of the retreat is \$75.

There is confusion around the issue of when to stop taking drugs meant to prevent opportunistic infections. Now that many people with HIV are seeing increased T-cell counts due to triple combination therapies, doctors are not sure if it is OK to stop taking drugs meant to prevent opportunistic infections and that were started when T-cell counts had dropped to those levels where the CDC recommends prophylaxis drugs. There are cases of people getting opportunistic infections such as CMV, PCP, and MAC (among others) with T-cell counts previously thought to be too high for people to worry about. Studies are being done, but are not completed. Until then, the current recommendation is to continue using preventative treatments based on the lowest T-cell count a patient has had.

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.

AIDS hotlines

Questions about HIV? Call toll-free
National AIDS Hotline: 1-800-342-2437
Maine AIDSline: 1-800-851-2437
Maine Teen Hotline: 1-800-851-2437
(on Wednesdays from 6-9pm)

tap on the internet

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

immediate seating

For free tickets to area events as they become available, sign up with Robert for "Immediate Seating." Robert can be contacted directly on Friday afternoons by calling TAP at 774-6877, or you can call other times during the week and leave a message for him.

free lunch

Enjoy a free lunch at The AIDS Project every Thursday at noon. Join other clients and TAP staff for a great meal, fun conversation, and good company.

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for people
infected and affected
by HIV/AIDS

TAP support groups

tuesdays

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: **1:00 p.m. to 2:30 p.m.**

Dates: **2nd and 4th Tuesdays**

Group: **Women's Drop-in Support Group**

A bi-weekly meeting of women living with HIV/AIDS or directly affected by the disease (through spouse/partner, parent, or child). Sponsored by 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 information.

thursdays

Time: **10:00 a.m. to 11:30 a.m.**

Group: **HIV Infected/Affected Drop-in Group**

A TAP-sponsored meeting for people infected 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 information.

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.

Wellness and You...

...is a collaborative fitness program from The AIDS Project and the University of New England.

For information on how to join, contact your case manager at The AIDS Project.

Ed Shannon has sent along some of comments made by the participants of the Wellness and You program. So here are some -- usually desperate and sometimes memorable -- quotes (with the names changed to protect the healthy).

"Judy, I can't do this. I hate getting up in the morning anyway. And besides, my morning big head and big hair takes too much time to brush out."

"Monte, I can't do this. Since my PCP I kinda look like Mr. Potato Head. Stick arms and legs and a big belly. No way! I can't ever look good. Not like when I used to look soooooo ...good!"

"You know, after my workout the other day, I felt kinda like my whole body got a good flushing. That familiar clogged up feeling is all gone."

"Hey, are these my abs? If they are, it'll be the first time in 10 years since I've seen them."

The Wellness and You program just might be for you. Check it out. Call your case manager!



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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sources for some of
the material in this
newsletter are:

Maine AIDS Care

Portland Press Herald

Sanford News



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