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In the Affirmative, Vol.6, No.7 (Mid-July/ Mid-September 1999)

Mick Martin

The AIDS Project

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The FTC Warns Against Some Home HIV Test Kits

Washington Post (06/19/99)

The U.S. Federal Trade Commission has issued a warning about some home HIV tests sold over the Internet.

In a consumer alert, the agency cautioned, "Using one of these kits could give a person who might be infected with HIV the false impression that he or she is not infected." FTC tests showed that, when a known HIV-infected sample was used, the tests indicated that the sample was not infected.

While Internet advertisements have falsely stated or suggested that the kits were cleared by various well-known health groups, the U.S. Food and Drug Administration has approved only Home Access Health’s Home Access Express home HIV test kit and the World Health Organization does not approve or license HIV tests, the FTC said.

An Alarming HIV Statistic

Washington Post (06/22/99)

Up to 25 percent of the estimated 650,000 to 900,000 HIV-infected individuals in the United States may be unaware of their infection.
Disregarding the dangers of assuming too much (since we all know what happens when we assume), let me highlight some of summer's correct and incorrect assumptions.

If you thought that the number of new clients coming to The AIDS Project for case management services dropped during the summer, you would be wrong. New intakes of clients traditionally increase in the summer. This year is no exception. So, if you thought HIV takes a vacation in the summer, think again.

However, if you thought that I would be taking a vacation from doing this newsletter, you would be correct. I always take the month of August off from publishing this newsletter. It has something to do with summer and something to do with my birthday. I’ll turn 45 in August. I presume you’ll understand I need the break. But the newsletter will be back in September, as always.

I always think that I won’t have enough news and information for another month’s newsletter, but then I always end up with more than I have room for. You would think I would presume correctly, given reality. I assume I will presume correctly next time. I am particularly pleased with the article about the Maine AIDS Hotline written by Doug Eaton, the Hotline’s coordinator. TAP runs the Hotline and the article by Doug is interesting reading.

I always assume you, our readers, know that TAP welcomes volunteers. In particular, you might think about volunteering to work on the Hotline.

Anyway, when putting together this newsletter, I always assume that what is news to me is news to most of you. That’s why I put so many articles about HIV in each month. I never assume that I know it all, and I assume you don’t either. The article about bad home HIV test kits advertised on the internet is something I assume you want to spread the news about. As we encourage more and more people to be tested, we need to make sure they get reliable testing, because I do assume that those of us with HIV are, by this very fact, educators to those around us.

On a lighter note, I always think that my lawn mower will break down at least once a summer. It did. Last week. It’s nice to know that some things can be counted on to happen just when you are in the middle of a job.

I want to mention last month’s Gay Pride Parade in Portland. I assumed that something unpleasant might happen. That someone in the crowd would yell out some offensive comment, that sort of thing. But I didn’t hear anything of the sort. The AIDS Project participated in the parade with clients, staff, board members, and family and friends wearing spiffy-looking TAP t-shirts as they marched from Monument Square to Deering Oaks. I particularly want to mention the good work done by TAP staffers David Aaron Swander and Daniel Schnorbus and TAP Board Member Michael Burnham in organizing TAP’s participation. And hats off to the folks who manned TAP’s information table in Deering Oaks that day. Nice work everybody.

So I have presumed and assumed your indulgences long enough. I hope you all have an enjoyable summer and that this fleeting season of sun and sea and summer squash rejuvenates your spirits and puts a little color into your life. As the song from the 70’s says, “See you in September.”

Sources for some of the information in this newsletter include:

Portland Press Herald
USA Today
Maine Bureau of Health - HIV/STD Program
CDC Hotline Community Bulletin
CDC National Center for HIV, STD, and TB Prevention

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HIV in Maine: Change in Reporting of HIV Cases

The following is the text of a memo sent out on June 25, 1999 to "Health Care Providers Involved in HIV-Antibody Testing" (and others) from the Maine HIV/STD Program. This memo confirms the new rules for reporting HIV cases in the state and why the rules are being put into place. The bottom line of the rules change is to better track HIV cases in Maine, to get a better handle on the scope of the disease as it now exists in the state.

Information provided by AIDS surveillance activities helps to identify how HIV is spread, the types of people most at risk for HIV transmission, and their regions of residence. This information is crucial for planning and evaluating effective HIV prevention programs, understanding patient needs for medical care, and securing fair and adequate funding for service needs and prevention education.

Today, nearly 20 years after the inception of AIDS surveillance, many thousands of people are benefitting from significant advances in the treatment of HIV disease. People with HIV are living longer, healthier lives, and fewer individuals are developing AIDS. As a result, AIDS surveillance information is providing increasingly limited insight into an evolving epidemic, and no longer adequately represents those populations most affected.

Because of this trend, many states are now using HIV data to supplement information provided by AIDS case reports. HIV data is useful because it provides information about the epidemic at an earlier stage than do AIDS case reports. In order to more effectively use Maine HIV data, the Maine Bureau of Health will be enhancing its HIV reporting requirements.

Currently, Maine providers are required to report confirmed, positive HIV tests with demographic information such as date of birth, county of residence, race, gender and HIV risk information. Under the current system, patient name reporting is not required for HIV, but is allowed. Beginning July 1, 1999, providers will be required to report either the name of the patient testing HIV-positive or a representative patient identifier code (called a Soundex code). State sponsored anonymous testing sites are exempted from this change in reporting rules. (All AIDS diagnoses must continue to be reported using patient name.)

Using a patient identifier will help the Bureau of Health to improve the quality of its HIV data collecting efforts and avoid duplicate reporting. Further, it will provide a fuller understanding of HIV disease progression by allowing us to link HIV and AIDS case data. This vital information will assist us as we plan and implement activities which prevent future transmission and care for those infected.

HIV Vaccine News

Breakthrough Offers New Hope for AIDS Vaccine

Nando Times Online (06/22/99)

An international team of researchers has found a link between HIV and key proteins the virus uses to attack cells, and they have developed a vaccine based on their discovery. HIV requires receptors, including the CD4 receptor and CCR5 proteins, for access into cells. Tests revealed a very close link between CCR5 and CD4 but not between other proteins and receptors involved in HIV's infection process. The study, published in the Proceedings of the National Academy of Sciences, notes that previous research suggests that those with naturally defective CCR5 genes can resist HIV infection.

The Field of Vaccine Candidates

American Medical News (06/14/99)

There are about 40 experimental HIV vaccines in clinical trials worldwide, although AIDSvax has progressed the farthest. For fiscal year 1999, the National Institutes of Health is spending $194 million in an effort to find a viable vaccine. The most common approach to a vaccine involves putting HIV genes into canarypox, where it replicates HIV protein, giving the host immunity. A more controversial method involves using a whole killed or live-attenuated virus for vaccination. Most vaccines successful against viruses have used either whole killed or live-attenuated vaccines; however, HIV enters cell genes and remains there permanently, complicating matters. Other possible HIV vaccines are using salmonella or the cowpox virus to induce immunity.

Scientists Say Too Few Are Volunteering for AIDS Vaccine

Minneapolis Star-Tribune Online (07/01/99)

In Minnesota, Twin Cities researchers are having trouble enlisting people for VaxGen's HIV vaccine trials. So far there are 130 volunteers but the goal is 300. According to the researchers, volunteers appear reluctant to sign on, in part, because AIDS seems more manageable to many and because of reservations about the vaccine. VaxGen is having trouble recruiting nationally as well, having only attained 65 percent of its 5,000-volunteer target.
Spotlight on... Maine AIDS Hotline
by Douglas Eaton

The Maine AIDS Hotline office is located in Portland, the largest city in the state. Established in 1984 and later funded by the CDC with a grant through the Maine Bureau of Health, the Maine AIDS Hotline is mandated to provide statewide HIV information and referral services to all populations in Maine. The state of Maine is considered a "rural" state by most accounts, with a total population of just over one million people. Nearly one half of the total population lives in the southernmost counties of York and Cumberland, which constitutes less than one third of the total area of the state.

It is interesting to track calls coming from rural areas and compare them to calls received from more urban centers. Callers from urban areas tend to request referrals for anonymous test sites, ask questions about HIV transmission, want clarification about the window period for HIV antibody testing, etc. Call volume from rural areas is less than the volume of calls from urban areas. The character of calls from rural areas often reflects the isolation many people feel living in bucolic areas, especially if they don't "fit in" with the dominant culture.

Rural callers often utilize Hotline workers as a sounding board for stories of frustration and even despair. A caller who live in the northernmost reaches of Maine calls the Hotline on a monthly basis just to check in with somebody who "can talk his language" (his words). Questions about sexuality, safer sex, and "finding" somebody are the usual topics of conversation with this man. His calls generally last about 30 minutes or more. This is not an atypical call; many male callers who are in their mid to late forties are seeking their first same-sex encounters and haven't the vaguest idea about how to connect with other men.

Many callers who disclose desiring same-gender sexual activity are currently in heterosexual marriages or are recently divorced. Since the population of Maine is so sparse, many people in a community are aware of each other's personal matters. In this environment it may be difficult for some men to own their homosexual feelings. They may find themselves accepting the paradigm of heterosexual marriage complete with children, only to experience a resurgence of their homosexual desire later in life. Hotline workers are encouraged to address issues of prevention and risk reduction without judgement about same-gender sexual activity revealed during this type of call. Risk reduction and prevention messages are given from the perspective of the callers having control of their own health. However, if a caller wants to explore their feelings concerning sexuality, the Hotline worker is trained to listen empathetically and provide appropriate referrals to community centers that offer a means for people to connect with each other.

Other callers from the rural reaches of Maine paint a vivid picture that safer sex messages haven't gotten to a large segment of the rural populations of Maine, especially to those in their late 30's and 40's. One caller reported that five of his "buddies" were sitting around drinking beer and watching a porn movie -- "now we're all married you know" -- he hastened, and one thing led to another and they ended up engaging in unprotected oral sex with each other. The combination of substance abuse, homophobia, guilt, denial, and lack of information about safer sex can be life threatening. The training of Hotline workers includes the use of the "reflective listening" tool. Hotline workers reflect back to the caller the risk activity the caller has described using the same terminology or slang and then proceed to engage the caller in appropriate dialogue about condom use or other protection methods. The use of the word "activity" is encouraged rather than "behavior" when discussing risk.

Hotline workers on the Maine AIDS Hotline are certainly learning a lot about the lively rural landscape of their state! It is this writer's opinion after four years of hotline work that the Hotline serves as a lifeline to rural populations. These populations may under-utilize the Hotline, but it is a vital resource to those who have taken the first step in education themselves about HIV.

AIDS Hotline is Seeking Volunteers

Doug Eaton, Hotline Coordinator, is seeking applications from qualified volunteers to fill vacancies on the Hotline. Doug feels that using clients as Hotline workers would enhance the service that the Hotline provides to those wanting information about transmission, safer sex, and referrals to testing sites.

If you would like to talk with Doug about this opportunity, give him a call at 775-1267 or 1-800-851-2437. If you get the answering machine, please leave a message and Doug will get back to you.
F.D.A. Approves Abbott AIDS Drug

New York Times (07/01/99)

Nearly a year after Abbott had to halt the sale of the capsule form of Norvir because of production-related problems, the company said it won FDA permission to sell a soft-gelatin capsule form of the AIDS drug. Since last July, Norvir has been available only in liquid form, but Abbott said the newly approved version would be available for consumer use soon. The capsules can be kept at room temperature for 30 days, but Abbott is encouraging patients to keep the product refrigerated.

Seminal HIV May Persist Despite Response to HAART

Reuters (06/28/99)

A study published in the June issue of Clinical Infectious Diseases underscores that HIV DNA and protease inhibitor-resistant mutations can emerge in the semen of patients receiving highly active antiretroviral therapy (HAART) for HIV. Investigators found that 9 percent of HIV-infected men studied had detectable cell-associated HIV RNA after one month of HAART and that 5 percent had cell-free HIV RNA. In addition, six months after HAART was started, indinavir-resistant mutations were reported in the seminal leukocytes of one patient, and a patient who had switched to saquinavir displayed protease inhibitor-resistant strains in seminal and blood leukocyte DNA specimens. Investigators warn HIV-infected individuals that neither triple combination therapy, nor undetectable levels of HIV load means that one should not avoid mucosal exposure to HIV-infected semen.

UN Calls for Boosting AIDS Protection for Women

Reuters (06/22/99)

UNAIDS officials are calling for more aggressive research into anti-HIV microbicidal gels for women. The agency said that it has sponsored clinical trials of an anti-HIV microbicide in Benin, Ivory Coast, South Africa, and Thailand since 1996, with little success according to early findings. However, independent experts reviewing the trial have advised continuing the study, which includes about 2,000 women at high risk of HIV infection. UNAIDS noted that 23 microbicides are now in testing for use against AIDS.
Just So You Know...

Mark Your Calendars!

The Women's Leadership Luncheon to benefit The AIDS Project will be held on Thursday, October 7, 1999.

The 14th Annual Spring for Life Art Auction to benefit The AIDS Project will be held on Saturday, March 25, 2000.

Just So You Know...

It has come to our attention that there is a website for HIV-positive heterosexuals. The site is sponsored by the New England Hetero Society. The site provides information and online support groups for heterosexuals with HIV and AIDS. It came to our attention while attending an HIV educational session with AIDS Response to the Seacoast in Portsmouth and from a client who had heard of the site.

To access the site, go to:
www.hetero.net

(Editors Note: I have no firsthand knowledge of this site, and I caution anyone going anywhere on the internet to be careful about revealing personal information, such as your name, address, phone number, etc. The internet is still largely unregulated and users should proceed with extreme caution.)

HIV News

Senate Approves Health Care for Disabled
New York Times (06/17/99)

The Senate passed the Work Incentives Improvement Act in a vote of 99 to 0. The bill, which garnered bipartisan support, discourages discrimination against people with disabilities in the workplace and gives America's 8 million disabled individuals incentive to take higher paying jobs. Provisions in the bill include allowing people who return to work to keep their Medicare coverage; enabling people with disabilities to buy Medicare coverage if their income would have previously disqualified them; allowing people who would have lost Medicare coverage due to improved health to pay to maintain coverage; and letting states provide Medicaid coverage to people with physical or mental conditions that are "reasonably expected" to become severe if no health care is available, such as people with HIV who have not yet developed symptoms. Indeed, AIDS Action's Daniel Zingale lauded the measure as "a huge victory for people with HIV."

No Gay Man Deemed Fit to Give Blood
Washington Post (07/06/99)

Debate continues to rage in the United States over whether men who have sex with men should be able to contribute to the nation's blood supply. U.S. blood banks have been asking men whether they have had sex with men since 1985; however, current research shows that gay men are no longer the group with the fastest-growing number of HIV cases. Critics say that the blood donation questionnaire stigmatizes homosexuals and encourages donors to lie, as well as sending the wrong message to the public about HIV risk groups. Due to new screening techniques, the nation's blood supply is safer than ever, with an estimated one in 600,000 to one in 1 million units of donated blood that is HIV-infected and avoids detection. The government remains concerned about HIV-tainted blood being donated while the virus is still undetectable. To this end, a five-year exclusion law is being considered for men who have sex with men. If the exclusion policy is adopted, it would increase much-needed blood donations by about 58,000; but it would also increase the number of tainted blood units that have to be detected in labs from 1,000 to 2,200.

HIV News

New York Study Finds Gay Men Using Safer Sex
New York Times (06/28/99)

A survey by New York City officials and Gay Men's Health Crisis (GMHC) last year indicates that homosexual men in New York City are significantly cutting back on risky sexual behavior. The study involved 7,650 gay and bisexual men between the ages of 12 and 88 in New York City. About one in seven participants were HIV-positive, compared to studies showing one infection in three in 1985. In addition, about nine out of 10 participants reported having been tested for HIV, with eight in 10 saying that they had been tested at some time during the three years preceding the study. The study found that men over 60 and under 24 were less likely to have been tested. Also, according to the NYC AIDS prevention planning group, use of condoms for first anal intercourse increased to about 78 percent compared to 34 percent in 1985. While investigators say the study indicates that prevention is working, they also note that more efforts must be made to extend the message to non-white gay men. Black and Hispanic homosexual men were found less likely to engage in risk reduction behaviors. As a result, GMHC officials are more aggressively targeting minorities with prevention efforts.

Many U.S. Teens Unaware of HIV Risk
Reuters (06/24/99)

A report by the Kaiser Family Foundation indicates that American teens are well aware of HIV prevention, but some still engage in risky behavior. The study was a part of a focus groups and interviews with teens at risk in four urban areas. The report also noted that if teenagers are in a youth-friendly, respectful situation, and confidential HIV testing option is offered, the majority would accept.

Next Issue

Mid-September 1999

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Viaticals: Warnings to Investors, Caution to Sellers

Editor's Note: Viaticals came of age during the height of the AIDS epidemic. For many years, it was not uncommon to hear of people with AIDS in Maine selling their life insurance policies to viatical companies for quick and needed cash. The following articles look at the business from the investors point of view. What these articles don't point out is that sellers are increasingly getting a smaller return on their policies as sellers live longer.

Viatical settlements are as safe an investment as a Savings Bond or a certificate of deposit. That's been the pitch some viatical firms have used to snag investors, regulators say. But the investments can be fraught with risks, regulators and consumer advocates warn.

Viatical (from the Latin word viaticum for "provisions for a journey") settlements are supposed to work like this: Terminally ill patients sell their life insurance policies to viatical settlement firms in exchange for a portion of the death benefit in cash. Patients often use the cash for medical expenses not covered by insurance or for other living expenses. The viatical settlement firms, in turn, sell the patients' policies or portions of the policies to investors at a discount to the death benefit.

The popularity of viatical settlements soared in the 1980s with the rise of AIDS cases. Now, the use of protease inhibitors is extending the lives of AIDS patients. Because of that, investors today are often misled about how long policyholders can expect to live, regulators say.

Gloria Grenning Wolk, author of Viatical Settlements: An Investor's Guide and operator of a consumer website (www.viatical-expert.net) says states need to come up with regulations for viatical settlements. She says that would also help differentiate legitimate firms from frauds.

Potential investors, regulators say, should be aware that:

> Life insurance companies may contest death benefit payments on policies less than two years old for a variety of reasons.

> Medical advancements may substantially prolong the life of the insured. The advent of the AIDS "cocktail drugs" is an example.

Investments in viatical settlements are highly illiquid. There is no established secondary market.

The National Association of Insurance Commissioners is preparing a pamphlet to be distributed later this year with tips for consumers about buying viaticals.

-In The Affirmative, 5/99

Selling viatical settlement contracts to Maine investors is now subject to state security law. Governor Angus King signed a bill, which was written and advocated by the Maine Securities Division, in May. A viatical settlement contract is an investment in the life insurance policy of a terminally ill person. The terminally ill persons sells the policy for cash and then the investor or investors collects the death benefit when the person dies.

The investments, largely unregulated in the United States, have become increasingly popular over the past few years. Some companies are now expanding the concept beyond people with terminal illnesses and are purchasing life insurance policies from the elderly. Nationwide, various states regulators are looking to clamp down on the industry, but Maine is the first to enact such a law.

Christine Bruenn, state securities administrator, said her department has seen increasing evidence of fraud and a lack of disclosure regarding risks. Viatical contracts have often been pitched as a guaranteed investment.

The new law requires that people selling viatical settlement contracts to investors must disclose that it is impossible to predict the actual death date of a terminally ill person, the possibility that the investor may have to pay additional money to cover premium costs, and the possibility that the policy may be contested.

-In The Affirmative, 5/99

**AIDS Update**

AIDS Cases Since Reporting Began

| Deaths: 410,800. | Deaths: 466. |

Maine AIDS Cases by Gender

| Male: 763 (90%) | Female: 90 (10%). |

AIDS Cases Diagnosed in Maine

in 1999: 5.

AIDS Cases Reported in Maine


(Main includes cases diagnosed before 1999, but not reported till 1999.)

Maine AIDS Cases by Race

| Native American: 1% | Asian/Pacific: <1% |
| Hispanic: 3% | Black: 3% |
| White: 93% | |

Maine AIDS Exposure Categories

| Child of Parent with AIDS: 1% | Transfusion/Blood: 1% |
| Hemophilia/Coagulation: 3% | MSM and IDU: 3% |
| Unidentified: 7% | IDU: 11% |
| MSM: 66% |

Statistics are from the Maine Quarterly AIDS Update from the Maine Bureau of Health, HIV/STD Program in Augusta.
SUPPORT GROUPS
FOR PEOPLE INFECTED AND AFFECTED BY HIV/AIDS

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.
Contact TAP at 774-6877 for more info.

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

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

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.
Contact TAP at 774-6877 for more info.

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

WELLNESS AND YOU PROGRAM
A stress reduction and physical activity program
designed for people living with HIV/AIDS. In this program
individuals can participate in a variety of supervised
physical activity, education, and specialized stress
management segments. Contact Daniel at TAP at 774-
6877 for more information.

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

THE MEETING ROOM
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.

I.V. LEAGUE
Meetings of the I.V. League support group are held on
Thursdays from 10:00 to 11:30 a.m. at First Parish Church
at 425 Congress St. in Portland. (Use the right side entrance
and ring the bell.) This group is for IV Drug Users past and
present.
For more information, call Steve Farrell at 874-8775.

For more HIV information, try checking out these websites.
www.thebody.com
www.hivpositive.com
www.projinf.org
www.aidsproject.org

TAP's York County Clients
Can Access The Internet
York County Clients of TAP can use the computer at its Kennebunk office to
access the internet. Call Denise Ferer at 985-8199 to set up a time to use the
computer.

Also, clients can now e-mail TAP's Kennebunk office at:
www.tap2@mail.javanet.com

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

TAP ON-LINE
Visit our new website at: www.aidsproject.org
To e-mail The AIDS Project,
send your message along to:
tap@aidsproject.org (Portland)
or tap2@mail.javanet.com (Kennebunk)

The Ille-Kosutic Duo will be performing a concert,
"Music & Literature: Literary Inspirations" to benefit The
AIDS Project. The concert will be Friday, August 20,
1999 at the First Parish Unitarian Church on Congress
Street in Portland. The performers, flutist Nina Ille and
pianist David Kosutic, first collaborated as students at the
Indiana University School of Music where they worked
extensively with noted chamber coaches Rotslav Dubinsky
and Luba Edlina of the Borodin Trio. The AIDS Project is
honored to be chosen as the beneficiary of this concert!
Tickets ($10, $25, $50, $75, $100 donations) may be
purchased on the night of the event at the First Parish
Church. Tickets are also available through "Immediate
Seating" at The AIDS Project. Anyone interested in volun­
teeering to help with this event, please contact Demetra
Giatas at TAP (774-6877).