

BA Fights

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with a name-based reporting system, there would be only a single list of names under strict security at the local health department, and there have been no documented breaches in security of reported information for any communicable disease at public health departments in the state's history. The confidentiality problem posed by the regulations is especially ironic, since confidentiality concerns have been the chief justification for non-name reporting of HIV.

In its conclusion, Beyond AIDS recommended that "...the proposed regulations be scrapped in favor of a name-based reporting system, the only type of HIV reporting system currently accepted by the CDC for counting of data...and the only type that can contribute to improved prevention of further HIV transmission."

In subsequent developments during January 2002, Beyond AIDS has assisted in the development of proposed California legislation to require an evaluation of any non-name HIV reporting system by mid-2003 regarding its ability to meet federal standards. The bill would require a prompt switch to a different reporting system if the coded system is failing. A resolution along the same lines has also been prepared for the California Medical Association House of Delegates meeting of February 22-26. ▲



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WINTER/SPRING 2002



Winter/Spring 2002
Volume II, Number 4

BEYOND AIDS
Lifeline
The Quarterly Newsletter of Beyond AIDS: Reversing the HIV Epidemic Through Sound Public Health Policy

Coming Up...

Beyond AIDS Goes
to Washington—

- Meetings with
Government
Policy Leaders
- East Coast Intern
Workshops
- Nettie Awards
Presentations
Washington, DC
...October 2002
Washington, DC

World AIDS Day
...December 1
2002

Events nationwide, see
www.worldaidsday.org

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Beyond AIDS Annual Meeting Cites
Achievements, Pledges Action



Members and seminar attendees pay rapt attention to presentations at the Annual Meeting while George Johnson videotapes.

Members from California and other states gathered in Ventura from Friday, November 30 through Sunday, December 2, 2001, for the Annual Meeting of Beyond AIDS, and to mark World AIDS Day. During the weekend conclave, they celebrated the remarkable recent achievements of the three-year-old organization, welcomed and trained eight new interns, presented five awards, and conducted educational presentations on various aspects of HIV and bioterrorism (see separate articles on last two items). The organization also committed itself to further legislative and public policy activism directed toward its mission of reversing the HIV epidemic through sound public health policy. The program had been rescheduled from September due to the events of "9-11."

The program began with a Friday night gathering at the home of President Cary Savitch, MD. California Assembly Member Dennis Mountjoy attended and offered to support renewed efforts for prenatal HIV testing legislation. Vice-President Ron Hattis related his experiences delivering emergency medical care at the Ground Zero (site

of the World Trade Center disaster). On Saturday, December 1, red ribbons were distributed in honor of World AIDS Day, and original AIDS quilts honoring individuals who died of the disease were displayed.

In a rapid series of reports, the members were informed of the incorporation in Virginia of the Beyond AIDS Foundation to utilize tax-deductible contributions for education and research. They learned about the significant improvements accomplished in the federal Ryan White CARE Act under the leadership of retiring Congressman Dr. Tom Coburn and Congressional aide and BA Board member Roland Foster.

A report on the prenatal testing bill initiated by the organization, Assembly Member Bob Pacheco's AB 2809, noted that it had been successful in passing the California Legislature but that it had unfortunately been vetoed by Governor Gray Davis. Ron Hattis reported on action in various states to promote name-based HIV reporting, including representation on the commit-

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you for your
generous
support of our
mission—
stopping the
spread of HIV.



Publisher
Kardon Pover, Inc.

President
Cary Savitch, MD

Vice President
Ron Hattis, MD

Treasurer
Yvonne Pover

Communications Mgr.
Dede Raver

611 Pennsylvania Avenue, NE
#1600
Washington, DC 20003-4303

Internet
Ron Voith, Webmaster

E-mail:
BeyondAID/inc@aol.com
www.beyondaids.org

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Annual Meeting

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Tasneem Husain, Ariel Stevenson, Alexis Stevenson, and Wes Bettger, Beyond AIDS interns, work the registration desk.

tee overseeing Oregon's reporting system, which took effect October 1; encouragement of plans for name-based reporting in Pennsylvania; and opposition to California's non-name reporting proposal. In subsequent discussions, the members indicated their interest in reintroducing prenatal testing legislation if practical. They reaffirmed Beyond AIDS' opposition to California's attempt to introduce HIV reporting by secret codes (see separate article).

George Johnson reported the results of the recent election, on behalf of the Nomination and Election Committee. Cary Savitch will continue as President, Ron Hattis as Vice-

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After 20 Years of AIDS, HIV Prevention Efforts Begin to Focus on the Infected

Number of HIV-Positive Men Having Unprotected Sex Rises

Since April, at least three Iowa men have told police they believed Aaron Dahlberg when he told them he was HIV-negative before having sex with them without the use of condoms. Now Dahlberg faces up to 25 years in prison if convicted of an Iowa charge of criminal transmission of HIV. Dahlberg is free on \$35,000 bond. Karen Egerton, a prosecutor for Iowa's Johnson County, said all of his accusers have so far tested negative, although the law doesn't require that victims be infected in order to prosecute. While Dahlberg says he's innocent, others say the case illustrates a disturbing new trend. After nearly 20 years and millions of dollars spent on AIDS awareness, an increasing number of HIV-positive gay and bisexual men are having unprotected sex, experts say.

"We're really five years behind the times in this," said Bob Tracy, community affairs director of the Minnesota AIDS Project. "Folks at the national level are saying we need to address this, but it just hasn't reached the community planning process yet."

Since the beginning of AIDS awareness nearly two decades ago, HIV prevention efforts have almost exclusively targeted one group: the uninfected. Now, better treatment allows

HIV-positive people to live longer lives. But the improved medicine also introduced an unexpected and unwelcome problem: a rise in the number of HIV-positive gay and bisexual men having unprotected sex. The trend has forced the Centers for Disease Control and Prevention and the National Institutes of Health to rethink its target audience. The CDC's education plan through 2005 now includes "a priority on prevention" for HIV-positive people.

Russ Lovaasen, a healthy-looking Minneapolis, Minnesota resident, has lived with HIV for 19 years. Sometimes he drops clues, such as sporting a rainbow-colored necklace adorned with a red ribbon, the international AIDS-awareness symbol. When he wore the necklace to a Twin Cities gay bar, he was shunned. But the second he removed the ribbon, he said, numerous men approached him. For many HIV-positive people, Lovaasen said, the fear of rejection fuels the decision to keep quiet. Sometimes that means putting others at risk. "The whole process of disclosure is a burden that's not always able to be carried by people who don't have the emotional or ethical resources to do it," he said.

Simon Rosser, director of the HIV/STI

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does not meet federal standards by then (unless the state is granted more time to comply), only AIDS cases and not the more numerous HIV infections that do not qualify as AIDS would be considered in the distribution of federal money.

Beyond AIDS testified that "...Non-name reporting does not facilitate partner notification, linkages to treatment and other services, prevention case management including assistance with behavior modification to prevent transmission, or assistance with medication compliance. Name-based reporting can facilitate all of these essential public health functions. As a result, the proposed reporting system will continue to permit untold numbers of new infections that would be preventable by a name-based reporting system." A name-based system "would treat HIV infections the same as over 80 other reportable diseases and conditions" in California.

The organization protested that the regulations would prohibit a health care provider from

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and health
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reporting a patient's personal information, which "creates a new legal barrier to proper communication between physicians and health departments regarding appropriate referrals and...public health outreach to infected persons. For any other reportable diseases, such a restriction would be deemed outrageous and a dangerous impediment to the statutory duties of the Health Officer as well as to the practice of good medicine."

The new draft requires the provider to maintain a list of names of persons testing HIV positive with their corresponding codes. That is necessary so that when the health department asks the provider for further information, such as risk history, for the case with a particular code, the provider's office can look up the correct patient chart. The cross-reference list would actually threaten patient confidentiality, noted the testimony, citing concerns in a published analysis by the Centers for Disease Control of problems with non-name reporting systems in two other states. In contrast,

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Membership Application/ Donor Form

Beyond AIDS, Inc.

Beyond AIDS Foundation

611 Pennsylvania Avenue, NE #1600
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Beyond AIDS Fights CA's Secret Code Reporting Plan

On December 26, 2001, Beyond AIDS submitted written testimony opposing the second draft of proposed California regulations that would make HIV reportable by secret "non-name" codes. The organization had earlier joined with other organizations and individuals in March 2001 to oppose the original proposal, which would have required physicians and other health care providers ordering an HIV-related test to construct a 17-digit code for each case of HIV that did not meet the criteria for AIDS.

On December 1, at the Annual Meeting, the consensus of the membership present was that Beyond AIDS should continue its opposition to the state's efforts to impose such coded reporting. The organization voted to continue to oppose the regulations, and to support legislative efforts to change the reporting system if it is adopted but proves inadequate.

In the newer version of the regulations released by the state Department of Health Services on December 6, the code is just as long, but portions

Beyond AIDS will continue its opposition to the state's efforts to impose coded HIV reporting.

of it would ordinarily be constructed by the testing laboratory. However, in order for the laboratory to be able to do this, the provider must include five different items of information when ordering a test. If the result should come back positive, the laboratory would report the result with the partial code to both the provider and the local health department. The provider must then add four social security digits to complete the code and submit it to the local health department. In both versions, anonymous testing would be preserved and would not be reportable.

Beyond AIDS warned that the new reporting system could cost California hundreds of millions of dollars in lost federal revenue. The complexity and sheer length of the required codes was "impractical and prone to numerous errors, especially in the private sector." As a result, the organization warned, the reporting system was unlikely to meet federal criteria for such things as completeness, accuracy, and timeliness of HIV reporting by July 2004. According to the 2000 Ryan White Care Act, if a state's reporting system

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Anthrax, AIDS Featured in Educational Program

The Annual Meeting of Beyond AIDS in Ventura, California included a "Medical and Legal Update" on HIV and bioterrorism, on December 1 and 2, 2001. Lectures providing up to five continuing education credit hours for physicians, nurses, and allied health professionals were provided, with sponsorship by Community Memorial Hospital of San Buenaventura. Assistance was received from several pharmaceutical companies including Lilly, Merck, Pfizer, and Schering, with others possibly contributing later. Educational sessions were mingled with business during the two days of meetings at St. Catherine by the Sea.

"Previous Beyond AIDS meetings had included educational presentations, but this was the first time we were able to grant credit..."

"Previous Beyond AIDS meetings had included educational presentations, but this was the first time we were able to grant credit..."

"Current Medications for Patients with HIV," in which James Brown from Bristol-Myers Squibb, Maggie Hermoso, RN from Roche, and Barbara Bentley from Schering participated. Attorney Karen Darnall spoke on "HIV and the Law: What California Healthcare Providers Should Know."

On December 2, the program focused particularly on training and orientation of the new interns, with a smaller attendance of physicians and nurses than on Saturday. Dr. Hattis gave a presentation on "Plague, Politics, and Public Health: An Epidemiological Overview of HIV," which was intended to have been completed by lunchtime but extended into the afternoon to accommodate questions and discussion that were generated.

Evaluations showed that the participants enjoyed the program. "We hope that this will be a precedent for future meetings and a special draw for health professionals to attend," said Dr. Hattis. He expressed appreciation to Community Memorial Hospital, the pharmaceutical companies, and the Sisters of St. Catherine by the Sea. ▲

Annual Meeting

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President, and Yvonne Pover as Treasurer. Holly Vioria was elected Secretary, Linda Doyle rejoined the Board as a Director, and Nettie Mayersohn and Jody Deramus were reelected as Directors. Roland Foster was commended as an outgoing Board member who had contributed greatly, both through his work on federal legislation and as Editor of the electronic newsletter HIV Updates, which now has both domestic and international versions. The separate Foundation Board, appointed by the main Beyond AIDS Board, will consist of Savitch, Hattis, Vioria, Pover, and Doyle.



The AIDS quilt display at Ventura meeting, World AIDS Day.

Dianharma reported on progress in Tacoma, Washington, under the leadership of crusading health officer Federico Cruz-Urbe of the Tacoma-Pierce Health Department who had pressured that state to include names in its reporting system and is now promoting routine prenatal testing. The membership voted to support Dr. Cruz's efforts.

The new interns present introduced themselves. They were Wesley Bettger and Betsy Kidder who had traveled from New York, Tasneem Husain who had flown in from Washington, DC, and Californians Jacob Haik, Tina Kao, LeAnne Johnson, Ariel and Alexis Stevenson. Their bright enthusiasm helped invigorate the meeting sessions. Other attendees then also gave personal introductions, including a poignant story from Bruce Kasper about the death



Sister Stephen Purcell



Beyond AIDS thanks the sisters of St. Catherine by the Sea for their wonderful hospitality.



Holly Vioria, Beyond AIDS Intern Program coordinator.

of his daughter Monique. As her body sickened from a mysterious illness, she and her parents were never informed that a donor of a blood transfusion she had received had later developed AIDS.

Beyond AIDS Board and state Assembly Member Nettie Mayersohn gave a live audio greeting from New York, telling the group that its efforts are unique and essential to improve the public health response to HIV/AIDS. Cary Savitch reported on international outreach including his trip to Japan, and his visit to the Gates Foundation in Seattle which is planning efforts in Africa.

The final Saturday events included an open Board meeting at which strategy for Beyond AIDS in 2002 was planned. A delightful dinner then honored the interns at the historic Biltmore Hotel in Montecito, a beachside community near Santa Barbara.



Ron Hattis and James Brown after panel discussion on HIV medications. (See Anthrax, AIDS, page 6).

Sunday, December 2 activities featured a workshop for the interns. This resulted in the selection of valuable project areas for their part-time volunteer work during the coming year.

Ron Hattis also demonstrated safe injection syringes designed to prevent reuse (a source of many Third World HIV and hepatitis infections) as well as needle stick injuries.

The Saturday and Sunday meetings were hosted by St. Catherine by the Sea, a retirement community for Catholic sisters. Sister Stephen Purcell coordinated the arrangements. Beyond AIDS expressed its sincere appreciation for free use of this beautiful facility, and to several pharmaceutical companies that covered the costs of refreshments and meals. ▲

Five Honored for HIV Prevention Work



Neena Ananda, crystal Nettie Award recipient (second from right), her family, and Pam Savitch, (second from left).

On December 1, the first five “Nettie Awards” were announced by Beyond AIDS, to individuals who had made outstanding humanitarian contributions to the cause of HIV prevention and control. The awards are named for Nettie Mayersohn, a courageous state legislator who has been a pioneer in HIV public health reform in New York State, and a founding Board member and inspiration for Beyond AIDS.



Cary Savitch, center, congratulates Joella Cudney and Robert Pacheco as they display their awards.

California Assembly Member Robert Pacheco and his former aide Joella Cudney accepted their awards in person. Both were honored for carrying and fighting for California Assembly Bill 2809, which passed the legislature but was vetoed by the Governor in 2000. The bill, initiated by Beyond AIDS, would have made it easier to test pregnant women for HIV so that they and their babies could

be treated to prevent the babies from becoming infected. A similar bill has since been reintroduced to the 2002 state legislature by Assembly Member Roderick Wright.

Dr. Federico Cruz-Urbe, health officer of the Pierce-Tacoma Health Department in Washington state, was honored for his leadership in making HIV reportable in his county and subsequently in the state, for pioneering effective prevention case management for infected persons, and for efforts to prevent newborn HIV infections. He was represented by Dian Sharma, who described his work and played his inspirational video message to Beyond AIDS. Former Congressman Tom Coburn, MD was

recognized for outstanding work in the U.S. Congress for HIV prevention and treatment. Dr. Coburn co-authored the Ryan White CARE Act renewal of 2000, and was responsible for numerous new provisions encouraging states to report HIV and to test pregnant women, and improving accountability for the use of federal prevention and treatment funds. Beyond AIDS has subsequently endorsed Dr. Coburn’s selection by President Bush to co-chair the Presidential Advisory Commission on HIV/AIDS (PACHA).

The most unusual and elaborately designed award was presented to 14-year-old Neena Ananda, with her parents at her side, for her spectacular benefit performance for Beyond AIDS of Indian dances in May 2001 (when Neena was only 13). The past year’s activities of the organization would not have been possible without this fundraiser. A video excerpt from the performance was played at the December 1 meeting. The entire Ananda family was thanked for presenting this event and for selecting Beyond AIDS as the beneficiary. Three additional persons have been selected for awards by the Board since the Annual Meeting, and will be announced in the next issue. ▲



Dr. Coburn’s Nettie award.

The awards are named for Nettie Mayersohn, a courageous state legislator who has been a pioneer in HIV public health reform.



Thomas A. Coburn, MD

Assemblywoman Mayersohn to U.S. Centers for Disease Control & Prevention: “Shame on You”

Rates of perinatal HIV transmission continue to drop in New York and 99.4% of all HIV exposed babies born in the state are accessing medical care, according to new data from the New York State Department of Health AIDS Institute.

Assembly member Mayersohn, the author of the Baby AIDS law in New York State, expressed her delight at the obvious success of the New York law, which requires that all newborns be routinely tested for HIV and parents be notified of the test results. Mayersohn, however, voiced her disappointment that the Centers for Disease Control and Prevention continues to resist supporting the enactment of a national Baby AIDS policy. “Shame on CDC,” she said. “How many more babies must be lost to HIV in the states without a similar safety net before the CDC and the AIDS advocates put aside their political and ideological agenda that stand in the way of saving lives.”

Mayersohn noted that the claims of opponents of the legislation have been completely discredited. “All the dire predictions that pregnant women would flee the health care system if New York State enacted a Baby AIDS law have proven false. Women are getting tested in higher numbers, more women are receiving prenatal care, and lives are being saved. Without this law, which went into effect in February 1997, these children would have gone unidentified and untreated—and countless babies would have died needlessly from this horrible disease.”

Assemblywoman Mayersohn further noted that the percentage of pregnant women being tested for HIV in New York is “steadily increas-



Nettie Mayersohn

“How many more babies must be lost to HIV in the states without a similar safety net before the CDC and the AIDS advocates put aside their political and ideological agenda that stand in the way of saving lives?”

ing.” As of June 2001, hospital data found that 93 percent of all women giving birth in the State knew their HIV status before delivery. Mandatory prenatal HIV counseling was an integral part of the state’s newborn screening laws. In comparison, the national rate of pregnant women being tested for HIV has stagnated. In 1998, the national average peaked at 60 percent and dropped to 56 percent in 1999.”

According to the New York Health Department data: Of the 4,022 HIV-exposed infants identified under the law since 1997, 99.4 percent have had follow-up medical care. The number of seropositive New York City newborns has dropped to the lowest rate ever recorded. In all, 830 HIV-infected women gave birth in New York State in 2000. This represents a 56 percent decrease from 1990. If the HIV status of a women admitted for delivery in New York is unknown, expedited HIV testing must be offered to the mother or performed on her newborn immediately after birth and test results must be available within 48 hours

According to the AIDS Institute, rates of perinatal HIV are decreasing as a result of testing and treatment to prevent transmission. Studies have found that administering the AIDS drug ZDV (AZT) to a woman during pregnancy and delivery, or even to a child immediately following birth, can dramatically reduce transmission from an infected mother to her child. Newer medication combinations are even more effective.

Mayersohn said that she expects the success of New York’s law to spur the introduction of federal legislation to require routine HIV testing of newborns in every state. ▲

Infected

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Intervention and Prevention Studies Center at the University of Minnesota, said “very, very few” people with HIV want to pass it on to others, so they’re willing to take precautions. “But every now and then, you just want sex to be spontaneous, beautiful, wonderful. That’s what people with HIV want, too. I’m not saying it’s right or wrong—it’s just something to understand,” Rosser said. Minnesota has a similar law

“...every now and then, you just want sex to be spontaneous...”

to Iowa’s against HIV transmission, but it’s rarely used. The Minnesota AIDS Project’s legal services program receives about half a dozen calls a year from people whose partners did not disclose they were HIV-positive until after having unprotected sex. “If the person is negative, we try to counsel them away from legal action,” Tracy said. ▲

[Associated Press, 8/13/01]