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.
**Annual Meeting**

continued from page 1

**BA Fights**

continued from page 6

The organization protested that the regulations would “create a new legal barrier to proper communication between physicians and health departments…”

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**Membership Application/Donor Form**

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**BA Fights**

continued from page 6

the uninfected. Now, better treatment allows

hiv-positive people to live longer lives. But the

improved medicine also introduced an unex-

pected and unenviable 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 Preven-

tion and the National Institutes of Health to

trink it’s target audience. The CDC’s educa-

tion plan through 2005 now includes “a priority

on prevention” for HIV-positive people.

Russ Lovasen, a healthy-looking Minnesotta-

ian, 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, Lovasen said, the fear of

rejection fuels the decision to keep quiet.

Sometimes that means putting others at risk.

Not everyone agrees. Lifeline’s Robert Posner

continually approaches strangers to let them

know he has HIV. Others say it’s not always safe

to make public their HIV status.

For any other

regarding appropriate referrals and…public health

outreach to infected persons. For any other

reporting systems in two other states. In contrast,

the new draft requires the provider to maintain

a list of names of persons testing HIV positive

with a particular code, the provider’s office

can look up the correct patient chart. The cross-

reference list would actually threaten patient

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cerns in a published analysis by the Centers for

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Disease C
Beyond AIDS Fights CA/Secret Code Reporting Plan

On December 20, 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 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 new version of the regulations released by the state Department of Health Services on December 6, the code is just as long, but portions of it would only 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 so-called “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 proves inadequate, Beyond AIDS will continue its opposition to the state’s efforts to impose coded HIV reporting.

Beyond 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 21 hours of continuing education credit for physicians, nurses, and allied health professionals were provided, with sponsorship by Community Memorial Hospital of Santa Barbara, Assistance was provided, with sponsorship by Community Memorial Hospital of San Buenaventura. Assistance was provided, with sponsorship by Community Memorial Hospital of San Buenaventura. Assistance was provided, with sponsorship by Community Memorial Hospital of San Buenaventura.


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. Matts 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. Matts. He expressed appreciation to Community Memorial Hospital, the pharmaceutical companies, and the sisters of St. Catherine by the Sea.


The Saturday and Sunday meetings were hosted by the Sisters of St. Catherine by the Sea. The meeting sessions were connected with the planning efforts of the state’s Annual Meeting.

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President, and Yvonne Paver as Treasurer. Molly Vikoria was elected Secretary. Linda Doyle rejoined the Board as a Director, and Kjetil Mayersohn and Jerry Darsem 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, from left, Matts, Vikoria, Paver, and Doyle.

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

Beyond AIDS thanks of the daughters of St. Catherine by the Sea for their wonderful hospitality.
Five Honored for HIV Prevention Work

Four 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.

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California Assembly Member Robert Pacheco and his former aide JoEllia 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 Rodenick Wright.

Dr. Frederico Cruz-Urube, 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 Dr. Neena Ananda, crystal Nettie Award recipient, and her family, and Pam Savitch, (second from left).

Assemblymember Mayersohn, the author of the Baby AIDS law in New York, was honored for the obvious success of the law, which requires that all newborns be routinely tested for HIV and that 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, "I am 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 healthcare 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."

Assemblymember Mayersohn further noted that the percentage of pregnant women being tested for HIV in New York is "steadily increasing, with 95 percent of all women giving birth in the state knowing 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-infected infants identified under the law since 1997, 99.4 percent have had follow-up medical care. The number of seropositive New York State newborns has dropped to the lowest rate ever recorded. In all, 850 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 woman 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. Never 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.

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

"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?"

Infected continued from page 2

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 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 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 who want HIV testing but are afraid they will be stigmatized. "The person is negative, we try to counsel them away from legal action," Tracy said.

(associated Press, 8/13/01)