



BEYOND AIDS Lifeline

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

Coming Up...

Beyond AIDS
Annual Meeting
...June 6-8, 2003
Ventura, CA



Our hosts with Cary at St. Catherine By the Sea

Beyond AIDS
Nettie Awards
Presentations
...June 7, 2003
Ventura, CA

Special Workshops
...June 8, 2003
Ventura, CA

What's Inside

President's
Message 2

Nettie Awards 4

CDC Moves to
Routine
HIV Testing 5

Prenatal Testing Bill
Revived in
California 5

Membership
Application 7

Routine Prenatal
HIV Testing in
Netherlands
Praiseworthy 8

Beyond AIDS Goes to Washington

Delegation Meets with White House, Surgeon General, Other Leaders

L-R: National AIDS Policy Director Joseph O'Neill, NY Assemblywoman Nettie Mayersohn, Counsel Bill Viscovich, and Pat Ware, Executive Director of the Presidential Council on HIV/AIDS, at the White House.



A multi-state delegation of Beyond AIDS leaders held a series of important meetings with federal leaders in Washington, DC and Rockville, MD, October 28-30, 2002. The delegation members presented the organization's recommendations on HIV control to White House, Health and Human Services, and Congressional officials. Participants were gratified by positive responses to our issues, and an apparent willingness of the current administration and House leadership to make progressive changes in HIV prevention strategy.

On Monday, October 28, Yvonne Pover and Barbara Ledeen from the greater Washington area, and Ron Hattis from California, met with former Board member and *HIV Update* editor Roland Foster at the House of Representatives and presented him with the Nettie Award (see story, page 4). Foster now works for a subcommittee there that has been influential in pressing for reform of government HIV/AIDS policy.

Dr. Hattis also discussed HIV issues with staff

See Washington, page 3



Bill Viscovich makes a point to CDC Director Julie Gerberding, MD.

A Leadership Role at CDC HIV Summit

About a hundred top HIV leaders and organization representatives from around the U.S., including members of Beyond AIDS, met in Atlanta on December 4 and 5, 2002 for an HIV Prevention Summit. The leadership group was convened by the Centers for Disease Control and Prevention

See CDC Summit, page 6



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



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President's Message

Could HIV Control be as Easy as ABC?

The HIV pandemic continues its advance in most parts of the world, with millions more at risk in populous countries of Asia and no evidence of control in most parts of Africa. But in Uganda and a few other countries including the Dominican Republic, there is evidence that HIV incidence and prevalence are actually coming down. What is the secret?

The Bush Administration has been especially interested in the Uganda story. It sent a delegation to study the issue, and has based its new global AIDS initiative in large part on the strategy used in Uganda. Worldwide attention is now being focused on this poor East African nation. Yet, in the 1980s, the prospects for Uganda appeared bleak. A McNeill-Lehrer TV report in the early 1990s showed entire villages decimated by AIDS, with only old people and young children surviving. But in 1986, under the leadership of President Yoweri Museveni, a revolution was launched to change the country's sexual mores. The message was what has become known as the ABC model: A) Abstain. B) Be faithful if you are already in a sexual relationship. C) Use Condoms if A and B fail.

The results were impressive, if not astounding. Between 1988 and 2000, surveys showed a dramatic decrease in sexual activity of 15-19 year olds, and in the number of sexual partners nationwide. In 1995, about 10 percent of Ugandan respondents reported having a casual sexual partner, down from almost 30 percent in 1989. Young women aged 15-17 were less likely to have ever been sexually active in 2000 than in 1988 (34% vs. 50%); among 18-19-year-olds, the proportion dropped from 81% to 77%. Among men, a decline occurred among 18-19-year-olds; 59% were sexually active in 2000 compared with 71% in 1995. This major decline in casual sex resembles a similarly large reduction in HIV prevalence, from 15 to 5 percent between 1991 and 2001.

While condoms were a part of this strategy, surprisingly they were a minor factor in the success story. Some increases in condom usage have occurred in single people, but few married couples use them. This is of some concern, as according to a report from the Institute for Youth Development, an estimated 40% of new HIV infections in Uganda are occurring in married individuals, $\frac{3}{4}$ of which are due to one partner having been infected before marriage. Elsewhere in the world, while condom use has had localized successes, such as a reduction in new infections of prostitutes in Thailand, most countries relying on condoms without changes in sexual behavior have had little success in controlling HIV transmission.

Edward C. Green, a medical anthropologist from the Harvard School of Public Health, and author of a new book "Rethinking AIDS Prevention," commented on the



Uganda experience in the *New York Times* on March 1, 2003:

"When Africans are asked how they have changed their behavior in the face of AIDS, the great majority don't talk a lot about condoms. They talk about becoming monogamous, says a 2002 United Nations study that summarized years of research. Furthermore, young people report waiting until they are older to begin sex...The ABC approach is not about that great conversation-stopper, 'abstinence only.' It is about

providing people with more options for preventing AIDS. Some people cannot or will not change their behavior, and so of course they need to use condoms. But while condom use was one of the options Uganda has promoted, faithfulness to one partner is probably the major contributor to the country's success...It's true that conservatives favor this approach, but that doesn't mean it doesn't work."

Beyond AIDS is not committed to a religious or ideological approach to HIV prevention. We support what works. Apparently the "ABC" approach does, at least in Uganda. Abstinence alone is not the answer, though avoidance of exposure is the most effective prevention and the Uganda experience shows that abstinence should be a backbone of any prevention program for young people. Certainly condoms alone are also not the answer, although condoms are important for those who are unable to be abstinent or to remain in a mutually monogamous relationship with a non-infected partner, and for couples in which one partner is already infected. What is needed is a comprehensive approach involving delay in onset of sexual activity, maintenance of faithful sexual relationships, and the use of condoms as a supplement as needed. While this is difficult to achieve, in concept it is as simple as ABC.

Beyond AIDS intern Betsy Kidder has written a thesis on the African AIDS problem, and has these observations: "From my research of the Ugandan approach to preventing HIV/AIDS, it is clear that President Museveni spearheaded the successful prevention effort...Through the policy of transparency and openness, the Ugandan government created an environment in which HIV/AIDS could be discussed, confronted, and finally prevented... The United States...may benefit greatly from studying the Ugandan approach, but should not overlook the need to adopt a prevention effort that is relevant to US societal norms."

Cary

Cary Savitch, MD; President, Beyond AIDS

Washington

continued from page 1

from the office of physician Congress member Dave Weldon, who has taken a leadership role on HIV issues. Dr. Weldon subsequently recommended the inclusion of Dr. Hattis to represent Beyond AIDS at the December HIV Prevention Summit (see story on page 1).

That evening, intern Alexis Stevenson arrived after a difficult journey from Cornell University in Ithaca, NY. In a mini-workshop also involving Yvonne Pover and Ron Hattis, local intern Tasneem Husain presented a draft brochure for Beyond AIDS that she had designed in Manhattan together with intern Wesley Bettger. This will be developed further for soliciting membership and donations.



Yvonne Pover, with interns Tasneem Husain and Alexis Stevenson in Washington.

On Tuesday, October 29, intern Alexis Stevenson joined Ron Hattis in meetings with Health and Human Services AIDS policy director Christopher Bates, who told them they were “preaching to the choir” as he agreed on the need for treating HIV like other communicable diseases. Elizabeth Onjoro, staff member to the Presidential Advisory Council on HIV/AIDS (PACHA), was present and also lent encouragement. The next



Intern Alexis Stevenson with Katherine Martin, Legislative Assistant to Rep. Elton Gallegly.



L-R: Bill Viscovich, Nettie Mayersohn, Surgeon General Carmona, and Ron Hattis meet at Public Health Service Headquarters.

**Beyond AIDS
delegation met
with Director
Joseph O'Neill,
MD and Patricia
Ware at the
White House
Office of
National AIDS
Policy, for what
stretched into an
two-hour long
meeting.**

appointment was with the Washington AIDS liaison of the Centers for Disease Control and Prevention (CDC), Pamela Dougherty, who was sympathetic and indicated that CDC policy was moving in our direction. Stevenson and Hattis then walked to the Capitol in the rain to meet with staff of other members of the House of Representatives.

The delegation grew on Wednesday, October 30 with the arrival of Board member Nettie Mayersohn and Bill Viscovich from New York. They joined Yvonne Pover, Ron Hattis, and Barbara Ledeen at the White House Office of National AIDS Policy, for what was scheduled to be a 45 minute meeting with the Director (“AIDS Czar”),



National AIDS Policy Director Joseph O'Neill and NY Assemblywoman Nettie Mayersohn.

Joseph O'Neill, MD and then-assistant Patricia Ware. The discussion outlined broad areas of agreement on the need for routine HIV testing and on reducing “AIDS exceptionalism,” and developed such energy and excitement that the meeting continued for two hours, with everyone skipping lunch! Dr. O'Neill indicated a special interest in promoting routine HIV testing in clinics treating sexually transmitted diseases (STDs). Ms. Mayersohn was presented with a surprise award at this meeting (see separate story “Awards” on page 4).

The highlight of that afternoon was a special meeting with Surgeon General Richard Carmona at

See Washington, page 7

Awards Go to Four Who Made a Difference



Nettie receives her special award from Ron Hattis in the White House Office of HIV/AIDS Policy.

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

ton”, page 1). Foster was recognized for his supporting role in drafting the Ryan White Act amendments of 2000 and other federal HIV legislation, as well as for his longtime work on the newsletter and his past service on the Board. “Foster remains a pivotal individual in bringing together the key players and issues for HIV reform,” according to Vice-President Ron Hattis.

Nettie Mayersohn herself was similarly surprised and delighted, while at the White House office of AIDS Policy, to be presented with a special award for her longterm leadership and inspiration on HIV/AIDS issues. “This was not a ‘Nettie,’ it was a special award for the person who inspired the ‘Netties,’” said Dr. Hattis. “This was the only Board vote from which *Nettie* has ever been excluded,” he added, to explain how the secret was kept.

Bill Lehrfeld, *Beyond AIDS* Washington, DC, nonprofit expert, tax attorney and benefactor, died suddenly just weeks before he was to be awarded his *Nettie* (see memoriam page 7). Yvonne Pover presented the award posthumously to his widow, Joyce Lehrfeld, in Washington, DC.

Herbert Gurian, the largest individual donor to *Beyond AIDS* and a tireless campaigner for HIV reform in the state of Florida, was sent his “*Nettie*” award in May 2003. “Herb has always come through when we have needed support or encouragement,” said Yvonne Pover.

Previous recipients have included

- ◆ Former Congress member **Rep. Tom Coburn, MD** (R-OK), currently Co-Chair of the Presidential Advisory Council on HIV/AIDS, for his work on HIV in Congress;
- ◆ California Assembly Member **Bob Pacheco** and his former Chief of Staff **JoElla Cudney** for carrying bill on prenatal HIV testing initiated by *Beyond AIDS* (which also passed the state legislature and was vetoed by the Governor);
- ◆ Tacoma, Washington Health Officer **Federico Cruz-Uribe** for courageous leadership that forced his state to adopt an HIV reporting system, pioneering a system of HIV case management, and attempting to prevent newborn infections; and
- ◆ **Neena Ananda**, for performing a benefit Indian dance program when she was only 13, that financed many of *Beyond AIDS* activities. ▲



To receive *HIV Updates* free by email, send a request to beyondaids@aol.com

The Board of *Beyond AIDS* has recognized four more individuals for outstanding contributions to HIV control. The “*Nettie*” Award is named for *New York* Assembly Member *Nettie Mayersohn*, author of the pioneer legislation in that state for baby AIDS testing, HIV reporting, and partner notification.



Roland Foster, a member of the first Board of Directors of *Beyond AIDS*, and Editor of the online newsletter *HIV Updates*, appeared to appreciate his surprise “*Nettie*” at the Rayburn House Office Building on October 28, 2002

(see also story “*Beyond AIDS* Goes to Washing-

CDC Moves to Routine HIV Testing, Unlinked from Counseling

Beyond AIDS Among Organizations Urging the Changes

A dramatic shift in HIV testing recommendations was published in the April 18, 2003 issue of the flagship publication "Morbidity and Mortality Weekly Report" (MMWR) of the Centers for Disease Control and Prevention (CDC). Previously, CDC had encouraged HIV counseling prior to testing, but recently the organization has become concerned that any requirement for more counseling than is needed to understand the test can actually serve as a barrier to routine testing. This was first recognized in a report on testing of pregnant women issued several years ago by the Institute of Medicine at the request of Congress. In its new recommendations, CDC especially emphasizes routine testing of pregnant women.

In March, Beyond AIDS had become aware that some AIDS organizations were urging CDC not to issue these recommendations, and were insisting on maintaining extensive counseling prior to testing. Beyond AIDS and a few allied groups wrote to

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has consistently
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CDC Director Gerberding to urge proceeding with the plan. In her response to the Foundation dated May 6, Dr. Gerberding expressed thanks for the letter of support for the new recommendations, and noted the CDC's recommendation for an "opt-out" testing approach for pregnant women (routine testing unless the women actively declines testing). The "opt-out" approach was however not mentioned in the April 18 MMWR issue.

An article also dated April 18 in the Los Angeles Times by Charles Ornstein quoted Rob Janssen, Director of HIV Prevention at the CDC, as supporting a \$90 million program focused on prevention of transmission by persons already infected with the virus. Beyond AIDS had met with Janssen and other CDC officials in April 2001 at the agency's headquarters in Atlanta, and had encouraged his early efforts to develop this approach of "prevention for positives." Beyond AIDS has consistently supported controlling HIV and other communicable diseases at their source. ▲

Prenatal Testing Bill Revived in California

Beyond AIDS to Continue Support for Legislation It Developed

In 2002, Beyond AIDS supported and helped craft California Assembly Bill 2930 (Wright), which would have made it easier to test pregnant women for HIV. The final version involved compromise language that drew a coalition of support including some AIDS organizations that disagree with Beyond AIDS on other issues such as name-based reporting. The bill passed both houses of the Legislature but was vetoed by Governor Gray Davis due to cost concerns, even though the long-term savings from preventing medical expenses of infected infants would have been considerable.

Now, an identical bill has been reintroduced by Assembly Member John Dutra (Democrat from the Bay-area Fremont district). Beyond AIDS is again supporting the legislation. Although only a few

Assembly
Member Dutra's
office:
916-319-2020;
fax support
letters to
916-319-2120,
attention Lisa
Gardiner.

dozen babies a year are still being born with HIV in California, each one is a tragedy, because if the mother's infection can be detected and the mother and baby can be treated by the time of delivery, almost all of these cases can be prevented.

AB 1676 would simplify the consent requirement for prenatal HIV testing, and would encourage its inclusion in routine prenatal test panels. If the test were missed during the prenatal period, it would need to be offered again at the time of labor and delivery. The bill can be viewed online at www.leginfo.ca.gov. Select "Bill Information" and in the box marked House enter "Assembly"; for Bill Number enter "1676." For information on how to help with letters and calls to legislators or testimony before legislative committees, write to beyondaids@verizon.net. ▲

CDC Summit

continued from page 1

(CDC) at the request of Congressional leaders, for the purpose of eliciting new ideas and perspectives on HIV prevention. CDC paid the travel expenses of the participants.

Dr. Ron Hattis officially represented the Beyond AIDS Foundation. However additional Beyond AIDS members participated on behalf of other constituencies, including Bill Viscovich representing the New York State AIDS Advisory Council, Franklyn Judson representing the Denver Department of Public Health, and Roland Foster representing the House Subcommittee on Criminal Justice, Drug Policy, and Human Resources. Dr. Joe McIlhaney of the Medical Institute for Sexual Health (and a member of the Presidential Advisory Council on HIV/AIDS) joined Beyond AIDS during the meeting.

These individuals and representatives of allied organizations made the voice of Beyond AIDS one of the most powerful at the summit. This influence was amplified by the circulation of a Beyond AIDS paper of "Discussion Points" for the summit that helped to guide the debate. The summit also presented an opportunity to meet CDC leaders such as Director Julie Gerberding, and was followed later by correspondence with these officials.

A remarkable feature of the summit was an unprecedented mixture of traditional AIDS groups with more conservative and church-based organizations. The resulting dialog revealed areas of agreement as well as divisions. The summit split into four groups to discuss Prevention for Adolescents and Youth, Knowledge of Serostatus and Linkage to Treatment, Measuring Effectiveness of Prevention, and Program Gaps and Research Needs. The Beyond AIDS paper had outlined key issues for each group, e.g., informing



CDC Director Dr. Julie Gerberding, MD with Beyond AIDS Vice President Dr. Ronald P. Hattis, MD.

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Roland Foster with Shepherd Smith, President, Institute for Youth Development, at the HIV Summit.



Beyond AIDS Scientific Chair Dr. Frank Judson, Dr. Ron Valdiserri, Deputy Director of the Center for HIV, STD, and TB Prevention, and Dr. Harold Jaffe, Director.

the public of the incomplete effectiveness of condoms, reconsidering consent forms as a barrier to testing, routine testing of newborns, determining whether anonymous testing is still needed, routine testing in prisons, assessing whether sexually provocative programs truly prevent HIV, and evaluating reporting systems in terms of facilitating partner notification and case management for infected individuals.

Ron Hattis met with vocal opposition at the closing session when he suggested that the distribution of needles for people to continue unhealthy drug abuse was in conflict with public health philosophy, and suggested that the components of needle exchange programs be separately evaluated for effectiveness in preventing new infections. He noted that in most states, needles and syringes are available at pharmacies without prescription, and suggested that public funds be redirected to attracting addicts to prevention services with offers of food, condoms, health care, and drug treatment referrals.

Beyond AIDS found itself in a moderating role in the highly charged debate on abstinence vs. condoms. Bill Viscovich and other members noted that abstinence is the safest sexual prevention method, and emphasized the proven effectiveness of programs to delay onset of sexual activity among teenagers. This issue drew support from both ends of the spectrum, but Beyond AIDS also supported the education about condoms in any comprehensive prevention program. Terms suggested for a combined program included "Abstinence Plus" and "ABC," for Abstinence, Be Faithful, and Condoms, as used in Uganda (see page 2). ▲



Roland Foster with Bill Viscovich.

In Memoriam: William J. Lehrfeld

William J. Lehrfeld, 66, Beyond AIDS benefactor and corporate counsel, died September 12, 2002 at his home in Washington, DC of stomach cancer. Washington tax lawyer, nonprofit expert, and former IRS attorney, Mr. Lehrfeld had served as a committee chair of the tax sections of the American and Federal Bar associations.

Over the years, his clients included The Heritage Foundation, the US Chamber of



Commerce, the Washington Legal Foundation and the Endocrine Society. he also served as tax counsel in the 1997 House ethics committee investigation of Rep. Newt Gingrich (R-GA) and was the author of more than 40 technical articles on tax law.

Beyond AIDS will be forever indebted to Bill Lehrfeld for all his pro bono work to incorporate us, and awarded his widow his Nettie Award posthumously. (See story on page 4). ▲

Washington

continued from page 3

the Public Health Service headquarters in Rockville. Nettie Mayersohn, Bill Viscovich, and Ron Hattis represented Beyond AIDS at this session. Dr. Carmona was in full uniform, as has been his style, and listened attentively, assuring the group that he would support data-driven policy. A pleasant surprise was the presence once again of Christopher Bates, whom Dr. Carmona had summoned

**Dr. Carmona
was in full
uniform**

from Washington to add expertise at the meeting. Mr. Bates said he would keep in touch with Beyond AIDS.

“These meetings marked a milestone in Beyond AIDS’ emergence as a player on the national HIV policy scene,” said Dr. Hattis in summarizing the accomplishments. “To maintain the momentum, continued involvement with federal policy and legislation will be necessary.” ▲

Membership Application/ Donor Form

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Washington, DC 20003-4303

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 Communications _____ Membership _____ Secretarial

*Beyond AIDS, Inc. is a nonprofit, section 501(c)(4) organization founded in 1998; because your contribution will be used in part to achieve better laws and public policies for HIV prevention, contributions are not tax-deductible.
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Netherlands Praised for New Routine Prenatal HIV Testing Plan

The Beyond AIDS Foundation has sent letters to the two top Dutch health officials, Secretary Clémence Ross-van-Dorp and Minister Aart Jan de Geus, praising a new policy in which all pregnant women in the Netherlands will be screened for HIV as well as hepatitis B and syphilis. The tests will be done at about the 12th week of pregnancy, unless the women “opt out” by active refusal. Ross-van-Dorp presented the plan in a speech to Parliament on April 11, 2003.

The Beyond AIDS response, prepared in part by intern Betsy Kidder and signed by President Cary Savitch, MD, “enthusiastically congratulates the Netherlands Ministry of Health, Welfare, and Sport on the recent policy change to make HIV testing more routinely available to pregnant women. Your government’s progressive action is highly commended, and we thank you for being an international leader regarding this vital issue.”

The letter also suggested consideration of mandatory testing of newborns whose mothers miss or refuse the testing during pregnancy. The Foundation offered any consultation or assistance that might be needed. ▲



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will your
grandchildren
live in?

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the Beyond AIDS
Foundation in
your will.

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