



BEYOND AIDS Lifeline

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

Coming Up...

2001 National HIV Prevention Conference
August 12-15, 2001
Hyatt Regency Hotel Atlanta.
For information, see www.2001hivprevconf.org/

Beyond AIDS Board and General Meetings
...September 15-16, 2001

All members, friends and associates of Beyond AIDS are welcome to attend; location TBA, but will most likely be in Ventura, CA area

Beyond AIDS Awards Presentations/Fundraiser
...Fall 2001

All members, friends and associates of Beyond AIDS are welcome to attend; date and location TBA, but will most likely be Ventura, CA

What's Inside

President's Message	2
Membership Application	2
Legislative Aide Speaks Out	4
First Person: A Doctor's Story	6
HIV Exposure Rates	7
Monograph Available	7
Use Your Will Power	8

Epidemic Intelligence Service Meetings April 20-27, 2001

Beyond AIDS Delegation Meets with CDC Leaders

On April 23 in Atlanta, GA, the Beyond AIDS Foundation launched an initiative to strengthen and improve national public health policy on HIV. A delegation organized by the Foundation, consisting of Drs. Ron Hattis, Fred Payne, and Franklyn Judson, and Yvonne Pover, met with the two top HIV prevention leaders of the Centers for Disease Control and Prevention, Drs. Helene Gayle and Rob Janssen, at the CDC's HIV/AIDS headquarters. The recently formed tax-deductible Beyond AIDS subsidiary utilized the opportunity offered by the 50th Anniversary of CDC's Epidemic Intelligence Service to deliver a list of recommendations to the CDC leaders for more effective control of the HIV epidemic.

The delegation noted that the incidence of new HIV cases has not decreased during the past decade despite prevention efforts to date, and



Dr. Rob Janssen, Director of CDC's HIV Prevention Division; Dr. Helene Gayle, Director of CDC's Center for HIV, STD, & TB Prevention; Dr. Ron Hattis, Beyond AIDS VP.

that longer life spans of infected individuals are increasing the number of persons living with the

See CDC, page 3

Beyond AIDS Leads Opposition to Proposed California Regulations

By Ron Hattis, Vice-President

In strongly worded comments submitted May 21, 2001, Beyond AIDS has opposed the latest attempt to require the use of secret codes for HIV reporting in California. The comments were in response to proposed HIV reporting regulations from the California Department of Health Services. These regulations would prohibit physicians from giving health officers the names of infected HIV-persons, and would require them to construct a complex 17-digit code or "unique identifier" for reporting every case of HIV that had not progressed to AIDS.

HIV is not yet reportable in California until the disease progresses to AIDS. Beyond AIDS wants all stages of the disease to be reportable to public health officers using names and identifying information, so that partner notification, referrals to care, and interventions to prevent transmission can be performed.

Since its founding in 1998, Beyond AIDS has fought one battle after another for name-based reporting and against coded reporting of HIV in

See California Regulations, page 7



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



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President's Message

Friends and Colleagues,

A recent article from the *Archives of Internal Medicine* again points out the limitations of Universal Precautions in preventing HIV infection. Several years ago a study at Johns Hopkins Medical School pointed out that 80% of HIV exposures could not be avoided even with the most rigorous compliance to universal precautions.

Last year German public health study reported that two-thirds of health care workers who became HIV infected on the job, acquired the infection from a blood splash, and not a percutaneous needle stick.

And in South Africa (unofficial communication)—40 percent of the pregnant women in SA are now HIV infected. The obstetricians delivering these babies “want out” recognizing the



odds are becoming stacked against them. OBGYNs are well aware of their own high rates of Hepatitis B (prior to the hepatitis B vaccine) as a consequence of blood exposures.

It is clear the only way for health care workers to be protected is for our communities to be protected, so that there is a lower prevalence rate. Only through sound public health

policy that decreases the prevalence of HIV in the community (and protects everyone) can health care providers be protected.

It is time to save a few starfish.

Best regards,

Cary

Cary Savitch, MD

President, Beyond AIDS

Membership Application/ Donor Form

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- YES! I want to join Beyond AIDS or renew my membership for
___\$20___\$30___\$40___\$50___other. (✓ one)
- I want to help improve public health laws and public policy on HIV. Please accept my additional (non-deductible) donation* of _____ to Beyond AIDS, Inc.
- I want to make a special contribution for public education and research. Please accept my tax-deductible donation** of _____ to Beyond AIDS Foundation.
- Add me to your e-mail list only, as a non-voting Associate Member. I am making a voluntary contribution of _____.
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*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.

**Beyond AIDS Foundation is a nonprofit Section 501(c)(3) organization founded in 2001 for education and research; contributions are fully tax-deductible.

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continued from page 1

disease. Two types of problem areas were identified, those in which political pressures have prevented adoption of standard public health approaches (such as name-based reporting and partner notification), and those in which gaps in the public health system have been major factors.



Dr. Hattis explains *Beyond AIDS* recommendations for changes in CDC's HIV strategy to Dr. Helene Gayle, Director, National Center for HIV, STD, & TB Prevention.

new administration in Washington, and to exert political will and courage to push for stronger and more effective public health strategies against the disease. The representatives also suggested that the composition of HIV/AIDS advisory groups throughout the country be revised to include more women and minority representatives, and organizations such as *Beyond AIDS* and organized medicine that support stronger public health approaches.

Dr. Hattis briefly reviewed the 22 specific *Beyond AIDS* recommendations, including more explicit CDC support for name-based reporting, direct public health outreach to infected persons for partner notification, and cross-training of Ryan White case managers to help patients prevent further transmission. He discussed suggested changes in two draft CDC documents on HIV testing and counseling and on prenatal screening.

Dr. Judson called on the CDC to reduce its emphasis on increasing anonymous HIV testing, because confidential (non-anonymous) testing makes it easier to follow up persons testing positive and to link them to services. Judson, the new Chair of *Beyond AIDS*'s Scientific Council, directs the public health department in Denver, CO, where no distinction has been made between HIV and AIDS for 15 years. Judson noted that name-based HIV reporting and confidential HIV testing have been successful in Denver.

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"Even though Dr. Coburn has retired from the US Congress, you can still receive HIV Updates free by e-mail or fax—contact Roland Foster: rfoster@childrensaidsfund.org"



Delegation members: Drs. Franklyn Judson, Ron Hattis, and Fred Payne await meeting with Gayle and Janssen at CDC.

Dr. Payne, who was one of the first Epidemic Intelligence Service Officers, asked the CDC to publish the data on which it bases its estimates of HIV incidence, to allow independent scientists to verify epidemiological trends. He shared copies of his monograph on "The Human Immunodeficiency Virus Epidemic in the United States," published by the Children's AIDS Fund, which Payne serves as Medical Advisor. It is co-authored by Dr. Judson as



Dr. Ron Hattis, CDC Director Dr. Jeffrey Copland and Dr. Helene Gayle at a Carter Center reception near the CDC.

well as by former Congressman Tom Coburn, MD,* and Shepherd Smith of the Institute for Youth Development. **See page 7 for ordering information.**

The delegation expressed support and encouragement for a recent CDC initiative introduced by Dr. Janssen. The new program, called SAFE (Serostatus Approach to Fighting the HIV Epidemic), would devote more emphasis to working with HIV positive individuals to avoid transmission to others, and assistance to high-risk HIV-negative persons. The *Beyond AIDS* document noted that past CDC recommendations have failed to tie

See CDC, page 8

(Pennsylvania) Health Dept. Proposes HIV Disclosure

By Hope Yen

The Pennsylvania Health Department unveiled this week a plan that would require physicians to report the names of HIV patients to state health officials. Under the new plan, HIV would be added to the list of 52 diseases and conditions now being reported to the state. According to State Health Secretary Robert Zimmerman, "Confidential reporting by name of patients with HIV is the most effective and efficient way to advance Pennsylvania's public health, and to help ensure those who are infected with HIV have timely access to education, medical care, and social services."

HIV would be added to the list of 52 diseases and conditions now being reported to the state.

Some AIDS activists expressed concern about the plan to use patients' names, suggesting that the proposal could make some people reluctant to be tested if they know the results will be reported to the government. The proposal must still go through several months of public review; however, if it is approved, Pennsylvania health officials hope the new rules could go into effect next year. ▲

Hope Yen, Pittsburgh Post Gazette Online (www.post-gazette.com, 2/22/01). © 2001 Pittsburgh Post Gazette. All rights reserved. Reprinted with permission. <http://www.aegis.com/channel/s/0102227.html>

Beyond AIDS Supports Pennsylvania Reporting Plan

On May 20, 2001, Beyond AIDS sent a letter of support for Pennsylvania's proposal for name-based HIV reporting. The organization considers this state critical in interrupting a recent trend among states that did not yet have HIV reporting, to adopt reporting regulations using unique identifiers (secret codes) rather than names for HIV. Following are excerpts from the letter approved by the Beyond AIDS Board, to Joel H. Hersh, Director of the Bureau of Epidemiology, Pennsylvania Department of Health.

"...We wish to congratulate you and the Department for your strong leadership, in the face of opposition that has frustrated similar attempts in several other states, to institute confidential name-based HIV reporting in Pennsylvania... Beyond AIDS strongly supports the position taken by the Pennsylvania Department of Health. We have studied this issue and have concluded that only confidential name-based reporting has the capability of contributing to the control of HIV transmission. With names, but not with secret codes, it is possible for local health departments to perform contact tracing and partner notification, and to assist in linkages to treatment and other services, including prevention case management and assistance with medication compliance. Only with names in a secure public health database can health departments provide outreach to infected persons, reliably obtain risk factor history informa-

tion for complete reporting, eliminate duplicate reports, and correctly monitor epidemiological trends in HIV transmission.

"The alternative of unique identifier reporting has failed in Texas and is believed by the state medical society and health officers of Maryland to be failing there. Codes also require the maintenance by providers of lists of names and codes...so that name-based reporting actually is more secure and better prevents breaches of confidentiality.

"Through our educational Beyond AIDS Foundation, our organization is currently providing consultation to the State of Oregon and is represented on its advisory committee for implementing a new system of HIV reporting expected to take effect in October 2001. We would like to offer any similar assistance to the state of Pennsylvania. Beyond AIDS representation can help support your efforts by providing a constituency in support of public health, and by counterbalancing and helping to answer the fears and concerns of certain other groups..."

Founding members Harriet and Lin Bowen of Lancaster, PA are monitoring this issue, and meeting with state public officials. Harriet is serving as the Pennsylvania liaison to the Beyond AIDS Board for this issue. ▲

Beyond AIDS strongly supports the position taken by the Pennsylvania Department of Health

California Legislative Staff Battle HIV Behind the Scenes

Legislators do the public debating and voting, but their staff members, most of them dedicated and intelligent individuals, often engage in passionate debates of which the public is unaware, that may determine the fate of legislation that affects the lives of millions. One such unsung champion, JoElla Cudney, former Chief of Staff to California Assembly Member Bob Pacheco, has been selected along with her former boss for Beyond AIDS' "Nettie Award." They are recognized for their tireless work to promote Beyond AIDS-initiated legislation (AB 2809) in 2000, sponsored by the California Medical Association, that would have made it easier to test pregnant women for HIV. (The bill passed both houses of the legislature after a heroic struggle but was vetoed by Governor Davis.)

The award is named for New York Assembly Member Nettie Mayersohn, a pioneer in HIV Legislation promoting public health.

Following are excerpts of a letter sent in February 2001 by another remarkable staffer, Mike Genest, an aide to the Republicans in the California state Senate who analyzes budget matters related to health, to his counterpart, Diane VanMaren, the Democratic Principal Consultant for Health to the Senate Budget and Fiscal Review Committee. Genest was attempting to persuade VanMaren to help kill the budget provision for "non-name" HIV reporting, that led to the proposed regulations now being fought by Beyond AIDS. Although his effort was unsuccessful, no one has argued these points more eloquently.

"Names based HIV reporting coupled with aggressive partner notification and contact tracing is our only hope to turn the tide in the AIDS epidemic. It is a sin against humanity for us to be distracted from the pursuit of a solution to the HIV problem by a misplaced, self-centered, childish concern for the supposed civil rights aspects of this issue..."

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"[T]he Golden Rule does [not] contain any exemption for sexual preference. But, science is science, and as imperfect as it can be, science has long since figured out how to fight communicable diseases...no communicable disease has ever been vanquished by vaccination and antibiotics alone. The effort always needs to include tactics to interrupt transmission..."

"[T]he fight against STDs has been waged with a combination of mandatory reporting (by name), contact tracing, and partner notification...it has long been a sad irony that syphilis and gonorrhea have been fought with great success, even in the gay community, using these very same tactics. To this day, state and county STD workers appear at the doorsteps of gay men with these diseases, having learned of them via mandatory names based reports of positive lab tests. They gently and humanely break the bad news. They sensitively and discretely inquire about partners, and they go to those partners and make sure they get tested. There is no outcry. There are no horror stories of people losing their jobs or their insurance. There is only science-based prevention..."

"Education, condom ads, gay rights may well be good and even just things. But that is another topic because none of these "strategies" has worked to slow HIV. And people are dying. One would hope that pro-life, pro-choice, fundamentalist, progressive, liberal and conservative could agree on one point: we should do what is necessary to save lives.

"It is no longer a morally acceptable position, at least in my humble view, to be neutral on this issue. We need names based mandatory HIV reporting coupled with aggressive contact tracing and partner notification. Lives hang in the balance, and the greatest civil right of all is the right to life."▲

HIV Updates online newsletter is still available free by e-mail or fax—
contact Roland Foster:

rfoster@childrensaidsfund.org

A Doctor's Story

By Cary Savitch, MD

Here is a story. It is fresh from today. And, it is why I know what we are doing in the Beyond AIDS movement is so very important.

The flesh wounds of AIDS—what is happening to real people. It goes beyond fighting the political wars—which we have little chance of winning overnight.

This afternoon, after making rounds all morning and afternoon, I was about to leave the hospital and head off to the next hospital. I got paged from the emergency room. The ER physician told me about a woman* who presented with a 4–6 week history of fevers. She had a dry cough, 10 pound weight loss, and looked weak. He also noted she had thrush (fungal infection of the mouth).

I went down to see her. She was lying on the bed, husband of 15 years sitting next to her. They have one child, and 3 current foster children. They have been together for 17 years total (15 years of marriage and 2 years prior to marriage). He is in the US armed services. No history of extramarital activity. No history of drugs, alcohol, transfusions. All children at home are healthy. The husband is healthy and says he gets HIV tested every few years in Navy and has always been negative.

There is one other piece of history. When they lived in Anytown, USA they had three other foster children. This goes back a number of years and they do not know the whereabouts of these children.

She is a nondiabetic and not on any antibiotics, so thrush in this circumstance is very unusual. When I examined her there was diffuse thrush of the tongue, hard and soft palate, and buccal mucosa. Her chest X Ray showed slight increase in interstitial markings—suspicious for *pneumocystis carinii*. So, despite the fairly negative history, I have to think of AIDS.

So far she does not fit into any of the usual risk factors. Right? I personally called the lab and asked them to call me at home tonight as soon as the test was completed. The call came (ten minutes ago)—sure enough.

We will have the Western Blot confirmatory test

I wish I could tell you her story is rare, but this is a drama which is repeated and repeated and repeated. Considering one woman becomes HIV-infected every 12 seconds, this woman's story won't jar many heads.

in two days. I am certain what the results will be. I will talk with her in the morning.

Now think. Foster children. Frequently these kids come from broken and drug related situations. I am guessing that one of these foster children in Anytown was HIV-infected. If this is so (remember this is still an "if") she was never told. She may have become HIV-infected in the care of that child.

Again, source of HIV infection is uncertain, and this is all supposition (we may never know the source of this lady's infection), but the virus did come from exposure to someone. Imagine this scenario—a public health dept. or doctor or clinic (or all the above) is certainly aware of this child's HIV infection (child could even be dead by now)—and she was probably never given that information—never told she was possibly at risk of acquiring a deadly virus (Germany reported last year that two thirds of their health care workers who got HIV infected on the job were exposed by blood splashes and not by needle sticks). Instead she was allowed to expose her current family, husband, or whoever else. And she was never given the opportunity of seeking earlier treatment.

This lady has been HIV-infected for a long time. I will have her CD4 count back soon, but my guess is it will be less than 100 and that she has been infected over 10 years.

It's all tremendously upsetting. Neither she nor her husband know the results yet. Tomorrow morning their lives will be turned upside down.

I wish I could tell you her story is rare, but this is a drama which is repeated and repeated and repeated. Considering one woman becomes HIV-infected every 12 seconds, this woman's story won't jar many heads.

The chronicle on HIV/AIDS is filled with shame. Public health officials are intimidated from responding and legislators are fearful to act. Doctors and other health professionals are too preoccupied with health insurance to worry much about public health and safety.

The antiretroviral drugs have limited benefit. We

continued on page 8

Do you have an interesting personal story or an unsung hero? Submit articles to the editor by email at BeyondAIDSinc@aol.com

**Certain details have been changed to protect patient identity.*

California Regulations

continued from page 1

California. For two years, powerful Assembly Member Carole Migden of San Francisco attempted to achieve coded "unique identifier" reporting by legislation. The organization was successful in obtaining a veto from Republican then-Governor Pete Wilson of one such bill (AB 1663) in 1998, and a second veto from Democratic Governor Gray Davis of a similar bill (AB 103) in 1999. A name-based reporting bill (SB 1029, Haynes) sponsored by Beyond AIDS, was defeated that same year.

However, in 2000, obscure budget language that most legislators probably did not even know they were voting for set aside about \$2.8 million for "non-name" HIV reporting. On this basis, and without other enabling legislation, the Department issued the proposed regulations.

Representing the Beyond AIDS Board of Directors, the letter argued that "name-based reporting saves lives; codes do not." It suggested that the regulations violate state and federal law, and cited evidence that the proposed codes would be unworkable and burdensome to physicians and could deter reporting.

The organization pointed out that inclusion of Social Security code numbers caused a coded

**Alerted by
Beyond AIDS,
individual
members and
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testimony.**

reporting system to fail and to be abandoned in Texas, and that the Centers for Disease Control and Prevention (CDC) cannot use any of the data provided by states that currently report HIV without names. It also noted that if there is not a complete, timely, and unduplicated reporting system meeting CDC requirements in place by 2005, "California will become ineligible for hundreds of millions of dollars in Ryan White funds each year."

Alerted by Beyond AIDS, individual members and allied groups submitted similar testimony. In a separate letter to the Governor's office, President Cary Savitch appealed to the Governor's staff: "...Cryptic code reporting is meant to block name reporting. Cryptic code reporting prevents public health officials from working directly with the index case... Gray Davis has a great opportunity (and a responsibility) to intervene and require HIV be a reportable disease by name. He must also insist, require... that partner notification be attempted in each and every case. This is our only hope in preventing new infections and getting those who are already HIV-infected into earlier treatment."

The Department of Health Services will analyze all comments and issue a decision at an unknown date. ▲

Monograph Available: All About the Epidemic



Lead author Fred Payne, MD

The Human Immunodeficiency Epidemic in the United States, 1980–2000; The Emerging Epidemic Among Heterosexuals

By Fred J. Payne, MD; Thomas A. Coburn, MD; W. Shepher Smith; and Franklyn N. Judson, MD

The monograph presents a concise and accurate account of the onset of the epidemic in the U.S. its present course and future prospects. The authors describe steps which must be taken now to begin to control this devastating epidemic. 19 pages, 78 references.

Available for a suggested contribution of \$6.00 each (quantity discounts available) plus shipping and handling from Children's AIDS Fund, PO Box 16433 Washington, DC 20041. Phone 703/471-8750, fax 703/471-8409 email info@childrensaidsfund.org



A Doctor's Story

continued from page 6

have no AIDS vaccine (and we may never). In the meantime, society believes we are doing all we can to stop the spread of this virus. Explain that to the 16,000 people around the world who will become newly HIV-infected in the next 24 hours.

Our children deserve better.

I will update you if I ever learn how this lady actually became HIV-infected. I don't expect public health officials will be of any assistance. ▲

January 27, 2001

CDC

continued from page 3

together testing, counseling, referrals, and partner notification, and have placed insufficient emphasis on working with HIV positive individuals. Drs. Janssen and Gayle asked the group to enlist support for the SAFE initiative.

Both sides seemed pleased by the exchange of views. The complete Beyond AIDS recommendations to the CDC can be found on the Web at www.beyondaids.org, and will be discussed in more detail in the next issue. ▲



Use Your WILL POWER!

Will your ideals and aspirations for our children's future live on?

Please remember the Beyond AIDS Foundation in your will.

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