

NAME DROPPING

HIV reporting proposal comes under fire by Jonathan Kipp

The Oregon Health Division launched its effort to hear feedback about a controversial HIV names reporting proposal during a hearing Sept. 27 at Portland's Airport Holiday Inn. The meeting, packed with mostly opponents to the policy, was the first of four scheduled throughout the state.

Tom McConnell, who testified at the hearing, says the enemy is not names reporting but fear and ignorance. He thinks people testing for HIV don't want to give their names to health care workers because they are afraid of the consequences. "My perception is that Oregon is still not a safe place to have AIDS," McConnell says.

The proposal would require a name at test time. After the health division completed its reports, the name would be changed into a code and purged from the system permanently.

However, the name could remain in the state's hands for as long as 90 days, when the name automatically would be coded, whether or not officials had completed their work. The new system, if adopted, would not affect the availability of anonymous testing in Oregon.

The hearing came just one day after a protest outside the health division's Portland office. About 50 activists gathered, costumes and props in tow, and shouted: "No names! No names!"

Protester Marta Guembes told the crowd, "We will never feel safe giving our names to someone who cannot keep them safe." She was one of several members of the Hispanic Services Roundtable, a group of Oregon activists who meet monthly to discuss issues concerning the community, who showed up to demonstrate.

Days earlier, Dr. Mark Loveless, Oregon Health Division HIV prevention manager, briefed the roundtable about the proposal, answered questions and addressed concerns. He cited many benefits to following the national trend of names reporting.

The proposal meets expectations for good public health and strives to assure full access to services for everyone who tests positive for HIV, Loveless says. Names reporting is also the most cost-effective system, he adds.

Loveless, who also testified during the first state hearing, says that the proposal protects confidentiality and that no list of people with HIV will be kept in the public health system, as many fear. Names reporting of those testing positive for HIV was almost unheard of until the late 1990s, when the face of AIDS started to change, he says.

Names of people with AIDS have been reported to public health systems since the beginning of the epidemic. Because the onset of AIDS almost always followed HIV transmission, tracking the epidemic gave health officials the information they desired: AIDS statistics reflected the HIV epidemic, says Dr. Martin Skinner of the Oregon Medical Association.

Loveless says only one-half of the AIDS cases are being reported today compared to the early 1990s. With the advent of new medicines and combination "cocktails," people with HIV are living longer and more productive lives and warding off the onset of AIDS.

Because of this, epidemiologists think they can't learn enough about the spread of HIV by keeping track of AIDS anymore. HIV names reporting, some health officials and prevention experts say, will provide a better understanding of all stages of the epidemic and give needed information for prevention and services planning.



PHOTO BY MARTY DAVIS

About 50 activists stage a protest Sept. 26 outside the Oregon Health Division's Portland office

Jack Cox, HIV Advisory Council of Oregon and Southwest Washington coordinator, attended the roundtable, organized the protest and testified at the state hearing. He agrees with Loveless and Skinner—but only to a point.

Cox says he and his colleagues, like the doctors, support expanded reporting. The method of reporting is what he, the protesters and most of those testifying at the state hearing adamantly disagree with.

Cox and the council support unique identifiers as a reporting method and want the Oregon Health Division to abandon its proposal of names reporting. It has too many risks, they say.

Confidentiality rules also need to be improved, Cox says. "We have breaches of confidentiality in Oregon."

The Centers for Disease Control and Prevention are recommending expanded reporting systems nationwide. A total of 32 states have names reporting, and six are experimenting with unique identifier systems in which codes are used in lieu of names.

Loveless said the CDC doesn't specify any methodology for names reporting but does have strict guidelines for confidentiality. He maintains that breaches of confidentiality have not occurred in Oregon's AIDS reporting system.

More than 4,500 AIDS cases have been reported by name since health officials began tracking the disease. The Oregon Health Division has been taking public comment and studying the options for expanded HIV reporting since late 1997.

The call for additional public comment is only the latest development in what has been a contentious struggle between activists and health division officials. Opponents of names reporting say such a system would prevent people from getting tested and defer crucial early treatment.

But Loveless disagrees. In other states, names reporting ultimately has not scared people away, he says.

After an initial slowing of individuals getting tested under the new system, the numbers soon return to normal, Loveless adds. "It doesn't appear any specific community stays away." **JM**

The final OREGON HEALTH DIVISION hearing will be held from 5 to 9 p.m. Oct. 23 in Room 329 at Portland State University's Smith Center.

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