



Senator Feinstein Calls on CDC To Accept California's HIV Data
May 7, 2004

Washington, DC – U.S. Senator Dianne Feinstein (D-Calif.) announced today that she has joined Senator Ted Kennedy (D-Mass.) and 13 other Members of Congress to request the Centers for Disease Control and Prevention (CDC) to accept code-based HIV data from 14 states, including California, and the District of Columbia for the national HIV/AIDS reporting database.

Data from these 15 jurisdictions is not currently included in national HIV surveillance reports.

These reports are critical for federal, state, and local governments and communities to target the delivery of HIV prevention, care and treatment services. California's Office of AIDS estimates that because CDC does not accept code-based data 30,000 currently reported HIV cases in California are not being counted.

Senators Barbara Mikulski (D-MD), James Jeffords (I-VT), Patty Murray (D-WA), Jack Reed (D-RI), Paul Sarbanes (D-MD), and Barbara Boxer (D-CA) along with Representatives Nancy Pelosi (D-CA), Henry Waxman (D-CA), Sherrod Brown (D-OH), Elijah Cummings (D-MD), Barney Frank (D-MA), Eleanor Holmes Norton (D-DC) and Jan Schakowsky (D-IL) joined Senators Feinstein and Kennedy in sending a letter to CDC Director Dr. Julie Gerberding to make this request.

Following is the text of the letter sent out May 4:

“We are writing to request that the Centers for Disease Control and Prevention (CDC) take immediate steps to accept HIV data from all states into the national HIV/AIDS reporting database, including the incorporation of HIV data from non-named reporting states.

Currently 14 states¹ and the District of Columbia collect HIV case data using a code-based system. These jurisdictions collect detailed HIV data and are willing to report it to the CDC. However, the CDC does not accept HIV data from these states and therefore excludes HIV cases reported from code-based states in national HIV surveillance reports. This leads to a significant underreporting of comprehensive HIV data. According to the CDC's *HIV/AIDS Surveillance Report, 2002*, the 15 code-based jurisdictions account for almost one-third of all AIDS cases in 2002 (28.7%).

In spite of requests from those 15 jurisdictions, CDC has failed to develop national performance and evaluative standards for completeness and accuracy. CDC expresses concern about duplicate cases across states as a major reason for not accepting data from code-based states. CDC also contends that scientific evidence of the efficacy of HIV code-based reporting is lacking. However, CDC has yet to provide standards and evaluation protocols to these states for the inclusion of their data into a national HIV data set.

The recent report from the Institute of Medicine (IOM), *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*, recommends that CDC accept HIV data from all states including those with code-based reporting systems. It further states that, 'CDC should include HIV reporting data from code-based states and estimate the degree of overcounting due to duplication while procedures and infrastructure for definitive unduplication are developed.' These findings echo what states and national HIV/AIDS advocates have been calling for during the past decade.

CDC's refusal to accept and utilize code-based data presents an inaccurate picture of the nation's epidemic and, in doing so, undermines the national effort to win the battle against HIV/AIDS. National surveillance data is critical to federal, state, and local governments and communities targeting the delivery of HIV prevention, care and treatment.

Furthermore, funding formulas for many of the HIV/AIDS related programs, such as those funded through the Ryan White CARE Act, are moving towards using HIV case data rather than more dated AIDS case data to allocate resources. When the CARE Act was first enacted, AIDS data was the most reliable measure of the epidemic. With the advent of antiretroviral therapies, people are not progressing to an AIDS diagnosis as was previously predictable. In addition, the introduction of HIV rapid tests and CDC's increased commitment to HIV testing will likely increase the number of known HIV cases in our country. Therefore, by using AIDS cases as the nation's primary measure of the HIV/AIDS epidemic and HIV cases from a limited number of name-based states as a secondary measure, we are not only underestimating the number of people living with the disease, we are using a skewed national estimate of the epidemic to allocate scarce resources.

During the 2000 reauthorization of the Ryan White CARE Act, the Department of Health and Human Services was tasked with determining whether HIV case data could be used for determining award amounts. The Secretary is to make this determination by July 1, 2004. The IOM report found that HIV data is not complete enough to make the switch from AIDS to HIV cases. For instance, Georgia began collecting HIV data as of January 2004. The IOM committee recommends that during the next four years CDC take several steps in collaboration with states to improve the 'consistency, quality, and comparability of HIV case reporting.'

We understand that CDC has the technical capacity to accept code-based data. Why is it then, that CDC does not have the capacity to use this data in national surveillance reports?

We also understand that several states, both code- and name-based, have approached the CDC asking for a meeting to begin the collaborative process to address CDC's concerns pertaining to the completeness and accuracy of data from code-based states, as well as concerns about the reporting of duplicative HIV cases. State health departments and their surveillance staff are willing to work with CDC on implementing a plan that will allow for the inclusion of their data in national reports.

We ask that you specifically address the following questions:

- What steps, and within what timeframe, is CDC taking to evaluate HIV data from code-based states and incorporate it into national data sets?
- What steps is CDC taking to strengthen state HIV surveillance? States will need adequate resources for continued implementation of core HIV surveillance systems.
- What steps is CDC taking to provide technical assistance to code-based states to strengthen their capacity to meet national performance standards for completeness and accuracy? States have identified barriers in the areas of duplication, completeness and

communicating about cases with name-based reporting states and are eager to share the identified barriers and proposed solutions with the CDC.

We thank you for responding to our concerns. We look forward to receiving your response and continuing our discussion on this important matter.

¹California, Connecticut, District of Columbia, Hawaii, Illinois, Maryland, Massachusetts, New Hampshire, Rhode Island, and Vermont use a code-based system. Delaware, Maine, Montana, Oregon, and Washington use a name-to-code system.”

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