THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

JUN 23 2016

The Honorable Kathy Castor
U.S. House of Representatives
Washington, DC 20515

Dear Representative Castor:

Thank you for your letter expressing your support for HIV prevention efforts in Florida and your concerns about the accuracy of HIV data from the Florida Department of Health. I appreciate your concerns about the apparent large reduction in Florida's reported number of HIV cases. The U.S. Department of Health and Human Services (HHS) is committed to working with all states to ensure they accurately capture and analyze HIV data and share them publicly so that policymakers and citizens remain informed and can act, especially when concerning trends emerge.

In response to your request, HHS's Centers for Disease Control and Prevention (CDC) conducted an analysis of data reported by the state of Florida on HIV diagnoses among Florida residents who were 13 years or older at the time of diagnosis and has briefed your staff on the results of the analysis. The data represent a decline of about 20 percent in year 2014 compared to year 2008. While these data also represent an increase of about 12 percent from 2013 to 2014, such comparisons are not advisable since the numbers in more recent years have not yet stabilized and are likely to change as data quality, collecting, and reporting improve. I have enclosed more detailed information about the CDC's analysis and ongoing efforts to assist state and local health departments to collect information on new and existing cases of HIV infection.

HHS shares your commitment to and support of national and state-level HIV prevention efforts. If you have any further questions or concerns, please do not hesitate to contact Jim Esquea, Assistant Secretary for Legislation at (202) 690-7627.

Sincerely,

Sylvia M. Burwell

Enclosure

cc: Tom Frieden, MD, MPH, Director, Centers for Disease Control and Prevention
Amy Lansky, PhD, MPH, Acting Director, Office of National AIDS Policy

Enclosure

CDC conducted an analysis of data reported by the state of Florida on HIV diagnoses among Florida residents who were 13 years or older at the time of diagnosis. Data are reported as rates per 100,000, rather than as absolute numbers of cases, to allow for comparison over time, as underlying population size can change from year to year.

Over the period 2008–2014, the rates of diagnoses of HIV in Florida were 39.1, 33.7, 29.9, 29.4, 28.3, 27.8 and 31.3 per 100,000 Florida residents 13 years or older, for each respective year (Source: NCHHSTP Atlas, gis.cdc.gov/grasp/nchhstpatlas/main.html?value=atlas). This represents a decline of about 20 percent in year 2014 compared to year 2008. While these data also represent an increase of about 12 percent from 2013 to 2014, such comparisons are not advisable since the numbers in more recent years have not yet stabilized and are likely to change as data quality, collecting, and reporting improve.

A review of HIV diagnoses data over the same period for some Southern states (Alabama, Georgia, Louisiana, Maryland, Mississippi, the Carolinas and Texas) and a few other states with rates in double digits similar to Florida's (California, New Jersey, and New York) show that most, but not all, of these states are also experiencing a decline in rates of HIV diagnoses over the 2008-2014 time period.

While states decide which state and/or local data to publish and when to publish them, recent data may be preliminary, as these data are often inaccurate, potentially causing confusion when, inevitably, the numbers change. Additionally, it is preferable to publish data by year of diagnosis. Changes in reported numbers from one year to another can reflect not only changes in the number of persons diagnosed, but also changes in reporting practices and delays in case reporting.

Florida's reporting, for example, illustrates why preliminary data need to be interpreted with caution. Publishing data without allowing time to determine where and when a case was first identified can lead to artificially inflated numbers. After receiving data from states, CDC transmits lists of cases that appear to be reported in more than one state so that the involved states can communicate to resolve the potential duplicates. Florida's decision to publish cases by "year of report" in the 2015 report and by "year of diagnosis" in the 2016 report can also add to misperceptions about the total number of HIV cases in the state. The artificial peak in newly reported HIV cases in 2008 is due, in part, to the state's enhanced laboratory reporting (ELR) laws in 2006 and expansion of ELR in 2007. The expanded laboratory reporting and identification of previously diagnosed cases led to an increase in the number of cases reported. In addition, technical difficulties prevented laboratory data sent electronically by laboratories to Florida in 2007 from being reported until 2008. This created a steep jump in the number of existing (as opposed to newly diagnosed) cases reported for 2008. The data shown by "year of diagnosis" in the 2016 report spreads these cases out into their earlier respective years of diagnosis.

In CDC's *HIV Surveillance Report, 2014* (www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-us.pdf), which was based on data reported through July 2015, we reported 5,037 cases of HIV in the state of Florida among people 13 years or older. The number

of HIV cases, reported by the Florida Department of Health (FDOH) for 2014 in their 2016 report (www.floridahealth.gov/diseases-and-conditions/aids/surveillance), 4,613, is lower because their data are from a later date (December 2015) than CDC's 2014 report. The later publication date of Florida's report gave the state time to remove duplicate cases and assign cases to the accurate year of diagnosis.

CDC funds and assists state and local health departments to collect information on new and existing cases of HIV infection. Data continuously come into state health departments from many sources, including local health departments, laboratories, hospitals, clinics, other HIV-testing facilities, and care providers. The raw data received from these many sources are far from perfect or complete. It is a routine and necessary practice for health departments to refine their data to ensure accuracy. This process includes but is not limited to determining where and when a case was first identified and assigning that case to the correct year and location, identifying identical cases that are reported from more than one source or location, identifying and addressing issues associated with missing data, and identifying and addressing data entry errors. States may publish HIV case data by year of report (the year the case was reported) or by year of diagnosis (the year a person is first diagnosed with HIV).

Because CDC funds FDOH to conduct HIV surveillance, our agency works closely with the department to ensure the appropriate handling and reporting of data. CDC staff provide ongoing technical assistance and conduct site visits to ensure the state adheres to agency program requirements and works to meet program goals.

CDC remains available to provide FDOH with any additional technical support and remains willing to review any data FDOH shares.