THE CSTE WASHINGTON REPORT

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EDITOR'S NOTE: The rate of fetal deaths, also known as stillbirths, occurring at 20 weeks of gestation or more declined substantially between 1990 and 2003, according to a report by the Centers for Disease Control and Prevention (CDC). Although fetal mortality rates declined among all racial and ethnic groups from 1990-2003, the fetal mortality rate for non-Hispanic black women was more than double that of non-Hispanic white women (11.56 per 1,000 vs. 4.94 per 1,000)."While we can see that progress has been made in preventing fetal mortality, it is also clear that substantial disparities remain along race and ethnic lines, said Marian MacDorman, Ph.D., lead author of the report--additional details are provided in this Washington Report.

The *CSTE Washington Report* is provided as an information resource for members of the Council of State and Territorial Epidemiologists on federal legislation and regulation affecting public health and epidemiology in the U.S. Legislation cited in the report can be accessed via http://www.thomas.loc.gov Regulations cited can be accessed via http://www.gpo.gov

HHS SECRETARY LEAVITT UNVEILS PLAN FOR "VALUE EXCHANGES" TO REPORT ON HEALTH CARE QUALITY AND COST AT LOCAL LEVEL --

HHS Secretary Mike Leavitt February 9 unveiled a plan for chartering local collaborative organizations that are working to improve quality and value in health care by assessing the performance of local health care providers and reporting these findings publicly. The plan would bring the local collaboratives into a nation-wide system, and the collaboratives would use nationally-recognized standards to measure and improve quality of care in their local areas.

"This plan is about giving consumers good information to make decisions about their health care, and giving providers information to help them improve care," Secretary Leavitt said. "It's also about hard work and trust. At the local level, providers and purchasers can meet eye-to-eye and achieve the trust that must underlie a system of improvement based on more open information."

Under the plan, HHS would select qualified regional collaboratives to be chartered as Value Exchanges. In such collaboratives, local area physicians, nurses, hospitals and other health care providers are working collaboratively with health plans, employers, unions and other health care purchasers to achieve reliable public reporting on quality and cost of care. As HHS-chartered Value Exchanges, they would continue to focus on quality improvement and would provide public reports on the performance of providers in their area.

The plan for Value Exchanges is part of the Value-Driven Health Care Initiative, a public-private effort launched by Secretary Leavitt last year to improve quality and lower costs in health care delivery. The first element of this Initiative, which is still on-going, aims at national coordination by calling on all health care stakeholders to commit to public reporting on quality and costs, including recognition of consensus standards of care. The initiative also supports interoperable health information technology and incentives for value purchasing in health care.

The Value Exchanges would be independent, non-profit organizations. In recent years, a number of collaboratives of this kind have been created independently in communities throughout the country. The new plan would help bring such collaboratives into a national system, as well as stimulating more communities to create such collaboratives. It would also create a national Learning Network to help the chartered Value Exchanges move quickly to expand and improve quality assessment.

Secretary Leavitt said that HHS will invite initial applicants to be chartered as Value Exchanges. HHS will also stimulate development of more collaboratives by formally recognizing early community efforts to bring stakeholders together for quality improvement and reporting.

The system would include two types of collaboratives:

Community Leaders -- Less-developed collaboratives, especially those aiming at growth in stakeholder participation and quality measurement capacity.

Value Exchanges -- Collaboratives that best meet criteria and are selected by HHS to be chartered and carry out quality improvement and public reporting.
Advanced collaboratives that meet additional criteria may qualify to pool their data with Medicare data for broadest-based measurement of provider performance and quality outcomes.

Existing local and regional collaboratives that have developed independently in recent years would be expected to form the initial core of Value Exchanges receiving HHS charters. In addition, six existing collaboratives were selected last year to pioneer the process of pooling local and Medicare data, under Medicare's "Better Quality Information to Improve Care for Medicare Beneficiaries" program. The six pilots will continue to function as special Medicare demonstrations.

In measuring providers' performance and publicly reporting the findings, the Value Exchanges would use nationally-recognized standards. These standards, developed through public-private efforts, also form the basis for ongoing Medicare quality and performance reporting. The Exchanges could also pioneer new quality improvement strategies and share results through the Learning Network.

The new system would be administered by HHS' Agency for Healthcare Research and Quality (AHRQ). AHRQ Director Carolyn M. Clancy, M.D., said providers would lead in the development of standards.

"The goal is to achieve both national coordination in developing standards and local control in applying them," Secretary Leavitt said. "The Value-Driven Health Care Initiative is aiming at both of these goals -- and at the same time, aiming to keep control in the private and professional sectors. The federal government can help organize -- but providers, purchasers and consumers themselves must be in charge and make the system work."

For more information: www.hhs.gov/transparency.

NEW REPORT SHOWS DECLINE IN STILLBIRTHS; RACIAL DISPARITIES PERSIST -- The rate of fetal deaths, also known as stillbirths, occurring at 20 weeks of gestation or more declined substantially between 1990 and 2003, according to a report by the Centers for Disease Control and Prevention (CDC). Although fetal mortality rates declined among all racial and ethnic groups from 1990-2003, the fetal mortality rate for non-Hispanic black women was more than double that of non-Hispanic white women (11.56 per 1,000 vs. 4.94 per 1,000).

"While we can see that progress has been made in preventing fetal mortality, it is also clear that substantial disparities remain along race and ethnic lines, said Marian MacDorman, Ph.D., lead author of the report.

The report, "Fetal and Perinatal Mortality, United States: 2003," was prepared by CDC's National Center for Health Statistics and looks at fetal deaths (stillbirths) as well as perinatal deaths (deaths occurring soon before or soon after birth).

Other findings include:

The fetal mortality rate (number of fetal deaths per 1,000 live births and fetal deaths) declined steadily by an average of 1.4 percent per year from 1990-2003.

The decline in the fetal mortality rate since 1990 occurred among pregnancies 28 weeks of gestation and longer; the fetal death rate for pregnancies 20-27 weeks of gestation has changed little since 1990.

The rate for American Indian women (6.09 per 1,000) was 24 percent higher than that for non-Hispanic white women, while the rate for Hispanic women (5.46 per 1,000) was slightly higher than the rate for non-Hispanic white women. The rate for Asian or Pacific Islander women (4.98 per 1,000) was similar to that of non-Hispanic white women.Relatively little is known about the causes of fetal mortality. However, recent research has identified a variety of risk factors, including smoking during pregnancy, maternal obesity, severe or uncontrolled high blood pressure, diabetes, infections, placental and cord problems, intrauterine growth retardation, and a woman having a previous perinatal death.

"Fetal and Perinatal Mortality, United States: 2003" is available at www.cdc.gov/nchs.

CDC REPORT PROVIDES FIRST STATE-SPECIFIC DATA ON PERSONS LIVING WITH HEART DISEASE -- The Centers for Disease Control and Prevention (CDC) February 15 released a report that finds a wide range of variation in the prevalence of coronary heart disease (a narrowing of the arteries that feed the heart), heart attack and angina (chest pain that occurs when the heart does not get enough blood). The report provides the first ever information on the percentage of people living with heart disease in all 50 states and U.S. territories. The report found that some states and territories had double the prevalence of heart disease as others. For heart attacks, rates ranged from 2.1 percent in the U.S. Virgin Islands to 6.1 percent in West Virginia, while the prevalence of any condition – heart attack, angina or coronary heart disease – ranged from 3.5 percent in the U.S. Virgin Islands to 10.4 percent in West Virginia.

The study, *Prevalence of Heart Disease – United States,* 2005 was published in today's *Morbidity and Mortality Weekly Report*. The study is based on an analysis of state-specific data collected from the Behavioral Risk Factor Surveillance System – a random phone survey of U.S. adults age 18 and older conducted by state/territorial health departments.

Overall, about 6.5 percent of those surveyed reported that a doctor or health care

professional had told them they had one or more of the following – heart attack, angina or coronary heart disease – with 4 percent indicating they had a heart attack and 4.4 percent reporting angina or coronary heart disease. Heart disease is the leading cause of death in the United States.

"These findings show the importance of preventing and controlling known risk factors for heart disease, such as high blood cholesterol, tobacco use, physical inactivity, high blood pressure, type 2 diabetes, and obesity," said Jonathan Neyer, the study's lead author and an epidemiologist in CDC's Division for Heart Disease and Stroke Prevention (DHDSP). "We hope this report will help states and U.S. territories better tailor their heart disease prevention efforts."

Residents of Alabama, Arizona, Florida, Kentucky, Louisiana, Missouri, Oklahoma, Tennessee, Texas, and West Virginia had the highest prevalence of these heart diseases. Many of these states are known to have a high proportion of residents with multiple heart disease risk factors and a disproportionately high number of heart disease deaths. The same was found among residents living in Puerto Rico.

The places reporting the lowest level of heart disease prevalence were: Nebraska, Wisconsin, Wyoming, New Mexico, Montana, Minnesota, Utah, Hawaii, Colorado, District of Columbia and the U.S. Virgin Islands.

The report also identified gender and racial/ethnic differences in heart disease prevalence. Men had a significantly higher prevalence than women (8.2 percent vs. 5 percent) for coronary heart disease or non-fatal heart attack, and angina. American Indians/Alaska Natives had the highest heart disease prevalence (11.2 percent) and Asians had the lowest prevalence (4.7 percent). There was little difference in heart disease prevalence among whites (6.9 percent), blacks (6.2 percent) or Hispanics (6.2 percent).

The report also identified differences in prevalence based on educational levels. Heart disease prevalence was nearly twice as high in individuals with fewer than 12 years of education (9.8 percent) compared to college graduates (5 percent).

CDC works with nearly 80 national organizations through the National Forum for Heart Disease and Stroke Prevention to achieve national goals for preventing heart disease and stroke. Funding is provided to state health departments in 32 states and the District of Columbia to support educational programs, policies, environmental strategies and systems changes that address heart disease. CDC's WISEWOMAN program funds 15 projects across the country that provides low income, underinsured and uninsured women (aged 40-64 years) with risk factor screening, lifestyle intervention strategies and referral services.

For more information about heart disease, please visit the Division of Heart Disease and Stroke Prevention's Web site at www.cdc.gov/dhdsp.

2,000 INFLUENZA VIRUS GENOMES NOW COMPLETED AND PUBLICLY

ACCESSIBLE -- The Influenza Genome Sequencing Project, funded by the National Institute of Allergy and Infectious Diseases (NIAID), one of the National Institutes of Health (NIH), announced February 21 that it has achieved a major milestone. The entire genetic blueprints of more than 2,000 human and avian influenza viruses taken from samples around the world have been completed and the sequence data made available in a public database.

“This information will help scientists understand how influenza viruses evolve and spread,” says NIH Director Elias A. Zerhouni, M.D., “and it will aid in the development of new flu vaccines, therapies and diagnostics.”

“Scientists around the world can use the sequence data to compare different strains of the virus, identify the genetic factors that determine their virulence, and look for new therapeutic, vaccine and diagnostic targets,” says NIAID Director Anthony S. Fauci, M.D.

The Influenza Genome Sequencing Project, initiated in 2004, has been carried out at the NIAID-funded Microbial Sequencing Center managed by The Institute for Genomic Research (TIGR) of Rockville, Maryland. Recently, growing sequencing capacity has enabled the production rate to increase to more than 200 viral genomes per month. Eclipsing today’s milestone of 2,000 genomes, the microbial sequencing center will continue to rapidly sequence more influenza strains and isolates and will make all the sequence data freely available to the scientific community and the public through GenBank, an Internet-accessible database of genetic sequences maintained by the National Center for Biotechnology Information (NCBI) at NIH’s National Library of Medicine, another major contributor to the project.

Seasonal influenza is a major public health concern in the United States, accounting for approximately 36,000 deaths and 200,000 hospitalizations each year. Globally, influenza results in an estimated 250,000 to half a million deaths annually. Seasonal flu shots are updated every year to target the latest strains in circulation. Developing such vaccines is challenging, however, because the influenza virus is prone to high mutation rates when it replicates, and these mutations can alter the virus enough that vaccines against one strain may not protect against another strain.

An even greater concern is the potential for an influenza pandemic caused by the emergence of a new, highly lethal virus strain that is easily transmitted from person to person. Influenza pandemics have occurred three times in the last century, the most lethal of which was the pandemic of 1918, which caused an estimated 40 to 50 million deaths worldwide.

“A few years ago, only limited genetic information on influenza viruses existed in the public domain, and much of the sequence data was incomplete,” says Maria Y. Giovanni, Ph.D., who oversees the NIAID Microbial Sequencing Centers. “The Influenza Genome Sequencing Project has filled that gap by vastly increasing the amount of influenza sequence data and rapidly making it available to the entire scientific community.

Subsequently, there has been a marked increase in the number of scientists worldwide depositing influenza genome sequence data into the public domain including scientists at St. Jude Children's Research Hospital and the Centers for Disease Control and Prevention."

Along with NIAID, TIGR and NCBI, other collaborators on the project include the Wadsworth Center of the New York State Department of Health in Albany, NY; the Centers for Disease Control and Prevention in Atlanta; St. Jude Children's Research Hospital in Memphis, TN; the World Organization for Animal Health / Food and Agriculture Organization of the United Nations (OIE/FAO) Reference Laboratory for Newcastle Disease and Avian Influenza in Padova, Italy; Ohio State University in Columbus, OH; Children's Hospital Boston; Baylor College of Medicine in Houston; and Canterbury Health Laboratories in Christchurch, New Zealand.

More information about the Influenza Genome Sequencing Project and access to the influenza virus sequence data is available at

NIAID's Influenza Genome Sequencing Project:
http://www.niaid.nih.gov/dmid/genomes/mscs/influenza.htm

TIGR's Influenza Virus Genome Project: http://msc.tigr.org/infl_a_virus/index.shtml

GenBank: http://www.ncbi.nlm.nih.gov/Genbank/
To help analyze and interpret the large quantity of sequence data generated by the Project, NIAID has funded the BioHealthBase Bioinformatics Resource Center, which is being developed by researchers at the University of Texas Southwestern Medical Center at Dallas and developers at Northrop Grumman Information Technology's Life Sciences division in Rockville, Maryland. This Center provides the scientific community with bioinformatics and software tools and a robust point-of-entry for accessing influenza genomic and related data in a user-friendly format. BioHealthBase has recently established a collaboration with the Influenza Sequence Database at Los Alamos National Laboratory to provide influenza researchers with computational data management and analysis resources to assist in interpreting the genetic data. Data from the Influenza Genome Sequencing Project, as well as all other publicly available influenza sequence data, are also available through NCBI's Influenza Virus Resource, which includes a host of analysis tools, such as sequence alignment and building "trees" that show evolutionary relationships.

More information on these databases and other influenza data analysis tools can be accessed at BioHealthBase

Bioinformatics Resource Center: http://www.biohealthbase.org/

NCBI's Influenza Virus Resource: http://www.ncbi.nlm.nih.gov/genomes/FLU/

Los Alamos National Laboratory Influenza Sequence Database: http://www.flu.lanl.gov/

Visit PandemicFlu.gov (http://www.pandemicflu.gov/) for one-stop access to U.S. Government information on avian and pandemic flu.
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