

THE CSTE WASHINGTON REPORT

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EDITOR'S NOTE: A three-day training course which provides a standardized curriculum to state and local public-health responders about how to identify and control human infections and illness associated with avian influenza A (H5N1) is being released on-line today. The course, entitled "CDC/CSTE Rapid Response Training: The Role of Public Health in a Multi-Agency Response to Avian Influenza in the United States" is the result of a partnership between the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE). The course is available at <http://www.cste.org/influenza/avian.asp>.-- 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>

CSTE AND NASPHV WEIGH IN ON LIFTING BAN ON SALE OF PET

TURTLES – In a joint effort, CSTE and the National Association of State Public Health Veterinarians (NASPHV) forwarded a letter this week to key Members of the House Energy and Commerce Committee opposing provisions in a Senate bill that would lift the existing Food and Drug Administration (FDA) ban on the sale of small pet turtles. A bill to reauthorize FDA drug and medical device user fees is moving quickly through Congress. The Senate version of the bill (S. 1082) includes a successful floor amendment sponsored by Sen. Mary Landrieu (D-LA) that would allow the sale of turtles under 4 inches in length if a state develops regulatory processes by which turtle breeders, distributors and sellers are licensed and by which sanitization of each turtle is required using a proven method that makes turtles Salmonella-free. The letter disputes the existence of any method to make turtles Salmonella-free and cites recent and historical research that confirms this and the ineffectiveness of public awareness campaigns. The concluding paragraph of the three page letter states:

“In summary, these bills rely heavily on turtle producers being able to produce Salmonella-free turtles using methods which appear unreliable, have had insufficient public health review, and which actually may increase the risk of introducing antibiotic-resistant organisms into the environment and of exposure of the public to the same organisms. There is no doubt in the minds of hundreds of public health experts in our associations that allowing small turtle sales will cause a repeat of the high levels of salmonellosis seen in children prior to the ban. Because of this, both CSTE and NASPHV recommend voting to oppose these and any similar bills or amendments in the Senate and House.”

AHRQ PUBLISHES LANDMARK FEDERAL HANDBOOK ON THE USE OF PATIENT REGISTRIES

--The Department of Health & Human Services' (HHS) Agency for Healthcare Research and Quality (AHRQ) May 16 released a new handbook that represents a groundbreaking federal initiative to help researchers and others use patient registries to evaluate the real-life impact of health care treatments.

A patient registry is a database of confidential patient information that can be analyzed to understand and compare the outcomes and safety of health care. The data may originate from multiple sources, including hospitals, pharmacy systems, physician practices, and insurance companies. Some registries include patients who have the same disease. Others are comprised of patients who have undergone a common surgical procedure or received a newly approved medication.

An analysis of patient registry data may offer insights that can improve health care and public health. For example, doctors may use a registry database to monitor disease patterns or identify unexpected adverse events in specific populations. Physician groups may analyze treatments to identify opportunities for quality improvement. Health insurers may review treatment trends before making coverage decisions. Researchers from academia, industry, and government may use registries to monitor the long-term comparative benefits, safety, and harms of medications or medical devices.

"This Registries Guide is a milestone in our growing efforts to draw from medical practice and learn which treatments really work best," said HHS Secretary Michael O.

Leavitt. "If we can learn more systematically from the experience of millions of patients and clinicians in day-to-day practice, then we can discover more quickly which treatments are truly most effective, and for whom."

The new 219-page document, *Registries for Evaluating Patient Outcomes: A User's Guide*, is the first government-supported handbook for establishing, managing, and analyzing patient registries. Development of the handbook was co-funded by AHRQ and HHS' Centers for Medicare & Medicaid Services (CMS). Thirty-nine contributors from industry, academia, and government collaborated to create the handbook.

Unlike randomized clinical trials, which study patients under strict eligibility and treatment protocols, patient registries document the experiences of patients in everyday clinical practice. Observing those patients' responses to treatment can provide important insights into which health care strategies work best in actual practice.

"This new reference will be a tremendous resource to researchers, patient groups, health insurers, pharmaceutical companies, and others who are eager to investigate which treatments work best," said AHRQ Director Carolyn M. Clancy, M.D. "Databases that depict outcomes in patient populations over time carry great potential for advancing the quality, safety, and effectiveness of health care."

Many patient registries are already in use. One of the best-known registries is the Surveillance Epidemiology and End Results Program, which is managed by the National Cancer Institute. That registry collects and publishes data on cancer patients, including demographics and information about their tumors, treatment, and followup status. Other registries, meanwhile, are analyzing treatment outcomes for illnesses such as depression, emphysema, Parkinson's disease, and heart disease.

Overall, the quality of current patient registries varies widely. AHRQ's new handbook identifies the best scientific practices for operating registries. Covered topics include: how registries should be designed, what types of data sources may be accessed, and how to encourage participation among patients and health care providers. Also included are chapters on detecting adverse events, interpretation of data, and how to handle issues related to ethics and publication of research papers. The handbook's summary chapter serves as a checklist for best practices.

"CMS is proud to support this handbook as a new tool for researchers to evaluate health outcomes," said Leslie V. Norwalk, the Acting Administrator of CMS. "Using registries to evaluate promising health care technologies and the processes for delivering care has the potential to improve quality of care for Medicare beneficiaries."

The patient registry guide is a product of the DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) network, an arm of AHRQ's Effective Health Care (EHC) Program. Development and editing of the document was led by Outcome Sciences of Cambridge, Mass., a member of the DEcIDE network. The project's principal investigators were Richard Gliklich, M.D., and Nancy Dreyer, Ph.D., of Outcome Sciences.

The guide is downloadable from the EHC Web site, <http://www.effectivehealthcare.ahrq.gov>, and soon will be available in two printed forms—as the full-length document and as a 13-page summary that includes the best

practices checklist. Copies may be ordered from the AHRQ Publications Clearinghouse by sending an E-mail to ahrqpubs@ahrq.gov or calling 1-800-358-9295.

CDC REPORT FINDS SIGNIFICANT DIFFERENCES IN STROKE

PREVALENCE AMONG U.S. STATES AND TERRITORIES-- Stroke prevalence varies widely from state to state, with some states and U.S. territories having more than double the stroke prevalence of others, according to a new report from the Centers for Disease Control and Prevention (CDC). The report, "Prevalence of Stroke - United States, 2005," published in CDC's Morbidity and Mortality Weekly Report, provides the first data on the percentage of stroke survivors in all 50 states, the District of Columbia and U.S. territories.

The study analyzed state-specific data for adults 18 and older collected from the 2005 Behavioral Risk Factor Surveillance System (BRFSS). Stroke prevalence ranged from a low of 1.5 percent in Connecticut to a high of 4.3 percent in Mississippi.

"Strokes are the third leading cause of death in the United States and a leading cause of serious long-term disability," said Jonathan Neyer, the study's lead author and an epidemiologist in CDC's Division for Heart Disease and Stroke Prevention. "These findings reaffirm the importance and need for people to take steps to reduce their risk of stroke. Avoiding tobacco use, being physically active, and maintaining healthy weight, blood pressure and cholesterol levels are steps everyone can take to lower their risk."

A stroke occurs when either the blood supply to part of the brain is blocked or when a blood vessel in the brain bursts, causing damage to a part of the brain. According to Neyer, high blood pressure, high blood cholesterol, heart disease, smoking, diabetes and atrial fibrillation, an irregular beating of the upper chambers of the heart, are some of the major risk factors for stroke. About 700,000 strokes occur in the United States each year. About 500,000 of these are first or new strokes. About 200,000 occur in people who have already had a stroke. Over 160,000 people die each year from stroke in the United States.

Nearly one out of four states, including the District of Columbia, had a high stroke prevalence of 3 percent and above. These include Alabama, Arkansas, Illinois, Kentucky, Louisiana, Michigan, Mississippi, Missouri, Nevada, Oklahoma, Tennessee, Texas, and West Virginia.

The lowest levels of stroke prevalence (less than the median of 2.6 percent) were found in Arizona, Colorado, Connecticut, Maryland, Massachusetts, Minnesota, Montana, New Jersey, North Dakota, Puerto Rico, Rhode Island, Vermont, Wisconsin, and Wyoming.

The prevalence of stroke was similar among men (2.7 percent) and women (2.5 percent). American Indian/Alaska Natives had the highest stroke prevalence (6 percent), while the prevalence of stroke in blacks (4.0 percent) was almost twice that of whites (2.3 percent), with Asians having the lowest rate (1.6 percent). Stroke prevalence was more than twice as high in individuals with fewer than 12 years of education (4.4 percent) compared to college graduates (1.8 percent).

CDC works with nearly 80 national organizations through the National Forum for Heart Disease and Stroke Prevention to achieve national Healthy People 2010 goals for preventing heart disease and stroke. CDC provides funding to state health departments in 32 states and the District of Columbia, as well as three stroke networks comprised of 14 states, to support educational programs, policies, environmental strategies and systems changes that address stroke. CDC's WISEWOMAN program funds 15 projects across the country that provide low income, underinsured and uninsured women (aged 40-64 years) with risk factor screening, lifestyle intervention strategies and referral services to reduce their risk for stroke.

For more information about stroke, please visit www.cdc.gov/dhdsp.

U.S. PREPAREDNESS TO RESPOND TO AVIAN INFLUENZA A (H5N1)

STRENGTHENED BY CDC/CSTE PARTNERSHIP –A three-day training course which provides a standardized curriculum to state and local public-health responders about how to identify and control human infections and illness associated with avian influenza A (H5N1) is being released on-line today. The course, entitled "CDC/CSTE Rapid Response Training: The Role of Public Health in a Multi-Agency Response to Avian Influenza in the United States" is the result of a partnership between the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE). The course is available at <http://www.cste.org/influenza/avian.asp>.

"We are pleased to release a new avian influenza training program that our state and local public-health partners can use to train rapid response teams," says Joshua Mott, an epidemiologist in CDC's Influenza Division who led the training development project. The training focuses on human health issues during an avian influenza investigation. Through lectures, reference materials and case studies, the course provides mechanisms to facilitate discussion and planning among people who may be called on to respond to avian influenza A (H5N1) in the United States.

To date, no H5N1 cases in birds or humans have been found in the United States or any other country in the Western Hemisphere. However, in parts of Asia, Africa and Europe, the H5N1 virus has caused widespread infections and deaths in poultry and 291 human illnesses, resulting in 172 deaths. Public-health officials around the world consider H5N1 to be the greatest current pandemic influenza threat.

Background: The CDC and CSTE worked with educators at the North Carolina Center for Public Health Preparedness to develop the curriculum for on-line release. The on-line version was modified from regional "train the trainer" courses that were conducted in early 2007 in Washington D.C.; Denver, CO; and Atlanta, GA. These regional courses included 295 participants and facilitators and represented local and state health agencies, federal agencies, including CDC and United States Department of Agriculture, and representatives from the wildlife protection and agricultural sectors, public-health laboratories, public-health veterinarians, nursing and industry. Training was provided to representatives of all 50 states; several large U.S. cities including Washington, D.C.,

Seattle, WA, Chicago, IL, Houston, TX and New York City, NY; and Puerto Rico, American Samoa and the Virgin Islands. A key component of the training was coordination between veterinary and human public-health agencies at the federal, state and local level.

"The unique aspect of the training is that it brings together human and animal health professionals, who would work together as part of a multidisciplinary response to an avian influenza threat," says Mott. "Importantly, this training program also teaches public-health response skills that are applicable to other emerging diseases."

CDC provided \$2 million in funding to CSTE to support development of the materials, to support the in-person trainings, to adapt the materials for on-line access, and to assist states in replicating the response training in their states using this curriculum.