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News Release

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HHS Launches New Family Health History Initiative

Nearly Every American Believes That Knowledge Of Family History Is Important, Yet Only One-Third Attempt To Gather It

HHS Secretary Tommy G. Thompson today launched a Family History Initiative to encourage all Americans to learn about their families' health histories as a way of promoting personal health and preventing disease.

"With this new family health history tool we are entering the next generation of prevention," Secretary Thompson said. "In addition to healthy eating and exercising, we know that technology and research can also prevent and treat disease before the disease becomes debilitating. The miracle of the human genome provides new hope for millions of Americans and a new path to health for all of us."

U.S. Surgeon General Richard H. Carmona declared Thanksgiving Day, when American families traditionally gather to celebrate and give thanks, to be the first annual National Family History Day. Americans are encouraged to use their family gatherings as a time to collect important family health history information that can benefit all family members.

To help gather family history information, HHS released a new, free computer program that organizes important health information into a printout that can be taken to a health care professional to help determine whether a patient is at higher risk for disease. The printout can also be placed in a patient's medical record. The new computerized tool, called "My Family Health Portrait," can be downloaded at www.hhs.gov/familyhistory/.

"The bottom line is that knowing your family history can save your life," Dr. Carmona said. "Millions of dollars in medical research, equipment, and knowledge can't give us the information that this simple tool can. And when a health care professional is equipped with a patient's family health history, he or she can easily assess the inherent risk factors and begin tests or treatment even before any disease is evident."

Most Americans believe that knowing their family health history can be beneficial, but relatively few have ever attempted to collect it in an organized way. According to results from the Healthstyles 2004 Survey, conducted in August by the U.S. Centers for Disease Control and Prevention (CDC) and to be published later this month, 96 percent of Americans believe that knowing family history is important to their health. The survey also shows, however, that only one-third of Americans has ever tried to gather and organize their families' health histories.

"We are proud to collaborate on this project because clearly the public is eager for a tool to help

them collect and organize their family health history," said Muin Khoury, M.D., Ph.D., director of CDC's Office of Genomics and Disease Prevention. "It is our hope as families gather this holiday season, they'll take the time to learn -- and record -- their families' health histories so that they can continue to have years of family gatherings together."

Family history is not new. Every young physician learns that it is a valuable clinical tool to help know what diseases to watch for in patients.

"Family history can be a window into a person's genome," said Francis S. Collins, M.D., Ph.D., director of the National Human Genome Research Institute, one of the 27 institutes and centers at the National Institutes of Health, and a leader of the now-completed Human Genome Project. "In the future, tests resulting from the Human Genome Project will make it possible to identify the glitches we all carry in our genes, glitches that increase our susceptibility to common illnesses. Until then, tracking illnesses from one generation of a family to the next can help doctors infer the illnesses for which we are at risk, and thus enable them to create personalized disease-prevention plans."

Gathering enough family history information to make useful predictions, however, has become increasingly difficult as health care has become more complex, and numerous pressures decrease the amount of time that doctors and nurses spend with their patients. Even when a health care professional attempts to collect a family health history, patients frequently do not know the details of what diseases run in their families. The Surgeon General's Family Health Initiative addresses these problems by helping people to gather and record the information before going to their medical appointments.

The "My Family Health Portrait" tool guides users through a series of screens that helps them compile, for each family member, information about six common diseases, including heart disease, cancer and diabetes. In addition, individuals are able to add conditions not on the list. After information is collected about grandparents, parents, siblings, children, aunts, uncles, and cousins, the tool creates a graphic print-out that organizes the information into a diagram that can be used by a health care professional to better individualize diagnosis, treatment, and prevention plans.

The tool allows users to go back and add information as it becomes available and is able to create a diagram for an individual without complete information about every family member.

The Agency for Healthcare Research and Quality (AHRQ) operates a national database of medical practice guidelines, developed by independent medical and professional organizations, that can help individuals and their health care professionals to customize prevention programs. Family health history is one of the criteria for many of the practice guidelines, which frequently recommend specific medical testing to detect an illness early. The guidelines can be found at the National Guideline Clearinghouse, www.guideline.gov. AHRQ is part of the U.S. Department of Health and Human Services.

The "My Family Health Portrait" software can be downloaded from the Internet and installed on computers using the Windows operating system with the .NET framework installed.

All personal information entered into the program is maintained on the user's computer only; no information is available to the federal government or any other agency. The software will be available in both English and Spanish.

In addition to the software tool, a print version of "My Family Health Portrait" will be available in English and Spanish through the Federal Citizen Information Center and at consolidated health centers nationwide. Consolidated health centers provide care to patients regardless of their ability to pay. HHS' Health Resources and Services Administration funds the national network of more than 3,600 community health centers, migrant health centers, health care for the homeless centers, and

public housing primary care centers.

To get a print version of the tool, individuals can contact the Federal Citizen Information Center at 1-888-8-PUEBLO (1-888-878-3256), write to: "My Family Health Portrait," Pueblo, CO 81009, or print out the tool at www.hhs.gov/familyhistory/.

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