

# UPDATES FROM US HEALTH AGENCIES

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Recent activity in government and non-government agencies may affect readers of *Ethnicity & Disease* and other healthcare professionals working with ethnic minority and under-served populations. Below are some current items of interest.

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## FROM THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

### US Surgeon General Urges Spanish-Speaking Americans to Know Their Family Health History

Calling on all Spanish-speaking Americans to “know their family history,” US Surgeon General Richard H. Carmona, MD, MPH, announced the availability of an updated version of a free, computerized tool in Spanish, designed to help Spanish-speaking families gather their health information. In addition, he praised the National Council of La Raza’s Institute for Hispanic Health (NCLR/IHH) for developing its own family history consumer outreach program for Spanish-speaking Americans. The program is based on the Surgeon General’s Family History Initiative.

Healthcare professionals have known for a long time that many diseases, such as cancer, diabetes and heart disease, can run in families. A detailed family history can predict the disorders for which a person may be at increased risk and can help to develop more personalized approaches to prevent illness or detect it early, when it is most treatable. However, with doctors and nurses spending less time with their patients, sufficient

family information is seldom gathered to make useful predictions.

To help families organize their health histories, the Surgeon General developed “My Family Health Portrait,” a computerized, information-organizing tool that makes creating a family health history easier and more efficient for both patients and healthcare professionals. Now, a new, free, web-based version of the tool is available in Spanish. It organizes a family’s health history into a printout that people can then take to their healthcare professional to help determine whether they are at higher risk for disease. The Spanish version of the tool is available on the internet at <https://familyhistory.hhs.gov/spanish>.

The tool guides users through a series of screens that helps them compile information for their family members on six common diseases—heart disease, stroke, diabetes, colon cancer, breast cancer and ovarian cancer—as well as information about any other conditions that are of particular interest to the

family. The tool focuses on these six common diseases because a genetic contribution is known for each and because a preventive strategy can be developed to avoid illness. The tool creates a graphic printout that organizes the information into a diagram or a chart that can be given to a healthcare professional to better individualize diagnosis, treatment, and prevention plans. The tool allows users to go back and add more information as it becomes available.

The new version of the “My Family Health Portrait” tool is web-based, which allows it to be operated on all computers with internet access running any of several standard browsers, regardless of the computer’s operating system. All personal information entered into the program resides on the user’s computer only. No information is available to the federal government or any other agency.

Dr. Carmona also recommended that families and employers in all parts of the country consider a partnership with the National Human Genome Research Institute and the Office of Rare Diseases, both part of the National Institutes of Health, to develop their own family history

curriculum based on the program, “Genetic Inheritance: Knowing Your Family Health History.”

NCLR/IHH has provided 33 *promotores de salud* (lay health educators) with linguistically and culturally appropriate materials to communicate the value of genetic information, and its relation to family history, to Spanish-speaking communities in an effort to improve their health. NCLR/IHH launched the yearlong education and training program in spring 2005.

Training sessions were taught with the assistance of doctors and genetic counselors with an expertise in genetics. *Promotores de salud* were provided with information on how to accurately collect family history, how to take advantage of genetic testing services, as well as how to engage their community in policy discussions to improve the quality of access to health care relative to genetics.

For additional information about the Surgeon General’s Family History Initiative, please visit [www.hhs.gov/familyhistory](http://www.hhs.gov/familyhistory).

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### FROM THE NATIONAL INSTITUTES OF HEALTH CLINICAL CENTER (NIHCC)

#### Study Finds Potential Marker to Identify Sickle Cell Patients at High Risk of Complications

Researchers studying sickle cell disease have found that an enzyme, which can be measured by a simple blood test, may help determine whether a patient has a high risk of developing certain serious complications associated with the disease. The study, led by researchers at NIHCC and the National Heart, Lung, and Blood Institute (NHLBI), published in the March 15, 2006, issue of *Blood*, the journal of the American Society of Hematology.

Researchers say the enzyme lactate dehydrogenase (LDH) appears to hold promise in patients with sickle cell disease as a marker for risk of pulmonary hypertension and other complications, including early death. Pulmonary hypertension—abnormally high blood pressure in the lungs—is common in sickle cell disease.

“Our findings suggest that patients with sickle cell disease and high LDH levels should have especially careful monitoring for pulmonary hypertension, a life-threatening complication,” says Gregory Kato, MD, the lead author of the study. Kato is a clinician in the NIHCC Department of Critical Care Medicine and director of the Sickle Cell Vascular Disease Unit in the NHLBI Vascular Medicine Branch.

Sickle cell disease is a hereditary blood disorder that, in the United States, is most prevalent in Blacks. An abnormal type of hemoglobin inside the red blood cells distorts their shape and interferes with blood flow. The enzyme LDH investigated in the study is found throughout the body, especially in red blood cells, the heart, liver, lungs and muscle. A blood test

measuring LDH levels is readily available and commonly used to determine tissue damage due to a variety of causes.

Researchers measured the LDH levels of 213 adults with sickle cell disease and then categorized the patients as having low, medium, or high levels. The frequency of several complications of the disease was determined in the three LDH groups.

The study found that patients in the highest LDH group were more likely to experience three circulatory problems: pulmonary hypertension, leg ulcerations, and priapism. Pulmonary hypertension was detected in 61% of patients with high LDH compared to 15% of patients in the lowest LDH group. Thirty-nine percent of people with high LDH reported leg ulcerations, and 60% reported priapism at some point in time. Mortality rates of study participants also were examined. Patients with

high LDH levels had a nearly four-fold increased risk of early death compared to patients with lower LDH levels.

The study also found that high LDH levels may help to explain why pulmonary hypertension develops in sickle cell disease. High levels of LDH appear to indirectly indicate that two other proteins, hemoglobin and arginase, have broken out of red blood cells. “Our recently published studies have suggested that when fragile red blood cells rupture and release their contents into the bloodstream, after years it may cause blood vessel walls to become diseased,” Kato says. “Our current findings further support this theory. Learning more about this chain of events will help us to identify additional potential treatments.”

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### FROM THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI)

#### Reducing Total Fat Intake May Have Small Effect on Risk of Breast Cancer, No Effect on Risk of Colorectal Cancer, Heart Disease, or Stroke

Following an eating pattern lower in total fat did not significantly reduce the incidence of breast cancer, heart disease, or stroke and did not reduce the risk of colorectal cancer in healthy

postmenopausal women, according to the latest clinical trial results from the National Institutes of Health’s Women’s Health Initiative (WHI). The study was designed to evaluate

a low-fat dietary pattern’s effect on the risk of cancer. However, investigators also evaluated the data to review the effect on cardiovascular disease.

Among the 48,835 women who participated in the trial, no significant differences in the rates of colorectal cancer, heart disease, or stroke were seen between the group who followed

a low-fat dietary plan and the comparison group who followed their normal dietary patterns. Although the women in the study who reduced their total fat intake had a 9% lower risk of breast cancer than did women who made no dietary changes, the difference was not large enough to be statistically significant.

By the end of the first year, the low-fat diet group reduced average total fat intakes to 24% of calories from fat but did not meet the study's goal of 20%. At year six, the low-fat diet group was consuming 29% of calories from fat. The comparison group averaged 35% of calories from fat at year one and 37% at year six. Women in both groups started at 35%–38% of calories from fat. The low-fat diet group also increased their consumption of vegetables, fruits, and grains.

Women were ages 50–79 years at trial enrollment in 1993–1998 and were followed for an average of 8.1 years. The study diet focused on reducing total fat, and unlike diets used to

reduce heart disease risk, did not differentiate between “good” fats found in fish, nuts, and vegetable oils and “bad” fats like saturated fat and trans fat found in processed foods, meats, and some dairy products. The study design reflected a widely believed but untested theory that reduction of total fat would reduce risks of breast or colorectal cancers. For heart disease, reduction in total fat was anticipated to be accompanied by a reduction in saturated fats, which are known to contribute to heart disease risk.

“The results of this study do not change established recommendations on disease prevention. Women should continue to get regular mammograms and

screenings for colorectal cancer, and work with their doctors to reduce their risks for heart disease including following a diet low in saturated fat, trans fat and cholesterol,” said NHLBI Director Elizabeth G. Nabel, MD.

The study also found that following a high-carbohydrate, low-fat eating pattern does not increase body weight, triglycerides, or indicators of increased risk of diabetes such as blood glucose or insulin levels in women.

Though the overall risk of colorectal cancer was unchanged in the dietary trial, secondary analyses suggested a possible benefit in women who were taking aspirin or combined hormone therapy (estrogen plus progestin); however, these find-

ings could have occurred by chance. Polyps and adenomas (thought to be precursors of cancer) were reduced by 9%, suggesting that a benefit for colorectal cancer risk might emerge over time.

The WHI is the most comprehensive study to date of the causes and prevention of the major diseases affecting the health of older women. Over 15 years, the study's findings on heart disease, breast and colorectal cancer, and osteoporosis have stimulated many changes in clinical practice. The WHI is also one of the largest studies of its kind ever undertaken in the United States and is considered a model for future studies of women's health.