

Secretary's Advisory Committee on Genetics, Health, and Society 6705 Rockledge Drive Suite 750, MSC 7985 Bethesda, MD 20892-7985 301-496-9838 (Phone) 301-496-9839 (Fax) http://www4.od.nih.gov/oba/sacghs.htm

June 7, 2005

The Honorable Michael O. Leavitt Secretary of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Leavitt:

I am writing on behalf of the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) to commend the Surgeon General's Family History Initiative and the efforts of the Department of Health and Human Services (HHS) to increase public awareness of the importance of family health history information. In keeping with its charge to assess how genetic technologies are being integrated into health care and public health, SACGHS has followed these efforts with great interest.

The Family History Initiative is an important program that provides the public and health providers with a free, user-friendly tool for gathering important health information. Family history is a valuable personal health resource that can help inform individuals and their health providers of health risks with a genetic basis. Increasing the use of family health history information is a positive step towards the goal of integrating genetics into healthcare. As such, this tool has the potential to result in enhanced individual and family health as well as improvements in public health in general.

The Family History Initiative has enjoyed substantial success since it was launched in November of 2004 with the first National Family History Day celebration on Thanksgiving Day. Specifically, it has been highlighted in more than 1,000 media stories, its website has received over 164,000 unique visits, and the tool itself has been downloaded 250,000 times. These data demonstrate the public's great interest in understanding the relevance of family history to personal health and in using their family histories to achieve better health outcomes. A more formal evaluation of the tool, to include a survey of tool users and focus groups, is currently underway.

We commend Surgeon General Carmona's leadership of this important national effort and the contributions of participating HHS agencies—the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH)—in developing and promoting the family history tool. The agencies' collaboration on this initiative could serve as a model for other Departmental efforts that will be needed to help integrate

genetics and genomics into healthcare and public health. Since National Family History Day will be an annual Thanksgiving Day event, we recommend that efforts be made to broaden Federal participation in the initiative and to support the family history tool's continued development and improvement in the coming years.

Thank you for continuing to encourage the use of family history through the Surgeon General's Family History Initiative and for your attention to this important matter.

Sincerely,

Reed V. Tuckson, M.D.

SACCHS Chair

cc: Richard Carmona, M.D., M.P.H., F.A.C.S., Surgeon General

Carolyn Clancy, M.D., Director, AHRQ

Francis D. Chesley, Jr., M.D., SACGHS *Ex Officio*, AHRQ, and Director, Office of Extramural Research, Education, and Priority Populations

Julie Gerberding, M.D., M.P.H., Director, CDC

Muin Khoury, M.D., Ph.D., SACGHS Ex Officio, CDC and Director, Office of Genomics and Disease Prevention

Betty M. Duke, Ph.D., Administrator, HRSA

Sam Shekar, M.D., M.P.H., SACGHS Ex Officio, HRSA and Director, Center for Quality,

HIV/AIDS Bureau

Elias Zerhouni, M.D., Director, NIH

Francis Collins, M.D., Ph.D., SACGHS Ex Officio, NIH and Director, National Human Genome

Research Institute