

**Key Outcomes of the Third Meeting of the  
Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS)  
March 1-2, 2004**

The goals of the third meeting of SACGHS were to complete a systematic priority setting process resulting in the identification of high priority issues that will be the Committee's topics of study for the next one to two years, and to develop a long range work plan for completing the studies. Further information about the issues under consideration is attached. The Committee identified its top priorities and developed a plan for implementing its decisions.

Enactment of Federal legislation to prohibit *genetic discrimination* in health insurance and employment remains the Committee's top priority. SACGHS heard public testimony suggesting that efforts were needed to encourage the House of Representatives to take up the Senate passed bill, S. 1053. SACGHS unanimously reaffirmed the importance of this critical issue and voted to send a second letter to the Secretary to convey the urgency of encouraging the House to move this bill forward at this juncture.

SACGHS decided that education and training of health professionals in genetics was a high priority issue and that, after additional fact-finding over the next few months on genetics educational efforts, they would be equipped to consider a resolution regarding those efforts at their next meeting in June. The Committee will be monitoring two other issues: *oversight of genetic technologies* – about which they believe significant progress is being made by federal agencies to improve oversight – and *patents and access*. The Committee decided to defer in-depth consideration of the *patents and access* issue until after the completion of a study by the National Academy of Sciences that is anticipated in the summer of 2005. The Committee also plans to prepare a report describing SACGHS' mandate and priorities and providing background information on the priority issues and policy considerations raised by them.

SACGHS also identified high priority issues that require more in-depth study. Coverage and reimbursement of genetic technologies and services will be the main focus of the Committee's efforts during the next year. The Committee plans to carry out additional data and information gathering and to prepare a report with recommendations for the Secretary. Three other issues were also identified as warranting in-depth study – *large population studies*, *pharmacogenomics*, and *direct-to-consumer marketing and direct access* – but for the most part these will be considered in the future. At the next meeting, however the committee will consider a resolution expressing concern about the proliferation of direct to consumer advertising of genetic technologies.

During the discussion of priorities, it became apparent that several issues were overarching and needed to be considered within the context of all of the Committee's discussions. *Access* and *public awareness* were regarded as such inherent issues, encompassed within and important parts of all of the top priority issues. In addition, the Committee considered *genetic exceptionalism* to be a philosophical question that should be considered on a case-by-case basis during their deliberations.

In addition to establishing priorities, SACGHS gathered extensive information on coverage and reimbursement of genetic technologies and services. CMS provided an overview of Medicare's coverage and payment policies and processes. The Committee also heard from experts on how third party payers make decisions about coverage of genetic technologies, how genetic services are financed (in an HMO model), and how cost effectiveness analyses of genetic technologies and services are conducted and utilized in decision making. Two providers of genetic technologies (a laboratorian and a clinician) presented their perspectives on coverage and reimbursement issues.