THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

June 27, 2011

R. Rodney Howell, M.D.
Committee Chairperson
Secretary's Advisory Committee on Heritable Disorders
in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, MD 20857

Dear Dr. Howell:

Thank you for your letters on behalf of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) regarding recommendations on screening for sickle cell disease carriers.

I am pleased to support your first three recommendations:

- All individuals should have the opportunity to find out their risk for various medical disorders, including their carrier status for genetic conditions such as sickle cell disease;

- Evaluation and testing for sickle cell disease and other genetic conditions should take place within the individual's medical home. That evaluation should include counseling regarding the implications of the information for the individual and assurance of the privacy of genetic information. Genetic testing should not be a pre-requisite for participation in sports, unless deemed medically necessary; and

- As part of the individual's annual medical evaluation for participation in sports, all potential athletes should receive education on safe practices for prevention of exercise and heat related illnesses.

At this time, the Committee's remaining two recommendations are not ready for adoption:

- The Secretary, HHS, instruct SACHDNC to work with the Sickle Cell Disease Association of America, relevant federal HHS agencies, athletic associations, community-based and health care professional organizations to develop guidelines and educational resources about screening for sickle cell trait in all persons, including athletes; and

- The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) conduct research to ascertain if some athletes with sickle cell trait are at increased risk of exercise-related sudden death.

You may be pleased to know that I recently unveiled a Department-wide initiative to improve care for individuals with sickle cell disease. Multiple components of HHS are already engaged in sickle cell disease research and care, and this initiative builds upon ongoing activities by enhancing coordination and integration of these activities. In addition, this initiative has led to the identification of and commitment to pursue new and promising opportunities. For example, NIH will collaborate with CDC to conduct research on the clinical implications for individuals with sickle cell trait. Research topics are expected to include renal disease, risk of thrombosis, impact on stress related situations such as dehydration, athletic participation and vigorous physical activity, and access to genetic counseling. I am hopeful that this interagency effort will improve the knowledge base related to the health impacts of sickle cell trait and inform future efforts related to your remaining two recommendations that could not be adopted at this time.

Please accept my personal thanks to you, the members, and the organizational representatives of the Committee for your valuable work to improve the health of our nation's infants and children.

Sincerely,

Kathleen Sebelius