



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Secretary's Advisory Committee on Heritable
Disorders in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, Maryland 20857
(301) 443-1080 – Phone
(301) 480-1312 – Fax
www.hrsa.gov/heritabledisorderscommittee

October 11, 2010

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Sebelius:

In follow-up to my letter, June 14, 2010, concerning recommendations from the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) on screening for sickle cell disease carriers, the SACHDNC is providing the following revisions to recommendations contained in that letter based on the SACHDNC's discussion of the Sickle Cell Disease Carrier Screening Workgroup's briefing paper, *Screening U.S. College Athletes for Their Sickle Cell Disease Carrier Status* at the last SACHDNC meeting. The revisions are considered refinements to add clarity to the original SACHDNC recommendations, rather than changes in the content of the recommendations. The changes below are **bolded** and *italicized* for emphasis.

Original: Recommendation 1

- All individuals should know their medical risk for various disorders, including their carrier status for various inherited genetic conditions such as sickle cell disease.

Revised: Recommendation 1

- 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.

Original: Recommendations 2 and 3

- Genetic testing or screening should not be a pre-requisite for participation in athletic endeavors.
- Evaluation and screening 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.

Revised: Recommendations 2 (combining recommendation 2 and 3)

- 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*.

No Change: Recommendations 4, 5, and 6

- 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.
- The Secretary, HHS, instruct SACHDNC to work with the SCDA, 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.
- The National Institutes of Health and the Centers for Disease Control and Prevention conduct research to ascertain if some athletes with sickle cell trait are at increased risk of exercise-related sudden death.

The report, *Screening U.S. College Athletes for Their Sickle Cell Disease Carrier Status*, and its recommendations from SACHDNC are now complete and are submitted for your information, review and consideration for approval.

Sincerely yours,

R. Rodney Howell, M.D.
Chairperson

Enclosures:

Tab A: [June 14, 2010 Letter to the Secretary](#)

Tab B: [Report: *Screening U.S. College Athletes for Their Sickle Cell Disease Carrier Status*](#)