SICKLE CELL DISEASE CARRIER SCREENING
Briefing Paper Workgroup Update

SACHDNC May 13, 2010 – Washington, DC

Briefing Paper Purpose

- Apprise Sec. HHS of new policies and practices concerning Sickle Cell Trait(1) carrier screening of college athletes
- Discuss the impact of college-athlete SCT screening policies/practices on the pubic health system
- Recommend appropriate responses and actions by HHS

1. The term Sickle Cell Trait (SCT) to be used throughout the report/recommendations

Workgroup Members and Chairs

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- R. Lorraine Brown – Genetic Services Branch, HRSA
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- Dr. Lanetta Jordan (chair) – Sickle Cell Disease Association of America
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- Dr. Kim Smith-Whitley (chair) – Children's Hospital of Philadelphia
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- Andrea Williams – Children's Sickle Cell Foundation, Inc.

Topics to-be Covered in Briefing Paper

- Research and findings on SCT status and health outcomes
- Issues and impact of athletic associations recommendations on affected populations, community service providers and public health (potential and observed)
- SCT status screening in the U.S. – current guidelines
- Recommendations on SCT screening

Background (1)

- **1968**: 1st documented deaths that were exercise related reported in New England Journal of Medicine
- **1970s**: Screening for SCT begins in some NBS programs
- **1987:** Military study published in the New England Journal of Medicine about risk of dying in extreme physical exercise
- **1994:** 42 states screen for hemoglobinopathies with various SCT disclosure policies

Source: U.S. Centers for Disease Control and Prevention. 2010

Background (2)

- **2007**: National Athletic Trainers' Association releases "Sickle Cell Trait and the Athlete" Consensus Statement "to raise awareness of this condition and provide measures to reduce the risk of exertional collapse related to sickle cell trait. "Exertional Sickling" is coined.
- **2009**: National Collegiate Athletic Association recommends that member institutions test student-athletes to confirm their Sickle Cell Trait status as result of a lawsuit
- **2009:** SCDAA approaches CDC for convening of 1st meeting to discuss public health implications of sickle cell trait
- **2010:** NCAA adopts mandatory screening policy

Source: U.S. Centers for Disease Control and Prevention. 2010

Update -NCAA Decision on Sickle Cell Trait Testing

- January 2010: SCT proposal requiring all athletes to be tested defeated
- April 2010: Division I Legislative Council amended proposal accepted
  - Division 1 student-athletes must be tested for sickle cell trait, show proof of a prior test or sign waiver releasing an institution from liability if they decline to be tested.
- Rule to take effect 2010-2011 academic year
- NCAA public information following the April 2010 decision; SCDAA response; media

(see Committee Briefing Book Tab 6a)

Recommendation Areas

- Universal safety precautions
- Consent and privacy
- Non-discrimination protections
- Implementation guidance
- Research and Evaluation

Preliminary Recommendations

1. All athletes should be taught and required to practice universal precautions when engaged in college sports without regard to Sickle Cell Trait status

2. Screening for genetic conditions should be voluntary. Athletes should not be denied participation in college sports because of their decision to opt-out of genetic screening on the pre-participation physical exam

3. Claims of discrimination based on an athlete's Sickle Cell Trait status should be investigated

Preliminary Recommendations

4. ACHDNC should be urged to work with the Sickle Cell Disease Association of America, Athletic Associations, community based and health care professional organizations to develop guidelines and educational resources about screening athletes for sickle cell disease carrier status.

   These materials should address:

   i. Maintenance of privacy of medical information of athletes
   ii. Types of tests for screening and diagnosing Sickle Cell Trait
   iii. Training in resuscitation techniques; appropriate emergency medical equipment at practice fields; and ready access to emergency medical assistance. College athletics physicians should be encouraged to conduct training exercises with athletic staff to ensure competent management of emergencies

Preliminary Recommendations

5. The Centers for Disease Control and Prevention should work with athletic associations and their member institutions to develop a registry of sudden death events related to athletic performance

6. The National Institutes of Health should develop research initiatives to improve understanding of why some athletes with SCT might be at increased risk of exercise-related sudden death

7. ACHDNC should establish an expert panel to select indicators and measures to be used to evaluate compliance with recommendations and policies regarding SCT screening and outline a process for monitoring compliance with the recommendations

Next steps and relevant activities

- Input from professional medical associations and other key stakeholder groups on preliminary recommendations
- December 2009 Scientific and Public Health Implications of SC Trait meeting summary (CDC)
- February 2010 Florida Sickle Cell Symposium and Scientific Meeting report—American Journal of Hematology
- Framing the Research Agenda for Sickle Cell Trait meeting, June 3-4, 2010 (NIH)