Ad Hoc Committee Update: Impact of NCAA Sickle Cell Trait Mandate

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Objectives

- Review SACHDNC report on screening of U.S. college athletes for sickle cell trait
- Describe the impact of NCAA policy on states
- Report work to date of the Ad Hoc Subcommittee
- Feedback/Next Steps
- Do the SACHDNC recommendations still stand?
- Is this an appropriate use of newborn screening resources?
- Can/should the DACHDNC provide additional guidance to the Secretary and/or states?
- How does this experience impact the broader discussion of notification of carrier status for other conditions?
Secretary’s Advisory Committee on Heritable Disorders of Newborns and Children (2010)*

- Individuals should have the opportunity to find out their risk of medical disorders, including carrier status for sickle cell disease.
- Evaluation should take place in the medical home and should include counseling and assurances about the privacy of genetic information.
- Genetic testing should not be a pre-requisite for participation in sports, unless deemed medically necessary.
- As part of routine medical care, all potential athletes should be given education of safe practices to prevent exercise and heat related illnesses.

* Recommendations accepted by Secretary Kathleen Sebelius June 27, 2011
SACHDNC Statement (2010)

- Reviewed by Ad Hoc Subcommittee
- Consensus: Recommendations made in 2010 are still valid
- No changes proposed
Information Provided by States

- Highly variable
- Not clear that any information is given besides actual test result
  - Some efforts providing additional information rebuffed by universities/athletic department personnel
- Need for disclaimer?
  - Risk of false positive and false negative results
  - Screening vs diagnostic testing
  - Issues with accuracy and matching
Is this an appropriate use of NBS?

- Burden and Cost
- If results provided without contextual information, is this consistent with the intent of newborn screening?
- Actions of states driven by public policy, health legislation
- If states see this as a reasonable use of NBS, what recommendations are given? To whom?
  - Data on current practices not available
  - Resources for information on sickle cell trait?
Educational Resources on Sickle Cell Trait

- CDC developing a Sickle Cell Trait Education Toolkit
  - Workgroups on general information, complications and athletics
- Materials vetted through SCDAA and ASH
- General FAQs currently in CDC clearance
- Plan for other items completed by Spring 2014
- Will be available for downloading from CDC website
Summary to date

- We believe that the SACHDNC recommendations should still stand.
- Late request for NBS results solely to address the NCAA mandate is not an appropriate use of newborn screening resources.
- How can DACHDNC provide additional guidance to the Secretary and/or states? - TBD.
Next Steps

- Gather additional information from states
  - Clarification on current guidelines for carrier notification
  - Ascertain what (if any) disclaimer about the results is given
  - Determine educational information is provided (if at all) with results

- Articulate the concerns raised by the NCAA mandate
  - Draft report

- Consider mechanisms by which SACHDNC can offer assistance to states