

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

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# Objectives

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- ▶ 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



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- ▶ 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)\*

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- ▶ 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

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▶ \* Recommendations accepted by Secretary Kathleen Sebelius June 27, 2011

# SACHDNC Statement (2010)

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



# Information Provided by States

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- ▶ **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?

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- ▶ 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

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- ▶ CDC developing a Sickle Cell Trait Education Toolkit
  - ▶ Workgroups on general information, complications and athletics
- ▶ Materials vetted through SCDA 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

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- ▶ 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

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- ▶ **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**

