Summary from the Public Health Implications of Sickle Cell Trait Meeting

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Newborn Screening and Genetic Testing Symposium
Orlando, FL
Background

1968: 1st documented deaths that were exercise related reported in New England Journal of Medicine

1970s: Screening for SCD begins in some NBS programs


1994: 42 states screen for hemoglobinopathies with various SCT disclosure policies

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.

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
Public Health Implications of Sickle Cell Trait Meeting

- December 17, 2009
- Atlanta, GA
- Partners
  - CDC
  - NHLBI/NIH
  - MCHB/HRSA
  - SCDAA

**Meeting Objective:**
- To identify the gaps in public health, clinical health services, basic research, and community-based outreach strategies.
- To set/inform the agenda for future initiatives.
Who Participated

- Medical Examiners
- Epidemiologists
- Hematologists
- Psychologists
- Health Education Specialists
- Athletic Trainers
- Army physician
- Genetic Counselors
- Ethicists
- CBOs
Discussion Topics & Objectives

- Sickle Cell Trait: Scientific Evidence for Medical Complications
- Prevention of Exercise-related Mortality for People with Sickle Cell Trait
- Sickle Cell Trait and the Athlete

Objectives:
- To overview the scientific literature on current issues related to adverse health outcomes associated with sickle cell trait.
- To identify the gaps in research and inform research agendas.
- To identify opportunities for prevention and inform public health prevention and health-related intervention agendas.
Discussion Topics & Objectives

- Military Considerations for Individuals with Sickle Cell Trait
  - To hear about the military policy, how it was implemented, and outcomes around reducing exercise-related deaths and other implications.
  - To begin to consider the strengths, weakness, opportunities, challenges of various screening models.

- Screening, Follow-up and Health Education for Sickle Cell Trait
  - To review current screening and health education of SCT being implemented in the U.S.
  - To consider various models to screening and health education for SCT.
Discussion Topics & Objectives

- Ethics, Stigma, Discrimination
  - To discuss the ethical considerations that need to be made in screening and health education for SCT.
  - To identify effective strategies for dealing with stigma and discrimination.
Meeting Process

- Presentations
- Facilitated Discussion
- SWOC
  - Purpose: identify the main Strengths, Weaknesses, Opportunities and Challenges that characterize a particular situation
Salient Themes

- clinical, behavioral, epidemiological, and health services research;
- communication education & awareness;
- ethical and legal concerns;
- screening, testing, and follow-up;
- prevention.
Gaps

Research

- Longitudinal monitoring
- Causality vs. association
- Clinical cause of death
- Prevalence among athletes
- Development of cost-effective molecular tests
- Case-control studies examining medical outcome and genetic modifiers
Gaps

Communication Education & Awareness

- Educational materials for: policymakers, public, media, coaches, employers, persons with SCT
- Development of programs to support public understanding of genetics
- Evaluation of health education models efficacy
Gaps

Ethical and Legal Concerns

- Protection of health without introduction of stigma (sports, employment, health care, insurance, incarceration)
- Privacy issues around test release to non-physicians
- Avoidance of SCT misinformation and genetic discrimination
Gaps

Screening, Testing, and Follow-up

- Policy to institute adequate funding for screening/FU strengthening and implementation
- Improved efficacy of NBS and reporting
- Informed testing results process
- System to access NBS information across lifespan
Gaps

Prevention

- Universal precautions
- Standardization of process
- Screening paired with counseling
- Models tailored to cultural context
Next Steps

- Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, Washington, DC, May 13-14
- SCT Meeting Report
- Framing the Research Agenda for Sickle Cell Trait, NIH, June 2-3
- Sickle Cell Disease Carrier Screening Policy Brief, HRSA
THANK YOU

For more information please contact Centers for Disease Control and Prevention

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