

NCAA Trait testing: Update and Unintended Consequences?

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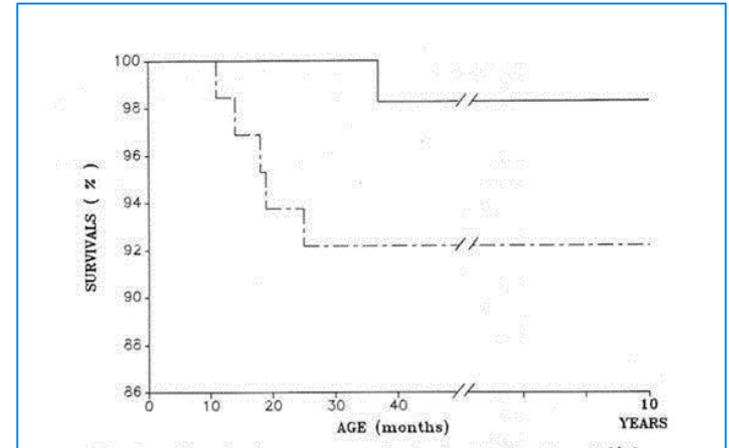
Objectives

- ▶ Review SACHDNC report on screening of U.S. college athletes for sickle cell trait
- ▶ Update on interim events
- ▶ Describe the impact of NCAA policy on states
- ▶ Consider broader implication of sickle cell trait notification from NBS on other inherited conditions
- ▶ Propose Next steps

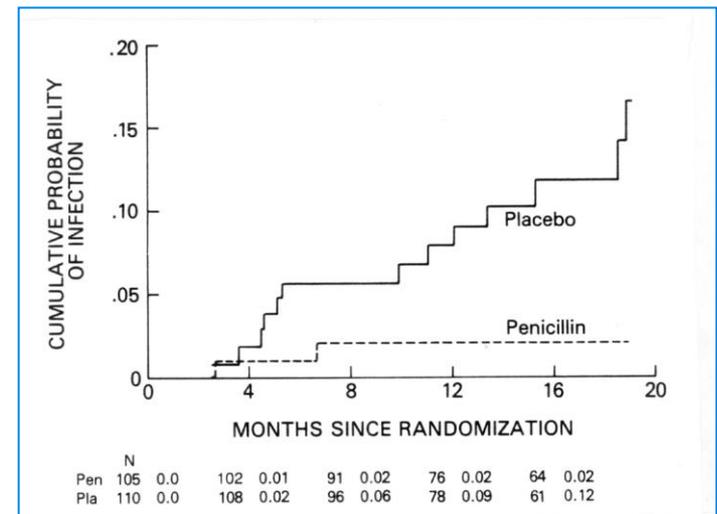


Newborn Screening for Sickle Cell Disease Saves Lives

- ▶ Infants and children diagnosed with SCD after the newborn period have decreased survival compared to infants diagnosed as newborns
- ▶ Infants diagnosed by NBS and randomized to daily penicillin had 86% decreased probability of pneumococcal infections
- ▶ “Effective intervention”, “simple reliable technique”, “compelling benefit” justified mass screening (NIH Consensus Statement 1987)
- ▶ 98% of children with SCD will reach adulthood



Vichinsky E et al, Pediatrics 81 (6): 749, 1988



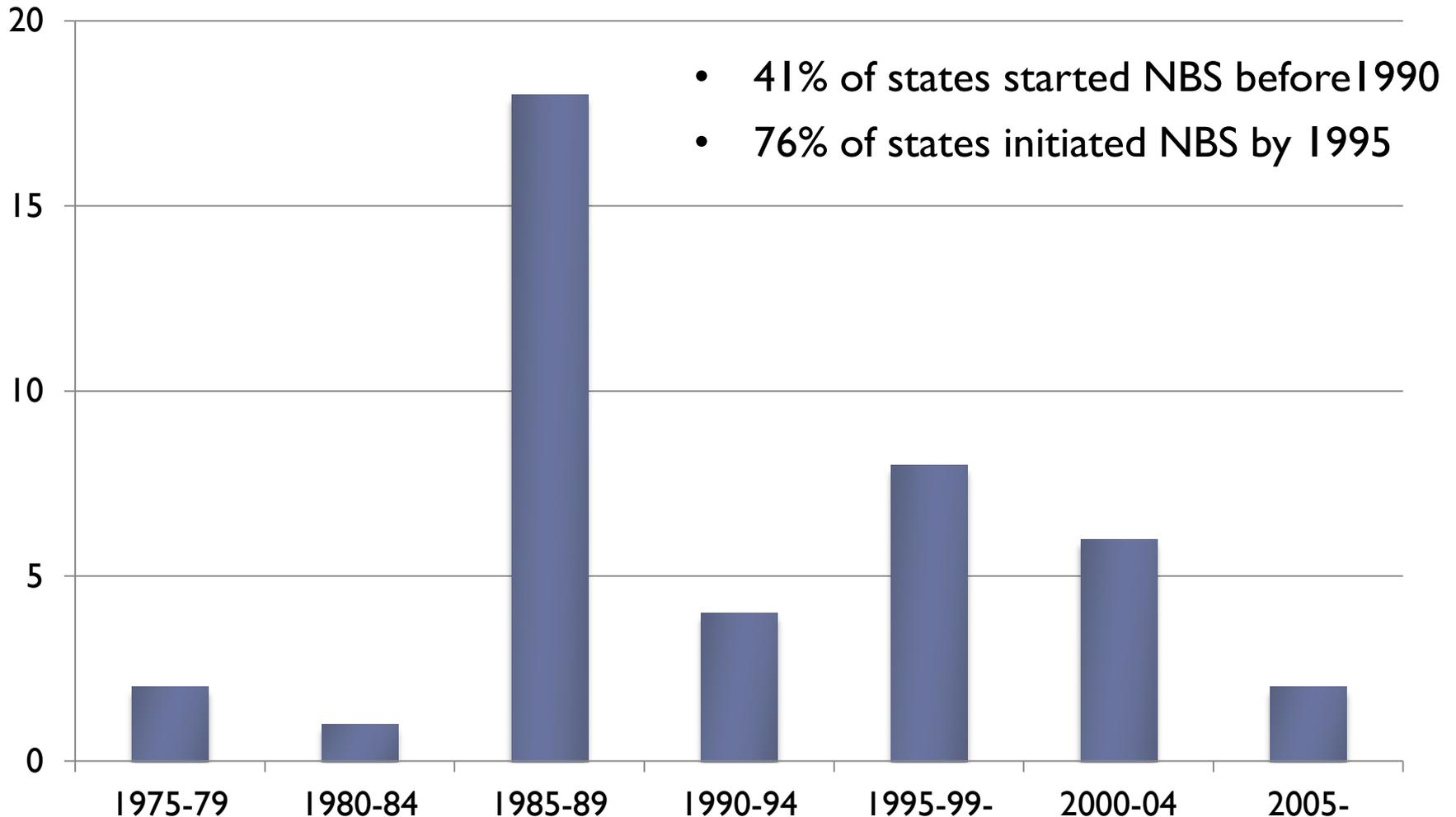
Gaston et al, NEJM 314(25): 1593, 1986

Newborn screening for SCD

Date of Universal Screening for Sickle Hemoglobinopathies Initiation by State

| | | | | | |
|---------------|--------------|----------------|--------------|----------------|--------------|
| ▶ Alabama | Jan 1, 1987 | Kentucky | Jan 1, 1995 | North Dakota | Apr 1, 2003 |
| ▶ Alaska | Oct 1, 2003 | Louisiana | Jan 1, 1992 | Ohio | Jul 1, 1989 |
| ▶ Arizona | Jan 1, 1988 | Maine | Jul 1, 2001 | Oklahoma | May 1, 1991 |
| ▶ Arkansas | Oct 1, 1988 | Maryland | Jul 1, 1985 | Oregon | Feb 1, 1995 |
| ▶ California | Feb 7, 1990 | Massachusetts | Mar 26, 1990 | Pennsylvania | Sep 28, 1992 |
| ▶ Colorado | Jan 1, 1979 | Michigan | Jul 1, 1987 | Rhode Island | May 1, 1990 |
| ▶ Connecticut | Jan 1, 1990 | Minnesota | Jan 1, 1988 | South Carolina | Jul 1, 1987 |
| ▶ Delaware | July 1, 1985 | Mississippi | Jan 1, 1990 | South Dakota | Jun 1, 2005 |
| ▶ D.C. | Jan 1, 1986 | Missouri | Apr 1, 1989 | Tennessee | Jan 1, 1988 |
| ▶ Florida | Jan 1, 1989 | Montana | Jul 1, 2003 | Texas | Nov 1, 1983 |
| ▶ Georgia | Oct 1, 1998 | Nebraska | Nov 1, 1996 | Utah | Sep 24, 2001 |
| ▶ Hawaii | Jul 1, 1997 | Nevada | July 1, 1990 | Vermont | Feb 4, 1996 |
| ▶ Idaho | May 19, 2004 | New Hampshire | May 1, 2006 | Virginia | Jul 1, 1989 |
| ▶ Illinois | Feb 1, 1989 | New Jersey | Apr 1, 1990 | Washington | Nov 1, 1991 |
| ▶ Indiana | Jul 1, 1985 | New Mexico | Oct 10, 1995 | West Virginia | Jul 1, 2003 |
| ▶ Iowa | Feb 5, 1988 | New York | Apr 1, 1975 | Wisconsin | Oct 31, 1988 |
| ▶ Kansas | Jul 1, 1993 | North Carolina | May 2, 1994 | Wyoming | Jan 1, 1987 |

Initiation of Newborn Screening for SCD



Sickle Cell Trait and NCAA

- ▶ In April 2010, NCAA announced policy requiring sickle solubility testing on all Division I student athletes
- ▶ Arose from settlement of a lawsuit brought by the family of a Rice University football player who died during pre-season training, later found to have sickle cell trait
- ▶ Opt-out provision if student can show prior testing or if student is willing to sign a waiver exempting the university and NCAA from liability
- ▶ As of January 2013, this policy has been extended to Divisions II and III student-athletes



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 on safe practices to prevent exercise and heat related illnesses

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

Other Policy Statements On Screening

- ▶ Sickle Cell Disease Association of America (2011)
- ▶ American Society of Hematology (2012)
 - ▶ ASPHO
 - ▶ APHA
 - ▶ APHL
 - ▶ SCDA
 - ▶ ASCP
- ▶ American College of Sports Medicine (2012)
- ▶ American Academy of Pediatrics/ American College of Medical Genetics and Genomics (2013)



American Society of Hematology position

- ASH does not support testing or disclosure of sickle cell trait status as a prerequisite for participation in athletic activities.
- ASH recommends the implementation of universal interventions to reduce exertion-related injuries and deaths, since this approach can be effective for all athletes irrespective of their sickle cell status.
- ASH believes that the NCAA policy, as currently written and implemented, has the potential to harm the student athlete and the larger community of individuals with sickle cell trait.
- ASH strongly supports increased biomedical and population-based research on sickle cell trait as it relates to exertion-related illness, as well as other clinical conditions



American Academy of Pediatrics

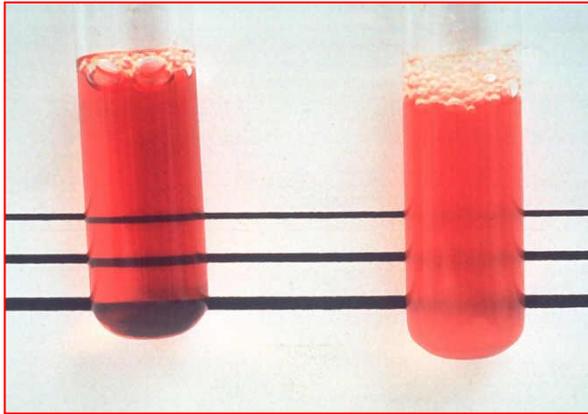
- ▶ Collaborative policy statement with the American College of Medical Genetics and Genomics on genetic testing and screening of children
- ▶ No specific position on sickle cell trait
- ▶ Do not support routine carrier testing in minors when such testing does not provide health benefits in childhood
- ▶ Advise against school-based testing or screening programs, because the school environment is unlikely to be conducive to voluntary participation, thoughtful consent, privacy, confidentiality, or appropriate counseling about test results

Fulfilling NCAA testing requirement

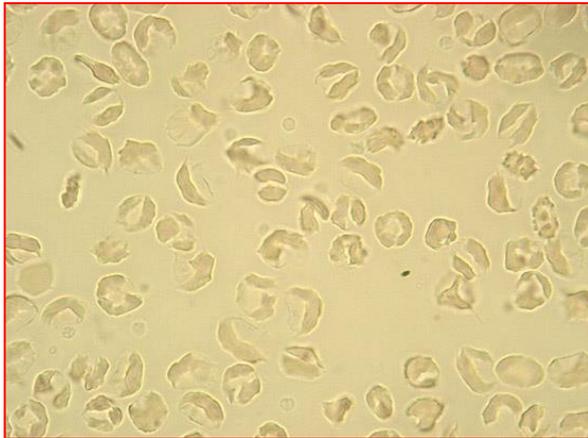
- ▶ Use of solubility test recommended but not required
 - ▶ Methodology problematic
- ▶ Obtain existing results from the primary care provider
- ▶ Have primary care provider re-test
- ▶ Obtain testing through college or university
- ▶ Contact state NBS program for results



Diagnosis of SCT: Screening Tests



Solubility test



Sickle prep

- ▶ Of no use as a primary screening tests
 - ▶ Positive = Presence of Hb S
- ▶ Negative in newborns, infants and others with high levels of Hb F; negative for Hb C
- ▶ Does not distinguish sickle cell trait (AS) from types of SCD
 - ▶ HbSC, Sickle-beta thalassemia
- ▶ In emergency, may help raise suspicion of SCD
- ▶ Can help distinguish Hb S from other hemoglobins with similar electrophoretic migration or chromatographic retention patterns.



Unintended Consequences: Impact of NCAA Policy on State Agencies

- ▶ Dramatic increase in requests during summer 2013 for NBS results for sickle cell status
- ▶ Practices and policies among states highly variable
- ▶ Logistics of retrieval of archived results
- ▶ Policy implications for release of medical information to third parties



Unintended Consequences: Impact of NCAA policy on the community

- Scenario #1: High school athletes who aspire to play college sports
- Scenario #2: Mom of a sickle cell disease patient (thus someone with SCT) fearful to continue her exercise program (to help her cardiovascular disease and obesity) because of her risk for “exertional death” from SCT.



Sickle Cell Trait: Unresolved Issues

- ▶ Is status reliably determined by methods used for NBS?
- ▶ What are current state practices for notification in the newborn period?
 - ▶ Resources for notification, follow up
- ▶ Mechanism for retrieval of data at a much later time?
 - ▶ Education/awareness of individuals and providers
 - ▶ Reproductive choices
 - ▶ Potential health consequences of carrier status
- ▶ How can providers access records of status readily?



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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?



Sickle Cell: Exemplar for Carrier Testing?

- ▶ *Healthy People 2020*: know your status
- ▶ Limited empirical evidence
- ▶ Consensus on disclosure?
- ▶ Biomedical ethics considerations
 - ▶ Respect for the decision-making capacities of autonomous persons
 - ▶ Obligation to provide benefits and to balance benefits against risk
 - ▶ Obligation to avoid harm (non-malificence)
- ▶ Logistics for public health entities



Proposed Next Steps

- ▶ Consider establishment of an ad hoc working group
- ▶ If appropriate, provide feedback to the Secretary of any new concerns
- ▶ Develop guidance for states on handling requests
- ▶ Envision a framework for dissemination of trait status across other inherited conditions

