John Parsons, Ph.D., ATC
Managing Director
NCAA Sport Science Institute
P.O. Box 6222
Indianapolis IN 46206-622
jparsons@ncaa.org

Brian Hainline, M.D.
Senior Vice President, Chief Medical Officer
NCAA Sport Science Institute
P.O. Box 6222
Indianapolis IN 46206-6222
bhainline@ncaa.org

LaGwyn L. Durden, MS, ATC, LAT
Director, Sports Medicine
NCAA Sport Science Institute
P.O. Box 6222
Indianapolis, IN 46206-6222
ldurden@ncaa.org

May 21, 2024

Dear Dr. Parsons, Dr. Hainline, and Ms. Durden:

We are submitting this letter for your consideration regarding the use of dried blood spot newborn screening sickle cell trait results as proof of NCAA student athletes' sickle cell trait status.

NCAA guidance states:
"A student-athlete must provide their school with documented results from a previous sickle cell solubility test or they must undergo testing during their preparticipation medical examination. Tests for sickle cell trait are currently performed on all newborns in the United States and many other countries, but few are aware of a positive result because the condition is not considered life threatening in most of the population. The requirement to test or provide documented results of a prior test are to make coaches and athletic trainers aware that some athletes may need to take precautions."[1]

Following this guidance, NCAA member collegiate institutions (schools) have recommended that their student athletes obtain their sickle cell trait newborn screening results as documentation of a previous sickle cell solubility test in order to satisfy the above NCAA requirement.

However, this re-purposing of newborn screening results is inappropriate, burdensome, and poses risks for student athletes, screening programs and perhaps the NCAA itself. Accordingly, the undersigned

[1] ACSM and NCAA Joint Statement *Sickle Cell Trait and Exercise.* Available at https://www.ncaa.org/sports/2013/12/18/acsm-and-ncaa-joint-statement-sickle-cell-trait-and-exercise.aspx Last updated February 8, 2023. Accessed October 3, 2023

public health experts and entities respectfully request that NCAA member schools no longer accept newborn screening results for the purpose of sickle cell trait status documentation.

To understand the pervasiveness of this issue, the Association of Public Health Laboratories (APHL) conducted an informal survey of state programs at a meeting of its newborn screening committees and subcommittees (which included representatives from all but five state newborn screening programs); nearly every state acknowledged the influx of requests for newborn screening results they receive from matriculating student athletes every fall. In large states like California, the program may receive 200 requests per week for these results. Fulfilling these requests requires verification of the student's identity in addition to locating the original results report from 18 years prior and pulls resources away from the primary function of the newborn screening program – to screen babies.

Aside from the resource and time requirements, newborn screening programs across the United States have several additional concerns about using newborn screening results as documentation of an adult's sickle cell trait status:

Inappropriate Use of Screening Results

- First and foremost, newborn screening is a screening test. It is not diagnostic and does not provide confirmation of a health condition. Additional confirmatory and/or diagnostic testing would be necessary to determine a newborn's sickle cell trait status.
- Newborn screening was established to determine an infant's risk of developing disease – it was never intended to be used for carrier screening or to identify infants with trait.
- NCAA regulations require that the physical exam of athletes include a sickle cell solubility test (SST) unless documented results of a prior test are provided to the institution. Most newborn screening programs do not conduct an SST through newborn screening testing. Other testing methodology, based on the physiology of newborns, is used to accomplish newborn screening. Newborn screening programs are not in a position to "certify" that screening results for a newborn are indicative of an adult's potential health condition.

Risk of Using Newborn Screening Results

By providing newborn screening results as proof of the student athlete's sickle cell trait status, the newborn screening programs may be at risk of liability. Newborn screening programs cannot assure the current validity and accuracy of tests or results conducted on a newborn at least 18 years ago - results on a newborn from older data systems, testing procedures, and testing policies.

Inappropriate Disclosures

- If a student athlete submits their newborn screening report to their school, they may be unintentionally providing other confidential newborn screening information that is unrelated to their sickle cell trait status.
- For various reasons, a student athlete or their parent may be unaware of the student's positive newborn screening result for sickle cell trait. If their first knowledge of this comes from the newborn screening report provided to the school, this could be quite distressing. The student athlete and their parent should receive counseling from their medical provider or genetic counselor as to the implications of this screening result and steps to follow up on the results.

- Relatedly, with required naming conventions used by birth registries and screening programs, a student's parentage as reported on the newborn screening result may differ from what is registered on the birth certificate.

We also feel it merits mentioning that the American Society for Hematology (ASH) issued a position statement against testing or disclosure of sickle cell trait status as a requirement for athletic participation in 2012. As co-signers, ASH asserts that their members continue to be in agreement with that position statement, which aligns with this letter.

Due to the issues listed above, many state newborn screening programs are no longer providing newborn screening results for the purpose of sickle cell trait status documentation.

Members of the Association of Public Health Laboratories, as state newborn screening administrators, directors, and staff, respectfully request that NCAA member schools no longer accept newborn screening results for the purpose of sickle cell trait status documentation. Student athletes should receive sickle cell trait testing as part of their preparticipation medical examination or sports physical, and in an environment that offers appropriate counseling and follow up on any positive results.

Respectfully,

Kimberly Noble Piper, RN, BS, CPH, CPHG Aaron Goldenberg, PhD, MPH
Co-chairs, APHL Ethical, Legal, Social, and Policy Issues (ELSPI) Subcommittee

cc ELSPI members:
Amy Gaviglio, MS, CGC
Anne Comeau, PhD
Heidi Elsinger,
George Dizikes, PhD, HCLD(ABB)
Eric Hendricks, JD
Natalie Ram, JD
Sarah Viall, PNP
Sue Berry, MD
Sydney Williamson-White, BSN, RN