

SICKLE CELL TRAIT TESTING FOR COLLEGE ATHLETES

Provided by the NC Council on Sickle Cell Syndrome and Related Genetic Disorders¹

The recent decision by the NCAA to require screening for sickle cell trait in college athletes in member schools has resulted in a greater awareness of sickle cell trait. If screening and counseling are done, it can be a positive experience when it is done properly and there is sufficient education for the individuals identified, their coaches, certified athletic trainers and families. If there is insufficient education, significant problems may occur, including unfair stigmatization and unnecessary concern and limitation of physical activity for young people with sickle cell trait. **It is vital that everyone involved understand that sickle cell trait is not a reason to exclude anyone from any kind of sports participation.**

Screening of all college athletes for sickle cell trait is controversial, and the Council recognizes this controversy. The Sickle Cell Disease Association of America and a large number of sickle cell experts do not recommend mass screening of athletes for sickle cell trait for several reasons. First, sickle cell trait does not significantly affect overall health, limit physical activities, occupations, or overall life expectancy. About 2.5 million people in the United States have sickle cell trait and there are about 200 million people with sickle cell trait worldwide. Many of the top professional athletes in the U. S. have sickle cell trait and most of them have not had any problems related to it.

Second, the football player whose death led to the NCAA recommendation for sickle cell trait screening died from exertional sickling, which is a form of exertional heat illness. This is an extremely rare and generally preventable complication of sickle cell trait. Extreme exercise to exhaustion especially under hot conditions can cause heat illness, with dehydration, muscle damage, sudden kidney failure, loss of consciousness and even death. This tragic event happens occasionally in military or athletic participation. Persons with sickle cell trait are at higher risk for this rare problem, but this problem also can occur in persons without trait. Preventive measures taken in military training are used to avoid too much exertion, dehydration and over-heating for **all recruits, not only those with sickle cell trait**. These measures greatly reduce the number of cases of exertional heat illness. Those who do not recommend screening for sickle cell trait in athletes feel that all athletes and their families should insist on such general preventive measures in sports training.

The NC Council on Sickle Cell Disease and Related Disorders recognizes that screening of athletes is going to take place because of NCAA requirements. The Council has provided this document to recommend best practices for how to perform screening and counseling for athletes in North Carolina in these situations. The information found in the [NCAA 2009-2010 Sports Medicine Handbook](#) and the [2007 NATA Consensus Statement on Sickle Cell Trait and the Athlete](#) stress that athletes with sickle cell trait can thrive when precautions are taken. The purpose of this statement is not to reiterate the information in those documents, but to provide more specific recommendations for sickle cell trait screening of college and university athletes in North Carolina. A common goal for all of these documents and efforts is to help athletes with sickle cell trait to compete safely and successfully.

¹ Created by NC General Statute 130A-131, The Council on Sickle Cell Syndrome and Related Genetics Disorders advises the NC Department of Health and Human Services regarding the needs of persons with these conditions and makes recommendations to meet these needs.

All college and university athletes and their families should know if the athlete has sickle cell trait and understand the medical and genetic consequences of having sickle cell trait.

1. Athletes who were born in states where newborns were screened for sickle cell disease at birth are encouraged to seek sickle cell trait status results from their primary health care provider or local health department in their community. Colleges and universities should only accept a written report of the newborn screening results from a certified laboratory, health department or licensed health care provider. Such a written report will obviate the need for repeat testing for that athlete. Athletes who were born in North Carolina to African American mothers after July 1987, and any athlete born in North Carolina after May 1994 should have sickle cell trait testing results available from newborn screening. Local health departments and/or the athletes' primary health care providers should be contacted since they may have these results.
2. Only if prior screening results are not available should athletes be tested for sickle cell trait. Prior to testing, all athletes should be informed about why the test is being performed. The flyer, "Information for Parents and Students concerning Sports Participation and Sickle Cell Trait," from the North Carolina Sickle Cell Syndrome Program is a good resource that can be used along with a verbal explanation at the time of testing.
3. All college athletes with sickle cell trait should receive formal counseling about their test results. Counseling about sports participation and training for the athlete with sickle cell trait should ideally be provided by the coaches, certified athletic trainers and sports medicine clinic personnel or other qualified health care personnel at the athlete's university or college (such as student health personnel). Counseling about the genetics of sickle cell trait and its implications for reproductive planning should be provided by the Sickle Cell Educator Counselors. Sickle Cell Educator Counselors are available in every part of the state, either through the State Sickle Cell Syndrome Program or one of the three sickle cell community-based organizations contracted by the state to provide counseling and education. The process of screening and counseling should be confidential, educational and ensure privacy for the athletes.
4. Coaches, certified athletic trainers and sports medicine clinic personnel can educate themselves, using the resources from the National Athletic Trainers' Association (NATA) and the National Collegiate Athletic Association (NCAA), to ensure that they are prepared to effectively counsel and support athletes with sickle cell trait. Coaches and certified athletic trainers should stay current in their knowledge on how best to institute measures to prevent dehydration and exertional heat illness for all people undergoing strenuous athletic activity. Everyone should work together to produce a safe environment for all athletes.
5. We recommend using laboratories listed on the attached list. These laboratories are reliable places for universities and colleges to obtain screening and follow-up testing for their athletes. At the current time, the North Carolina State Laboratory of Public Health, which performs newborn screening including sickle cell disease and trait, does not have the excess capacity to perform a high volume of additional sickle cell testing for athletes at the universities and colleges in North Carolina.
6. The Council concurs with the NCAA's planned use of the sickle cell solubility test for first level screening of athletes in those instances where an institution has large numbers of tests to run on healthy individuals, such as athletes, AND when newborn screening results are

not available. This first level of screening must be followed by alkaline electrophoresis, isoelectric focusing or High Performance Liquid Chromatography (HPLC) in those athletes with positive screening results. A health care provider should order and follow up on the results of the electrophoresis, isoelectric focusing or HPLC. Note that screening of athletes, when done on a large scale at a college or university, represents a special situation in which all of the following criteria are met: there is a concern of cost because of large numbers of athletes to be tested, the individuals to be tested are not severely anemic (a reasonable expectation in athletes), and the athletes are adolescents or adults. **Only when all of these criteria are present should the sickle solubility test be used as a screening test.** Solubility testing should not be used in any situation in which the individuals to be tested do not meet the above criteria, or when funding is such that one of the other tests can be performed on everyone. When a health care provider is testing an individual, the recommendation is to perform electrophoresis, isoelectric focusing or HPLC.

Where can I learn more?

To find out more information, contact the North Carolina Sickle Cell Syndrome Program at (919) 707-5700 or visit <http://www.ncsicklecellprogram.org>.

The websites of the NCAA (2009-2010 Sports Medicine Handbook)², National Athletic Trainer's Association (NATA)³, and NCAA (Sickle Cell Trait Educational Materials and Resources)⁴ also have more information on the topic of Sickle Cell Trait and Sports.

² NCAA 2009-2010 Sports Medicine Handbook, pages 86-89 http://www.ncaapublications.com/Uploads/PDF/Sports_Medicine_Handbook8cd2dbe-6aa9-4d9a-bbee-2e426d0759a2.pdf

³ 2007 NATA Consensus Statement on Sickle Cell Trait and the Athlete <http://www.nata.org/statements/consensus/sicklecell.pdf>

⁴ NCAA Sickle Cell Trait Educational Materials and Resources

http://www.ncaa.org/wps/portal/ncaahome?WCM_GLOBAL_CONTEXT=/ncaa/NCAA/Academics+and+Athletes/Personal+Welfare/Health+and+Safety/SickleCellTrait