



Personal Genetics Education Project

Ethical, Legal and Social Issues in Personal Genetics

SNAPSHOT

After 10 Years of Testing All College Athletes for Sickle Cell Trait, What Have We Learned?

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SNAPSHOT

After 10 Years of Testing All College Athletes for Sickle Cell Trait, What Have We Learned?

Big Picture

- What is Sickle Cell Trait? And why do athletes in particular need to take precautions if they have the trait?
- Since colleges and universities began screening athletes for Sickle Cell Trait in 2010, are they safer? What were the hopes and worries about screening student-athletes who play college sports?
- What should prospective student-athletes, as well as others, know about the program and its successes and limitations?

What is Sickle Cell Trait?

Sickle Cell Trait is a common genetic variation that affects a person's red blood cells. The main building block of red blood cells is a protein called hemoglobin. Hemoglobin gives red blood cells their shape and is also key in binding and transporting oxygen.

The function of hemoglobin can be affected by differences in the DNA of the genes that code for this protein. We call these differences in the DNA code "variants". Some variants are more common than others, and some can affect a person's health.

For example, in one of the hemoglobin genes, there is a variant (**S**, Fig. 1) that causes red blood cells to have a 'sickle' or 'crescent' shape (like the letter 'C') and a variant (**A**,

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Fig. 1) that does not cause cells to sickle. The difference between these 2 variants is a single letter in the DNA code. People have two copies of this gene, one inherited from each biological parent. Therefore, people may carry these variants in 3 different combinations: SS, AA, or AS (Fig. 1).

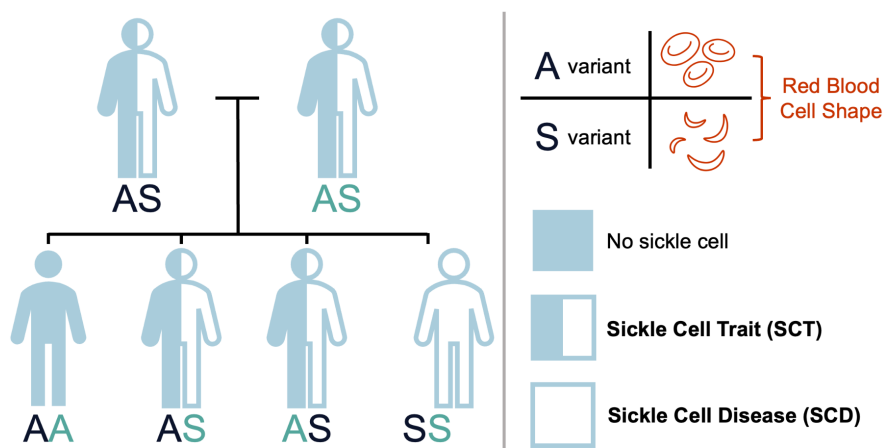


Figure 1: The Genetics of Sickle Cell

- If a person has AA, their red blood cells typically have a flexible, round shape and can easily move through the body to deliver oxygen.
- If a person has SS, their red blood cells can have a rigid, 'sickle' shape. These cells have problems moving through the body and delivering oxygen to a person's organs and tissues. The result is a serious medical condition called **Sickle Cell Disease (SCD)** - also known as Sickle Cell Anemia).
- If a person has AS, this is known as **Sickle Cell Trait (SCT)**. SCT is found in more than 3 million people in the United States, and 100 million people across the globe. People with SCT do not typically have the symptoms of SCD, but are at increased risk for serious health complications in certain situations, such as exercising in extreme conditions. Extreme conditions can include very hot weather, longer-than-recommended training, and high altitude. These extreme conditions can cause distress (such as dizziness, weakness or vomiting during or after the workout) in any person, irrespective of their SCT status.

Who Might Have Sickle Cell Trait?

Watch this video: [Did You Know Sickle Cell Has Many Faces?](#)

As was shown in the video: any person, no matter where they are from, can carry the variant that can cause sickled red blood cells (S, Fig. 1). However, because SCT provides some protection against malaria, the S variant is more common in people with ancestry from parts of the world with a recent history of malaria, such as Sub-Saharan Africa, parts of Asia, the Arabian Peninsula, and parts of the Mediterranean.

Why did the NCAA Decide to Screen Every Athlete in Every Sport?

All athletes playing on college sports teams governed by the National College Athletic Association (NCAA) are required to confirm their SCT status by taking a blood test or by providing prior test results. This mandatory SCT screening program was put in place in 2010 as a result of a lawsuit in response to the death of Dale Lloyd II. Dale collapsed during football practice at Rice University, and the medical examiner stated that he died from SCT complications. Dale was one of 10 NCAA football players with SCT who died during or after intense athletic conditions in extreme conditions between 2000-2010. His parents, Dale and Bridgette Lloyd, sued Rice University and the NCAA. As a result of this lawsuit, the NCAA agreed to mandate an SCT screening program with the goal of preventing future deaths.

Like Dale, a significant number of the NCAA athletes with SCT who died were Black football players in Division I (DI, the highest level of competition in college athletics) programs. SCT screening initially only included students playing DI level athletics, but by 2014 all NCAA athletes were required to confirm their SCT status. Why did the NCAA decide to screen every athlete in every sport?

In the US, SCT is more common among people who identify as Black or African-American, as this group of people has ancestry from Sub-Saharan Africa. As

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mentioned before, this is a part of the world where the S variant is more common due to a recent history of malaria. However, it is *incorrect* and can be harmful to conclude that SCT is only found in people with specific ancestries. Any person - regardless of their race, ethnicity, or ancestry - can carry the S variant. Therefore, targeting only certain groups for SCT screening (or exempting others) means some people who have SCT would go undetected.

What are Some of the Hopes and Concerns about the NCAA Screening Program for Sickle Cell Trait?

What is the best way to keep athletes safer? The SCT screening program was met with a mix of relief and concern. For some, including families who had suffered a loss, they hoped universal SCT screening might keep athletes safer. Some questioned whether SCT was the key cause of death in these cases and expressed concerns about the training conditions. The human body can be pushed past its limits when exercising in extreme conditions, as described in the earlier section of this lesson, “What is Sickle Cell Trait”. Various lawsuits seeking justice for the deaths of athletes with SCT also mention excessive sprinting, lack of water, and signs of distress (such as dizziness, weakness or vomiting during or after the workout) that were ignored. Thus, many people called for changes in guidelines and safety precautions that would benefit all students, irrespective of their SCT status. As a part of the settlement with the Lloyd family, the NCAA rolled out an educational program alongside SCT screening. The intent is to encourage university athletic departments to improve health and safety protocols on and off the field, for all students.

Please watch this video to see how the NCAA talks about these guidelines and SCT screening to its athletes: [Sickle Cell Trait and the Student-Athlete Video](#).

What has the impact of this policy been? Since the SCT screening program began, researchers estimate an 89% reduction in deaths amongst DI football players - the group that has been most vulnerable to death associated with SCT. This estimate was

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calculated based on the number of student-athletes who had died in the decade before the screening program was fully implemented. However, it remains unclear whether the reduction in student-athlete deaths was due to (1) the SCT screening program, (2) the educational program to encourage changes in health and safety protocols for all students, or (3) both.

Concerns about misuse. SCT screening has a complex history, and critics of the NCAA's program have expressed concerns that Black student athletes could be subjected to racist or discriminatory decisions. They have pointed to examples, such as the Air Force Academy's SCT screening program which began in 1973. The Academy screened applicants for SCT and refused admission to those with SCT. This policy was ended in 1981 soon after a former cadet brought a class action lawsuit that argued the Academy's policy was being used to deny entry to Black students. As mentioned in the NCAA video, athletes with SCT should not be excluded from participation in sports. Whether the NCAA's SCT screening program results in students experiencing discrimination continues to be an area of inquiry and research for policymakers and ethicists.

What Should Students Know about the NCAA's SCT Screening Policy?

Here are several big-picture ideas about testing for genetic traits such as SCT and SCD, and about rights related to your health, safety, and personal genetic information.

1. NCAA rules require all athletes to confirm their SCT status, in part because SCT can impact anyone, regardless of race, ethnicity, or ancestry. Alongside the SCT screening program, the NCAA rolled out an educational program to improve health and safety protocols for all athletes on and off the field.

2. Any athlete can experience health problems when exercising in extreme conditions. On top of that, SCT and other factors (such as asthma and cardiac conditions) are

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known to put athletes at additional risk of serious complications. Thus, being aware of your SCT status, and other health conditions, may be helpful in preventing serious harm.

3. Having SCT is not a barrier to participating in sports, as noted in the NCAA video.

Though it is important for athletes to take reasonable precautions, exercising can provide benefits for those with both SCT and SCD.

4. Genetic counseling provides support to people undergoing screening for genetic traits, such as SCT and SCD. Genetic counselors are health professionals trained to provide information to people considering testing, and then support people once they receive their results. Genetic counseling is not required nor commonly offered as part of SCT screening programs. However students may wish to inquire about the availability of these services at their institution or with their doctor.

5. The Genetic Information Non-discrimination Act (GINA) protects people from being discriminated against because of their genetic make-up. Some NCAA student athletes might be concerned that their SCT screening results could negatively affect other parts of their lives. In the United States, GINA is a federal law passed in 2008, and it prohibits employers from making hiring, firing, or promotion decisions based on a person's genetic information. GINA also prohibits health insurers from using genetic information (a) to deny a person the right to buy health insurance and (b) to raise or lower the cost for buying health insurance.

6. Some schools offer a waiver to the required SCT status confirmation, meaning, you can choose to opt out of testing. While some divisions within the NCAA are considering ending the waiver option, students who choose that option agree to give up a host of legal rights, including the right to sue the university in the event of an injury related to SCT.

Student Worksheet

Name: _____

Date: _____

1. What is the difference between Sickle Cell Trait and Sickle Cell Disease?
2. What prompted the NCAA to begin screening all its athletes for SCT?
3. Can anyone have SCT, regardless of race, ethnicity, or ancestry? (Y/N)
4. Early research of Division I football programs suggests an 89% reduction in student-athlete deaths associated with SCT over the past 10 years. One reason might be because of SCT screening. What is another reason that might explain this decrease?
5. What is the name of the law that protects genetic information in the workplace and in health insurance?
6. Imagine you are about to start competing on a college team and it's time for your SCT screening. What are two questions you have for the athletic director about the screening you are being offered?

Teacher's Guide

Related pgEd SNAPSHOT

[‘The Many Faces of Sickle Cell Disease’](#) is a companion module on Sickle Cell Disease that dives further into the reasons why the variant that can cause sickled red blood cells (S, Fig. 1) is more common in people with ancestry from certain parts of the world. It also provides students an opportunity to consider a video that documents some perspectives of people with SCD.

Additional Resources for Teachers

[This 1981 NYT article](#) gives an account of the SCT screening program at the Air Force Academy between 1973-1981, which ended soon after a former cadet brought a class action lawsuit that argued the Academy’s policy was being used to deny entry to Black students.

[The American Society of Hematology](#) provides further information on Sickle Cell Trait and athletics, as well as their stance on mandatory SCT screening programs.

For personal perspectives on sickle cell, loss and advocacy:

Dr. Tomia Austin, Executive Director of The As One Foundation, [hosts Bridgette Lloyd for a conversation](#). The One Foundation (January 2022)

[“Devard Darling carries on legacy of twin Devaughn with foundation to learn about sickle cell”](#) by Antwan Staley, *Tallahassee Democrat* (March 2021)

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Research related to the adoption and longer-term impact of the NCAA's SCT screening program:

For a survey of athletic trainers and team doctors related to NCAA testing and SCT:

McDonald, M. A., Creary, M. S., Powell, J., Daley, L., Baker, C., Royal, C.D. (2017).

Perspectives and Practices of Athletic Trainers and Team Physicians Implementing the 2010 NCAA Sickle Cell Trait Screening Policy. Journal of Genetic Counseling, 26 (6), 1292-1300. <https://doi.org/10.1007/s10897-017-0107-6>

For insights on how athletic staff and student-athletes perceive the NCAA's testing program: Baker, C., Powell, J., Le, D., Creary, M. S., Daley, L. A., McDonald, M. A., & Royal, C. D. (2018). *Implementation of the NCAA Sickle Cell Trait Screening Policy: A Survey of Athletic Staff and Student-athletes. Journal of the National Medical Association, 110(6), 564–573. <https://doi.org/10.1016/j.jnma.2018.03.004> (note: abstract only, full paper is paywalled)*

To explore research seeking to quantify deaths of athletes with SCT pre and post NCAA testing policies that require SCT screening: Buchanan, B. K., Siebert, D. M., Zigman Suchsland, M. L., Drezner, J. A., Asif, I. M., O'Connor, F. G., & Harmon, K. G. (2020). *Sudden Death Associated With Sickle Cell Trait Before and After Mandatory Screening. Sports health, 12(3), 241–245. <https://doi.org/10.1177/1941738120915690> (note: abstract only, full paper is paywalled)*

To learn about earlier efforts to estimate how the NCAA policy might prevent harm to athletes with SCT: Tarini, B. A., Brooks, M. A., & Bundy, D. G. (2012). *A policy impact analysis of the mandatory NCAA sickle cell trait screening program. Health services research, 47(1 Pt 2), 446–461. <https://doi.org/10.1111/j.1475-6773.2011.01357.x>*

Student Worksheet: Teacher Notes

1. If a person has SS, their red blood cells can have a rigid, 'sickle' shape. These cells have problems moving through the body and delivering oxygen to a person's organs and tissues. The result is a serious medical condition called **Sickle Cell Disease (SCD)** - also known as Sickle Cell Anemia).

If a person has AS, this is known as **Sickle Cell Trait (SCT)**. People with SCT do not typically have the symptoms of SCD, but are at increased risk for serious health complications in certain situations, such as exercising in extreme conditions. Extreme conditions can include very hot weather, longer-than-recommended training, and high altitude. These extreme conditions can cause distress (such as dizziness, weakness or vomiting during or after the workout) in any person, irrespective of their SCT status.

2. The NCAA began screening all athletes in response to a lawsuit after the death of a football player, Dale Lloyd II, as a way to reduce risks and keep athletes healthy. Because SCT can affect any person, regardless of their race, ethnicity, or ancestry, the policy requires all athletes to be tested.
3. Yes
4. Alongside the SCT screening program, the NCAA rolled out an educational program, which encourages university athletic departments to improve health and safety protocols on and off the field. Also, students may question how this research was done. Depending on their background knowledge about experimental design, they might point out that this was not a controlled experiment with a comparison between a control group and an experimental group.

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5. The Genetic Information Non-discrimination Act or GINA.
6. Student answers will vary, and the questions could be the basis for more in-depth research, writing assignments, or further classroom discussion or extensions. One point to emphasize, if it is raised, is that athletes with SCT are able to compete in any NCAA sport, and finding that an athlete has SCT should not be a reason for someone to be denied a place on a team.