



Personal Genetics Education Project

Ethical, Legal and Social Issues in Personal Genetics

Title: Protecting Athletes with Genetic Conditions

Aim: Whose responsibility is it to ensure that athletes with medical conditions are both safe and treated fairly?

Time: This lesson can be adjusted to fill 1 or 2 classes.

Guiding questions:

- Why might having information about one's sickle cell trait status be helpful?
- How do certain medical conditions, such as sickle cell trait, impact athletes?
- How might genetic testing protect athletes?
- Who is most responsible for protecting athletes – administrators, coaches, parents or athletes themselves?

Learning objectives:

By the end of the lesson, students will be able to:

- Understand the causes and effects of sickle cell trait and sickle cell anemia.
- Explain how sickle cell trait impacts people, specifically athletes.
- Discuss who should take responsibility for protecting athletes and why.

Materials: Handouts provided in the lesson, articles.

Common Core Standards:

RST.9-10.1. Cite specific textual evidence to support analysis of science and technical texts, attending to the precise details of explanations or descriptions.

RST.11-12.7. Integrate and evaluate multiple sources of information presented in diverse formats and media (e.g., quantitative data, video, multimedia) in order to address a question or solve a problem.

RH.11-12.1. Cite specific textual evidence to support analysis of primary and secondary sources, connecting insights gained from specific details to an understanding of the text as a whole.

Background information and note to teachers:

Genetic testing is increasingly playing a role in sports. As the genetic basis for many health conditions are revealed, some doctors, coaches, and academic and athletic organizations are wondering: can genetic analysis provide health and safety benefits for athletes?

Recently, the National Collegiate Athletic Association (NCAA), the governing body of college sports, began screening all of its athletes for the genetic condition, sickle cell trait (SCT). SCT is caused by a variant of the hemoglobin gene called hemoglobin S. Each person has two copies of the hemoglobin gene, one copy that is inherited from his/her mother and the other copy that is inherited from his/her father. Most people have two copies of the A variant of the hemoglobin gene (hemoglobin A). People with the condition sickle cell anemia have inherited two copies of the hemoglobin S variant (one from each parent), causing the person's red blood cells to adopt a sickle shape and leading to chronic symptoms. In contrast, people with SCT have inherited one copy of the hemoglobin S variant and one copy of the hemoglobin A variant. People with SCT do not have the symptoms of sickle cell anemia, but are at increased risk for harmful complications under certain conditions, such as intense exercise. In addition, they can pass on the hemoglobin S variant to their children.

The NCAA hopes that SCT screening will save lives. Several young men, typically African American (the population with the highest frequency of SCT in the United States), have died in the course of sports practices or games from complications related to SCT. Following the death of 19-year-old student Dale Lloyd II, who died after a football practice as a result of complications from SCT, Lloyd's parents sued Rice University and the NCAA. As a result of the lawsuit, the NCAA agreed to implement an SCT screening program in an effort to inform students of their SCT status and prevent future deaths. (Note: sickle cell testing is mandated in all 50 states as part of standard newborn screening, but many people are not aware of their status.) Critics of the NCAA policy argue that screening is not the most efficient way to prevent death. They suggest that improved safety conditions and increased awareness of dehydration and muscle exhaustion would be more effective and benefit all players, regardless of genetic factors.

In a related debate, some doctors and athletic groups are advocating that all young people playing high-intensity sports, such as soccer, be screened for a dangerous heart condition, called hypertrophic cardiomyopathy (HCM). HCM is a thickening of the heart wall muscles that has been linked to sudden death in athletes, often during or right after high-intensity physical activity. Many believe testing for HCM will save lives, in part by identifying children most at risk and excluding them from high-risk, high-intensity sports. While

HCM is not covered in this lesson, it could be a useful addition to the classroom discussion and may help to frame the issues more broadly. For more about HCM and athletes, see pgEd's "Athletics and Genetics" lesson at <http://www.pgEd.org/lesson-plans/>.

This lesson asks students to examine how genetics might impact their own athletic choices and options. They will be asked to consider how learning about their own genetic information might influence their athletic path. Students do not need to have a background in genetics, as this lesson focuses mainly on social and ethical issues related to genetic testing. This material is relevant to multiple subjects, including biology, health, social studies, law, physical education and psychology.

Here is an outline of the resources and activities in this lesson.

1. Reading for students (page 3)
2. Reading and notes (page 4, handout on pages 7-9)
3. Proposal (pages 4-5, handout on page 9)
4. Presentations and group discussion (page 5)
5. List of additional resources (page 5)
6. Short quiz (answer key on page 6, handout on page 11)

Reading for students:

Students should read the following article for homework before the lesson:

["In N.C.A.A., Question of Bias Over a Test for a Genetic Trait,"](#) January 2012, by Katie Thomas and Brett Zarda, *New York Times*.

This article was written before the NCAA voted to implement the SCT screening policy. As of Fall, 2013, the NCAA screens all athletes at any level of play, including Division I, II and III schools. The article addresses the discussion surrounding this policy, balancing the interest to protect athletes' safety with concerns about the possibility of discrimination and the effectiveness of widespread screening.

Activities: Reading and notes (15 minutes), proposal (30-50 minutes), presentations, group discussion (15-20 minutes).

In Part 1, students will read a handout about SCT. In Part 2, students will break into groups to draft a 1-2 page letter that explains whether they would support or oppose a screening policy for high school athletes. In Part 3, each group will present its policy to the class.

Part 1: Reading and notes (15 minutes)

1. Students will read a handout (pages 6-8 of this document) about sickle cell anemia and SCT, and briefly answer the following three questions, also included in the handout. The handout is based on materials from the [Health Guide on Sickle Cell Anemia](#) from the *New York Times* and the article on [Sickle Cell Trait](#) from the Centers for Disease Control and Prevention (CDC).

1. What happens when red blood cells become sickle-shaped?
2. Why is sickle cell trait more common in people of African and Mediterranean descent than in other groups? How can hemoglobin S be considered a “beneficial mutation”?
3. How does sickle cell trait affect athletes? What do they need to do to make sure they stay healthy?

Part 2: Write a short proposal about genetic testing, safety and athletes. (30-50 minutes)

Students will write a proposal explaining their ideas for a school policy on SCT and student-athletes.

1. Break the class into groups of 3 to 4 students. Assign each group to represent a different stakeholder (school administrators, parents, athletic directors and students) and write a 1-2 page proposal that explains their ideas for a policy. They should address their letter to the superintendent. You do not need to assign a point of view for each group (e.g. pro or con), but instead ask students come to a consensus about what the policy should be and why. You can assign more than one group to each stakeholder if you have a larger class.
2. Distribute the following article for students to read in their groups, as the article provides depth to the discussion about the intent of screening all athletes as well as the reasons that a number of hematologists oppose universal screening. In addition, distribute the student assignment handout (page 9 of this document), as it outlines the questions and expectations for the persuasive letter.

[“Blood Doctors Call Foul On NCAA's Screening For Sickle Cell,”](#) January 2012, by Scott Hensley, *National Public Radio*.

Questions and concerns for students to consider and address:

1. Should your school screen all athletes or potential athletes for SCT? Why or why not? Do the benefits of doing so outweigh the negatives?
2. Why do some people think everyone should be screened (called universal screening)?

3. Why are others, including the American Society of Hematology (an organization of blood doctors), against universal screening?
4. Explain your reasons for creating this policy. How could your policy help students? Could it harm students in any way?
5. How can you ensure that your policy is fair to all students?
6. If you argue for SCT screening, how will this policy be implemented? How will the school pay for the screening? What will happen to students who test positive? Note: Students who test positive for SCT in the NCAA are still allowed to play.
7. If you argue against SCT screening, what other measures might you propose to keep student-athletes safe?
8. How will you evaluate the success of your policy?

Part 3: Presentations and group discussion (15-20 minutes)

If time allows, each group should outline the main ideas of its policy on chart paper and then make a presentation to the class. Students will need to explain their evidence and reasoning and be able to answer questions from other students.

Additional resources for teachers:

["Families of Athletes to Sue Over Heat-Related Deaths,"](#) July 2012, by Lizette Alvaraz, *New York Times*. (Note: This article is focused on high school students.)

["N.C.A.A. Council Approves Testing for Sickle-Cell Trait,"](#) July 2010, by Katie Thomas, *New York Times*.

["Sickle Cell Trait and Sports: Is the NCAA a Hematologist?,"](#) May 2013, by Janis Abkowitz, *American Society of Hematologists*.

["Mile-High Health Concerns Leave Steelers Star On The Bench For Playoff Game,"](#) January 2012, by Bill Chappell, *National Public Radio*.

Image credits:

Page 7: From the National Heart, Lung, and Blood Institute, National Institutes of Health (<http://www.nhlbi.nih.gov/health/health-topics/topics/sca/>, accessed Feb 1, 2016).

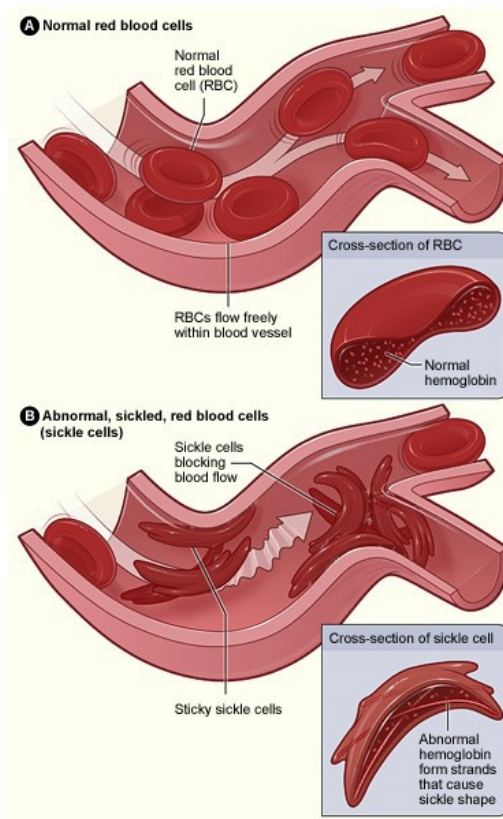
Page 8: "Autosomal recessive" by Colin ML Burnett.
(<https://commons.wikimedia.org/wiki/File:Autorecessive.svg.png>, accessed Feb 1, 2016). Available under a Creative Commons Attribution-Share Alike 3.0 Unported license (<https://creativecommons.org/licenses/by-sa/3.0/deed.en>).

**"Protecting Athletes with Genetic Conditions" quiz answer key
(see page 10 for quiz):**

- 1.) C
- 2.) T
- 3.) B
- 4.) T

Sickle Cell Anemia

Hemoglobin is a protein found in red blood cells that carries oxygen. Sickle cell anemia is caused by an abnormal version of the hemoglobin protein. This abnormal version, called hemoglobin S, changes the shape of red blood cells, especially when the cells are exposed to low oxygen levels. While normal red blood cells are donut-shaped and flexible, red blood cells that contain hemoglobin S become shaped like crescents or sickles and are inflexible. These fragile, sickle-shaped cells deliver less oxygen to the body's tissues. They also can get stuck more easily in small blood vessels and break into pieces that interrupt healthy blood flow; interrupted blood flow can cause extreme pain. Other complications of sickle cell disease are anemia (a shortage of healthy red blood cells), fatigue, jaundice and blindness.

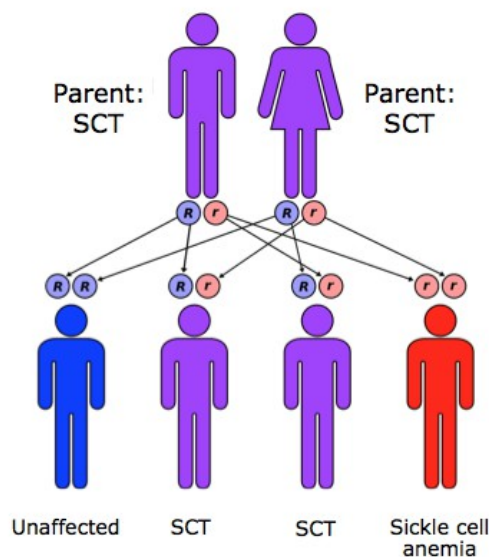


Source: National Heart, Lung, and Blood Institute, National Institutes of Health.

Sickle Cell Trait

Sickle cell anemia is inherited from *both* parents. That is, individuals who have sickle cell anemia have inherited two copies of the hemoglobin S gene, one gene from their father and one gene from their mother. In contrast, individuals who inherit one gene for hemoglobin S from one parent and one gene for normal hemoglobin (A) from the other parent have **sickle cell trait (SCT)**. People with SCT do not have the symptoms of sickle cell anemia, but can be at risk for complications under certain conditions. Also, they can pass on the hemoglobin S gene to their children.

SCT and sickle cell anemia (also called sickle cell disease) are much more common in people of African and Mediterranean descent. This is because SCT has been shown to provide resistance to malaria, a disease spread by mosquitoes that is common in areas where mosquitoes thrive. It is estimated that 1 in 12 African Americans (roughly 8%) have SCT.



Source: [Colin ML Burnett, CC BY-SA 3.0](#)

Most people with SCT do not have any symptoms of sickle cell anemia, although in rare cases people with SCT might experience harmful complications in certain extreme conditions. One such condition is low oxygen levels, which one might encounter while mountain climbing or in cities far above sea level, such as Denver, Colorado. National Football League star Ryan Clark, who has SCT, does not play at Mile High Stadium in Denver in an effort to avoid health complications. Dehydration, a condition where one's body loses too much water, also poses a risk.

Sickle Cell Trait and Athletes

Some people with SCT have been shown to be more likely to experience heat stroke and muscle breakdown when doing intense exercise, such as competitive sports or military-style training, at unfavorable temperatures (very high or low) or conditions. In very rare cases, workouts in extreme conditions can lead to death.

Studies have shown that drinking enough water and avoiding getting overheated during exercise can reduce the chance of complications. People with SCT who participate in competitive sports, including high school and college level student-athletes, should be careful when training and competing. Experts suggest a number of precautions to prevent SCT-related illness. These include pacing oneself, warming up slowly and resting when needed. In addition, it is advised to drink water before, during and after exercise and avoid extreme heat and humidity. It is also very important to seek medical care immediately when feeling ill.

*Adapted from the CDC and New York Times
[Centers for Disease Control and Prevention – Sickle Cell Trait](#)
[New York Times Health Guide-Sickle Cell Anemia](#)*

Questions:

1. What happens when red blood cells become sickle-shaped?

2. Why is sickle cell trait more common in people of African and Mediterranean descent than in other groups? How can hemoglobin S be considered a “beneficial mutation”?

3. How does sickle cell trait affect athletes? What do they need to do to make sure they stay healthy?

Name_____

Date_____

Protecting Athletes with Genetic Conditions

Assignment:

Imagine that the superintendent is deciding on a school policy for sickle cell trait (SCT), a medical condition that could have a potentially serious impact on student-athletes. As a group, write a 1-2 page proposal addressed to the school superintendent. The proposal should explain your SCT screening policy, and how you will institute and evaluate it. You need to consider and address the following questions and concerns:

1. Should your school screen all athletes or potential athletes for SCT? Why or why not? Do the benefits of doing so outweigh the negatives?
2. Why do some people think everyone should be screened (called universal screening)?
3. Why are others, including the American Society of Hematology (an organization of blood doctors), against universal screening?
4. Explain your reasons for creating this policy. How could your policy help students? Could it harm students in any way?
5. How can you ensure that your policy is fair to all students?
6. If you argue for SCT screening, how will this policy be implemented? How will the school pay for the screening? What will happen to students who test positive? Note: Students who test positive for SCT in the NCAA are still allowed to play.
7. If you argue against SCT screening, what other measures might you propose to keep student-athletes safe?
8. How will you evaluate the success of your policy?

You should not number and answer each question. Your proposal should be written in the format of a formal letter that addresses the questions raised above.

Name_____ Date_____

“Protecting Athletes with Genetic Conditions” quiz

1. Which of the following answers is *incorrect*?
Sickle Cell Trait is a genetic condition that a) runs in families b) can affect anyone, but predominately is found in people of African or Mediterranean descent c) increases your risk of developing diabetes d) is tested for in all college athletes playing in the NCAA.
2. Sickle cell anemia causes red blood cells to change shape and can block the normal transport of oxygen through a person’s blood vessels. T/F
3. Sickle cell trait can be beneficial because a) it never causes harm to a person with it b) it can protect against malaria c) it increases the flow of oxygen in blood d) it helps athletes perform better.
4. Athletes with sickle cell trait need to take extra measures to make sure they are safe during practices and games in heat or at high altitude. T/F