

personal genetics education project

Social, Legal and Ethical Issues in Personal Genetics

Title: Debating the social and ethical issues in personal genetics and sports

Aim: How might personal genetics impact and transform athletics?

Time: 1-2 days

Guiding questions:

1. What can we learn about personal genetics by discussing athletics?
2. How can the debates from the world of athletics speak to broader concerns about ethics, choice, and informed consent?

Learning objectives:

By the end of the lesson, students will:

- Understand that athletics is a field where genetics is increasingly important.
- Know that sports function as a microcosm for larger debates about genetics and ethics.
- Realize that they may have personal choices to make related to athletics and their genomes – whether it be for themselves or for family members in the future.
- See that the scientific community is still debating the predictive value of genetic tests for sports performance.

Materials: Articles, handouts (scenarios in lesson plan)

Common Core Standards:

RST.11-12.1. Cite specific textual evidence to support analysis of science and technical texts, attending to important distinctions the author makes and to any gaps or inconsistencies in the account.

RH.11-12.2. Determine the central ideas or information of a primary or secondary source; provide an accurate summary that makes clear the relationships among the key details and ideas.

Before the lesson:

Students do not need to have a background in genetics, as this lesson focuses on social and ethical issues related to genetic testing. This lesson is appropriate for multiple subjects, including biology, health classes, social studies, law, and/or psychology. In addition to the *New York Times* article below, teachers may want to look at the reading list at the end of this lesson in advance of presenting this lesson, to gain perspective on the scientific debates about just how much genetic factors may play into sports performance.

For students: Have students read the article below for homework before the lesson (it will be discussed in the Do Now):

["Born to Run? Little Ones Get Test for Sports Gene"](#) New York Times, November 30, 2008 by Juliet Macor.

Do Now:

Have students answer the following questions independently:

Do you wish your parents had genetically tested you as a child to see if there is a certain sport at which you might excel, or to see if you had a special gift for musical ability? (Note: There is a test for a "sports gene" which is controversial from a scientific and ethical standpoint, though a test for musical ability does not exist). Why or why not? What could be a benefit and what could be a negative thing to having this information at an early age? After answering all of the questions, students should share answers with the class and discuss. (7 minutes)

Activity:**1. Pair-Share:** (10 minutes)

Have students briefly discuss the article they read for homework and pair-share. In pairs (or small groups) have students answer and discuss the following questions about the article:

- A. Why do some parents want to have their children tested for athletic ability?
- B. Why do some experts, including some doctors, think genetic testing for young children's sports ability is unwise?
- C. Who would likely have access to these tests? Does that access give one group more of an advantage over others? Is that fair?
- D. How accurate are these sorts of tests? Do you think they are actually useful?

After students have worked together in pairs/groups, have some students share their answers with the class.

2. Scenarios and discussion (30 – 35 min):

You will break students into two groups, then into smaller groups of 4-5 within those two larger groups. The two groups will each be given a scenario, and each smaller group will look at it from a different perspective.

Have each group answer the questions that go along with their role; you can have students answer individually or one record the answers for the group, depending on your preference. Bring the class back together, and have one person from each of the larger group give a brief explanation of the scenario for the students from the other group. Have each group discuss their answers based on their role.

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 1: Scenario A – Genetic Testing for Sports Ability
Role: Student 1

You are 15 years old, and when you were 6, your parents had you genetically tested. Turns out your genetic profile convinced them to have you go out for the track team. You are a state champion sprinter in the 50 and 100 meter run. You practice daily, travel to meets, make friends and impress coaches. Whether your genes have anything to do with your success is a question you wonder about, as you have practiced daily for many years and work really hard. Your parents have spent money for you to go to track camps, on coaches, sneakers, even nutritionists. There is talk of college scholarships (worth 100k over four years). However, you are sick of track and want to try a team sport, like soccer, or maybe take a break from sports altogether and join Student Government and the yearbook committee.

1. What would you do? What might be good about quitting track, and what might be difficult about doing so? Who would you talk to about your feelings with?
2. How do you think your parents might feel about your decision? Do you think it was right for them to get you tested as a child? Why?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 1: Scenario A – Genetic Testing for Sports Ability
Role: Student 2

You are 15 years old, and when you were 6, your parents got genetic testing for you. The results showed that you did not have the genetic profile that predicted you might excel at endurance sports. But you played and loved soccer, a sport where you can be running for the whole game, and did very well. A teammate had the same test done when he was 12, and it showed he has the "best" type of genetic profile for soccer. He is sharing this information with the college scouts who have been visiting your school to recruit players.

1. What, if anything, will you share with a scout about your genetics? If your teammate offers the information and you don't, what do you think the scout might assume?

2. What might you do if they ask you? Is it fair if the scouts consider this information? Why?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 1: Scenario A – Genetic Testing for Sports Ability
Role: Parent

Your child is 15 years old, and when she was 6, you got her genetically tested to see what sports she might excel at. Her genetic profile convinced you to have her try out for track, because her genes showed that she would be very fast (not surprising, as you were a sprinter in high school and college). She is a state champion sprinter in the 50 and 100 meter run. You have invested a lot of time and money over the years in her sport, paying for coaches, camps, sneakers, nutritionists, and spent hours driving her to and from practices and meets around the state. You are extremely proud of how hard she has worked and of her achievements in track. You are counting on scholarship money for her to go to college, because you can't afford to pay for it all yourself. You start to get a sense that she is getting bored with track, and she has hinted she might want to try some other after school activities, either a different sport or something totally unrelated to athletics.

1. What would you do? Would you allow her to quit running, or try to stress to her the importance of excelling and following through with her commitment? Why?
2. Do you think this decision is mostly up to you, or to her? How do you think she would react if you put pressure on her to keep running? If she doesn't get a scholarship, what is "plan B" for paying for school?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 1: Scenario A – Genetic Testing for Sports Ability

Role: Coach

You have a student on your team who is the best runner you've ever coached. In fact, you were friends with her parents and encouraged them to have her genetically tested at age 6 to find out at what sports she might excel. When it turned out to be running, her parents hired you so she could start training before high school. You have known her for 10 years and think of her as a daughter. She has helped you become a sought-after coach, as she is a state champion sprinter. Recently she has begun to seem bored at practice and hinted she might want to try another sport or another after-school activity all together. You would hate to have her leave the team, especially because she anchors the relay team. You know she is genetically gifted at sprinting and don't like to picture her talents going unused.

1. What would you do? Is it your place to counsel her to keep running and stay on your team?
2. Is there any conflict of interest, since she helps your team win and makes you look good to your peers and boss? Should that impact whether you encourage her to run or to try another activity she is interested in? Why or why not?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 2: Scenario B – Genetic Testing for Alzheimer’s Disease
Role: Parent

Established research shows a link between having a genetic variant in the ApoE gene (called ApoE4) and increased risk of Alzheimer’s disease (AD), a progressive neurological disorder with no known cure or treatment. As the disease advances, symptoms include confusion, aggression, mood swings, language breakdown, long-term memory loss, and the general withdrawal of the sufferer as his or her senses decline. Gradually, bodily functions are lost, ultimately leading to death.

Preliminary research shows that this same ApoE4 variant may worsen concussion symptoms like memory loss and headache. Researchers are just beginning to investigate the possibility that, long-term, if you carry the ApoE4 variant, concussions may cause you have an even earlier onset of Alzheimer’s disease.

You are 40 years old. You lost your grandmother and aunt to AD, watching them suffer for many years. Your 14-year-old son wants to go out for the football team. Youth football players suffer the greatest number of concussions, on average, of the most popular youth sports in the US.

1. Do you let him join the team? What issues do you need to think about to make your decision?
2. Do you test him for the ApoE4 variant? Should it be your decision or your child’s? What might it mean for you and the rest of your family?
3. How might a positive or negative test result influence your decision to let him join the team or not? Do you think a 14 year old can handle this information? Why?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 2: Scenario B – Genetic Testing for Alzheimer’s Disease
Role: Student

Established research shows a link between having a genetic variant in the ApoE gene (called ApoE4) and increased risk of Alzheimer’s disease (AD), a progressive neurological disorder with no known cure or treatment. As the disease advances, symptoms include confusion, aggression, mood swings, language breakdown, long-term memory loss, and the general withdrawal of the sufferer as his or her senses decline. Gradually, bodily functions are lost, ultimately leading to death.

Preliminary research shows that this same ApoE4 variant may worsen concussion symptoms like memory loss and headache. Researchers are just beginning to investigate the possibility that, long-term, if you carry the ApoE4 variant, concussions may cause you have an even earlier onset of Alzheimer’s disease.

You are 14 years old. Your great-grandmother and great-aunt died from AD, and you know your mother watched them suffer. It was hard for your mom but you were young and don’t know many details about what happened. You love sports and want to play football, but your mom isn’t sure it’s a good idea. Youth football players suffer the greatest number of concussions, on average, of the most popular youth sports in the US.

1. Should you get the test to see if you carry the ApoE4 variant? Would you want to know you might develop a terrible disease, even if it is 50 years from now? Why?
2. How might taking the test influence your decision about playing football? How might it influence other aspects of your life?
3. If you learned you were at a greater risk than average for this disease, whom would you tell? How would you decide when to tell them?

Name _____ Date _____

Directions: Read the scenario with your group and discuss the questions as a group. After the discussion, each student should answer the questions that follow.

Group 2: Scenario B – Genetic Testing for Alzheimer’s Disease
Role: Doctor

Established research shows a link between having a genetic variant in the ApoE gene (called ApoE4) and increased risk of Alzheimer’s disease (AD), a progressive neurological disorder with no known cure or treatment. As the disease advances, symptoms include confusion, aggression, mood swings, language breakdown, long-term memory loss, and the general withdrawal of the sufferer as his or senses decline. Gradually, bodily functions are lost, ultimately leading to death.

Preliminary research shows that this same ApoE4 variant may worsen concussion symptoms like memory loss and headache. Researchers are just beginning to investigate the possibility that, long-term, if you carry the ApoE4 variant, concussions may cause you have an even earlier onset of Alzheimer’s disease.

You have a 14-year-old patient who wants to play football. Youth football players suffer the greatest number of concussions, on average, of the most popular youth sports in the US. His great- grandmother and great-aunt died from AD, and you know that AD runs in families. He and his family are trying to decide if he should play, or possibly take the genetic test to find out if he is a carrier of the Apoe4 variant. If he takes the test and it’s negative, he can play without the added worry of its impact on developing AD. But if it’s positive, you have just encouraged a 14-year-old to find out he will probably develop a deadly disease.

1. What would you counsel them to do? Do you think a 14-year-old can handle that information? Why?
2. Do you think parents should find out this kind of information about their children? Why or why not?
3. If the test is positive but he still really wants to play, should his parents be able to forbid him? Or is it his decision, because it’s his DNA? Explain.

Summary/Other questions to consider if the student's discussion is brief, or you want to add other ideas:

1. Is there anything ethically troublesome with getting this testing done? Why or why not?
2. Is getting tested to see who is possibly genetically "gifted," to the extent that it's possible, similar to an athlete using performance-enhancing drugs?
3. Should parents be allowed to have this type of genetic test done on their children? Why or why not?
4. Would you consider getting this type of test for your children in the future? Why or why not?

Homework:

Have students answer the following questions for homework. Each answer should be at least one paragraph long.

1. You are a high school senior being recruited to play at a number of Division I schools. You are much sought after based on your athletic performance for the last 4 years. You had several genetic tests done to get a sense of how your genes might affect your performance and injury risks. The news was mixed. You appear to have the variants associated with distance running success, but also may have a predisposition to rupture your Achilles.

Do you share this report with the scouts? Why or why not? How might a coach use this information?

2. You are a college basketball coach. You have several full scholarships to give out each year, each worth potentially \$160,000 in tuition over 4 years. It is a highly competitive program, and if the team doesn't win, your job may be on the line. You have one more slot to fill. The two athletes, C. and K., are almost exactly equal: high school captains, championship teams, B averages, and very small differences in height and weight. K. submitted the results of her genetic testing. She has two "good" copies of a gene responsible for collagen production, which could mean she has a below average risk of tearing her ACL. ACL tears are very common, and devastating, for female athletes and often end their careers.

Do you use this information to make your decision? If so, how? Whom do you offer the scholarship to? Might your boss or the scholarship committees have an opinion on this matter? Should that matter?

Teacher resources:

Since many of these issues are complex and still evolving, we have included a few articles that provide an overview of the scientific issues that students are likely to ask about:

"The ACTN3 sports gene test: What can it really tell you?" Wired, Nov 30, 2008. Daniel MacArthur
<http://www.wired.com/wiredscience/2008/11/the-actn3-sports-gene-test-what-can-it-really-tell-you/>

"Scientist study link between genes and concussions". Globe and Mail, March 9, 2011. Smith and Attfield.
<http://m.theglobeandmail.com/sports/hockey/scientists-study-relationship-between-genes-and-concussions/article1934489/?service=mobile>

NIH's "Alzheimer's Disease Genetics Fact Sheet"
<http://www.nia.nih.gov/Alzheimers/Publications/geneticsfs.htm>

"Coping with bad genetic news". Technology Review, July 16, 2009. Emily Singer
<http://www.technologyreview.com/biomedicine/23010/page1/>

Genetics and Public Policy Center's Overview of the Genetic Information Nondiscrimination Act (GINA):
www.dnapolicy.org/gina

Companies selling "sports gene" tests directly to consumers (no doctor's prescription or referral needed):
www.athleticcode.com
www.atlasgene.com
www.sportsxfactor.com