Personal Genetics Education Project

Ethical, Legal and Social Issues in Personal Genetics

Title: Athletics and Genetics

Aim: How might personal genetics impact and transform athletics?

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

Guiding questions:

- What can we learn about personal genetics by discussing athletics?
- How can we use genetic testing most effectively to protect athletes' safety and health?
- How can the debates from the world of athletics speak to the broader issues of informed consent, personal choice and the rights of children.
- What factors, aside from genetics, impact athletic performance and success?

Learning objectives:

By the end of the lesson, students will:

- Understand that athletics and genetic analysis increasingly intersect.
- Know that sports can function as a microcosm for larger discussions about genetics and ethics.
- Realize that they may have personal choices to make with respect to athletics and their genomes whether for themselves or their family.
- Be able to explain the discussions within the scientific community and general public about the predictive value of genetic tests for sports performance.

Materials: Articles, handouts, laptop, projector or Smartboard.

Common Core Standards:

CCSS.ELA-Literacy.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.

CCSS.ELA-Literacy.RST.9-10.2: Determine the central ideas or conclusions of a text; trace the text's explanation or depiction of a complex process, phenomenon, or concept; provide an accurate summary of the text.

CCSS.ELA-Literacy.RI.9-10.8 Delineate and evaluate the argument and specific claims in a text, assessing whether the reasoning is valid and the evidence is relevant and sufficient; identify false statements and fallacious reasoning.

Background information and note to teachers:
Genetic testing is increasingly playing a role in sports. As the genetic basis for many health conditions is revealed, some doctors, coaches, and academic and athletic organizations are wondering whether genetic analysis can provide health and safety benefits for athletes. Can genetics help minimize the risk of injury? In addition, as scientists uncover numerous genes linked to athletic performance, questions have emerged about whether genetics might play a role in guiding young people toward the sport in which they are likely to have the most success.

Recently, the National Collegiate Athletic Association (NCAA), the governing body of college sports in the United States, began screening all of its athletes for sickle cell trait (SCT). Often, people with SCT do not experience any symptoms, but are at increased risk for health problems and even death when doing intense exercise. Several young men have died in the course of sports practices or games from complications related to SCT. The hope is that universal testing will save lives, though critics argue that it would be more effective to improve safety conditions for all athletes. (Note, pgEd has an entire lesson devoted to genetic testing of athletes for SCT, available at http://www.pgEd.org/lesson-plans/.) In a related debate, some doctors and athletic groups are asking for population-wide screening for a dangerous heart condition called hypertrophic cardiomyopathy (HCM) in all young people playing high-intensity sports like soccer. Many believe testing for HCM will save lives by identifying children most at risk and excluding them from high-risk, high-intensity sports.

In this lesson, students are asked to consider how their own genetic information might influence their athletic path through two main examples. First, we examine athletic performance and its numerous genetic and environmental influences. Students then are asked to discuss issues related to genetic testing for the gene ACTN3, which is linked to muscle contraction and, more broadly, sprinting ability. Second, we explore genetic testing for the APOE gene, which has a well-established link to Alzheimer's disease and a more preliminary link to concussion recovery. Students are asked to weigh the benefits and implications of APOE testing for young athletes who play sports that put them at increased risk for concussions, given that the possible connection between APOE and concussions is still being evaluated and that the test can also reveal risk for developing Alzheimer's disease later in life.

Students do not need to have a background in genetics, as this lesson focuses mainly on social and ethical issues related to genetic testing. However, the concept of genetic complexity is important, as students will need to understand that a single gene or group of genes are unlikely to be responsible for an

individual's athletic talents. This material is relevant to multiple subjects, including biology, health, social studies, law, physical education and psychology. For teachers interested to expand on the scientific content, we have prepared a more detailed scientific supplement, found at http://www.pged.org/lesson-plans/.

David Epstein's book "The Sports Gene" is an excellent, but long, read if you want to establish a very detailed background for a discussion about athletics and genetics. Reeves Wiedman's review of the book, "Searching for the Perfect Athlete," in *The New Yorker* gives a succinct summary of Epstein's key themes.

NOTE: Many of the questions posed in this lesson do not have simple, definitive answers and are intended to serve as a launching pad for discussion. The topics referenced in the pair-share exercise are explored more deeply in the slideshow, so while students may initially come to these questions only with their own opinions, the lesson provides a great deal of factual material for students to learn and analyze. The overall theme of this lesson is that environmental and genetic influences of complicated human traits, like athleticism, are not easily disentangled. Scientists continue to make discoveries and debate the meaning of their discoveries; therefore, we believe teachers can embrace the debate and reasonably expect students to weigh the evidence and issues and come to divergent conclusions.

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

1. Reading for students (page 3)
2. Do Now exercise (page 4)
3. Pair-share activity (page 4, handout on page 11)
4. PowerPoint slideshow (page 5, slide notes on pages 5-9)
5. Scenarios (page 9, handouts on pages 12-18)
6. Homework assignment (page 9, handout on page 19)
7. List of additional resources (pages 9-10)
8. Short quiz (answer key on page 10, handout on page 20)
9. Scientific supplement (http://www.pged.org/lesson-plans/; next to the files for this lesson)

Reading for students:
In advance of the lesson, ask students to read the following article, which explores the issues surrounding genetic testing of children to examine athletic performance. This reading will be discussed in the pair-share exercise (page 4).

> "Born to Run? Little Ones Get Test for Sports Gene," November 2008, by Juliet Macur, *New York Times*.

Activities: Do Now exercise (7 minutes), pair-share exercise (10 minutes), slideshow (20-30 minutes) and scenarios (30-35 minutes).

Part 1. Do Now exercise (7 minutes)
Have students individually answer the following questions and then share their answers in a brief classroom discussion. This question is on Slide 2 in the slideshow.

> 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 might have a special gift for music? Why or why not?
>
> What could be a benefit and what could be a disadvantage to having genetic analysis of this sort performed at an early age?

Note: An important concept to raise is that many physical, mental and behavioral traits are very difficult to predict or ensure. This is because such traits are the result of an individual's environment and lifestyle as well as an individual's genetic make-up. In addition, the genetic basis of many traits is extremely complex and beyond our current understanding.

Part 2. Pair-Share (10 minutes)
We recommend pausing after Slide 2 in the slideshow to have students briefly discuss the homework article, "Born to Run? Little Ones Get Test for Sports Gene," and pair-share. Have students discuss the following questions about the article in pairs or small groups and then share with the class. These questions are provided on a handout on page 11.

> A. Why do some parents want to have their children tested for athletic ability? Why would some choose not to test their children?
>
> B. Why do some experts, including some doctors, think genetically testing children for their ability to play certain sports is a good idea? Why do others disagree?
>
> C. Who would likely have access to these tests (i.e. who can afford them)? Does that access give some individuals an advantage over others? If so, what can be done to avoid giving an advantage to some and not others?
>
> D. Does genetics alone determine who you are? What other factors influence the kind of athlete you will become?

Part 3. Slideshow (20-30 minutes)
We provide a PowerPoint slideshow that highlights two main ideas. First, young people are increasingly able to learn about their genetic make-up in the context of sports performance and injury prevention. With this information comes the need to understand the concept of genetic complexity and that genetic make-up is one of several factors that contribute to a person's athletic ability. Second, the APOE example highlights the question of how to make decisions on preliminary information and unclear risks. The slideshow is located on the pgEd website along with this lesson, and accompanying explanatory notes for the slideshow are provided below.

Slideshow notes:

Slide 2: The questions for this "Do Now" activity are a good way to start discussions. Allow students a few minutes to respond and discuss. Refer to the "Do Now" section on page 4.

We recommend pausing after Slide 2 to have students briefly discuss the homework article and pair-share (see "Pair-Share" section on page 4).

Slide 3*:* This slide outlines three areas in which genetics and athletics intersect. These will be explored in the remainder of the slideshow.

Slide 4: This slide discusses a genetic condition, sickle cell trait (SCT), which presents additional health risks to athletes. In the United States, all college athletes are tested for SCT. Often, people with SCT do not experience any symptoms, but are at increased risk for heat stroke and even death when doing intense exercise (http://www.cdc.gov/ncbddd/sicklecell/traits.html). Several young men, including the two college football players shown on this slide, have died in the course of sports practices or games from complications related to SCT. In the United States, SCT is most common amongst African Americans, found in ~8% of this population. The hope is that testing will save lives by making student athletes with SCT and their coaches more aware of the risks and preventative measures. However, critics argue that the most effective way to prevent death is not through testing, but rather through improved safety conditions and awareness of dehydration and muscle exhaustion, which would benefit all players regardless of genetic factors. pgEd has an entire lesson devoted to genetic testing of athletes for SCT, available at http://www.pged.org/lesson-plans/.

Slide 5: HCM, a thickening of the heart muscle, is a leading cause of sudden cardiac death in young athletes in the United States. HCM often first presents itself when a young athlete collapses and dies on an athletic field. Some doctors, parents and advocates believe all athletes should be screened for HCM as standard practice for participation in all endurance or high-energy sports. HCM can be detected via a number of physiological tests, including electrocardiogram

(ECG). HCM can be caused by mutations in any one of over a dozen genes, making genetic diagnosis relatively complex. People with HCM are advised to not play high-intensity sports, and, in one region in Italy, where all children are screened by ECG as young teenagers, they have seen HCM death rates fall. The controversy over HCM testing in athletes stems from concerns that population-wide screening for a relatively rare disease will be costly. Additionally, there are philosophical questions about whether to seek out medical information that, on one hand, may limit the opportunity to play sports for a significant number of children, but which would likely prevent children with HCM from dying as a result of their athletic endeavors.

HCM affects between 600,000 - 1.5 million Americans, and about 1% of people with HCM will die each year of sudden cardiac arrest (www.mayoclinic.org). However, HCM is the cause of sudden death in 36% of young athletes who die of sudden cardiac death. This is a good opportunity for students to discuss how society decides to screen athletes for certain conditions, and how common a trait needs to be before we screen everyone for this trait, as well as a mini-lesson about statistics.

Slide 6*:* A child is getting the inside of her cheek swabbed to collect DNA that will be sent to a company for genetic testing to examine the types of sports at which he might excel (i.e. endurance sports, such as soccer, versus power sports, such as sprinting and ice hockey). There is a lot of controversy about testing children for athletic ability. How heavily should a parent weight such information in encouraging a child to participate in one sport or another? Questions also persist about the usefulness of one or even a handful of genetic variants as the basis for any sort of decision-making regarding athleticism, which is influenced by many genes as well as one's environment and lifestyle.

Slide 7: A number of companies offer genetic tests that are marketed to parents, athletes, trainers and doctors as tools to examine a person's predisposition to succeed at certain types of sports and susceptibility to certain types of injury. These tests report on genetic markers that have been linked to athletic performance and risk for injuries, such as soft tissue injuries, but questions about the predictive value of these tests persist. The concept of genetic complexity is a theme throughout this slideshow as well as in the scenarios that follow. Teachers may want to periodically check that students understand this concept as the lesson progresses.

Slide 8: This slide briefly describes four genes, ACTN3, APOE, COL5A1 and COL5A2, which have been linked to traits relevant to athletics. For the purposes of this lesson, detailed scientific explanations of these genes are not necessary. Our scientific supplement, found at http://www.pged.org/lesson-plans/, augments the descriptions of ACTN3 (alpha-actinin-3) and APOE (apolipoprotein E). Note: ACTN3 is often referred to as the "speed gene" in the media. This is a

good place to ask students if they believe a single gene could be responsible for a complex behavior, such as sprinting, and to also ask them to consider how the term "speed gene" might be misleading.

Slide 9: This slide provides additional background on the alpha-actinin-3 gene (ACTN3), as this gene is the focus of one of the scenarios. There are two versions of the ACTN3 gene that are commonly found in people, R and X. Almost all elite sprinters carry at least one copy of the R version, but so does ~80% of the general population. In other words, the R version of ACTN3 alone cannot predict who will become an elite sprinter; while the vast majority of elite sprinters carry the R version, there are exceptions. The key concept to highlight here is genetic complexity. This single genetic variant does not account for athletic success, i.e., there is no "speed gene" as students might have seen in the press. Numerous genes have been linked to traits related to athletic performance, and this list is likely incomplete. Furthermore, genes are one part of an intricate puzzle that also includes environmental factors, such as nutrition, training and cultural pressures.

Slide 10: Some companies have sold tests that look at which version of the APOE gene people have. One version of the gene, APOE4, has a link to the length of time it takes a person to recover from a concussion. The companies have marketed a genetic test for the APOE4 variant as one part of the decision-making process on returning an athlete to play after a concussion. APOE4 also has a well-established link to an increased risk of developing Alzheimer's disease. However, companies that sell these tests rarely make clear on their websites or in marketing material that the APOE gene is connected to Alzheimer's. Parents may be unaware that in addition to learning about concussion risk, they may be learning about their child's (and potentially their own) likelihood of developing Alzheimer's disease. Is it the company's job to inform potential customers of this link or should the consumer be responsible for understanding what the test may reveal? You can read more about the connection between APOE4, concussions and Alzheimer's here: "Genetics Affects Concussion Recovery," from *Penn State News.*

Slide 11: Michael Phelps has won more medals than any other Olympian in history. His genetic make-up has likely contributed to his physical gifts, including height, wingspan, as well as large hands and feet, but his success is also a product of drive, ambition, and a family who was willing and able to nurture his talents. More about Michael Phelps can be found in this *Scientific American* article, "What Makes Michael Phelps So Good?" by Adam Hadhazy. Olympic champion Usain Bolt is one of the greatest sprinters of all time. He hails from Jamaica, a small country with a large proportion of world-class sprinters. Why are so many sprinters Jamaican and, on a related note, why are so many champion distance runners from East Africa? This is a complex question and the subject of much research and debate. In short, it is thought that genetics, evolution, geography and culture all play a role and that these factors are not easily

disentangled from one another. Jon Entine writes on this subject in *Forbes,* "The DNA Olympics-Jamaicans Win Sprinting "Genetic Lottery" – and Why We Should All Care."

Slide 12: In this slide, we ask what factors lead to excellence in sports. This typically leads to good discussion among students and encourages them to consider what makes an elite athlete. The picture on the left shows professional hockey players in the National Hockey League (NHL). Hockey players' success is impacted by a number of traits, including strength, muscle mass, muscle fiber composition, lung capacity and susceptibility to injury. Many of these traits are influenced by genetics and research has begun to uncover some of the genes that are involved. These traits and success overall are also impacted by environmental and lifestyle factors. We often ask students why so many hockey players come from Western Canada and not, for example, Hawaii? A person's physical attributes are important, but access to rinks and a culture where hockey is revered also are part of the equation. The picture on the right is Serena Williams at the US Open in 2013. She and her sister Venus are both very successful athletes who have practiced and worked incredibly hard, are driven and competitive, and began playing tennis competitively as children. It is important to note that sometimes people are wildly successful even without the typical attributes of a star athlete, and a person who is a huge success at one sport may be dismal at another.

This slide is a chance for teachers to reinforce once again the idea that a single "sports gene" is a myth, and that the idea of genetic complexity is a useful lens through which to understand athletic performance. Taken from an article in The Conversation, author Colin Moran states, "Recent research has identified nearly 700 genetic variants that are involved in determining height, for instance, although more remain undiscovered – and it is likely that a similar number will be involved in sporting ability. If so, an average person would effectively have around 350 "talented" versions and around 350 "untalented" versions. Some people would have slightly more "talented" versions, making them slightly different from average – perhaps helping them get into club or county teams. A smaller number still would have quite a few more "talented" versions, making them more extreme, perhaps helping get them into international teams."

Slide 13: Olympic softball pitcher Jenny Finch throws at 65 miles per hour, roughly 30 miles per hour slower than many Major League Baseball (MLB) pitchers. Why, then, was she able to strike out an impressive list of MLB's top hitters, including Albert Pujols? One theory posits that MLB hitters, like many professional athletes, have the ability to process and react to visual information faster than the average person. An alternate theory suggests rather that MLB hitters, through thousands of hours of practice, have learned visual cues for reading pitchers within their league. For instance, a shoulder twitch might mean a fastball is coming or a hip movement might inadvertently signal a curveball. This

example is a reminder that many amazing athletic feats are not only a product of physical gifts, but also of training and repetition. More on Jenny Finch and visual reaction time can be found in this excerpt, "Why MLB Players Can't Hit Jenny Finch and the Science of Reaction Time," from David Epstein's book, "The Sports Gene."

Slide 14: The following questions are designed for an open-ended classroom discussion. They can be adapted for debates, homework assignments or research projects.

- How effective might genetic analysis be in predicting athletic performance?
- Should genetic analysis be used to screen athletes for health conditions? Why or why not?
- From a scientific perspective, what are the most important facts when examining the link between athletic performance and genetics?
- What should a family consider when a child is thinking about playing a contact sport? How can genetic information both illuminate and complicate how parents decide what is right for their children?

Part 4. Scenarios and discussion (30-35 minutes)

This activity asks students to assume various roles to discuss scenarios about genetics and athletics. In the scenario about the track star, there are four different roles (see pages 12-15), and in the second scenario about football and ApoE4, there are three different roles (see pages 16-18).

Divide students up into at least seven groups to explore the seven roles. Have each group read its scenario and answer the accompanying questions. Bring the class back together to discuss their answers and differences of opinion. You can have the members of each group speak for themselves or have one student speak on behalf of the entire group. If you used both the track and football scenarios, either you or a student from the first group to present should explain the scenario to the class.

Homework assignment:
We have provided two scenarios on page 19 for students to read and respond to the questions in writing. These scenarios address issues in genetic testing to examine a person's risk for certain sports injuries.

Additional resources for teachers:
These articles and video highlight the scientific and societal questions related to genetics and sports. They may be useful for extending the lesson or for students who simply want to learn more about the issues.

Video: "Are athletes really getting faster, better, stronger?" March 2014, by David Epstein, *Ted Talk*.

"Hematologists disagree with sickle cell testing as a prerequisite to play sports," January 26, 2012, by Katherine Hobson, *Wall Street Journal*.

"Hidden threats to young athletes," May 2013, by Bill Pennington, *New York Times*.

"Coping with bad genetic news," July 2009, by Emily Singer, *Technology Review*.

"Scientists study relationship between genes and concussions," March 2011, by Beverley Smith and Paul Attfield, *Globe and Mail*.

"Head Injuries Rattle Even Devout Football Parents," October 2012, by Tom Goldman, *WBUR*.

"The ACTN3 sports gene test: What can it really tell you?," November 2008, by Daniel MacArthur, *Wired*.

Genetics and Public Policy Center, Overview of the Genetic Information Nondiscrimination Act (GINA)

For teachers interested to expand on the scientific content in this lesson, we have prepared a more detailed scientific supplement, found on the pgEd's lesson plan page (http://www.pged.org/lesson-plans/). For detailed information on the genes mentioned, we recommend the Genetics Home Reference page maintained by the National Institutes of Health (NIH). For more information on APOE and the link to Alzheimer's disease, you may reference the NIH's "Alzheimer's Disease Genetics Fact Sheet."

"Athletics and genetics" quiz answer key (see page 20 for quiz):
1. T
2. T
3. F
4. F
5. C

Pair-share exercise

Directions: Discuss the following questions on the homework article.

A. Why do some parents want to have their children tested for athletic ability? Why would some choose not to test their children?

B. Why do some experts, including some doctors, think genetically testing children for their ability to play certain sports is a good idea? Why do others disagree?

C. Who would likely have access to these tests (i.e. who can afford them)? Does that access give some individuals an advantage over others? If so, what can be done to avoid giving an advantage to some and not others?

D. Does genetics alone determine who you are? What other factors influence the kind of athlete you will become?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario A – Genetic testing for sports ability
Role: Student 1

You are 16 years old. When you were 6, your parents had you genetically tested to see at which sports you might excel. The test they chose included the ACTN3 gene, which has been linked to muscle fiber composition.

There is a version of the ACTN3 gene that has been linked to sprinting ability. Almost all elite sprinters have at least one copy of this version, but so does ~80% of the general population. The predictive value of these markers is unclear for the general population or a typical youth sports participant.

Based on your results, your parents decided that you could be an excellent sprinter and signed you up for the track team. You are now a state champion sprinter. You practice daily, travel to meets, make friends and impress coaches. You wonder whether your genes have anything to do with your success, as you know that there are many factors other than genetics that can influence athletic ability. Eating a healthy diet and working hard at a sport you enjoy are important for athletic success, and you have done exactly this.

Your parents have spent money for you to go to track camps, have access to coaches and nutritionists, and have the best running shoes. You plan to compete for college track scholarships, possibly worth up to $160,000 over four years. For the most part, you have enjoyed running, but now you are getting tired of track and want to try soccer or maybe take a break from athletics altogether.

Questions:

1. What will you do? What might be good about quitting track, and what might be difficult about doing so? With whom will you talk as you make your decision?

2. How do you think your parents will feel about your decision? Do you think it was right for them to get you tested as a child? Why?

3. Do you think the genetic test you took as a child impacted your path as an athlete? What if your test results had been different? Do you think you would have had the same level of success?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario A – Genetic testing for sports ability
Role: Student 2

You are 16 years old. When you were 6, your parents had you genetically tested to see at which sports you might excel. The test they chose included the ACTN3 gene, which has been linked to muscle fiber composition.

There is a version of the ACTN3 gene that has been linked to sprinting ability. Almost all elite sprinters have at least one copy of this version, but so does ~80% of the general population. The predictive value of these markers is unclear for the general population or a typical youth sports participant.

Your genetic profile suggests that you might excel at power sports, such as sprinting, ice hockey or other sports that require short, intense bursts of speed. However, you play and love soccer, an endurance sport where you run the entire game, and you have done very well. You wonder if you've had to work harder for your success because of your genetic profile. Of course, you know that there are many factors other than genetics that can influence athletic ability. Eating a healthy diet and working hard at a sport you enjoy are important, and you have done exactly this.

A teammate took the same test when he was 12, and the report indicated that he might be well-suited to sports like soccer that involve endurance running. He is sharing his genetic information with college scouts who have been visiting your school to recruit players. You hope to earn a scholarship to play soccer in college.

Questions:

1.What, if anything, will you share with a scout about your genetics? If your teammate offers genetic information and you do not, how do you think this might reflect on you?

2. What will you do if a scout asks you for your genetic profile? Is it fair if the scouts consider this information? Why?

3. Do you think the genetic test you took as a child impacted your path as an athlete? What if your test results had been different? Do you think you would have had the same level of success?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario A – Genetic testing for sports ability
Role: Parent

Your child is 16 years old. When she was 6, you had her genetically tested to see at which sports she might excel. The test you chose included the ACTN3 gene, which has been linked to muscle fiber composition.

There is a version of the ACTN3 gene that has been linked to sprinting ability. Almost all elite sprinters have at least one copy of this version, but so does ~80% of the general population. The predictive value of these markers is unclear for the general population or a typical youth sports participant.

Based on your daughter's genetic profile, you started her running track. You wonder whether her genes have anything to do with her success, as you know that there are many factors other than genetics that can affect athletic ability. Eating a healthy diet and working hard at a sport you enjoy are important for athletic success, and she has done exactly this.

Your daughter is a state champion sprinter. You have invested a lot of time and money over the years in her sport, paying for coaches, camps, running shoes and nutritionists, and you have spent hours driving her to practices and meets around the state. You are extremely proud of how hard your daughter has worked and what she has achieved.

You are counting on scholarship money for her to go to college. She has started to hint that she might want to try some other after-school activities, either play a different sport or perhaps audition for the school play.

Questions:

1. What will you do? Will you allow your daughter to quit running or will you stress to her the importance of excelling and following through with her commitment? Why?

2. Whose decision is it? Yours or hers?

3. Might you worry she would be wasting her gifts by not pursuing a sport in which she shows so much promise? Does your daughter's genetic profile affect how you think about her choices?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario A – Genetic testing for sports ability
Role: Coach

You have a student on your team who is the best runner you have ever coached. You are friends with her parents and encouraged them to have her genetically tested at age 6 to find out at which sports she might excel. The test they chose included the ACTN3 gene, which has been linked to muscle fiber composition.

There is a version of the ACTN3 gene that has been linked to sprinting ability. Almost all elite sprinters have at least one copy of this version, but so does ~80% of the general population. The predictive value of these markers is unclear for the general population or a typical youth sports participant.

When the test report suggested sprinting, her parents hired you as a private coach. You have known her for ten years and think of her as a daughter. She is a state champion sprinter, and this has helped you become a sought-after coach.

Recently, she has seemed bored at practice and hinted she might want to try another sport or even take a break from athletics altogether. You would hate to have her quit, especially because she anchors the relay team. You know she is gifted at sprinting and do not like to imagine her talents going unused.

Questions:

1. What would you do? Would you try to get her to stay on the team or let her do what she wants? Why?

2. Is it appropriate for you to advise her one way or another since she helps your team win, making you look good in front of your colleagues? Should that impact whether you encourage her to run or to try another activity? Why or why not?

3. What role do you think her genes and your shared knowledge of her genetic profile have played in her career?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario B – Genetic testing for APOE and risk for Alzheimer's disease
Role: Parent

Established research shows a link between a version of the APOE gene, called APOE4, and increased risk of Alzheimer's disease (AD), a progressive neurological disorder with no known cure or treatment at this time. 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 people who carry this same APOE4 variant may suffer longer recovery times from 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 to have an earlier onset of AD.

You are 40 years old. You lost your grandmother and aunt to AD after watching them suffer for many years. You know that AD often runs in families. Your 15-year-old son wants to try out for the football team, but you are concerned about the concussion risk. In the United States, kids who play youth football suffer more concussions on average than those who play other sports.

Questions:

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 on whether to let him join the team? How might a 15-year-old handle this information?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario B – Genetic testing for APOE and risk for Alzheimer's disease
Role: Student

Established research shows a link between a version of the APOE gene, called APOE4, and increased risk of Alzheimer's disease (AD), a progressive neurological disorder with no known cure or treatment at this time. 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 people who carry this same APOE4 variant may suffer longer recovery times from 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 to have an earlier onset of AD.

You are 15 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 when they died and do not know many details about what happened. Your mom has told you that AD often runs in families. You love sports and want to play football, but your mom is not sure it is a good idea. In the United States, kids who play youth football suffer more concussions on average than those who play other sports.

Questions:

1. Should you get the test to see if you carry the APOE4 variant? Would you want to know that you are at increased risk for AD, even if it is 50 years from now? Why?

2. How might taking the test influence your decision about playing football? Do you think this information about a genetic risk factor might influence other aspects of your life?

3. If you learned you were at increased risk for AD, who would you tell and why?

Name_____ Date_____

Directions: Read the scenario and discuss the questions as a group.

Scenario B – Genetic testing for APOE and risk for Alzheimer's disease
Role: Doctor

Established research shows a link between a version of the APOE gene, called APOE4, and increased risk of Alzheimer's disease (AD), a progressive neurological disorder with no known cure or treatment at this time. 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 people who carry this same APOE4 variant may suffer longer recovery times from 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 to have an earlier onset of AD.

You have a 15-year-old patient who wants to play football. In the United States, kids who play youth football suffer more concussions on average than those who play other sports. Your patient's 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 football or possibly take the genetic test to find out if he carries the APOE4 variant. If he takes the test and it is negative, it will ease his mother's concerns about letting him play. However, if it is positive, you have just encouraged a 15-year-old to find out he is at a higher than average risk for this deadly disease.

1. What would you counsel them to do? How do you think a 15-year-old might handle this 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 football, should his parents forbid it or should he be able to make this decision on his own? Explain.

Homework:
Read the scenarios and answer the questions that follow. Justify your answers with information from the slideshow and/or ideas from the class discussion. Each answer should be at least one paragraph long.

1. You are a high school senior being recruited to play basketball at a number of highly competitive Division I schools. You are much sought after based on your athletic performance over the last four 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 variants associated with sprinting success (and you certainly sprint up and down the basketball court), but you may be more likely than the average person to have problems with your Achilles tendon and anterior cruciate ligament (ACL) injuries.

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 $160,000 in tuition over four years. It is a highly competitive program and, if the team does not win, your job may be on the line. You have one more slot to fill. On paper, the two athletes, Chris and Katie, are very similar: both are high school captains on championship teams, earn B averages, and put up similar career athletic statistics. Katie submitted the results of her genetic testing indicating that she has a below average risk of tearing her ACL. ACL tears are very common for female athletes and often end their careers. Chris did not submit any additional information.

Does this information impact your decision? If so, how? To whom do you offer the scholarship and why?

Name_____ Date_____

"Athletics and Genetics" quiz

1. Genetic testing may be able to provide an athlete with potentially useful information about injury risk and prevention. T/F

2. All college athletes are screened for sickle cell trait before they are cleared to play on a team. T/F

3. Doctors, scientists and coaches all agree that student athletes all should be screened for sickle cell trait, as the most effective way to prevent injuries and deaths. T/F

4. Genetic testing can currently predict athletic ability in children. T/F

5. APOE4, a genetic variant linked to an increased risk for Alzheimer's disease, may also be linked to an increased risk of a) heart failure b) high blood pressure c) concussion complications d) brain tumors.