Personal Genetics Education Project

Ethical, Legal and Social Issues in Personal Genetics

Title: Genetics, jobs and your rights

Aim: What progress has been made to protect privacy rights to allow people to feel safe learning about their genetic make-up or considering volunteering in medical research?

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

Guiding questions:

- What is genetic discrimination? How have workers experienced discrimination based on their DNA?
- How can the Genetic Information Nondiscrimination Act (GINA) benefit workers, employers and health insurers?
- Can genetic information impact the kinds of jobs a person could perform?

Learning objectives:

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

- Teach fellow students about an example in which genetic testing and the workplace have intersected.
- Recognize how lawmakers and others are working to ensure fairness in the workplace and the health insurance industry.
- Describe the protections United States citizens are afforded under GINA.
- Debate whether it is fair that a person's genetics may especially qualify them, or disqualify them, for a certain career.

Materials: Articles, handouts.

Common Core Standards:

CCSS.ELA-Literacy.RH.9-10.3 Analyze in detail a series of events described in a text; determine whether earlier events caused later ones or simply preceded them.

CCSS.ELA-Literacy.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.

CCSS.ELA-Literacy.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.

Background information and a note to teachers:
The lesson explores the Genetic Information Nondiscrimination Act (GINA), called the "first civil rights legislation of the 21st century" by former Massachusetts Senator Ted Kennedy. GINA and its protections are relevant to students, as many students are already working or will be soon. Learning about the history of genetic discrimination in the workplace, along with the progress being made to ensure workers do not have information about their DNA used inappropriately, is key to seeing the potential of personal genetics come to fruition. One of the major hopes around the passage of GINA is that people will feel more confident participating in genetic research knowing they now have federal protection.

GINA, which was passed by the United States Congress and signed into law in 2008 by President George W. Bush, has two main provisions. First, it forbids employers to use genetic information to make decisions about hiring, firing and promotion. Second, GINA forbids group and individual health insurers from using genetic information to adjust premiums, add or drop people from policies or deny coverage. GINA protects a person's genetic information revealed when a person seeks genetic testing or participates in a research study. It also protects a person's family medical history, including a family member's genetic information. For example, an employer could not ask an employee if Huntington's disease runs in his or her family. Interestingly, GINA does not cover people serving in the military or extend protections to those seeking life or long-term disability insurance.

Many feel that the passage of GINA in advance of widespread access to genetic testing was a progressive, forward thinking. GINA also recognizes that a key to genetic research is for people to be willing to participate and feel confident in sharing their DNA with scientists. Only a few cases of genetic discrimination received prominent media attention in the years leading up to the passage of GINA, and thus far a small number of claims have been made since GINA was adopted. Many of the lawsuits illuminate the fact that genetic testing is often complex and inconclusive, and that many medical conditions cannot be easily identified as a result of genetic analysis. In 2015, the first lawsuit filed under GINA went to court. As described in the Washington Post on May 30th, 2015 in the article "Test for 'Devious Defecator' was Unlawful, Judge Rules," the legal issue started when a grocery warehouse company realized it had an employee who "began "habitually defecating in one of its warehouses." To solve the mystery, the

company requested some of its employees submit to cheek swabbing to compare their cheek cell DNA to DNA from the "offending fecal matter" left in the warehouse. The two men whose DNA was requested in the company's investigation sued under the GINA provision that forbids an employer from requesting or requiring employee DNA. The plaintiffs, Jack Lowe and Dennis Reynolds, were awarded $2.25 million in damages.

Genetic tests could protect workers from harm if a previously unknown condition, such as a heart condition, were uncovered through testing; however, employers are not able to offer, require or consider such a test under GINA in the context of hiring, firing or promoting an employee. National Football League player Ryan Clark was diagnosed as a child with the genetic condition sickle cell trait (SCT), putting him at increased risk for harmful complications under certain extreme conditions, such as low oxygen levels. On one occasion, he became severely ill and required emergency surgery as a result of playing a football game at high altitude. Going forward, Clark and his coaches agreed that, out of an abundance of caution, he should not play at Mile High Stadium in Denver because of the high altitude. This serves as an example of a scenario in which genetic information can be useful to make work-related decisions about health. However, it is important for students to understand that Clark's team did not require him to have genetic testing; in fact, it is likely that his condition would be protected under other federal anti-discrimination laws. Clark came forward with information related to his genetic make-up and health, and did not experience any mistreatment from his employer.

Since GINA was passed, much has been written to summarize the history of genetic discrimination and to explain the law itself. In advance of teaching the lesson, teachers may find the following resource helpful: Genetic Alliance: Genetic Discrimination.

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

1. Reading for students (page 4)
2. Do Now exercise (page 4)
3. Jigsaw activity (pages 4-8, graphic organizer handout on pages 9-10)
4. Homework assignment (page 8, handout on pages 11-13)
5. Short quiz (answer key on page 8, handout on page 14)

After teaching this lesson, we would appreciate your feedback via this quick survey, as well as your student's feedback via this brief survey.

Reading for students:
In advance of teaching this lesson, we recommend students read the following short articles that provide some basic information about GINA.

"Senate backs privacy for genetic data," by Ricardo Alonso-Zaldivar, April 2008, *Los Angeles Times*.

"Test for 'Devious Defecator' was Unlawful, Judge Rules" by Nita Farahany, May 30, 2015, *Washington Post*

Activities: Do Now (7 minutes), Jigsaw (45 minutes).

Part 1: Do Now (7 minutes)

Ask students to write a short response to the following questions and share their answers as time allows.

- Think about the career you someday hope to have. What is it about that job that holds your interest?

- Think about your life experiences, family, environment and even your DNA. Do any of these factors make you think you are especially qualified for the career you hope to have? Do any of these factors present a particular challenge?

Note for teachers: As students respond, revisit some of the main themes from the homework article related to GINA's provisions and protections to ensure that students understand that employees and job applicants are protected from discrimination based on their genetic information.

Part 2: Classroom jigsaw activity (45 minutes)

Students will examine cases, spanning two decades, in which employers attempted to use genetic testing or genetic information to make decisions about hiring or firing. The idea is for students to become aware of the protections that GINA offers. One of the most important messages in the examples we use is that genetic tests vary in how well they predict whether a person will develop a disease or exhibit a genetic trait. A person at increased genetic risk for a disease will not necessarily develop that disease. Employers and employees, like many people, may be looking to genetics for answers about traits and diseases that often are not forthcoming.

The format for this lesson is a jigsaw. In brief, to conduct a jigsaw, students are assigned a "home" group and an "expert" group. Each "expert" group will be given an article and will become the expert on that topic. Then, students will return to their "home" group to teach the other students. A detailed video explanation of the jigsaw technique can be found here: http://www.theteachertoolkit.com/index.php/tool/jigsaw.

Step one: First, assign students to a "home" group and an "expert" group. If your classroom is seated in groups, they already have a "home" group. You may pre-arrange the "expert" groups or have students count off to form groups, and then have students move to their "expert" group.

Step two: Distribute one of the articles listed below to each "expert" group as well as the graphic organizer handout on pages 9-10. Have students read and analyze the article to learn about their topic. To ensure students understand their topic and are able to share the information with their classmates, have them answer the following questions, also listed on the handout.

1. How did the company use or try to use genetic information about its employees or job applicants?
2. Was a person fired or not hired because of a genetic test or medical condition?
3. Was there a lawsuit? If so, what was the result? Was an employee rehired, was there a settlement, etc.?

News articles for jigsaw activity:
Below, we have five cases for students to examine. Depending on the size and length of your class, you may want to explore only 3 or 4 of the topics. In some cases, we have provided more than one article per topic, so that you can choose which article will work best for your students. You may choose to edit for length. These summaries are provided as a handout for students on pages 11-13 to distribute following the jigsaw activity.

1. Employee fired for revealing she has narcolepsy:
   - "Fired Police Dispatcher Sues Hillside: Plaintiff Has Narcolepsy," by Steve Schmadeke, March 2009, *Chicago Tribune.*
   - "Narcoleptic police dispatcher reaches settlement with Hillside after firing," November 2009, *Chicago Tribune.*

Narcolepsy is a sleep disorder that causes excessive sleepiness and frequent daytime naps, called sleep attacks. Narcolepsy likely results from a combination of genetic and environmental factors (for more, refer to the Genetics Home Reference), and may be an autoimmune disease. It is a

condition that is varied and complex, with some people responding well to medication while others do not. In this case, a police dispatcher disclosed a medical condition, narcolepsy, for which she was being treated and, as a result, was fired. The case was settled with a payment to the employee. It is important to note that in this case, the employee had been living with narcolepsy, and the genetic factors related to her specific case are not mentioned in the story. As such, this case is more likely to fall under other federal anti-discrimination laws, rather than GINA. It may be interesting to ask students how it would influence their perspectives if the employee had disclosed that she had a higher genetic risk for narcolepsy, rather than having the condition.

2. Burlington Northern Railroad case and pre-existing conditions:
   - "Nurse Derails Genetic Testing," by Lisa Girion, February 2001, *Los Angeles Times*.
   - "Genetic Testing Case Settled," by Kristen Philipkoski, April 2001, *Wired Magazine*.

This case is an early example of employers and employees struggling with the use of genetic information in the workplace. A Burlington Northern Railroad worker who hammered railroad ties was having arm and hand pain that he thought was carpal tunnel syndrome that developed as a result of repetitive tasks on the job. The employee filed a workers' compensation claim, and the company sent him to a doctor for an exam. He later learned he was genetically tested without his knowledge. The test itself was controversial as the role of genetics in carpal tunnel syndrome is unclear; although the test was intended to look for a genetic predisposition to carpal tunnel syndrome, it actually looked at a genetic marker linked to a rare medical condition, one symptom of which resembles carpal tunnel syndrome. The employer was accused of trying to use the genetic test to prove that the worker had a pre-existing condition as a reason to deny the workers' compensation claim. The case, which pre-dated GINA, was eventually settled in favor of the employee. GINA seeks to ensure that workers are comfortable coming forward with workers' compensation claims knowing their genetic privacy is protected.

3. Genetic testing and athletes' health:
   - "Curry's DNA fight with Bulls 'bigger than sports world'," by Jim Litke, September 2005, *ESPN.com*.
   - "Bulls Curry is Traded to Knicks," by Howard Beck, October 2005, *New York Times*.

   Note: For this case, we recommend that students read both articles to get a balanced perspective from both sides.

Eddy Curry, a basketball player who played for the Chicago Bulls, experienced heart flutterings that several doctors diagnosed as a heart condition known as benign arrhythmia, clearing him to play. One doctor recommended to the team that Curry get genetic testing for hypertrophic cardiomyopathy (HCM), a thickening of the heart muscle, that is a leading cause of sudden cardiac death in young athletes in the United States. 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. However, genetic testing can play a role in diagnosis and interventions. During a contract negotiation, the Bulls required that Curry submit to genetic testing for HCM. Curry refused and was later traded to another team. With the passage of GINA, Curry and others in his situation are extended protections that ensure they cannot legally be asked to take a DNA test as a condition of employment. To explore issues related to protecting athletes, please see pgEd's lesson plan, "Protecting athletes with genetic conditions: Sickle cell trait."

4. Genetic testing in professional baseball:
   - "Baseball's Use of DNA Raises Questions," by Michael S. Schmidt and Alan Schwarz, July 2009, *New York Times*.
   - "Should Major League Baseball be allowed to use DNA tests to determine the true age of prospects?" by Lynne Peeples, July 2009, *Scientific American*.
   - "A Future in Baseball, Hinging on DNA," by Alan Schwarz, July 2009, *New York Times*.

Major League Baseball (MLB) has an unusual issue. Some prospects, and potential MLB employees, have been accused of borrowing someone else's identity in an effort to appear younger and, therefore, more desirable to teams. MLB has tried a number of approaches, including genetic testing, in an attempt to confirm the age and identity of these prospects. The MLB is one of the first high profile employers to alter some of its employment practices as a result of GINA.

5. First GINA case settled, highlighting rules about the use of family medical history:

   - "Fabricut to Pay $50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit," May 2013, United States Equal Employment Opportunity Commission

When Rhonda Jones applied for and was offered a permanent job as an office worker at Fabricut, she was asked for information about her family

medical history, including cancer, heart disease, diabetes and "mental disorders." During a pre-employment physical, the company's physician noted the possibility of Jones having carpal tunnel syndrome. While Jones' doctor disagreed with the carpal tunnel diagnosis, Fabricut rescinded the job offer. The United States Equal Employment Opportunity Commission (EEOC) charged Fabricut with a violation of GINA for collecting family medical history and with a violation of the Americans with Disabilities Act for rescinding the offer when Fabricut believed Jones had carpal tunnel syndrome. Fabricut settled the case out of court and agreed to pay $50,000 (US) in damages.

Step three: Have students leave their "expert" groups and return to their "home" groups to teach the other members about their topic. Each student should take 5-7 minutes to explain the topic they learned about from their article. Students should complete and hand in the graphic organizer (pages 9-10) to make sure they understand each topic and that groups are accomplishing their goals.

Homework
The following questions can be used for a class discussion to summarize the issues or can be answered for homework in the form of a written response. We have provided the questions and the summaries of the issues highlighted in the news articles as a handout on pages 11-13.

1. If you were in charge of making sure your business followed the rules of GINA, what would you say are the main points for everyone in your company to understand?

2. Think about the cases you studied in class. Is it possible for you to put yourself in the shoes of the employer in any of the cases? Describe the employer's viewpoint on the case. Do you agree with how the case you studied was resolved? Why or why not?

"Genetics, jobs and your rights" quiz answer key (see page 14 for quiz):
1. According to the Genetics Home Reference, "genetic discrimination occurs when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder."
2. B
3. T
4. Based on the articles, answers can include: professional sports, police dispatch, railroad, office worker.
5. Answers will vary.

Name_____ Date_____

"Genetics, jobs and your rights" graphic organizer

As you read your article, answer the following questions so you are able to share the information with your classmates.

1. How did the company use or try to use genetic information about its employees or job applicants?
2. Was a person fired or not hired because of a genetic test or medical condition?
3. Was there a lawsuit? If so, what was the result? Was an employee rehired, was there a settlement, etc.?

Fill in the graphic organizer below with what you have learned about all of the cases from your article and from your classmates.

	What is the main idea of the article?	What role did genetics play in this story?	What do you think about how the case was resolved? Were the outcomes fair? Explain.
Police Dispatcher/ Narcolepsy			
Burlington Northern Railroad			

	What is the main idea of the article?	What role did genetics play in this story?	What do you think about how the case was resolved? Were the outcomes fair? Explain.
Eddie Curry/NBA			
Major League Baseball			
Rhonda Jones/ Fabricut			

Homework:

Answer the following questions using information from the articles and ideas from the class discussion. Each answer should be at least one paragraph long. Summaries from the cases are included below to inform your response.

1. If you were in charge of making sure your business followed the rules of GINA, what would you say are the main points for everyone in your company to understand?

2. Think about the case you studied in class. Is it possible for you to put yourself in the shoes of the employer in any of the cases? Describe the employer's viewpoint on the case. Do you agree with how the case you studied was resolved? Why or why not?

Case summaries:

1. Employee fired for revealing she has narcolepsy:

- "Fired Police Dispatcher Sues Hillside: Plaintiff Has Narcolepsy," by Steve Schmadeke, March 2009, *Chicago Tribune.*
- "Narcoleptic police dispatcher reaches settlement with Hillside after firing," November 2009, *Chicago Tribune.*

Narcolepsy is a sleep disorder that causes excessive sleepiness and frequent daytime naps, called sleep attacks. Narcolepsy likely results from a combination of genetic and environmental factors, and may be an autoimmune disease. It is a condition that is varied and complex, with some people responding well to medication while others do not. In this case, a police dispatcher disclosed a medical condition, narcolepsy, for which she was being treated and, as a result, was fired. The case was settled with a payment to the employee. It is important to note that in this case, the employee had been living with narcolepsy, and the genetic factors related to her specific case are not mentioned in the story. As such, this case is more likely to fall under other federal anti-discrimination laws, rather than GINA. How would it influence your perspectives if the employee had disclosed that she had a higher genetic risk for narcolepsy, rather than having the condition?

2. Burlington Northern Railroad case and pre-existing conditions:

- "Nurse Derails Genetic Testing," by Lisa Girion, February 2001, *Los Angeles Times*.
- "Genetic Testing Case Settled," by Kristen Philipkoski, April 2001, *Wired Magazine*.

This case is an early example of employers and employees struggling with the use of genetic information in the workplace. A Burlington Northern Railroad worker who hammered railroad ties was having arm and hand pain that he thought was carpal tunnel syndrome that developed as a result of repetitive tasks on the job. The employee filed a workers' compensation claim, and the company sent him to a doctor for an exam. He later learned he was genetically tested without his knowledge. The test itself was controversial as the role of genetics in carpal tunnel syndrome is unclear; although the test was intended to look for a genetic predisposition to carpal tunnel syndrome, it actually looked at a genetic marker linked to a rare medical condition, one symptom of which resembles carpal tunnel syndrome. The employer was accused of trying to use the genetic test to prove that the worker had a pre-existing condition as a reason to deny the workers' compensation claim. The case, which pre-dated GINA, was eventually settled in favor of the employee. GINA seeks to ensure that workers are comfortable coming forward with workers' compensation claims knowing their genetic privacy is protected.

3. Genetic testing and athletes' health:

- "Curry's DNA fight with Bulls 'bigger than sports world'," by Jim Litke, September 2005, *ESPN.com*.
- "Bull's Curry Traded to Knicks," by Howard Beck, October 2005, *New York Times*.

Eddy Curry, a basketball player who played for the Chicago Bulls, experienced heart flutterings that several doctors diagnosed as a heart condition known as benign arrhythmia, clearing him to play. One doctor recommended to the team that Curry get genetic testing for hypertrophic cardiomyopathy (HCM), a thickening of the heart muscle, that is a leading cause of sudden cardiac death in young athletes in the United States. 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. However, genetic testing can play a role in diagnosis and interventions. During a contract negotiation, the Bulls required that Curry submit to genetic testing

for HCM. Curry refused and was later traded to another team. With the passage of GINA, Curry and others in his situation are extended protections that ensure they cannot legally be asked to take a DNA test as a condition of employment.

4. Genetic testing in professional baseball:

- "Baseball's Use of DNA Raises Questions," by Michael S. Schmidt and Alan Schwarz, July 2009, *New York Times*.
- "Should Major League Baseball be allowed to use DNA tests to determine the true age of prospects?" by Lynne Peeples, July 2009, *Scientific American*.
- "A Future in Baseball, Hinging on DNA," by Alan Schwarz, July 2009, *New York Times*.

Major League Baseball (MLB) has an unusual issue. Some prospects, and potential MLB employees, have been accused of borrowing someone else's identity in an effort to appear younger and, therefore, more desirable to teams. MLB has tried a number of approaches, including genetic testing, in an attempt to confirm the age and identity of these prospects. The MLB is one of the first high profile employers to alter some of its employment practices as a result of GINA.

5. First GINA case settled, highlighting rules about the use of family medical history:

- "Fabricut to Pay $50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit," May 2013, United States Equal Employment Opportunity Commission

When Rhonda Jones applied for and was offered a permanent job as an office worker at Fabricut, she was asked for information about her family medical history, including cancer, heart disease, diabetes and "mental disorders." During a pre-employment physical, the company's physician noted the possibility of Jones having carpal tunnel syndrome. While Jones' doctor disagreed with the carpal tunnel diagnosis, Fabricut rescinded the job offer. The United States Equal Employment Opportunity Commission (EEOC) charged Fabricut with a violation of GINA for collecting family medical history and with a violation of the Americans with Disabilities Act for rescinding the offer when Fabricut believed Jones had carpal tunnel syndrome. Fabricut settled the case out of court and agreed to pay $50,000 (US) in damages.

Name_____ Date_____

"Genetics, jobs and your rights" quiz

1. Define genetic discrimination:

2. The Genetic Information Nondiscrimination Act (GINA) makes it illegal to: a) share your genetic information on the internet b) have your genetic information used in employment decisions and for setting health insurance fees c) purchase genetic tests at your local pharmacy d) have your genetic information used in decisions about life insurance plans.

3. Companies have tried to use an employee's genetic information as a way to make decisions about hiring, firing or promotions. T/F

4. Name at least two types of jobs or industries in which employers have tried to use genetic information to decide to hire or fire someone.

5. Think about your own career plans. Do you feel your interests are a result of your genes, your environment, your family and upbringing, or a combination of these factors? Please explain.