



# Personal Genetics Education Project

## Ethical, Legal and Social Issues in Personal Genetics

### SNAPSHOT

## Privacy Protections for Genetic Information: Meet GINA

Adapted for PBS LearningMedia in partnership with WETA for use with

KEN BURNS PRESENTS  
**THE GENE**  
AN INTIMATE HISTORY

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## SNAPSHOT

# Privacy Protections for Genetic Information: Meet GINA

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## The Big Picture

- U.S. law protects people's genetic information at work and in the health insurance market (with some exceptions).
- What is GINA (the Genetic Information Non-discrimination Act) and what are the specific rights and protections it offers?

Scientists rely on people contributing their genetic information to research databases and participating in clinical trials. We will explore reasons why some people participate in research and examine a U.S. law that provides protections for research participants and others who seek to learn about their DNA.

### Why do some people choose to participate in genetic research?

**Do Now:** Watch [this clip](#) from the PBS documentary, *The Gene: An Intimate History*, to meet the Yoder family, who had two children with spinal muscular atrophy (SMA).

Research is an important part of the scientific process for learning about the often-complex relationship between genes and human health, developing new therapies, and determining the effectiveness of new approaches for treating or preventing disease. By agreeing to participate in research, people are putting their trust into the privacy protections being offered by researchers and their hospitals or research centers. In addition to these protections, the U.S. government adopted a law in 2008 to protect

people from their genetic information being used to discriminate against them in the workplace or the health insurance market. This law is known as the Genetic Information Non-discrimination Act or GINA, for short.

## What is the Genetic Information Non-discrimination Act?

**Do Now:** Watch this [video](#) about GINA from former U.S. Representative, the late Congresswoman Louise Slaughter, to learn about the content and history of this law.

GINA was passed by the United States Congress in 2008. This law prohibits employers from making hiring, firing, or promotion decisions based on a person's genetic information. GINA also prohibits health insurers from using genetic information (1) to deny a person the right to buy health insurance and (2) to raise or lower the cost for buying health insurance.

### What is genetic discrimination?

Genetic discrimination is the unfair treatment of individuals or groups of people based on real or perceived genetic conditions, genetic pre-dispositions, genetic risk factors related to health and disease traits, or ancestry.

There are exceptions and limitations to what GINA covers. For example, GINA does not apply to employers with fewer than 15 employees. In addition, GINA's protections do not extend to all types of insurance. For example, life insurance and long-term care insurance (which helps pay for a person's care if they need many months or years of medical or nursing because of a condition or illness) are not covered by GINA. It is important to be aware of these exceptions, so people can consider the potential benefits of learning about their genetic information against the risk that they may be denied coverage for these types of insurance as a result.

## GINA goes to court: The first case brought to trial is the “devious defecator”

The first time a GINA case went to trial was in 2015. The court was asked to decide whether an employer could legally collect DNA from employees in order to resolve a situation of misconduct. The legal issue started when a grocery warehouse company realized it had an employee who began “habitually defecating in one of its warehouses.”

**Do Now:** Read “[Test for ‘Devious Defecator’ was Unlawful, Judge Rules](#)” by Nita Farahany, *Washington Post*.

To solve the mystery of who was defecating in the warehouse, the company requested some of its employees to have their cheek swabbed to collect a DNA sample that could

be compared to the “offending fecal matter” left in the warehouse. Two employees who were asked to provide their DNA sued the company. In their case, they argued that their employer violated the part of GINA that forbids employers from requesting or requiring employees to share their DNA. In 2015, a federal jury awarded the plaintiffs, Jack Lowe and Dennis Reynolds, \$2.2 million in damages.

## Privacy Protections for Genetic Information: Meet GINA

### STUDENT HANDOUT: DISCUSSION QUESTIONS

Name: \_\_\_\_\_ Date: \_\_\_\_\_

1. What types of protections does GINA give people when it comes to genetic information and employment and health insurance?
2. How might GINA's protections help people feel more confident their genetic information won't be used against them if they decide to participate in a research or clinical study, like the ones we learned about in *The Gene*?
3. What are some limitations of GINA?
4. Why did Jack Lowe and Dennis Reynolds, the plaintiffs in the "devious defecator" case, have a claim under GINA's protections?