



# Personal Genetics Education Project

## Ethical, Legal and Social Issues in Personal Genetics

### Overview/Teacher Background for pgEd's lessons

#### **Introduction:**

pgEd's mission is to start conversations about the ethical, legal, social and scientific issues emerging as genetics plays a larger role in society. One way we do this is by creating scientifically accurate and highly engaging curriculum, and making it widely available to educators.

As the study of human genetics advances, genetic analysis is becoming a larger part of healthcare, and is impacting different areas of society. New techniques are allowing researchers to increasingly understand the connections between genes and human health, with the hope of improving medical care and extending people's lives.

Technical advances are happening alongside another movement that seeks to engage the general public with the science of genetics – through personal genome analysis. The technology that made the Human Genome Project possible will soon be affordable and available to a broader population – in 2015, a full genetic sequence can be purchased for less than \$3,000 (US). While it is likely that there are many useful or interesting things a person might learn from their DNA sequence, the path to truly understanding the utility and limits of this information will be a lengthy and sometimes confusing one.

Students currently in secondary school or college will enjoy enormous opportunities related to scientific leaps in the area of genetics, and will be asked to solve novel dilemmas on how genetics will be used in medicine and in society. Exploring the social and ethical issues while examining the key scientific principles makes for a learning opportunity that engages students and prepares them for the decisions they will face in the near future.

## **Guiding Questions:**

- How is genetics becoming more personal?
- How might personal genetics impact individuals and society?
- Do the benefits of personal genetics outweigh the risks?

## **Learning Objectives:**

When this unit is completed, students should be able to:

- Understand and articulate the ways genetics might impact their personal lives.
- Explain how it will present ethical and practical challenges for society.
- Begin to form an opinion, based on evidence, about personal genetics.
- See that they have a voice in the debate and are keenly needed to join the broader discussion.

## **Preparing to Teach this Unit:**

All of our lesson plans are self-contained pieces, meaning, each lesson has background reading for teachers and students, a classroom activity, discussion points, sometimes a slide presentation or video clip, and a student quiz or assessment. What follows are resources for a teacher who may just be diving into the field of personal genetics, and is looking to get a “big picture” look at the latest genetic research and the issues percolating around the personal, societal, and scientific possibilities in genetics. This list is far from exhaustive, and each lesson plan has extensive readings and resources.

The Personal Genetics Education Project website at [www.pged.org](http://www.pged.org) provides a resources for understanding what personal genetics is, how it works, its implications for medicine, the likely benefits and risks for an individual and their family. We also offer a number of interactive materials, such as our highly successful and engaging set of quizzes, [Map-Ed](#), and a video library, [“Personal Conversations/Personal Genetics.”](#)

NOVA has created a documentary, [“Cracking Your Genetic Code,”](#) and has made it available for free on their website. From 2012, this hour-long show highlights scientific progress, shows real families who are impacted by new

research, and examines some of the scientific and ethical issues through interviews with leading scientists and thinkers.

We recommend the New York Times Pulitzer Prize winning series the "[DNA Age](#)." Although the articles are from 2006-2008, many of the issues tackled in this series are as relevant as ever. In particular, the article, "[Facing Life with a Lethal Gene](#)" by Amy Harmon, is an excellent example of how discoveries made in the lab can profoundly affect people's lives and the complex personal and social issues genetic testing puts into play. Many of the pieces in the series also have videos that are very thought provoking and moving.

"[One in a Billion](#)" is another award winning piece of journalism, telling the story of a young boy, Nic Volker, who is considered one of the first patients where a genome sequence helped identify his illness and led directly to a successful treatment.

### **pgEd's Unit Lesson Plans:**

- What is personal genetics?
- Genomes for all? Discussing the implications of direct-to-consumer genetic testing
- Genetics and jobs: Will genetic knowledge shape our career paths?
- Genetics and reproduction
- Athletes and genetics
- Protecting athletes with genetic conditions: Sickle cell trait
- What is personalized medicine?
- DNA, crime and law enforcement
- History, genetics and eugenics
- Using primary sources to examine the history of eugenics
- Genes, environment and genetic complexity: Genetics and aggression
- Your genome: What does your DNA say about you? (A scientific primer)

## **Organizations, links, scientific resources and more:**

pgEd recognizes that many teachers do not have access to many of the scientific journals. Freely accessible journal articles can be found through [PubMed Central](#), a digital library sponsored by the National Institutes of Health.

## **Genetic analysis projects and companies:**

(Note: inclusion is not an endorsement)

Ancestry.com ([www.ancestry.com](http://www.ancestry.com))

23andme ([www.23andme.com](http://www.23andme.com))

Color Genomics ([www.getcolor.com](http://www.getcolor.com))

Counsyl ([www.counsyl.com](http://www.counsyl.com))

Athletigen ([www.athletigen.com](http://www.athletigen.com))

The ClinSeq Project ([www.genome.gov/20519355](http://www.genome.gov/20519355))

Genomes2People ([www.genomes2people.org](http://www.genomes2people.org))

The Personal Genome Project – United States ([www.personalgenomes.org](http://www.personalgenomes.org))  
and Canada ([www.personalgenomes.ca](http://www.personalgenomes.ca))

The 100,000 Genomes Project ([www.genomicsengland.co.uk](http://www.genomicsengland.co.uk))

## **Public policy and advocacy:**

The Genetic Alliance ([www.geneticalliance.org](http://www.geneticalliance.org))

Center for Genetics and Society ([www.geneticsandsociety.org](http://www.geneticsandsociety.org))

Council for Responsible Genetics ([www.gene-watch.org](http://www.gene-watch.org))

GovTrack – search engine to explore bills being brought before Congress ([www.govtrack.us](http://www.govtrack.us))

## **Writers, bloggers and current news and views:**

DNA Science Blog: Genetics in Context  
([blogs.plos.org/dnascience/author/rlewis/](https://blogs.plos.org/dnascience/author/rlewis/))

GenomeWeb ([www.genomeweb.com](http://www.genomeweb.com))

Nature's News and Comment – Biotechnology  
(<http://www.nature.com/subjects/biotechnology>)

National Geographic Phenomena: A science salon hosted by National Geographic (<http://phenomena.nationalgeographic.com/>)

Science Blogs ([www.scienceblogs.com](http://www.scienceblogs.com))

pgEd on Pinterest – updated at least weekly, sometimes more often.  
([www.pinterest.com/pgEDorg](http://www.pinterest.com/pgEDorg))