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Language Matters: practical tools and tips for learner engagement on the personal and social impacts of genetics

Presented by



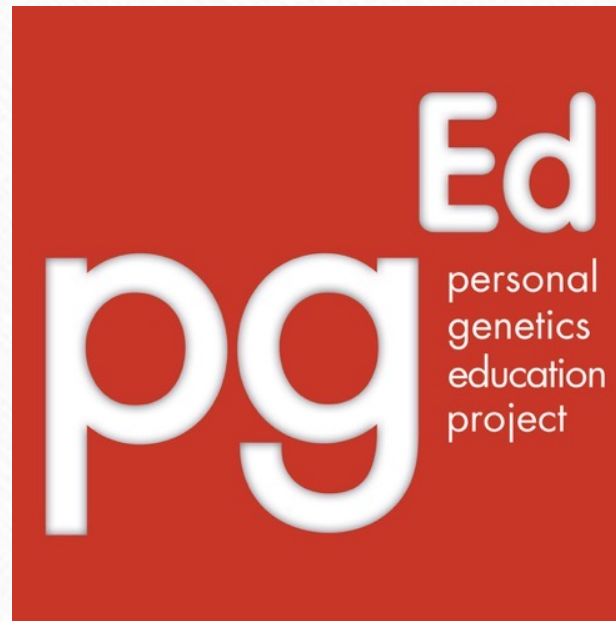
Personal Genetics
Education Project

December 6, 2022

12:00-1:00pm ET Virtual Seminar

1:00-1:30pm ET Informal Conversation

Personal Genetics Education Project



pgEd.org

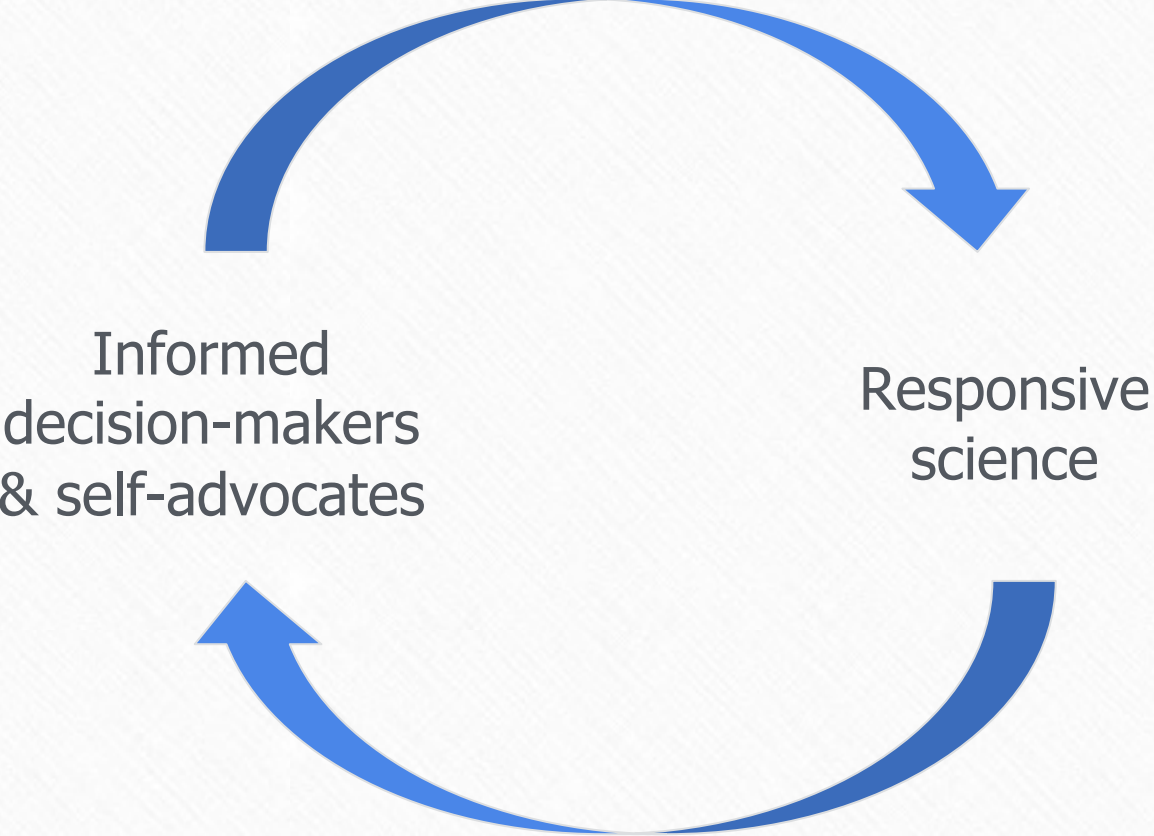


Towards an equitable and safe future
as genomic technologies
enter societal use

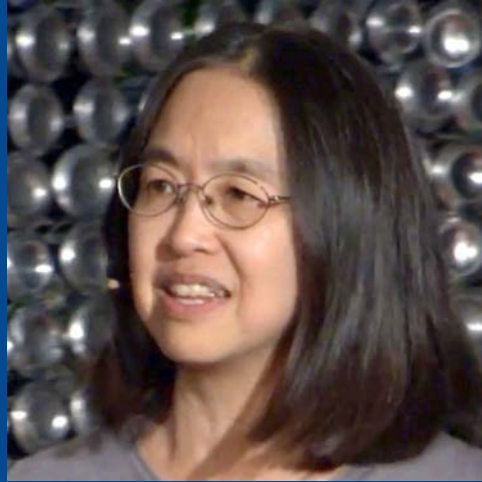
Towards an equitable and safe future
through education and conversation
as genomic technologies
enter societal use



Why conversation?



pgEd
team



Ting Wu



Nadine Vincenten



Cliff Tabin

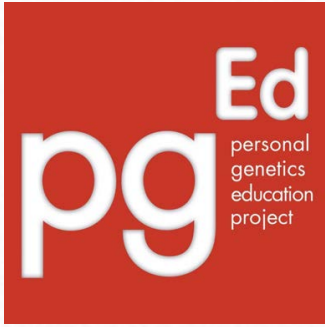


Robin Bowman



Gillian McNeil

+ 2 new people
joining in Jan 2023!!



Take a moment to introduce yourself in the chat:

- Your name
- Where you are calling in from
- Why you decided to attend today's program

Having Children

**Going to the
Doctor**

**Participating in
Clinical Research**

Genetics
gets
Personal

**Taking an
Ancestry Test**

Going to Vote

**Interaction with
Law Enforcement**

Meeting people where they are

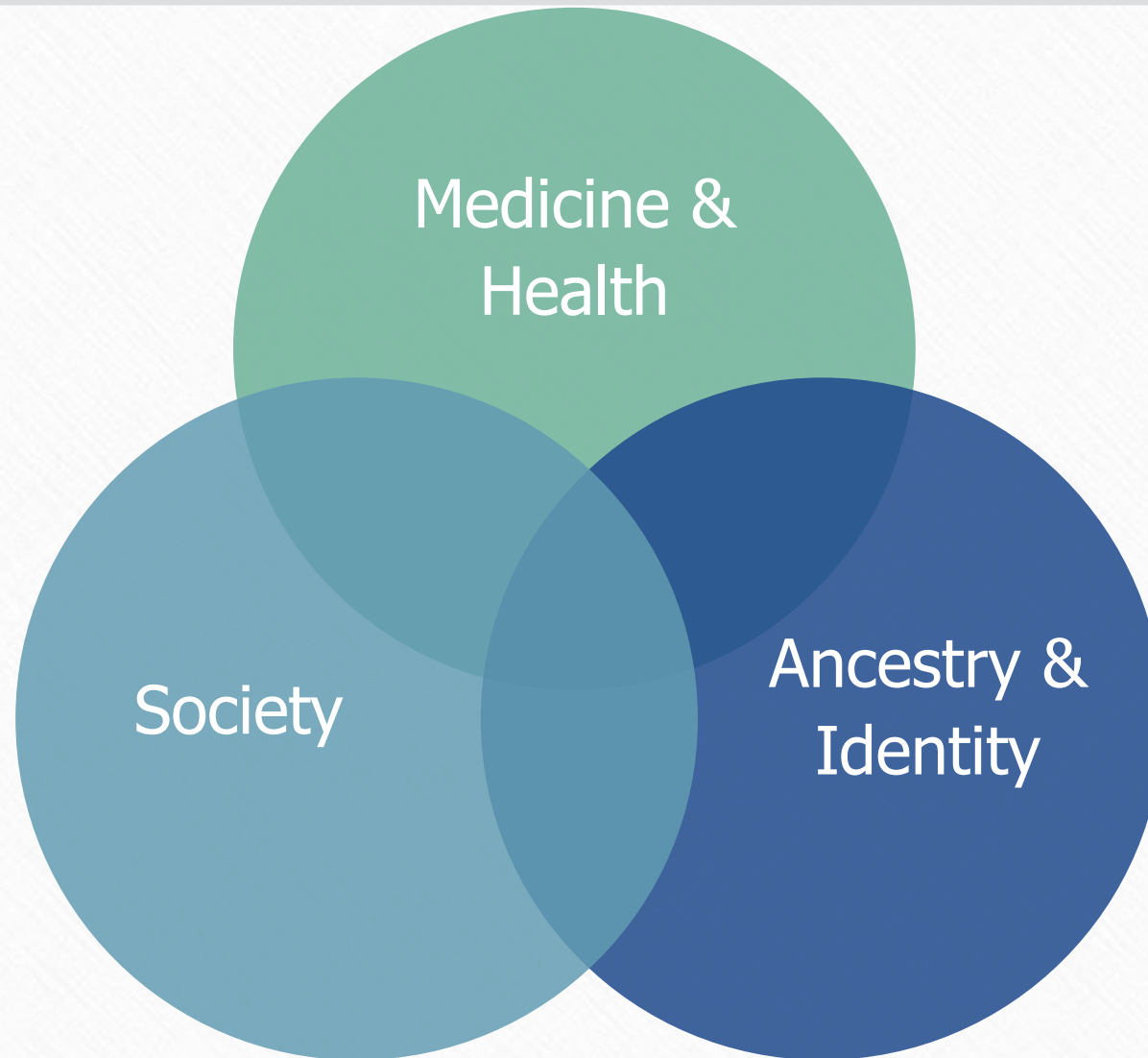


Free Resources

- Lesson Plans
 - Slideshow
 - Lesson plan document
 - Background information
 - Slide notes
 - Activity/homework/quiz
- Distance Learning Resources
 - Snapshots
 - Recorded presentations
 - PBS LearningMedia

www.pged.org

How is personal genetics affecting real people?



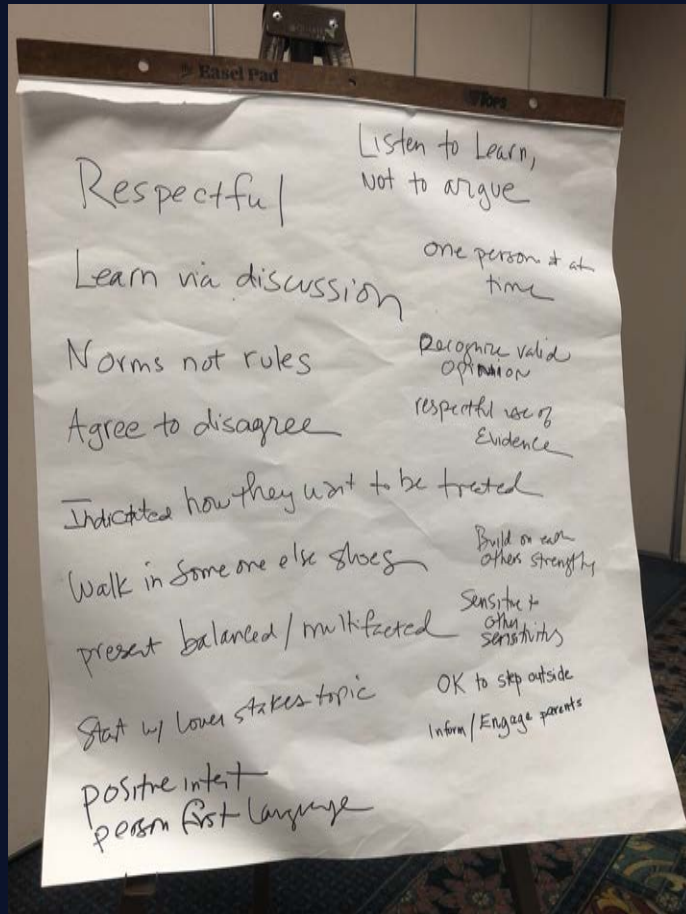


Topics

- Introduction to Personal Genetics
- Consumer Genetics
- Personalized Medicine
- Ancestry Testing
- Genetics, Jobs & Your Rights: GINA
- Reproductive Genetic Testing
- Genome Editing & CRISPR
- Birth of CRISPR-edited Twins
- Genome Editing & the Environment
- Athletics & Genetics
- Sex, Genetics & Athletics
- The Many Faces of Sickle Cell Disease
- DNA, Crime & Law Enforcement
- Genetics, History & the American Eugenics Movement



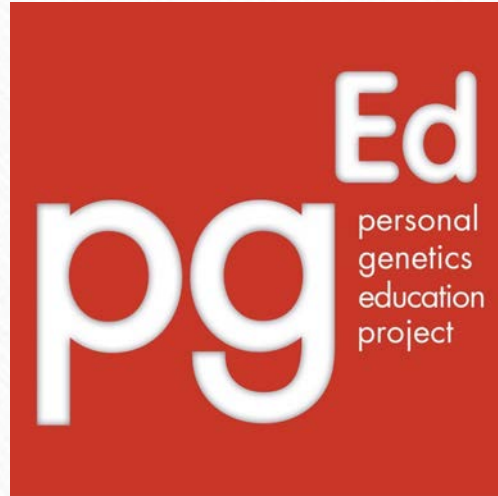
Community Agreements



- Create a “brave space”
 - Intentionally shaped by and inclusive of all identities and social groups
 - Encourages equitable participation

Sample agreements

- Speak from your own experience.
- Realize impact can be different than intent. Own the impact of your words.
- Listen to understand, not to respond. The focus should be on learning, not debating.
- You don't have to agree but you must be civil. Critique ideas, not people.
- It is ok to change your mind.
- Share the floor/pass the mic. (Step up, step back.)
- "Challenge by choice" – each individual can choose if/when to participate.



Introduction to Personal Genetics

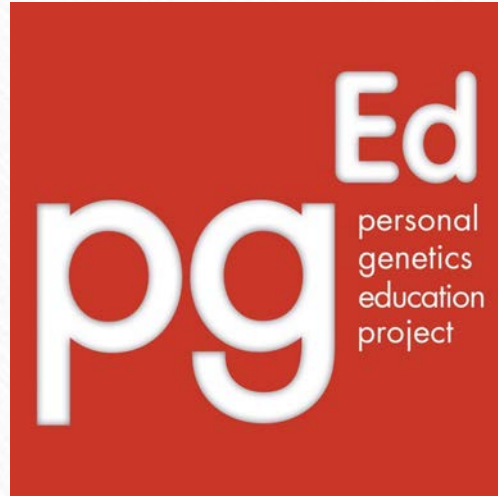
Do Now: Discuss the following with the person (or people) next to you:

1. What are the potential health benefits to knowing about your genetic make-up?
2. What are the possible downsides to knowing?
3. Aside from health and medical information, what else might you be curious to learn about from your DNA?

Four Corners Activity

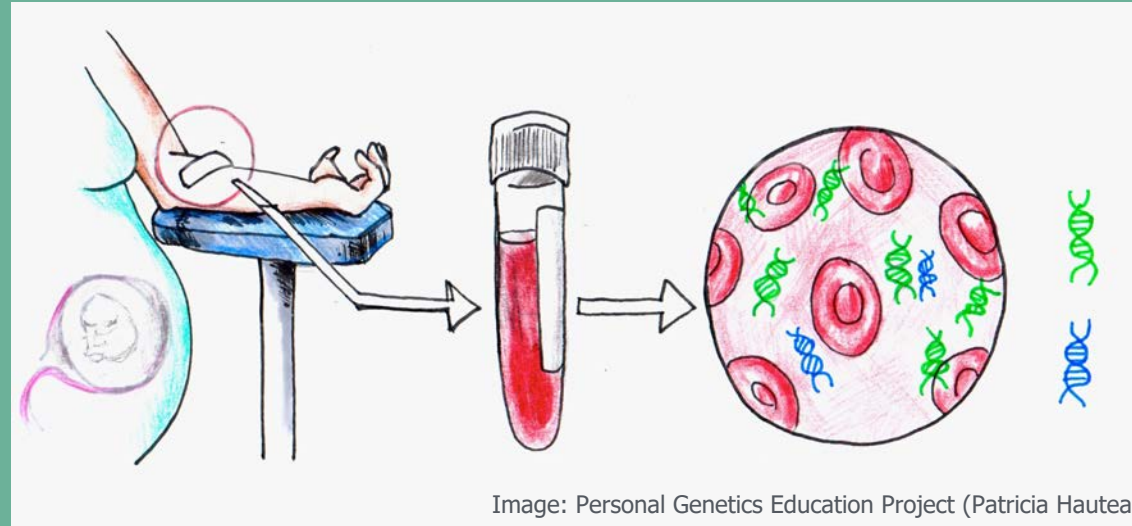
I want to find out my
likelihood of developing a
disease only if there are
ways to prevent or treat it.

Parents undergoing in vitro fertilization should have the option to screen embryos for variants likely to cause a serious disease.



Reproductive Genetic Testing: Technology, Access, and Decision-making

NIPT allows for an analysis of fetal DNA at an early stage of pregnancy.



- Non-invasive prenatal testing (NIPT) involves analyzing a blood sample taken from a pregnant person to learn about traits of the fetus.
- This test looks at small pieces of DNA that circulate in the pregnant person's bloodstream.
- Some of these pieces of DNA come from cells of the placenta that broke open and can reveal information about the developing fetus.

NIPT allows for an analysis of fetal DNA at an early stage of pregnancy.

pgEd uses the term “pregnant person” in recognition that not everyone who enters pregnancy would become a “mother” (e.g., in case of surrogacy) or identifies as a woman.

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Exploring Difference in the Biology Classroom

Webinar Series

How to represent wide-ranging family structures and personal identities using the latest pedigree nomenclature

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6-7pm ET

Expert Panel & Q&A

7-7:30pm ET

Discussion: Classroom
Integration Strategies



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Case Studies

StockSnap, Pixabay



A family weighs its options to help a sick child.

1. What would you do as a parent if you were in this situation? Why?
2. How could this impact how each child sees their role in the family?



StockSnap, Pixabay

A family decides whether to have a baby with what is traditionally thought of as a genetic disorder or disability.

There are debates about whether PGD should be used to select for traits traditionally considered a disability.

Who do you think should decide how PGD is used: parents, doctors, lawmakers, religious leaders or others?

Scenario:

A family decides whether to have a baby with what is traditionally thought of as a genetic disorder or disability.



Derek Braun, Ph.D.



Teresa Blankmeyer
Burke, Ph.D.



Rachel Boll, M.A.



Jeanne Reis, M.Ed.



Scenario:

A family decides whether to have a baby with what is traditionally thought of as a genetic disorder or disability.

You and your partner are both deaf and proud members of the Deaf culture, with its language and values.



You and your partner are both deaf and proud members of the Deaf culture, with its **advantages**, language, and values.

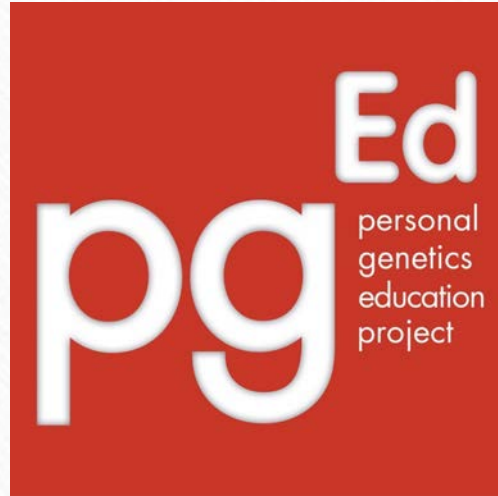
Scenario:

A family decides whether to have a baby with what is traditionally thought of as a genetic disorder or disability.

However, deaf people often have a difficult time in school and in finding a job, and can face social isolation.



However, longstanding barriers in education, employment, and other domains are likely to be faced by and impact your deaf child and family.



Engineering the world around us: Genome editing and the environment

Cassava

Cassava is an important food crop for over 800 million people worldwide



Colombia, South America



Ghana,
Africa



Vietnam,
Asia

Cassava

Cassava is an important food crop for over 800 million people worldwide



Colombia, South America



Ghana, Africa



Vietnam, Asia

Image left: Neil Palmer, CC BY-SA 2.0

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Image right: Neil Palmer, CC BY-SA 2.0

Cassava can cause a disease called Konzo

- Cassava naturally produces a toxin, which is present at higher levels when the plant is grown in drought conditions.
- At high levels, this toxin can cause Konzo, a disease that leads to paralysis and can potentially be deadly.
- Soaking the cassava in water and eating a protein-rich diet can prevent Konzo and make cassava a safe source of food.
- Konzo is a disease of poverty, because poverty often limits access to water and a protein-rich diet.



IITA, CC BY-NC-SA 2.0

You are an **elected official**, and you need to make an informed recommendation.

Read your assigned topic, and ask yourself: **What else do I need to know? Who should I ask?**



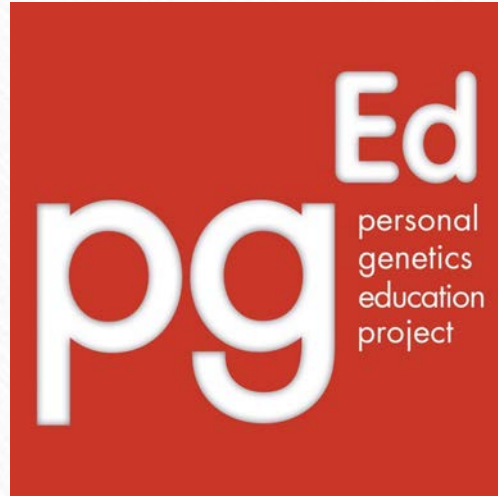
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Should genetically modified mosquitoes be released into the environment to combat Zika virus?



Sex, Genetics & Athletics

Do Now: Discuss the following with the person (or people) next to you:


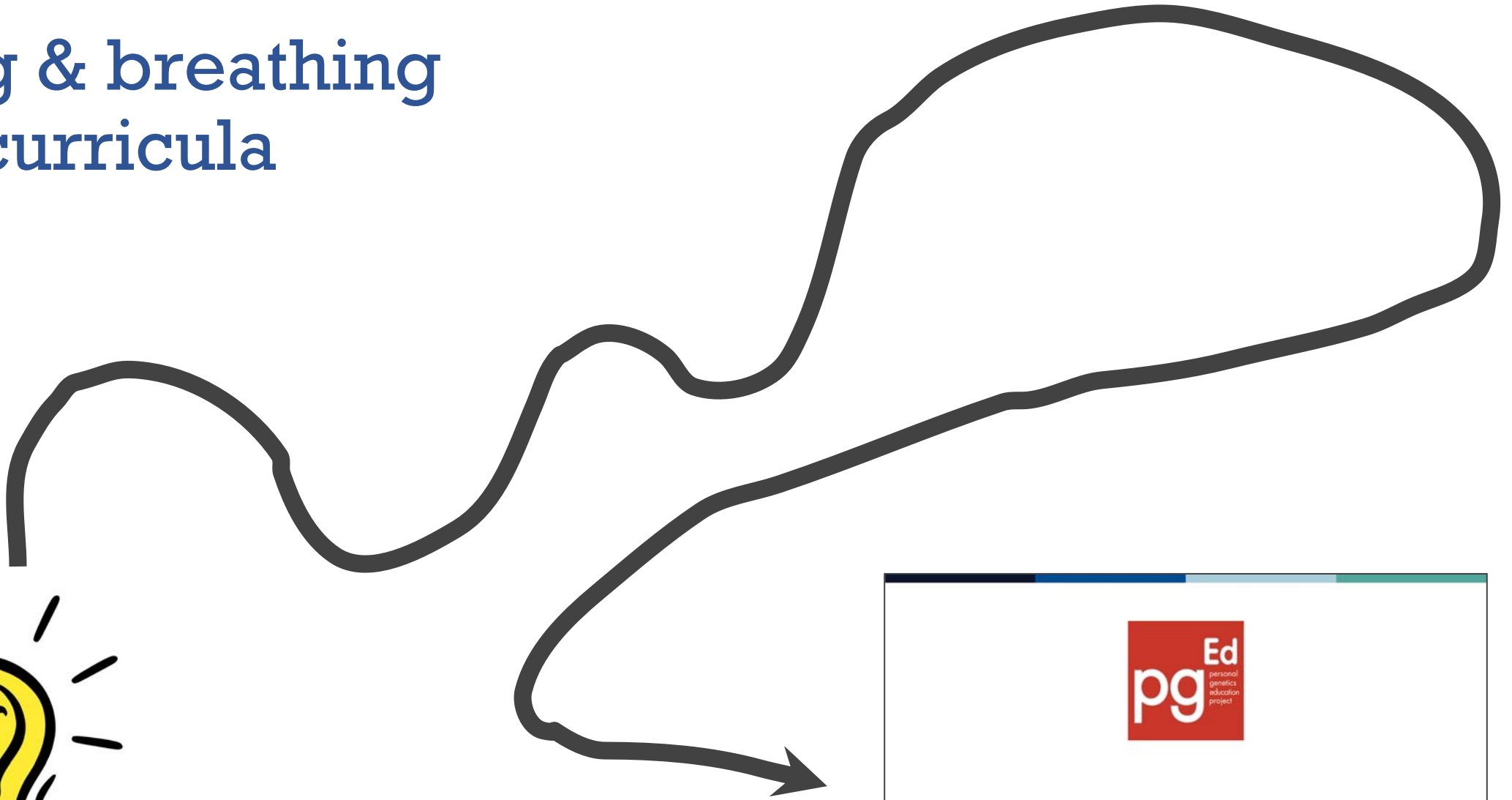
Imagine you are an elite female athlete competing at the international level.

You identify as a woman and haven't considered other possibilities. One of your competitors questions whether you are "truly biologically female" and anonymously asks officials to investigate your sex.

The group that makes the rules about who can compete is deciding whether you qualify as a female and should be able to participate.

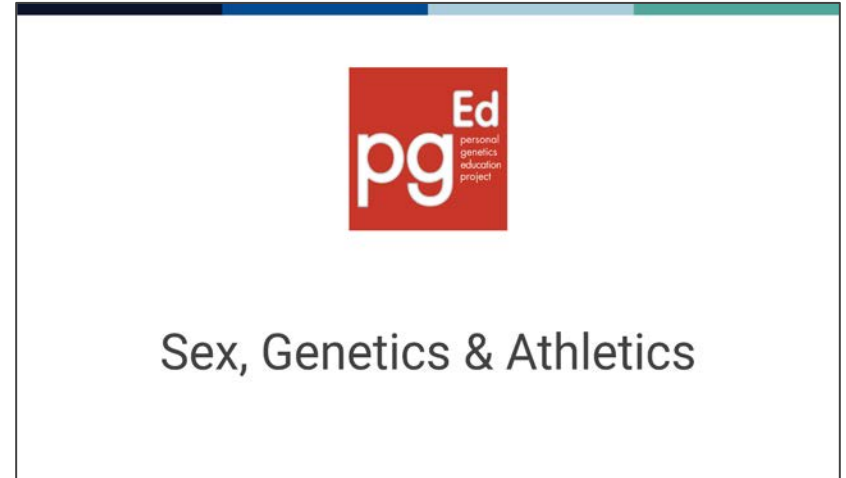
1. How do you think you would respond to this type of investigation?
2. What do you think the investigation might involve?
3. What could the other athlete be thinking about?

Living & breathing curricula



Sex, Genetics & Athletics

Iterative co-creation



And many, many students
along the way

Two Categories of Intersex Variations

Sex Chromosome Aneuploidy

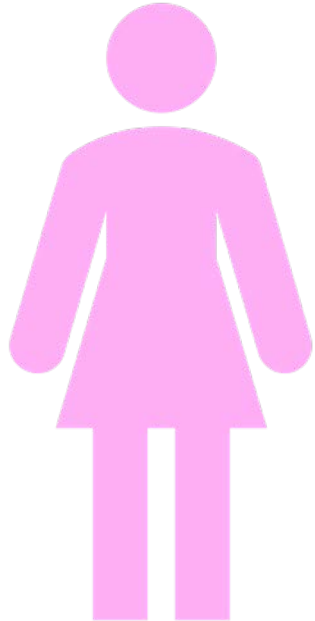
Having an atypical number of sex chromosomes

Other Variations that Affect Sexual Development

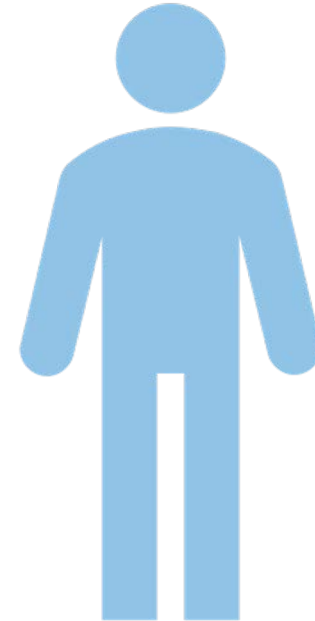
These conditions may affect anatomy, hormone production, the body's response to hormones, or any combination of the above.

Human Sex Determination: How We're Taught it Works

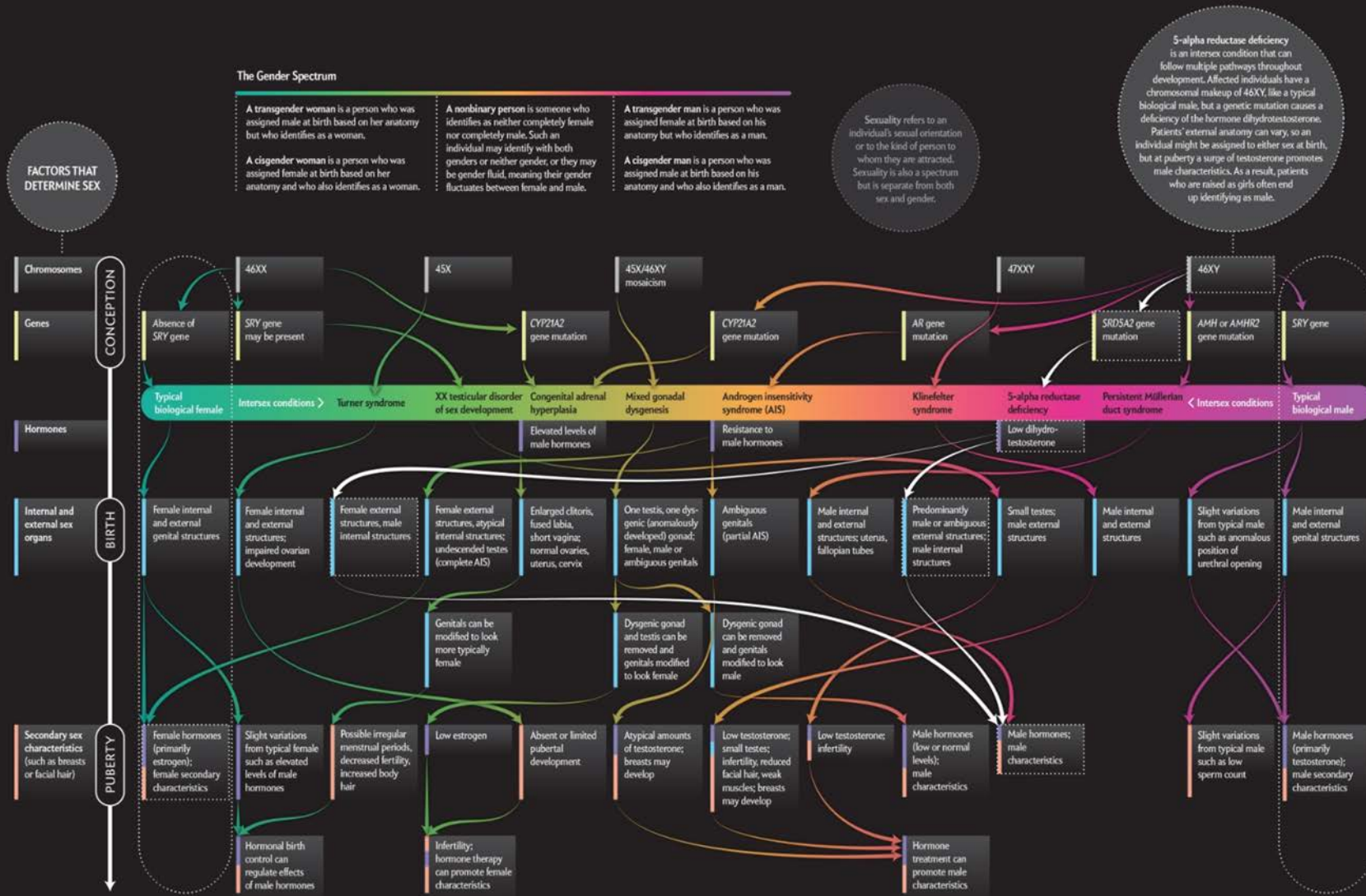
XX



XY



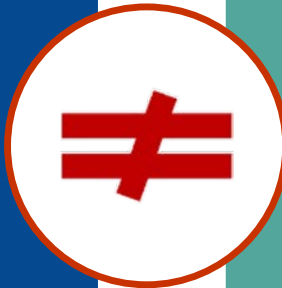
Human Sex Determination: How it Actually Works



What's the Difference Between Sex & Gender?

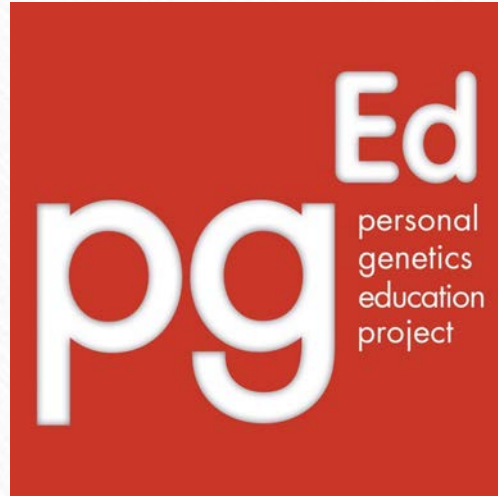
SEX

- Classification of people into male, intersex, and female
- Based on physical characteristics including:
 - Chromosomes
 - Sex hormones
 - Reproductive organs



GENDER

- A person's sense of being a man, woman, both, or neither
- Based on societal ideas about masculinity and femininity
- A person's gender may be different than a gender typically associated with their sex assigned at birth



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Sept. 29, 2022, 12:00-1:30 p.m. EDT

Discussing Genetics: Science Engagement with Faith Communities

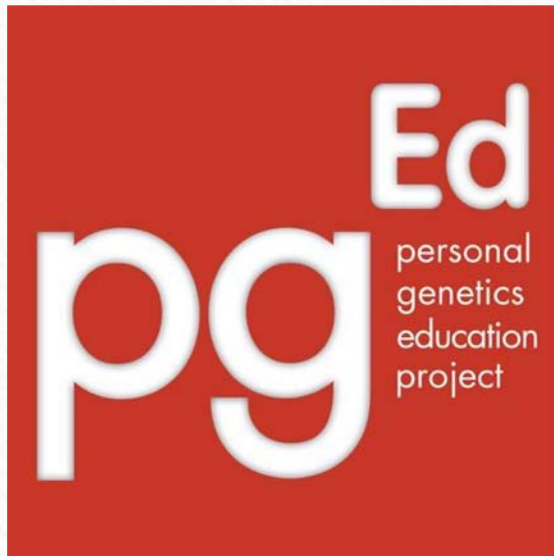
Meeting the Moment:
strategies for contributing
to a broad conversation on
genetics and society



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Thank you!!

Idea or questions? Reach out!

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