Genetics Gets Personal: Teaching Ethical, Legal and Social Issues in Personal Genetics

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XIAP
(X-linked inhibitor of apoptosis)

Treatment:
bone marrow transplant


Why is talking with students so urgent?

“Under $1000 dollars in this decade”
“Widely available in the next 5-10 years”
“Transforming health care for the next generation”

- Average age to marry in the US, 2000-2003: Men 26.7, Women 25.1
- Average age of first-time mothers in the US, 2003: 25.2

Sources: census.gov, cdc.org, NYT
pgEd’s goal is to encourage thoughtful discussion about personal genetics so people can make informed choices for themselves, their families and society.
Careers in Human Genetics

Undergraduate Degree BA/BS
- Laboratory technician
- Biotech sales/marketing
- K-12 science teacher*
- Clinical trials administrator/research associate
- Patent agent*
- Science writer
- Forensic scientist
- Science outreach
- Dietitian/Nutritionist*
- Genetics clinical nurse**

Law Degree JD
- Intellectual property/patent attorney*
- Bioethicist

Medical Degree MD/DO
- Independent clinical researcher
- Physician/Clinical geneticist

Master’s Degree MA/MS
- Genetic counselor**
- Physician assistant**
- Speech-language pathologist**
- Technical writer/illustrator
- Community college professor
- Public health researcher
- Bioinformatician
- Technology transfer associate

Doctoral Degree PhD
- Audiologist**
- Independent basic researcher
- College professor (teaching focus)
- Science museum director
- Management consulting
- Scientific editor
- Biocurator

Clinical laboratory geneticist*
- Science/health policy

http://www.ashg.org/education/career_flowchart.shtml
Genome analysis for diagnosis

Cerebral palsy > dopa-responsive dystonia > change in SPR gene

**Treatment**: precursor to dopamine and precursor to serotonin

Genetic testing to learn about disease risk

http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html

http://www.babysfirsttest.org/newborn-screening/screening-facts
Reproductive genetic testing

Carrier testing

Prenatal testing


Ancestry testing

http://www.pbs.org/wnet/finding-your-roots/
http://www.mtv.com/shows/generation_cryo/series.jhtml
Genome analysis in research

Personal Genome Project

The MedSeq Project: Integration of Whole Genome Sequencing into Clinical Medicine, (HG006500)

Principal Investigator:
Robert C. Green

Co-Principal Investigators:
Mike Murray, Christine Seidman, Heidi Rehm, Zak Kohane and Amy McGuire
Challenges in personal genetics

1. How clinically useful are personal genome sequences?

2. How much information would you want to know? How much information should you be able to access?

3. Will fair weight be given to environmental & social factors?

4. How will your genetic information affect your family?

5. How much should we be concerned about discrimination at work and by insurance companies?

6. How can we ensure access for all?
Genetic Information Non-discrimination Act (GINA)

“The first civil rights legislation of the 21st century”

-Senator Ted Kennedy
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Social issues in personal genetics

- How do we decide to use new reproductive technologies?

- DNA and the law - Can we use DNA to keep us safe and preserve civil liberties at the same time?

- Athletics and genetic testing – how much can DNA reveal about ourselves and our potential?
Use of PGD to address diseases

Fanconi anemia (disorder of DNA repair)

**Treatment:** PGD, umbilical cord blood stem cells

PGD: Preimplantation Genetic Diagnosis

Schwartz
2011 Jewish News
Should people be allowed to test embryos:

1. for a deadly disease that a child would almost certainly develop?
   Yes or No

2. for a deadly disease that a child might develop?
   Yes or No

3. for a potentially deadly disease that is likely to develop in adulthood, typically after age 40?
   Yes or No

4. to choose the gender of the child?
   Yes or No
Public attitudes regarding PGD

Hudson 2006 Fertility & Sterility
What role should the government play in regulating PGD?

- Supports no government regulation: 17%
- Supports regulation of ethics only: 1%
- Supports regulation of safety, quality, and ethics: 37%
- Wants a total ban on PGD: 20%

Hudson 2006 Fertility & Sterility
Discussion Questions for Students

• What are the potential opportunities and challenges of PGD?

• After the discussion, did you change your opinion about whether you think people should be allowed to use PGD?

• If you were conceived by IVF+PGD, should your parents tell you?

• Do we need rules to guide how this is used? If yes, what sort of rules? Whose job would it be to enforce them?
Stop the Genetic Dragnet

Police currently collect samples of DNA from detainees—retaining the DNA even if a suspect turns out to be innocent.

In 2009 the San Francisco police arrested Lily Haskell when she allegedly attempted to come to the aid of a companion who had already been taken into custody during a peace demonstration. The authorities released her quickly, without pressing charges. But a little piece of Haskell remained behind in their database.

Haskell is one of hundreds of thousands who have had their DNA extracted as part of an enormous expansion of what were once categorized as criminal data banks. Police in about 25 states and federal agents are now empowered to take a DNA sample after arresting, and before charging, someone. This practice occurs even though many of those in custody are never found guilty. If they are cleared, their DNA stays downtown, and they must undergo a cumbersome procedure to clear their genetic records.

Courts nationwide are now wrestling with the civil-liberties implications. Some have held that the practice violates the Fourth Amendment protection against “unreasonable searches and seizures.” Other courts, including one that heard a legal challenge brought by Haskell, have agreed with law-enforcement officials that lifting DNA is no different from taking a fingerprint, an established routine even for those not convicted. Ultimately the U.S. Supreme Court will probably decide this matter.

not identical match to the DNA at the crime scene. The police would then have a whole new set of potential leads who would come under scrutiny as possible perps.

Although this process may nab criminals who would otherwise elude capture, it may also ensnare the innocent. Most of the possible leads produced by searches in partial database matches will have done nothing wrong. These persons of interest are likely to be concentrated in minority communities whose denizens represent a disproportionate fraction of the databases. Moreover, the seeming infallibility of DNA may prompt police to place too much reliance on familial search methods instead
“A Not So Perfect Match”
The Darryl Hunt case on 60 Minutes

Journal Photo by David Sandler
Genetic testing and athletics

www.nytimes.com/2008/11/30/sports/30genetics.html
Genetic testing and safety in athletics

Return-to-play is the priority no matter the age or level of play.

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Athleticode’s APOE Test

www.athleticode.com
ACTN3 R577X Polymorphism and Explosive Leg Muscle Power in Elite Basketball Players.
(PMID:23689106)

Faculty of Health and Sport Science, University of Zaragoza, Huesca, Spain.
International Journal of Sports Physiology and Performance [2013]
Map-Ed

www.Map-Ed.org

a personal genetics game

Genetics is getting personal. Are you ready? Answer the following questions and then pin yourself on the map to show you're aware!

Let's Begin!

Already played? Want to see the map?

Go To Interactive Map
Map-Ed: 5 concepts

Do your genes determine everything about you and your future?

Pick any two people in the world. How similar are their genomes?

What is a mutation?

Can some mutations be beneficial?

Can your genes influence how well certain medications will work for you?
Ting Wu
Director

Lauren Tomaselli
Director of Curriculum & Training

Dana Waring
Director of Education