

Online Ethics Center FOR ENGINEERING AND SCIENCE

## **Additional Resources**

#### Description

Additional resources for unit 1 of the course "Genomics, Ethics, and Society."

#### Body

# News stories on Genomics, Ethics & Policy

<u>Scientific American story on incidental findings</u>

<http://www.scientificamerican.com/article/what-rare-disorder-is-hiding-inyour-dna/> Incidental findings in genomic medicine are findings that emerge during a test for something else, and they pose a number of problems. We consider this issue further in unit 7 on privacy.

- <u>An interesting news story on sequencing a fetal genome</u> <http://www.bionews.org.uk/page\_474185.asp>
- <u>Designer babies -FT opinion piece</u> <http://www.ft.com/intl/cms/s/0/8fc7854a-7bb3-11e4-a695-00144feabdc0.html#axzz3ppegHD3F> Short opinion piece on the ethics of designer babies - we'll return to this question in unit 6.
- <u>The Guardian article on human genome sequencing</u>
  <a href="http://www.theguardian.com/science/2013/sep/09/genetics-ethics-human-gene-sequencing">http://www.theguardian.com/science/2013/sep/09/genetics-ethics-human-gene-sequencing</a>>

## **Links to Discussions and Papers**

- Lecture by Bartha Knoppers on "Genomics: from persons to populations and back again" <a href="http://www.nrcresearchpress.com/doi/full/10.1139/gen-2013-0148?mobileUi=0.VJNZtBBAMw>">http://www.nrcresearchpress.com/doi/full/10.1139/gen-2013-0148?mobileUi=0.VJNZtBBAMw></a>
- <u>Caulfield et al opinion piece on ELSI and genomic policy</u> <http://www.biomedcentral.com/content/pdf/gm425.pdf> This controversial opinion piece in *Genome Medicine* reflects on the influence of research into Ethical, Legal and Social Impacts (ELSI) in the formation of policy about genomic medicine.
- Andrews and Paradise on "Gene Patents: The Need for Bioethics Scrutiny and Legal Change" <a href="http://digitalcommons.law.yale.edu/yjhple/vol5/iss1/13/></a>

## Links to useful videos

- Obama on genetics and policy (especially on personalized medicine)
  <a href="https://www.youtube.com/watch?v=g5140mlC3Uk>">https://www.youtube.com/watch?v=g5140mlC3Uk></a>
- <u>Amy McGuire on Ethical, Social and Legal issues in Genomics</u> <https://www.youtube.com/watch?v=9GHScUIyRhE>
- <u>The Political Implications of Human Genomics</u> <https://www.youtube.com/watch?v=1CpDFsDPMCI> A discussion on the rapid growth of genomic science, how political views and public policy have not caught up, and its likely effect on our identities and on the criminal-justice system (you-tube description) from the John W. Kluge Center at the Library of Congress by Prof Jennifer Hochschild.

## Websites of Relevant Individuals and Institutions

- Genome Web site useful up to date news < https://www.genomeweb.com/>
- Home page, Wellcome Trust Sanger Institue for genomic research site <https://www.sanger.ac.uk/>
- <u>National Human Genome Research Institute Policy & Ethics Issues</u> <http://www.genome.gov/27527631>
- <u>World Health Organization ELSI and human genomics</u> <http://www.who.int/genomics/elsi/en/>

# Links to background info about genomics and genetics

• Human Genome Project

<http://web.ornl.gov/sci/techresources/Human\_Genome/index.shtml> The section on Educational Materials provides useful background information.

 <u>Brown's Genomes 2</u> <http://www.ncbi.nlm.nih.gov/books/NBK21128/> Introductory textbook available through PubMed.

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### Rights

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#### **Resource Type**

Instructor Materials