Genetics & Society in Edinburgh (SOCI 138GS)

Global Seminar in Edinburgh, Summer Session I, 2023 Tuesday and Thursday, 9:30am-12:30pm, Edinburgh Training & Conference Centre Professor Daniel Navon (<u>dnavon@ucsd.edu</u>). Office hours by appointment.

For well over a century now, genetics has powerfully shaped how we think about human difference. This class will explore the many ways that studying our genomes and inheritance patterns has informed public understanding and policy on topics like race and ethnicity, disability, reproduction, rare disease, intelligence, sociality, delinquency, and personal identity in the United States. We will also see how social forces shape genetics research itself and discuss controversies surrounding topics like gene patenting, forensic science, newborn screening, cloning, and genetic testing for disease, risk and ancestry. Throughout, we will adopt a comparative perspective by examining the way ideas about genetics and heritability have moved back and forth between the UK and US-from phrenology and Darwin in the 19th Century, through the eugenics movement of the early 20th Century, on the rise of modern medical genetics in the post-World War II period, and through to our "post-genomic" present. In addition, we will trace several notable stories where Edinburgh played an especially pivotal role: as the leading global center for phrenological research and the intellectual cauldron that set Darwin on his world-changing path; as a pathbreaking center for the early study of chromosome abnormalities, including the infamous XYY mutation that captivated criminologists, popular media, science fiction writers, and children's rights advocates in the US; and as the site where the first cloned mammal, Dolly the sheep, was born, lived out her endlessly discussed life, and eventually found her was into a glass display at the National Museum of Scotland just a stone's throw for the University of Edinburgh. Readings will be drawn from the genetics literature, popular culture, and the social sciences. There will also be field trips and guest lectures to help us take full advantage of the Edinburgh and its rich history. By the end of the class, students will possess the knowledge base to critically assess the promises and potential pitfalls of contemporary genetics, genomics, and biomedicine more broadly.

Assessment

Assessment for the class will consist of class participation, reading response memos, and a final take-home exam, essay, or podcast. The breakdown of final grades will be as follows:

<u>Class attendance and participation</u>: 20% of your grade. You will lose 2pts for every unexcused absence. Regular participation is also required, but you do *not* need to speak more than your classmates to receive full points.

<u>Weekly memos</u>: 30% of your grade. You must submit three memos (300–500 words each) that summarize and engage with one reading marked with an asterisk (*) from that week. Memos must be submitted by 11:59pm on the Wednesday of weeks 1, 2, and 4. They will receive 0 (fail), 5 (half-points), or 10 points (pass); most good faith efforts will pass.

<u>Midterm:</u> 20% of your grade. You must submit a short take-home exam by the end of Week 3. Prompts and guidelines will be provided at the beginning of the week.

<u>Final</u>: 30% of your grade. You must submit a short take-home exam by 11:59pm on the Wednesday of Week 5. Prompts and guidelines will be provided at the end of Week 4.

<u>Alternative Final</u>: You may choose to submit an in-depth essay or podcast in lieu of the final exam. Topics must be approved in advance. We will discuss this option in class.

Readings

All texts are available on Canvas or hyperlinked in the syllabus. I recommend setting up a VPN to access online readings off campus. See instructions <u>here</u>. Let me know if you have trouble accessing the readings.

Some readings will contain technical genetics terms. I strongly recommend that you consult publicly available resources like the <u>NHGRI glossary</u> or Wikipedia as necessary.

Don't worry too much if it looks like there's a lot of reading for a given class—many of the texts are very short newspaper articles or papers from the genetics literature.

Course policies

Cheating and plagiarism:

Students are expected to do their own work and to cite sources according to established norms as outlined in the UCSD Policy on Academic Integrity. The policy can be found <u>here</u>. A FAQs page on what counts as cheating can be found <u>here</u>. Students in violation of UCSD academic integrity standards will receive a failing grade on the assignment or exam and/or the entire course. They may also be referred for additional disciplinary action elsewhere at UCSD. If you are unsure about what is considered either plagiarism or cheating, please ask.

Missing/late exams and assignments:

Failure to turn in your essays on time without a valid excuse will result the deduction of one full letter grade for every day (or part thereof) after the deadline. Excuses communicated after the deadline will only be accepted in exceptional circumstances.

Struggles with the class:

If you are having trouble with any aspect of the class, including deadlines, it is always best to contact me as soon as possible. That way we can address the problem before you have fallen too far behind or lost too many points from your final grade. We understand that these are challenging times, and that many of you are facing extraordinary external pressures.

Disability accommodations

Students requesting accommodations for this course due to a disability must provide a current Authorization for Accommodation (AFA) letter issued by the Office for Students with Disabilities (OSD). Students are required to present their AFA letters to Faculty (please make arrangements to contact me privately) and to the OSD Liaisons in the Sociology Department in advance so that accommodations may be arranged.

Fieldtrips

All fieldtrips are mandatory, and the things we see and learn may be integrated into the exams.

Weekly themes and readings

Week 1: Introductions and historical origins

Tuesday: Introduction-plus genetics and society meets COVID-19

Fieldtrip, 2pm. Walking tour to see city center, plus Darwin's residence and other relevant sites. Meet outside the National Museum (see IFSA itinerary).

Thursday: Historical origins in Edinburgh, and what do we mean by 'gene'?

- *Poskett, James. 2019. *Materials of the Mind: Phrenology, Race, and the Global History of Science, 1815-1920.* Chicago: University of Chicago Press. Introduction and Chapter 1.
- * Keller, Evelyn Fox. 2002. *The Century of the Gene*. Harvard University Press. Introduction and Chapter 2.
 - <u>Recommended</u>: *Shapin, Steven. 1979. "The Politics of Observation: Cerebral Anatomy and Social Interests in the Edinburgh Phrenology Disputes." *The Sociological Review* 27(1_suppl):139–78.
 - o Scientific American. <u>Genes vs. DNA vs. Chromosomes</u> (video).
 - *Mayr, Ernst and William B. Provine. 1981. "<u>The Evolutionary Synthesis</u>." Bulletin of the American Academy of Arts and Sciences 34(8):17–32.
 - o 'Darwin in Edinburgh':

Fieldtrip, 2:30pm. Visit to the University's <u>Anatomical Museum</u> to view the collection of the Edinburgh Phrenological Society and discuss the colonial impact of phrenology.

Week 2: From eugenics to modern human genetics

Tuesday: Eugenics-origins, nightmare, and eventual unraveling

- * Kevles, Daniel J. 1998. In the Name of Eugenics: Genetics and the Uses of Human Heredity. Cambridge, MA: Harvard. Chapter VII.
- * Stern, Alexandra Minna. 2005. *Eugenic Nation: Faults and Frontiers of Better Breeding in* <u>Modern America</u>. Berkeley: University of California Press. Chapters 3 and 4.
- Muir, Becca. 2020. "<u>The Secret History of Britain's Universities and Eugenics</u>." *Prospect Magazine*, July 28.
 - o <u>Recommended: Buck v. Bell, 274 U.S. 200</u> (1927). US Supreme Court Ruling.
 - *MacKenzie, Donald. 1976. "Eugenics in Britain." *Social Studies of Science* 6(3/4):499–532.
 - * Galton, Francis. 1904. "Eugenics: Its Definition, Scope, and Aims." American Journal of Sociology 10(1):1–6.
 - * Paul, Diane B. 1995. *Controlling Human Heredity, 1865 to the Present*. Humanities Press. Chapters 1-3.
 - Shoichet, Catherine. 2020. "<u>The US Has a Horrifying History of Forced</u> <u>Sterilizations. Some Fear Hysterectomies in ICE Custody Could Be a New</u> <u>Chapter</u>." *CNN*, September 16.

Thursday: The new human genetics, 'geneticization', and the ghost of eugenics

- * Comfort, Nathaniel. 2014. <u>The Science of Human Perfection: How Genes Became the Heart</u> of <u>American Medicine</u>. Reprint edition. Yale University Press. Chapters 5 and 6.
- * Lindee, M. Susan. 2008. *Moments of Truth in Genetic Medicine*. Johns Hopkins University Press. Chapter 4.
 - <u>Recommended</u>: Jacobs, Patricia A., et al. 1959. "Evidence for the Existence of the Human 'Super Female." *The Lancet* 274(7100):423–25.
 - *McKusick, Victor A. 1993. "<u>Medical Genetics</u>." *JAMA: The Journal of the American Medical Association* 270(19):2351–56.
 - o Lennox, B. 1961. "Chromosomes For Beginners." The Lancet 277:1046-51.
 - o * Hedgecoe, Adam. 2001. "Geneticization: Debates and Controversies." eLS.

Week 3: Genetics meets race and sex, behavior and culture

Tuesday: Sex and crime, intelligence and race

- * Panofsky, Aaron. 2014. *Misbehaving Science: Controversy and the Development of Behavior Genetics*. Chicago: University of Chicago Press. Chapter 3.
- * Gould, Stephen Jay. 1994. "Curveball." The New Yorker, November 28, 139–49.
- *de Chadarevian, Soraya. 2020. *Heredity under the Microscope*. Chicago, IL: University Of Chicago Press. Chapter 3: X and Y
- Gould, Stephen Jay. 1996. *The Mismeasure of Man*. W. W. Norton & Company. Epilogue to Chapter 4, pp. 173-5.
 - <u>Recommended:</u> * Richardson, Sarah S. 2013. *Sex Itself: The Search for Male and Female in the Human Genome.* University of Chicago Press. Chapter 5.
 - Brown, W. M., W. H. Price, and P. A. Jacobs. 1968. "Further Information on the Identity of 47,XYY Males." British Medical Journal 2(5601):325–28.
 - Kingsbury, Kathleen. 2009. "<u>Which Kids Join Gangs? A Genetic</u> <u>Explanation</u>." *Time*, June 10.

Thursday: Culture, 'biosocial' identity, and the genetics of race and ancestry

- *Nelkin, Dorothy and M. Susan Lindee. 2004. *The DNA Mystique: The Gene as a Cultural Icon*. University of Michigan Press. Introduction and Chapter 6.
- *Wailoo, Keith. 2013. "Who Am I? Genes and the Problem of Historical Identity." Pp. 13–19 in *Genetics and the Unsettled Past: The Collison Between DNA, Race, and History*, edited by K. Wailoo, A. Nelson, C. Lee. New Brunswick: Rutgers University Press.
- SKIM: Moffat, Alistair. 2017. The Scots: A Genetic Journey. Birlinn. Intro & Chapter 10.
 - <u>Recommended:</u> *Hacking, Ian. 2006. "<u>Genetics, Biosocial Groups & the</u> <u>Future of Identity</u>." *Daedalus* 135(4):81–95.
 - *Fullwiley, Duana. 2007. "<u>The Molecularization of Race: Institutionalizing</u> <u>Human Difference in Pharmacogenetics Practice</u>." *Science as Culture* 16(1):1–30.
 - *Nelson, Alondra. 2008. "<u>Bio Science Genetic Genealogy Testing and the</u> <u>Pursuit of African Ancestry</u>." *Social Studies of Science* 38:759–83.
 - Anon. 2019. "<u>Scotland's Genetic Landscape Reflects Dark Age Populations</u>." BBC News, September 3.

Week 4: Genetic testing for risk, disease, and ancestry

Fieldtrip, Monday afternoon (time TBD): A visit to <u>The MRC Institute of Genetics and</u> <u>Molecular Medicine</u> (IGMM) at The University of Edinburgh—the point-of-origin of the XYY story from Week 3 and the leading center for clinical genomics in Scotland. (See IFSA itinerary.)

Tuesday: Prenatal genetic testing and newborn screening

- *Timmermans, Stefan and Mara Buchbinder. 2013. Saving Babies? The Consequences of Newborn Genetic Screening. Chicago: University of Chicago Press. Chapters 1-2.
- *Parens, Erik and Adrienne Asch. 2003. "<u>Disability Rights Critique of Prenatal</u> <u>Genetic Testing: Reflections and Recommendations</u>." *Mental Retardation and Developmental Disabilities Research Reviews* 9(1):40–47.
 - <u>Recommended</u>: *Lippman, Abby. 1991. "<u>Prenatal Genetic Testing and</u> <u>Screening: Constructing Needs and Reinforcing Inequities</u>." *American Journal* of Law & Medicine 17:15.
 - Knoppers, Bartha M., Karine Sénécal, Pascal Borry, and Denise Avard. 2014.
 <u>"Whole-Genome Sequencing in Newborn Screening Programs</u>." *Science translational medicine* 6(229):229cm2–229cm2.
 - Navon, Daniel. 2022. "<u>New Prenatal Genetic Screens Pose Underappreciated</u> <u>Ethical Dilemmas</u>." *Scientific American*.
 - Anon. n.d. "Scots Parents Fear New Down's Syndrome Testing Will Lead to More Abortions." Daily Record.
 - Devlin, Hannah. 2021. "<u>Scientists Raise Concerns over UK Baby Genome</u> <u>Sequencing Plan</u>." *The Guardian*, December 2.

Thursday: Clinical genomics, rare diseases, and direct-to-consumer testing

*A special hourlong guest lecture on clinical genomics from University of Edinburgh Professor Steve Sturdy

- Harmon, Amy. 2007. "After DNA Diagnosis: 'Hello, 16p11.2. Are You Just Like Me?" *The New York Times*, December 28.
- *Mnookin, Seth. 2014. "One of a Kind." The New Yorker, July 21.
- *Caulfield, Timothy and Amy McGuire. 2012. "<u>Direct-to-Consumer Genetic Testing:</u> <u>Perceptions, Problems, and Policy Responses</u>." *Annual Review of Medicine* 63(1):23–33.
- Green, Robert C., Denise Lautenbach, and Amy L. McGuire. 2015. "<u>GINA, Genetic</u> <u>Discrimination, and Genomic Medicine</u>." New England Journal of Medicine 372(5):397– 9.
 - <u>Recommended</u>: *Skomorowsky, Anne. 2016. "<u>The X-Factor in Infertility and</u> <u>Neurological Health</u>." *Scientific American*, March 1.
 - *Lindee, M. Susan. 2008. *Moments of Truth in Genetic Medicine*. The Johns Hopkins University Press. Chapter 6.
 - Hayden, Erika Check. 2008. "<u>Biological Tools Revamp Disease</u> <u>Classification</u>." *Nature* 453(7196):709.
 - Rochman, Bonnie. 2012. "<u>Why Cheaper Genetic Testing Could Cost Us a</u> <u>Fortune</u>." *Time*, October 26. Retrieved December 21, 2012.

Week 5: Our 'postgenomic' era and its many dilemmas

<u>Tuesday: The Human Genome Project, postgenomics, and thorny issues of ownership</u> *A special hourlong guest seminar on epigenetics and society from University of Edinburgh Professor Martyn Pickersgill

- *Rose, Hilary and Steven Rose. 2013. *Genes, Cells and Brains: The Promethean Promises of the New Biology*. Verso Books. Chapter 1.
- *Pickersgill, Martyn, Jörg Niewöhner, Ruth Müller, Paul Martin, and Sarah Cunningham-Burley. 2013. "<u>Mapping the New Molecular Landscape: Social</u> <u>Dimensions of Epigenetics</u>." *New Genetics and Society* 32(4):429–47.
- *Skloot, Rebecca. 2011. *The Immortal Life of Henrietta Lacks*. New York: Broadway Books. Excerpt.
- Liptak, Adam. 2013. "Justices, 9-0, Bar Patenting Human Genes." The New York Times, June 13.
 - o <u>Recommended</u>: "<u>Henrietta's Tumor</u>." Radiolab 2009.
 - Callaway, Ewen. 2013. "<u>Deal Done over HeLa Cell Line</u>." *Nature* 500(7461):132–33.
 - Collins, Francis S. 1999. "<u>Medical and Societal Consequences of the Human</u> <u>Genome Project</u>." New England Journal of Medicine 341(1):28–37.
 - Watters, Ethan. 2006. "DNA Is Not Destiny: The New Science of Epigenetics | DiscoverMagazine.com." *Discover Magazine*, November 22.

Fieldtrip, Wednesday 2:30pm: We will visit the National Museum of Scotland, and especially its <u>Science and Technology galleries</u>, where we will pay our respects to the stuffed remains of Polly the sheep—the first mammal ever cloned.

Thursday: New breakthroughs, new eugenics? Cloning, gene-editing, etc.

- *Franklin, Sarah. 2007. *Dolly Mixtures: The Remaking of Genealogy*. Durham: Duke University Press Books. Intro, and chapters 1 and 3.
- *Duster, Troy. 2003. Backdoor to Eugenics. Routledge. Chapter 7 and Afterword.
- Pollack, Robert. 2015. "Eugenics Lurk in the Shadow of CRISPR." Science 348(6237):871–871.
 - <u>Recommended:</u> Baltimore, David et al. 2015. "<u>A Prudent Path Forward for</u> <u>Genomic Engineering and Germline Gene Modification</u>." *Science* 348(6230):36–38.