

POLITICAL SCIENCE 429/626

Genetics and Justice

Course Instructor - Dr Colin Farrelly
(Hagey Hall: Room 306)
Office Hours: TBA

Course Description

Advances in biological knowledge bring us closer to a world where we may have the ability to manipulate our genetic make-up. With this ability comes new questions concerning demands of distributive justice. This course examines key developments in the field of human genetics, and demonstrates why and how current theories of justice may require revision in light of these changes. Issues addressed include insurance and privacy, the therapy/enhancement distinction, the morality of inclusion, future generations, reproductive freedom and gene patents. The course is designed to explore the different challenges society faces as a consequence of human genetic research.

Format: There will be one three-hour class per week that will consist of a series of discussions and student contributions through the term. The class will meet Mondays from 1:30- 4:20pm in **PHY 313**.

Assessment: Students will be required to attend and participate in class (**worth 20%**), give a seminar *powerpoint* presentation (approximately 10 minutes long - **worth 20%**), an in-class self-reflection test (**worth 20%**), and write a major research paper (approximately 3 000 words- **worth 40%**).

Required Textbook: Allen Buchanan, Dan Brock, Norman Daniels and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2002). Most of the other readings are taken from articles and reports that you can access online. Readings listed in **bold** indicate readings that are not available online. These readings will be placed in the photocopy room in the PSCI department (in the pigeon hole for PSCI 429). Please be sure to **promptly replace these articles** when you are done photocopying them.

Each week there is a list of required readings which will be the focus of the first part of class. In the second part of the class we shall focus on the seminar readings.

SCHEDULE:

Week 1 (Jan. 7th): Introduction

Organisational meeting and introduction to the course.

Week 2 (Jan. 14th): Genetic Intervention: Pros and Cons

Required Readings: *From Chance to Choice*, chapters 1 and 2

Seminar Readings: *From Chance to Choice*, Chapter 2 [on eugenics]

Tuija Takala “The Right to Genetic Ignorance Confirmed” *Bioethics*, 13(4), 1999, pp. 288-293.

Week 3 (Jan. 21st): Equal Opportunity

Required Readings: *From Chance to Choice*, chapter 3

Seminar Reading: Françoise Baylis; Jason Scott Robert, “The Inevitability of Genetic Enhancement Technologies” *Bioethics*, vol. 18(1), pp. 1-26.

Week 4 (Jan. 28th): Therapy/Enhancement Distinction

Required Readings: *From Chance to Choice*, chapter 4

Seminar Readings: David Resnick, “The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics”, *Cambridge Quarterly of Healthcare Ethics*, 9. 2000, pp. 365-77.

Robert Williamson and Ainsley Newson, “Should We Undertake Genetic Research on Intelligence” *Bioethics*, 13(3), 1999, pp. 327-42.

Week 5 (Feb. 4th): Insurance, Privacy and Discrimination

Required Readings: one of the seminar readings

Seminar Readings:

Madison Powers “Privacy and Genetics” *Companion to Genethics*, ch. 27
Michael Yesley “Genetic Difference in the Workplace” *Companion to Genethics* ch. 29
Tom Sorrell “The Insurance Market and Discriminatory Practices”, *Companion to Genethics* ch. 30.

Week 6 (Feb. 11th): Future Generations

Required Readings: *From Chance to Choice*, chapter 5

Seminar Readings: Elizabeth F. Cooke “Germ–line Engineering, Freedom, and Future Generations” *Bioethics*, 2003, 17(1), p. 32-58.
Seana Shiffrin “Wrongful Life, Procreative Responsibility, and the Significance of Harm” *Legal Theory* 5, 1999, pp. 117-48.

Week 7 (Feb. 18th): Reading Week

Week 8 (Feb. 25th): Reproductive Freedom

Required Readings: *From Chance to Choice*, chapter 6

Seminar Readings: Farhat Moazam “Feminist Discourse on Sex Screening and Selective Abortion of Female Foetuses” *Bioethics*, 18(3), 2004, pp. 205-21.

David McCarthy “Why Sex Selection Should be Legal” *Journal of Medical Ethics*, 27, 2001, pp. 302-07.

Week 9 (March 3rd): Reproductive Freedom (Part II)

Required Reading: [HFEA report on Sex Selection](#) [click link to access]

Seminar Readings: Rosalind McDougall, “Parental Virtue: A New Way of Thinking about the Morality of Reproductive Actions” *Bioethics*, Volume 21 Number 4 2007 pp 181–190.

Justine Burley, “The Price of Eggs: Who Should Bear the Costs of Fertility Treatments?” in *The Future of Human Reproduction* (eds. by Harris and Holm)

Week 10 (March 10th): The Morality of Inclusion

Required Readings: *From Chance to Choice*, chapter 7

Seminar Readings: Julian Savulescu “Procreative Beneficence: Why We Should Select the Best Children” *Bioethics* 2002, 15(5), pp. 413-26.

Edward Stein, “Choosing the Sexual Orientation of Children” *Bioethics*, 12(1), 1998, pp. 1-24.

Week 11 (March 17th): *Beyond Therapy* Report

Required Readings: Read any 2 chapters from President’s Council on Bioethics Report *Beyond Therapy* available at: <http://www.bioethics.gov/reports/beyondtherapy/index.html>

Seminar Readings:

Beyond Therapy report chapters 1 and 2

Beyond Therapy report chapters 3 and 4

Beyond Therapy report chapters 5 and 6

Week 12 (March 24th): Tackling Aging

Required Reading: Olshansky, S.J., Perry, D., Miller, R., Butler, R. 2006. “In Pursuit of the Longevity Dividend” *The Scientist* 20: 28-36. [available online for free at: http://www.edmontonagingsymposium.com/files/eas/Longevity_Dividend.pdf]

Seminar Readings: Nick Bostrom, “The Fable of the Dragon-Tyrant” *Journal of Medical Ethics*, Vol. 31(5), 2005, pp. 273-277.

Aubrey De Grey, “Life extension, Human Rights, and the Rational Refinement of Repugnance”. *Journal of Medical Ethics* 2005;31:659-663.

Week 13 (March 31st): Cloning and Stem Cells

In-class self-reflection test

Required readings: Matti Häyry “Philosophical Arguments for and Against Human Reproductive Cloning” *Bioethics*, 2003, 17(5), pp. 447-60.

Seminar Readings:

Julian Savulescu “The Embryonic Stem Cell Lottery and the Cannibalization of Human Beings” *Bioethics*, Vol. 16(6), 2002, pp. 508-29.

Week 14 (April 7th): Last class: Essays are due.

Overview of course and any outstanding seminar presentations.

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Essays: These should be approximately 3000 words long. You can write an essay on any of the issues covered in the course. Below is the mark sheet I use when assessing your papers. Essays are due April 7th. The late penalty is -2% per day, including weekends. Also, late papers only receive a grade, *no comments or feedback are given.*

Mark Sheet for Essays

Student Name/Number:	Course: PSCI 429/626 Genetics and Justice					
Essay title:						
Scale: 5 - excellent, 4 - good, 3 - satisfactory, 2 - poor, 1 - very poor						
*please note: the numbers above are merely guidelines and are not equivalent to numerical grades. Furthermore, some categories are weighted more heavily than others.						
	5	4	3	2	1	
Structure and organization						
Topic well defined						Topic poorly defined
Essay well structured						Essay badly structured
Quality of discussion and analysis						
Shows theoretical awareness						Shows no theoretical awareness
Conceptual clarity						Conceptual confusion
Logical and coherent						Illogical and incoherent
Analytical						Descriptive
Critical						Uncritical
Shows independent thought						Does not show independent thought
Literature review and sources						
Evidence of reading/research						No evidence of reading/research
Effective use of evidence/literature						Ineffective use of evidence/literature

Further Readings:

Useful books include:

John Harris and Justine Burley (eds), *A Companion to Genethics*
Justine Burley (ed), *The Genetic Revolution and Human Rights*
John Harris, *Clones, Genes and Immortality*
John Harris and Soren Holm (eds) *The Future of Human Reproduction*
David Held, *Genethics*
Walter Glannon, *Genes and Future People*
Philip Kitcher, *The Lives to Come*
John Harris, *Enhancing Evolution*
David Magnus, Arthur Caplan, Glenn McGee (eds), *Who Owns Life?*
Nussbaum and Sunstein (eds), *Clones and Clones : Facts and Fantasies about Human Cloning*

Articles: most of these can be accessed online

(key journals include *Bioethics*, *Journal of Medical Ethics*, *American Journal of Bioethics*, *Kennedy Institute of Ethics Journal* and *Cambridge Quarterly of Healthcare Ethics*)

Frances Kamm, "Is There a Problem with Enhancement?" *American Journal of Bioethics* 5(3): pp. 5-14 (and open peer commentaries).

Special Issue of *The Kennedy Institute of Ethics Journal* on "Genetic Enhancement", Vol. Vol. 15(1), 2005.

Martin Borrow and Sandy Thomas "Patents in a Genetic Age" *Nature*, 409, 2001, pp. 763 – 764.

Robert Williamson and Ainsley Newson, "Should We Undertake Genetic Research on Intelligence" *Bioethics*, 13(3), 1999, pp. 327-42.

Walter Glannon "Genes, Embryos and Future People" *Bioethics*, 12(3), 1999, pp. 187-211.

Philip Kitcher "Creating Perfect People" in *Companion to Genethics*, chapter 17.

Julian Savulescu "Is there a "right not to be born": Reproductive decision making, options and the right to information" (editorial) *Journal of Medical Ethics*, 28, 2002, pp. 65-67.

Edward Stein, "Choosing the Sexual Orientation of Children" *Bioethics*, 12(1), 1998, pp. 1-24.

John Robertson, "Preconception Gender Selection" *American Journal of Bioethics*, Vol. 1(1),

pp. 2-9 (and open peer commentaries as well).

C.L. Ten “The Use of Reproductive Technologies in Selecting the Sexual Orientation, the Race, and the Sex of Children” *Bioethics*, 12(1), 1999, pp. 45-48

Ruha Raikka “Freedom and a Right (Not) to Know” *Bioethics* 12(1), pp. 49-63.

Michael Reiss “The Ethics of Genetic Research of Intelligence” *Bioethics* 14(1), pp. 1-15.

Stephen Robertson and Julian Savelescu “Is There a Case in Favour of Predictive Genetic Testing in Young Children” *Bioethics*, 2001, 15(1), pp. 26-49

Hudson J. “What kinds of people should we create?” *Journal of Applied Philosophy* 2000; 17(2):131-43.

Colin Farrelly, “The Genetic Difference Principle” *American Journal of Bioethics*, Vol. 4(2), 2004, W21-28.

Farrelly, “Genes and Equality”, *Journal of Medical Ethics* 30, 2004, pp. 587-92.

Lori d'Agincourt-Canning “Experiences of Genetic Risk: Disclosure and the Gendering of Responsibility” *Bioethics*, 2001, 15(3), pp. 231-47.

Julian Savulescu “Procreative Beneficence: Why We Should Select the Best Children” *Bioethics* 2002, 15(5), pp. 413-26.

Inmaculada de Melo-Martín ” On Cloning Human Beings” *Bioethics*, 2002, 16(3), pp. 246-265.

Walter Glannon “Identity, Prudential Concern, and Extended Lives” *Bioethics*, 2002, 16(3), pp. 266-83.

David McCarthy “Why Sex Selection Should be Legal” *Journal of Medical Ethics*, 27, 2001, pp. 302-07.

John Robertson “Extending PGD: Medical and NonMedical Uses” *Journal of Medical Ethics*, 29, 2003, pp. 213-16.

John Harris, “Sex Selection and Regulated Hatred” *Journal of Medical Ethics*, 31, 2005, pp. 291-94.

Matthew Liao, “The Ethics of Using Genetic Engineering for Sex Selection” *Journal of Medical Ethics*, 31, 2005; 31: 116 - 118.

Ludvig Beckman “Genetic Privacy from Locke’s Point of View” *The Journal of Value Inquiry*, 38, 2004, pp. 241-251

John Harris “A Response to Walter Glannon “ *Bioethics*, 2002, 16(3), pp. 284-91.

Walter Glannon “A Reply to Harris” *Bioethics*, 2002, 16(3), pp. 292-97.

Elizabeth F. Cooke “Germ–line Engineering, Freedom, and Future Generations” *Bioethics*, 2003, 17(1), p. 32-58.

Matti Häyry “Philosophical Arguments for and Against Human Reproductive Cloning” *Bioethics*, 2003, 17(5), pp. 447-60.

Michael Heller and Rebecca Eisenberg, “Can Patents Deter Innovation? The Anticommons in Biomedical Research”, *Science*, vol. 280, 1 May, 1998, pp. 698- 701

Adam Moore, “Owning Genetic Information and Gene Enhancement Techniques: Why Privacy and Property Rights May Undermine the Social Control of the Human Genome”, *Bioethics*, vol. 14, no. 2, (April 2000)

Colin Farrelly “Genes and Social Justice: A Rawlsian Reply to Moore”, *Bioethics* 16(1), 2002, pp. 72-83.

Françoise Baylis and Jason Scott Robert, “The Inevitability of Genetic Enhancement Technologies”, *Bioethics*, 2004, 18(1), pp. 1-26.

Inmaculada de Melo-Martín “On Our Obligation to Select the Best Children: A Reply to Savulescu” *Bioethics*, 2004, 18(1), pp. 72-83.

Farhat Moazam “Feminist Discourse on Sex Screening and Selective Abortion of Female Foetuses” *Bioethics*, 2004, 18(3), p. 205-220.

Robert Elliot “Genetic Therapy, Person-regarding Reasons and the Determination of Identity” *Bioethics*, 1997, 11(2), pp. 151-60.

Ingmar Persson “Genetic Therapy, Person-regarding Reasons and the Determination of Identity- A Reply to Robert Elliot” *Bioethics*, 1997, 11(2), pp. 161-69.

Rebecca S. Eisenberg, “How Can You Patent Genes?” *American Journal of Bioethics*, Summer 2002.

David Resnick, “The Morality of Human Gene Patents” *Kennedy Institute Journal of Ethics*, Vol. 7(1), 1997, pp. 43-61.

Mary Briody Mahowald, “Self-Preservation: An Argument for Therapeutic Cloning, and a Strategy for Fostering Respect for Moral Integrity” *American Journal of Bioethics*, vol. 4(2), 2004.

J.W. Gordon “Genetic Enhancement in Humans” *Science*, 1999, 283, p. 2023-24.

H. Hayry, “How to Assess the Consequences of Genetic Engineering” In *Ethics and Biotechnology*. Edited by A. Dyson and John Harris. Pp. 144-156

J. Harris “Intimations of Immortality” *Science*, 2000, 288, p. 59

Rosamond Rhodes , “Genetic Links, Family Ties, and Social Bonds: Rights and

Responsibilities in the Face of Genetic Knowledge” *Journal of Medicine and Philosophy*, vol. 23 (1), 1998

Hudson J. “What kinds of people should we create?” *Journal of Applied Philosophy* 2000; 17(2):131-43.

John Harris “Scientific Research is a Moral Duty” *Journal of Medical Ethics* 31, 2005: 242-248.

Arthur Caplan “Death as an unnatural process” *European Molecular Biology Organization, EMBO Reports*, vol. 6, special issues, 2005, S72-S75.

Nick Bostrom, “The Fable of the Dragon-Tyrant” *Journal of Medical Ethics*, Vol. 31(5), 2005, pp. 273-277.

Nick Bostrom, "In Defence of Posthuman Dignity," *Bioethics*, Vol. 19, No. 3, 2005, pp. 202-214.

Nick Bostrom, “Human Genetic Enhancements: A Transhumanist Perspective” *Journal of Value Inquiry*, Vol. 37, No. 4, 2003, pp. 493-506.

Lachs J. “Grand dreams of perfect people” *Cambridge Quarterly of Healthcare Ethics* 2000; 9(3):323-9.

John Robertson “Extending Preimplantation Genetic Diagnosis: the Ethical Debate” *Human Reproduction* Vol. 18(3), 2003, pp. 465-71.

Lagay FL. “Science, rhetoric, and public discourse in genetic research” *Cambridge Quarterly of Healthcare Ethics* 1999; 8(2):226-37.

Mehlman MJ, Rabe KM. “Any DNA to declare? Regulating offshore access to genetic Enhancement” *American Journal of Law and Medicine* 2002; 28(2-3):179-213.

Newell C. “The social nature of disability, disease and genetics: a response to Gillam, Persson, Holtug, Draper and Chadwick”. *Journal of Medical Ethics* 1999; 25 (2):172-5.

Perils in free market genomics. *Nature* 1998; 392(6674):315.

Tuija Takala “The Right to Genetic Ignorance Confirmed” *Bioethics*, 13(4), 1999, pp. 288-293.

Richter G, Bacchetta MD. “Interventions in the human genome: some moral and ethical considerations”. *Journal of Medicine and Philosophy* 1998; 23(3):303-17.

Sara Boering “Gene Therapies and the Pursuit of a Better Human” *Cambridge Quarterly of Healthcare Ethics* 9, 2000, pp. 330-341.

Michael Sandel, "The Case Against Perfection" (available online at http://www.catholiceducation.org/articles/medical_ethics/me0056.html)

Peter Wenz "Engineering Genetic Injustice" *Bioethics* 19(1), 2005, pp. 1-11.

Scully JL. "Drawing a line: situating moral boundaries in genetic medicine". *Bioethics* 2001; 15(3):189-204.

Whole issue of *Bioethics*, vol. 16(6) 2002 on Stem Cell Research

Whole issue of *Bioethics* August 2004 on Pharmacogenomics

Useful Internet Sources:

[HFEA report on Sex Selection](#)

Human Genome Project Information: Ethical, Legal and Social Issues- http://www.ornl.gov/TechResources/Human_Genome/elsi/elsi.html

Universal Declaration on the Human Genome and Human Rights
<http://www.nus.edu.sg/irb/Articles/IBC-Universal%20Declaration%20on%20the%20Human%20Genome.pdf>

President's Council on Bioethics:

Report on Beyond Therapy: <http://www.bioethics.gov/reports/beyondtherapy/index.html>

Report on Cloning: <http://www.bioethics.gov/reports/cloningreport/index.html>

Report on Stem Cell Research: <http://www.bioethics.gov/reports/stemcell/index.html>

Nuffield Council on Bioethics:

http://www.nuffieldbioethics.org/filelibrary/pdf/g&hb_summary.pdf

[report on genetics and human behaviour]

http://www.nuffieldbioethics.org/filelibrary/pdf/genetic_screening.pdf

[report on genetic screening]

<http://www.nuffieldbioethics.org/filelibrary/pdf/theethicsofpatentingdna.pdf>
[report on DNA patenting]

http://www.nuffieldbioethics.org/filelibrary/doc/stem_cell_therapy2.doc
[discussion paper on stem cell therapy]

Wellcome Trust: The Human Genome- <http://www.wellcome.ac.uk/en/genome/>

National Human Genome Research Institute: Genetic Discrimination or Employment- <http://www.genome.gov/11510227>

****[very helpful] A Multimedia Guide to Genetic Disorders is available on the web at:** <http://www.yourgenesyourhealth.org/>

Myriad Genetic Laboratories: <http://www.myriad.com/med/index.htm>

CNN: Blueprint of the Body: On the Threshold of a brave new world: <http://edition.cnn.com/SPECIALS/2000/genome/story/overview/>

John Harris “Immortal Ethics” (audio clip):
<http://www.gen.cam.ac.uk/iabg10/ppts/Harris.mp3>

Bioethical Debate: audio clip of Arthur Caplan and Julian Savulescu discussing the ethics of using science to improve humans:
<http://wnyc.com/shows/lopate/episodes/11182004>

Please Note:

“Note on avoidance of academic offenses: All students registered in the courses of the Faculty of Arts are expected to know what constitutes an academic offense, to avoid committing academic offenses, and to take responsibility for their academic actions. When the commission of an offense is established, disciplinary penalties will be imposed in accord with Policy #71 (Student Academic Discipline). For information on categories of offenses and types of penalties, students are directed to consult the summary of Policy #71 which is supplied in the Undergraduate Calendar (section 1; on the Web at http://www.adm.uwaterloo.ca/infoucal/UW/policy_71.html). If you need help in learning how to avoid offenses such as plagiarism, cheating, and double submission, or if you need clarification of aspects of the discipline policy, ask your course instructor for guidance. Other resources regarding the discipline policy are your academic advisor and the Undergraduate Associate Dean.”