

POLITICAL STUDIES 402/857

Science and Justice

Course Instructor - Dr Colin Farrelly

(Mackintosh-Corry Hall, Room C405)

Office Hours: Tuesdays 9-11am

Course Description

Advances in biological knowledge bring us closer to a world where we may have the ability to directly manipulate our genetic make-up. With this ability comes new questions concerning the demands of distributive justice. This course examines key developments in biology (especially human genetics), and demonstrates why and how theories of justice may require revision in light of these changes. Issues addressed include insurance and privacy, the therapy/enhancement distinction, aging, the morality of inclusion, future generations, and reproductive freedom. The course is designed to explore the different challenges society faces as a consequence of the genetic revolution and to help equip students with the critical and analytical skills needed to think rationally and cogently about the regulation of new biomedical technologies.

Format: There will be one three-hour class per week that will consist of a series of discussions and student contributions throughout the term. The class takes place Tuesdays 11:30-2:30 in **M-C-B313**.

Assessment: For undergraduate students: Students will be required to attend and participate in class (**worth 20%**), give a seminar *powerpoint* presentation (15 minutes max. - **worth 20%**), an in-class self-reflection test (**worth 20%**; which takes place on March 29th), and write a major research paper (approximately 3000 words- **worth 40%**) due in the last class.

For graduate students: a seminar *powerpoint* presentation (15 minutes max. - **worth 20%**); an in-class self-reflection test (**worth 20%**; which takes place on March 29th), and write a major research paper (4000-5000 words- **worth 60%**) due in the last class.

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.

Each week there is a list of **required readings** which will be the focus of the first part of class. All students are expected to have at least read these readings each week. In the second part of the class we shall focus on the seminar readings which will be the subject of the presentations. All of the seminar readings can be accessed via the University library, so please make every effort to learn how to search for the articles on the library system.

SCHEDULE:

Week 1 (January 11th): Introduction

Organisational meeting and introduction to the course.

Week 2 (January 18th): Genetic Intervention: Pros and Cons

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

Seminar Reading: Tuija Takala "The Right to Genetic Ignorance Confirmed" *Bioethics*, 13(4), 1999, pp. 288-293.

Week 3 (January 25th): Equal Opportunity

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

Seminar Reading: James Flory and Philip Kitcher, "Global Health and the Scientific Research Agenda" *Philosophy and Public Affairs*, 32(1), 2004.

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

Week 4 (Feb.1st): 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. 8th): Aging and Life Extension

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 6 (Feb. 15th): Privacy, Insurance and Discrimination

Required Readings: John R. Alford and John Hibbing "The Origin of Politics: An Evolutionary Theory of Political Behavior" *Perspectives on Politics* (2004), 2 : 707-723.

Seminar Readings: Eli Feiring, "Reassessing Insurers' Access to Genetic Information: Genetic Privacy, Ignorance and Injustice" *Bioethics*, April 2008.

Paul W. Brandt-Rauf and Sherry I. Brandt-Rauf "Genetic Testing in the Workplace: Ethical, Legal, and Social Implications", *Annual Review of Public Health*, April 2004, Vol. 25: 139-153.

Week 7 (Feb. 22nd): Reading Week

Week 8 (March 1st): 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 9 (March 8th): 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.

Rosalind McDougall, "Parental Virtue: A New Way of Thinking about the Morality of Reproductive Actions" *Bioethics*, Volume 21 Number 4 2007 pp 181-190.

Week 10 (March 15th): 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 22nd) *Beyond Therapy* Report

Required Readings: Read any 2 chapters from President’s Council on Bioethics Report *Beyond Therapy* available at: <http://bioethics.georgetown.edu/pcbe/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 29th): Embryos and Human Cloning

In-class self-reflection test (2 hours)

Required Readings: Toby Ord “The Scourge: Moral Implications of Natural Embryo Loss” *The American Journal of Bioethics*, Volume 8(7) July 2008 , pages 12 – 19.

Seminar Readings: President’s Council on Bioethics Report *Human Cloning and Human Dignity* available at: <http://bioethics.georgetown.edu/pcbe/reports/cloningreport/>

Chapters 5-6

Chapters 7-8

Week 13 (April 4th): Last class: Essays are due.

Overview of course and any outstanding seminar presentations.

Essays: 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 4th. The late penalty is -2% per day, including weekends. Also, late papers only receive a grade, *no comments or feedback are given*. Extensions are only granted in cases where there is a medical reason and the extension must be granted by me before the deadline (under no circumstances will extensions be granted after the deadline).

Mark Sheet for Essays

Student Name/Number:	Course:					
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:

(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

Tuha 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 Savulescu "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.

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)

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

Colin Farrelly, "Global Aging, Well-Ordered Science and Prospection" *Rejuvenation Research* October 2010.

----- "Equality and the Duty to Retard Human Aging" *Bioethics* October, 2010.

----- "Why Aging Research?" *Annals of the New York Academy of Sciences* 1197 (2010): 1-8.

----- "Framing the Inborn Aging Process and Longevity Science" *Biogerontology* 11(3) (2010): 377-85.

----- "Preimplantation Genetic Diagnosis, Reproductive Freedom, and Deliberative Democracy" *Journal of Medicine and Philosophy*, 34(2) (2009):135-154.

----- "Towards a More Inclusive Vision of the Medical Sciences" *QJM: An International Journal of Medicine*, 102 (2009): 579-582.

----- "Genetic Justice Must Track Genetic Complexity" *Cambridge Quarterly of Healthcare Ethics*, Vol. 17(1) (2008): 45-53.

----- "Aging Research, Priorities and Aggregation" *Public Health Ethics*, Vol. 1(3) (2008): 258-67.

----- "Has the Time Come to Take on Time Itself?" *British Medical Journal*, Vol. 337 (2008): 147-48.

----- "Gene Patents and Justice" *Journal of Value Inquiry*, Vol. 41 (2-4) (2007): 147-163.

----- "Sufficiency, Justice and the Pursuit of Health- Extension" *Rejuvenation Research* Vol. 10(4), (2007): 513-20.

----- "The Genetic Difference Principle" *American Journal of Bioethics*, Vol. 4(2) (2004): W21-28.

----- "Genes and Social Justice: A Rawlsian Reply to Moore" *Bioethics* 16(1) (2002): 72-83.

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://bioethics.georgetown.edu/pcbe/reports/beyondtherapy/index.html>

Report on Cloning: <http://bioethics.georgetown.edu/pcbe/reports/cloningreport/index.html>

Report on Stem Cell Research: <http://bioethics.georgetown.edu/pcbe/reports/stemcell/index.html>

Synthetic Biology: <http://www.bioethics.gov/documents/synthetic-biology/PCSBI-Synthetic-Biology-Report-12.16.10.pdf>

Nuffield Council on Bioethics:

<http://www.nuffieldbioethics.org/sites/default/files/Genetics%20and%20human%20behaviour.pdf>

[report on genetics and human behaviour]

<http://www.nuffieldbioethics.org/genetic-screening> [report on genetic screening]

<http://www.nuffieldbioethics.org/patenting-dna> [report on DNA patenting]

<http://www.nuffieldbioethics.org/stem-cells> [discussion paper on stem cell therapy]

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

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/>

[“Should we accept performance-enhancing drugs in competitive sports?”](#)

Moderator: Bob Costas

Students are advised that incomplete standing will be granted only with the permission of the chair of undergraduate or graduate studies (as appropriate) and only where there is a clear demonstration of need. Applications for "Incomplete" standing must be made in the first instance to the instructor on the form available in the General Office. The simple fact of nonsubmission of work does not constitute an application and will result in a grade of zero for that assignment.

Students who feel that there are reasons to have their grades reviewed should follow the steps set out in the Faculty of Arts and Science's Regulation 13, "Review of Grades and Examinations."

Academic Integrity : *Academic integrity is constituted by the five core fundamental values of honesty, trust, fairness, respect and responsibility (as articulated by the Centre for Academic Integrity, Duke University; see www.academicintegrity.org) all of which are central to the building, nurturing and sustaining of an academic community in which all members of the community will thrive. Adherence to the values expressed through academic integrity forms a foundation for the "freedom of inquiry and exchange of ideas" essential to the intellectual life of the University. Queen's students, faculty, administrators and staff therefore all have ethical responsibilities for supporting and upholding the fundamental values of academic integrity. See <http://www.queensu.ca/secretariat/senate/policies/AcadInteg.html>. The Arts and Science Undergraduate Society (ASUS) provides important academic resources at www.queensasus.com*

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