CENTRAL EUROPEAN UNIVERSITY DEPARTMENT OF POLITICAL SCIENCE MA PROGRAM

Fall Semester, 2017–2018

HUMAN RIGHTS AND EMERGING TECHNOLOGIES (CROSS-LISTED WITH GENDER STUDIES) 4 credits

Prof. Judit Sándor

Classes Meet: Mondays- Wednesdays 13:30–15:10

Office Hours: Tuesdays-Thursdays 14:00–16:00 Vigyázó F. u. 2. 205.

Location: N15/202

Course Description

At the beginning of the 21st century the emerging new technologies have become inherently political. Neuroscience, genetics (genetic testing, screening, and DNA fingerprinting), the various assisted reproductive technologies, nanotechnology, robotics, information technologies, and their combination now constitute subjects of governance. Furthermore, as these technologies are increasingly used by governments, it has become difficult to scrutinize or control them, to limit their use or to apply equal access to them. In this process of scrutiny a human rights approach may provide some guidance. Human rights have developed an established set of norms, a specific language, an institutional network and infrastructure for thinking about new technologies, their relevance, or the potential challenges posed by their application. Another benefit of this approach is to provide an alternative to the prevailing economic and technocratic model of innovation.

This course deals with the status of, and current challenges to, human rights in this context. By analyzing relevant texts and landmark cases, new generations of human rights will be explored. Is it possible to interpret human rights norms on the level of the human cells? Should access to transplantation, tissues in biobanks, umbilical cord blood, or the results of stem cell research be based on principle of solidarity? Or do we have to acknowledge that we are inevitably drifting towards a more commercial paradigm? The course will focus on recently emerged new technologies and their implications in the domain of human rights, such as right to privacy, international, national and personal security and DNA testing. The main methodology of this course is qualitative analysis of normative texts and cases that contain elements from both the human rights and public policy.

Uses and effects of biotechnological advances by now have become the subject of intense debates in society. Yet, the policy impacts of life sciences have remained so far understudied or at least not adequately elaborated – even though issues such as reproduction and gender; the new and emergent forms of discrimination; intellectual property and benefit sharing; and the protection of vulnerable groups, would provide a broad scope of study in this area. During the course the students will analyze normative texts and cases that contain elements from both the human rights and new technologies. The Reader and the attached bibliography shall provide the basic literature for further studies.

Goals of the course

In order to achieve this end, the main goals of this course are:

- to examine various forms of new technologies and related policies as challenges to human rights;
- to encourage critical analytical thinking about the role of human rights in shaping and restricting and applying new technologies and science; and
- to analyze various examples and case studies on science and technology and their impact on human rights.

Learning outcomes by the course

- Skills to analyze and to understand human rights problems raised by new challenges of technological advances;
- Capability to find, to analyze and to interpret cases, including their relevance in the political context; and
- Familiarity with basic human rights and to understand their role in the international politics.

Course requirements

Students are required to participate in the discussion of the social and legal issues implicated in the cases and in the literature. Reading assignments and the schedule of the course are enclosed in the detailed syllabus. Course requirements include attendance at lectures and seminars.

Evaluation: active participation in seminar discussion, based on the required readings and seminar presentations (30% of the final grade), and a final essay – a 10 to 12-page research paper on a topic to be chosen after consultation with the instructor (70% of the grade). The paper is due on December 18 of 2017. The topic of the final essay should relate to the themes and concepts of the course and the title should be approved on the basis of a written proposal to be submitted at midterm.

Basic materials for this course:

Roger Brownsword, Morag Goodwin (2012) *Law and the technologies of the Twenty-First Century* Cambridge. Cambridge University Press

Jasanoff, Sheila (2011) *Reframing Rights: Bio-Constitutionalism in the Genetic Age*. Cambridge, MA: MIT Press.

Francioni, Francesco (2007) *Biotechnologies and International Human Rights*. Oxford and Portland, OR: Hart Publishing.

Rose, Nikolas (2007) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century.* Princeton: Princeton University Press.

Schedule

Week Zero September 11, 2017

Introduction: Basic Concepts in the Field of Contemporary Human Rights

Historical and philosophical origins of human rights; emergence of the modern state, the place of the individual therein; and the role of international law in delineating the relationship between the individual and the state. Ratification and implementation of treaties; the successive 'generations' of human rights and the creation of new human rights. The difference between civil rights and human rights, natural and positive rights.

Required:

Sheila Jasanoff (2016) The Ethics of Invention New York. W.W. Norton Company 1-31

Recommended:

Roger Brownsword, Morag Goodwin (2012) Law and the Technologies of the Twenty-First Century (Law in Context) Cambridge. Cambridge University Press 169-224

Week One September 18–20, 2017

Technology, Science, and the Notion of Human Dignity

In our biologized culture not only medical conditions but also personalities, capacities, and identities in general may appear to be explicable in biological terms. Politicians and law making bodies have proposed and enacted laws to limit some of the applications that can be seen as a violation of human rights.

Required:

Rose, Nikolas (2007) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century.* Princeton: Princeton University Press, 41–76.

September 20, 2017 **Legal Concept of Human Dignity**

Required:

Aharon Barak (2015) Human Dignity Cambridge. Cambridge University Press 3-33

Recommended:

Lemke, Thomas (2011) *Biopolitics: An Advanced Introduction*. New York: New York University Press. 9-32

Week Two September 25, 2017

Anti-Discrimination and Its Implications in Science Eugenics

Eugenics refers to the field of study that aims to improve the human race through genetic means. The word 'eugenics' comes from a Greek word that means 'wellborn'. Supporters of eugenics seek to change the human race through negative or positive artificial selection, such as the controlled breeding of people who have certain physical characteristics or mental abilities.

Required:

Duster, Troy (2003) *Backdoor to Eugenics*. New York: Routledge, 60–79. *Recommended:*

Stern, Alexandra Minna (2005) *Eugenic Nation*. Berkeley: University of California Press, 82–114.

September 27 Contemporary Genetics and Discrimination

Required:

Agamben, Giorgio (1995) Biopolitics and the Rights of Man. In *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford University Press, 126–159.

Myles W. Jackson (2015) The Genealogy of a Gene Cambridge. The MIT Press. 143-187.

Recommended:

Wailoo, Keith and Stephen Pemberton (2006) *The Troubled Dream of Genetic Medicine*. Baltimore: Johns Hopkins University Press.

Cases:

Buck v. Bell

A. S. v. Hungary (4/2004)

Week Three October 2–4, 2017

Freedom of Science and Privacy in Research

October 2, 2017 **Freedom of Scientific Research**

Required:

Santosuosso, Amadeo, Valentina Sellaroli, and Elisabetta Fabio (2007) What Constitutional Protection for Freedom of Scientific Research? *Journal of Medical Ethics*, vol. 33, no. 6 (June 2007), pp. 342–344. http://www.jstor.org/stable/27719875

Beiner, Ronald (2010) Three Versions of the Politics of Conscience: Hobbes, Spinoza, Locke. San Diego Law Review, vol. 47, no. 4. (Fall 2010), 1107–1124.

Recommended:

Cohen, Eric (2006) The Permanent Limits of Modern Science: From Birth to Death. *Social Research*, vol. 73, no. 2 (Summer 2006), 785–804.

Cases:

Mouvement Raëlien v. Switzerland [2012] ECtHR (Application no. 16354/06)

October 4, 2017 **Right to Privacy**

Right to privacy has numerous challenges due to the new technologies, such as DNA sampling, genetic testing, drones, and various forms of surveillance technology. Unmanned aircrafts have been known by many names, including drones, remotely piloted aircrafts (RPAs), or unmanned aircraft vehicles (UAVs). Technology associated with drones is developing at a rapid and unrelenting pace. On the heels of such progress, law-makers are still attempting craft appropriate legislation in response to the many concerns citizens possess regarding privacy and safety.

Levy, Joshua S. (2011) Towards a Brighter Fourth Amendment: Privacy and Technological Change. *Virginia Journal of Law & Technology*, vol. 16, no.4 (Winter 2011), 499–540.

Week Four October 9, 2017 Privacy and Secret Surveillance

Neil M. Richards (2013) Privacy and technology: The Dangers of Surveillance. Harvard Law Review, 126 Harv. L. Rev. 1934

October 11, 2017 **Security, Privacy and Drones**

Schlag, Chris (2013) The New Privacy Battle: How the Expanding Use of Drones Continues to Erode Our Concept of Privacy and Privacy Rights. *Pittsburgh Journal of Technology, Law, and Policy*, vol. 13, no.2 (Spring 2013), 1–22.

Steve Ragatzki (2017) Filling in the Gaps in FAA Drone Regulation: A Proposed Dual-Zone Model Personal Privacy 25 Mich. St. J. Int'l L. 193

Recommended:

Wittes, Benjamin and Gabriella Blum (2015) *The Future of Violence: Robots and Germs, Hackers and Drones. Confronting a New Age of Threat.* New York: Basic Books, 93–122.

Week Five October 16–18, 2017 Boundaries to Life and Reproductive Freedoms

Required:

Rothschild, Joan (2005) *The Dream of the Perfect Child*. Bloomington: Indiana University Press, 13–68.

Habermas, Jürgen (2003) The Future of Human Nature. Cambridge: Polity Press, 44–66.

Recommended:

Styhre, Alexander and Rebecka Arman (2013) *Reproductive Medicine and the Life Sciences in the Contemporary Economy*. London and Burlington: Ashgate.

Sheena Meredith (2005) *Pregnant Women and the Law.* Aldershot: Ashgate, 5–37.

Cases:

Tysiąc v. Poland [2007] ECtHR (Application no. 5410/03)

October 18, 2017 **Reproductive Technologies and Human Rights**

Inhorn, Marcia C. (2007) Reproductive Disruptions and Assisted Reproductive Technologies in the Muslim World. In Marcia C. Inhorn, ed. *Reproductive Disruptions Gender, Technology and Biopolitics in the New Millennium*. New York: Berghahn Books, 183–199.

Cases: Mennesson v. France (Application no. 65192/11), Parrillo v. Italy (Application no. 46470/11)

Week Six October 23–25, 2017

October 23, 2017 **Right to Life and End of Life**

Required:

Shahaduz Zaman Hamilton Inbadas, Alexander Whitelaw, David Clark (2017) Common or multiple futures for end of life care around the world? Ideas from the waiting room of history in: Social Science & Medicine 172 (2017)72-79

Agamben, Giorgio (1995) Potentiality and Law. In *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford University Press, 39–48.

October 25, 2017 **Right to Life (Legal Cases)**

Sándor, Judit (2012) Bioethics and Basic Rights: Persons, Humans, and the Boundaries of Life. In Michel Rosenfeld and András Sajó, eds. *The Oxford Handbook of Comparative Constitutional Law*. Oxford: Oxford University Press, 1142–1165.

Case of Lambert and Others v. France (Application no. 46043/14) *Vo v. France* [2004] ECtHR (Application no. 53924/00) Gross v. Switzerland ECtHR (Application no. 67810/10)

Week Seven
October 30- November 1, 2017

Genetics and Human Rights

To what extent ethic of autonomy and equality can be used to explain what is wrong with eugenics? In the age of genomics the use of the word 'eugenics' reappears not only among critics but also among those who defend human enhancement. Is liberal eugenics defensible?

The analysis of the mandated genetic screening on Cyprus poses the questions of whether compulsory genetic screening is in harmony with human rights.

Required:

Buchanan, Allan, Dan W. Brock, Norman Daniels, and Daniel Wikler (2000) *From Chance to Choice*. Cambridge: Cambridge University Press, 61–82.

Duster, Troy (2003) The Genetic Screening of "Target" Populations. In *Backdoor to Eugenics*. New York: Routledge, 39–59.

Laurie, Graeme (2002) Genetic Privacy. Cambridge: Cambridge University Press, 86–182.

Further Readings:

Wailoo, Keith and Stephen Pemberton (2006) *The Troubled Dream of Genetic Medicine* Baltimore: John Hopkins University Press, 116–161.

Cases:

S. and Marper v. The United Kingdom [2008] ECtHR (Application nos. 30562/04 and 30566/04) R.R. v. Poland [2011] ECtHR (Application no. 27617/04)

Week Eight November 6–8, 2017

Access to health Care and New Technologies. Prohibition of Financial Gain, Privacy

November 6 **Allocation of Organs**

Required:

Lock, Margaret (2002) The Social Life of Human Organs. In *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press, 315–341.

Dyer, Phil and Shelagh McGuinnes (2011) *The Allocation of Organs: The Need for Fairness and Transparency.* In Anne-Maree Farrell, David Price, Muireann Quigley, eds. *Organ Shortage Ethics, Law and Pragmatism.* Cambridge: Cambridge University Press, 122–138.

November 8 Access to Health

Required:

Murphy, Thérèse (2013) *Health and Human Rights*. Oxford and Portland, OR: Hart Publishing, 23–57.

Recommended:

Kaushik, Sunder Rajan (2006) *Biocapital: The Constitution of Postgenomic Life* (Promise and Fetish Genomic Facts and Personalized Medicine, or Life Is a Business Plan). Durham: Duke University Press, 138–181.

Week Nine November 13–15, 2017

Gender Based Discrimination and Commodification

Should women's rights be created as a separate category? Can women's rights be separate from cultural constraints? Should formal equality be the goal of women's lobbying for rights protection? The Bejing Conference – Outcome and achievements

Required:

Roberts, Dorothy E. (1996) Reconstructing the Patient: Starting with Women of Color. In Susan M. Wolf, ed., *Feminism and Bioethics*. Oxford and New York: Oxford University Press, 116–144.

Anne Fausto-Sterling (2012) Sex/Gender Biology in a Social World (Chapter 3. Of Molecules and Sex) New York. Routledge pp. 12-27

Recommended:

Inhorn, Marcia C. and Frank van Balen, eds. (2002) *Infertility Around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Berkeley: University of California Press.

November 15, 2017 Commodification

J. Brad Reich & Dawn Swink (2011) Outsourcing Human reproduction: Embryos & Surrogacy Services in the Cyberprocreation Era: in: Journal of Health Care Law & Policy 14 J. Health Care L. & Pol'y 241

Siddharth, Kara (2009) *Sex Trafficking: Inside the Business of Modern Slavery*. New York: Columbia University Press, 108-128.

Week Ten November 20–22, 2017

Governance, Ethics and Biopolitics

"In the context of biotechnology, globalization adds further complexity to policy-making in an area that is already clouded by moral ambiguity, regulatory uncertainty, and rapid scientific advance. Globalization forces, such as the rapid dissemination of scientific knowledge and the international nature of the biotechnology industry, suggest that the world community should, as much as possible, coordinate regulatory policy. Without such coordination, there is likely to be a degree of corporate forum-shopping and we will be unable to respond rapidly to emerging intellectual property issues or broader ethical, social, and legal concerns." *Timothy Caulfield*

November 20, 2017 **Biobanks**

Required:

Gottweis, Herbert and Alan Petersen (2008) *Biobanks: Governance in Comparative Perspectives*. London: Routledge, 22–39.

Rose, Nikolas (2007) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century.* Princeton: Princeton University Press, 9–40.

November 22, 2017 **Technological Innovation and Intellectual property**

Required:

Dutfield, Graham (2003) *Intellectual Property Rights and the Life Science Industries: A Twentieth Century* History. Ashgate: Aldershot, 135–173.

Recommended:

Jasanoff, Sheila, ed. (2004) *States of Knowledge*. The Co-Production of Science and Social Order. New York: Routledge, 1–46.

Etzkowitz, Henry (2008) *The Triple Helix*. New York: Routledge 7–27.

Week Eleven November 27, 2017

Human Rights and Human Enhancement, Neuro-enhancement

Autonomy and Freedom of Science

What is the difference between the correction of a physical or mental impairment, on one hand, and enhancement, on the other? How should law react to the new technological possibilities for enhancement? Can enhancement challenge the notion of equality, equal opportunity, disability?

Required:

Erdman, Joanna N. (2015) Bioethics, Human Rights and Childbirth. *Health and Human Rights*, vol. 17, no. 1 (June 2015), pp. 43–51. http://www.jstor.org/stable/healhumarigh.17.1.43.

Kamm, Frances (2009) What Is and Is Not Wrong with Enhancement? In Julian Savulescu and Nick Bostrom, eds., *Human Enhancement*. Oxford: Oxford University Press, 91–131.

Sandel, Michael J. (2007) *The Case Against Perfection*. Cambridge: Harvard University Press, 1–44.

Recommended:

Harris, John (2007) *Enhancing Evolution: The Ethical Case for Making People Better*. Princeton: Princeton University Press, 109–142.

Naam, Ramez (2005) *More than Human: Embracing the Problems of Biological Enhancement.* New York: Broadway Books, 11–41.

November 29, 2017 **Neuro-enhancement**

Recommended:

Farah, Martha J. (2010) Neurocognitive Enhancement: What Can We Do and What Should We Do? In Martha J. Farah, ed., *Neuroethics*. Cambridge: Massachusetts Institute of Technology, 30–42.

Greely, Henry, et al. (2010) Toward Responsible Use of Cognitive-Enhancing Drugs by the Healthy: Policy Suggestions. In Martha J. Farah, ed., *Neuroethics*. Cambridge: Massachusetts Institute of Technology, 73–79.

Schwartz Cowan, Ruth (2008) *Heredity and Hope*. Cambridge: Harvard University Press, 41–71.

Cases:

Sentges v. Netherlands [2003] ECtHR (No. 27677/02)

Week Twelve December 4, 2017 Artificial Intelligence and Robotics

Hutan Ashrafian (2015) Artificial Intelligence and Robot Responsibilities: Innovating Beyond Rights in: Sci. Eng. Ethics (2015) 21:317-326

European Parliament resolution of 16 February 2017 with recommendations to the Commission on Civil Law Rules on Robotics (2015/2103(INL))

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December 6, 2017 **Conclusions**

Conclusions drawn from the class and preparation for the final essay

Appendix

Basic Legal Documents relevant to this course:

- Universal Declaration on Human Genome and Human Rights of November 11, 1997 (available at http://unesdoc.unesco.org/images/0012/001229/122990eo.pdf)
- Universal Declaration on Bioethics and Human Rights of October 19, 2005 (available at http://unesdoc.unesco.org/images/0014/001461/146180E.pdf)
- Universal Declaration of Human Rights of December 10, 1948
- International Covenant on Civil and Political Rights of December 16, 1966 (Treaty Series, Vol. 999. Entered into force on March 23, 1976)
- International Covenant on Economic, Social and Cultural Rights of December 16, 1966 (Treaty Series, Vol. 993. Entered into force on January 3, 1976)
- International Convention on the Elimination All Forms of Racial discrimination of March 7, 1966
- European Convention on Human Rights and Fundamental Freedoms, November 4, 1950, with Protocols
- Convention on the Prevention and Punishment of the Crime of Genocide of December 9, 1948
- Convention on the Elimination of All Forms of Discrimination Against Women, 1979
- American Convention on Human Rights
 http://www.oas.org/dil/treaties B-32 American Convention on Human Rights.pdf
- African Charter on Human and Peoples' Rights
 http://www.achpr.org/instruments/achpr/ adopted by the OAU Assembly on 28 June 1981, in Nairobi, Kenya.
- African Charter on the Rights and Welfare of the Child http://www.achpr.org/instruments/child/