FRS 140: BIOETHICS AND PUBLIC POLICY
Spring Semester 2018

FRS 140 is offered in a seminar format that requires the sustained attentive participation of all members of the seminar. To facilitate this critical objective attendance is compulsory since the ongoing vitality of our discussions depend on everyone’s participation. A seminar is a cooperative activity. Moreover all sessions of FRS 140 will be in a “Lap-Top Free Zone” [ditto I-Pads, I-Phones [except for emergencies] etc.]. The only exception to this latter proscription is when you are making a presentation and you intend to use Power Point slides or other electronic presentation vehicles.

The requirements for this seminar are straight forward and can be briefly summarized as follows: Compulsory attendance at all meetings of the seminar; Completion of the assigned readings; A full length [10 pages double spaced] book review [due BEFORE Spring break]; Four to five small group presentations [with an accompanying 4-5 double spaced page joint essay that should be distributed to the seminar participants two days before our scheduled meetings] and; A final 20-30 page individual research paper [approximately 4000-5000 words] due on Dean’s date. **No later than May 1, 2018** each student will submit a one page synopsis of their proposed research paper so I can review and respond to these proposals before you launch into research and writing.

**All written assignments should be submitted in Word format through Blackboard.**

Your course grade will be assembled as follows: your final research paper will count for 40% of your grade; your full-length book review for 20%, the liveliness and thoughtfulness of your class participation [including those discussions you participate in leading and their accompanying essays] will constitute 40% [20% points for your essays/presentations and 20% points for your leadership in discussions].

**Textbook**

Book Review Assignment

All seminar participants are required to write a Book Review [approximately 10 pages double spaced] of the following volume:


Weekly Readings

[All required weekly readings must be done before the seminar meets for the week in question. (e.g., the readings for February 7th should be done before the first meeting of the seminar, etc.)]

February 7th Meeting:

A Brief Introduction/Overview of Normative Ethics and the Subject Matter of Bioethics

In this first of our seminar meetings I will be doing more lecturing than in our remaining seminars. In future seminars I expect to more fully share the “leadership” with members of the seminar.

In the first segment of this week’s seminar I will outline the overall scope of the bioethics/public policy issues that will be dealt with in this seminar. This will include the briefest introduction to the development of various approaches to setting ethical norms, a brief review of the major public policy tools available to address issues in bioethics and the relationship of bioethics to the law [particularly the U.S. Constitution]. Some common themes that will continue to arise in the seminar will be identified.

In the second segment of this week’s seminar we will begin to focus more directly on the material in this week’s required readings. Our objective in this segment (which will continue into next week’s session) is to gain an initial acquaintance with the nature and the kinds of questions raised by normative ethics and some of the proposed frameworks that have been developed for considering answers to these questions. Particular attention will be devoted to distinguishing moral views based on consequences vs. duties vs. rights. The Gutmann and Thompson and the Warren readings focus on two specific issues that will come up again and again throughout the seminar namely: the problem faced by public policy makers in dealing with morally contested issues in a pluralistic democracy (Gutmann and Thompson) and the issue of Moral Status (Warren).
February 14th Meeting:

Introduction (continued): Science Policy, Medical Ethics, “Concerns”

Since a great many contemporary bioethical issues arise from developments on the scientific frontier and contain potential challenges for public policy in the second meeting of this seminar we will consider, in brief, an overview of the history of science and technology policy in the U.S. Since the U.S. government finances a great deal of both biomedical research and the provision of medical care public policy cannot escape its own moral responsibilities with respect to many bioethical issues.

This week’s seminar will begin with a review of the material covered in our first meeting. In addition there will be three segments of new material. One will deal with the development of science policy in the U.S., since the increasing involvement of the federal government in biomedical research and health care delivery has tied biomedical matters including bioethics to public policy. A second segment is aimed at an initial understanding of both the history and nature of: medical ethics or the nature of the mutual obligations of physicians (and other care givers) and patients to each other. This is, perhaps, the oldest branch of what is now known as bioethics. Moreover, medical ethics and federal policy is also intimately connected to a relatively more recent issue in bioethics namely: the treatment of human subjects participating in medical experiments. A third segment will deal with some more general “concerns” regarding scientific and technological progress (i.e. How are we to understand our simultaneous embrace of new technology and our continuing sense of unease regarding its meaning for our lives?)

Science Policy [Some History]


Medical Ethics

“Ancient“ and Contemporary Approaches:

Vaughn, Chapter 3, pp. 81-90, 104-109, 123-127 [be sure to review carefully "The Hippocratic Oath" [page 83]. In this chapter I would ask you to look carefully at the Goldman reading and to thoughtfully scan the remaining readings and cases.


Concerns Regarding Scientific and Technological Progress


February 21st Meeting:

Scientific Medicine and the Protection of Human Subjects

This is an issue that is associated with the rise of scientific medicine in the 19th century and the resulting increase in the desire to carry out experiments using human subjects. There are earlier examples of circumstances where the investigation of the human body and/or specific diseases raised the issue of the investigator's ethical obligations to human subjects, but our focus will be on developments beginning with the rise in modern scientific medicine and continuing until today. We will discuss a series of examples where human subjects were seriously abused and the impact of these events on the articulation and development of attitudes related to the protection of human subjects.

Vaughn, Chapter 6, pp. 239-272, 278-284.


[Focus on the following cases: The Nazi Medical Experiments; The Imperial Japanese Experiments in China; The Randomized Controlled Trials of Streptomycin; The Gelsinger Case.]


Federal and International Regulations Regarding the use of Human Subjects in Medical Experiments

Our primary focus on this topic will be on the nature and development of the specific U.S. regulations regarding the protection of human subjects. In this respect it is particularly important to review The Belmont Report and the United States “Code of Federal Regulations (CFR), Title 45 Part 46”. With respect to “CFR 45-46” the reading is hardly exciting or “gripping”, but it is critical to understand how difficult it is to translate ideas into regulations. Keep your focus on the challenge of protecting human subjects through voluntary informed consent and independent review of the risks, protections,
and benefits of research protocols that employ human subjects. We will also take up the challenges of obtaining voluntary informed consent in more unusual settings (i.e. with vulnerable populations, with third party consent and when working in other countries).

In the case of international research we will review various international documents such as the Nuremburg Code and the Declaration[s] of Helsinki [Vaughn pp 259-260], dealing with the protection of human subjects in medical experiments. With respect to policy our attention should focus on whether or not contemporary oversight mechanisms should be enhanced.


United States “*Code of Federal Regulations, Title 45 Part 46*”.  


**February 28th Meeting:**

**The Moral Status of the Human Embryo and the Issue of Abortion**

This session will focus on aspects of what is in the U.S. the most politically polarizing and controversial issue within bioethics namely the moral status of the fertilized human ova and its implication for such issues as abortion, IVF, certain types of embryonic stem cell research, reproductive or therapeutic cloning and potential use of gene editing techniques [for research or clinical purposes] on embryos. Our discussions will focus on the general issues of how one might think about the moral status of the human embryo and the implications this holds for public policy on the issue of abortion.
In this session we will also review both the ‘facts’ regarding the changing incidence of abortion, both where it is legal and illegal and some of the key arguments in the pro-life/pro-choice approaches.

**The Moral Status of the Human Embryo:**

As already noted a significant portion of contemporary bioethical controversies concern the moral status we assign, or should assign to the fertilized human ova and the resulting “early stage” embryo. The issue of moral status also arises in the debate regarding the appropriate use of non-human animals which we will discuss in a subsequent seminar.


**Abortion:**

The issue of Abortion is one of the most polarizing issues in America and one on which thoughtful persons have strong disagreements. Our task is to try to develop a clear understanding of the arguments behind the different views.

Vaughn, Chapter 7, pp. 309-348, 352-363, 397-408. This is a long chapter, but this is an important and very controversial issue for U.S. policy makers [and many others]. Moreover the selected reading are excellent.


Pope Francis “*Misericordia et Misera*” Apostolic Letter, Nov. 20th 2016. [Course Pack]
March 7th Meeting:

Assisted Reproductive Technologies (ART); Human Reproductive Cloning; Human Embryonic Cells

**ART:** The development of ART has enabled a large number of intentional parents to overcome various fertility problems or other challenges and enjoy the fulfillment of raising a family where the children [in most cases] have some biological relationship to at least one of the parents. It has also raised a number of new issues regarding our understanding of the meaning of family, the regulation of medical practice, and the role of public policy and the law with respect to defining the legal frameworks within which family are defined and their rights and responsibilities are articulated. Our discussion will also include matters surrounding surrogacy and gamete donation.

**Human Reproductive Cloning:** The birth of the sheep Dolly through the Somatic Cell Nuclear Transfer [SCNT] technique ushered in considerable controversy over whether this technology might become a widespread social practice in the arena of human reproduction. We will examine the nature of this concern not only as it has evolved over the last generation, but as with ART it’s many social precursors [e.g. adoption].

**Embryonic Stem Cells:** Once the capacity to isolate and culture these human precursor cells was demonstrated a new horizon was opened on the possibility for new clinical modalities, but this very capacity raised ethical issues some of which are unresolved while others have been resolved through new techniques for deriving these cells [or something very close to these cells].


March 14th Meeting:

The Status of Non-Human Animals. Experimentation with Animals, Animal Rights etc.

There has been a long history of debate over the appropriate relationship of the human species to non-human animals. For some this reduces to a discussion of what the moral status of non-human animals is, but historically there has never been complete agreement on this issue. For others a large number of additional matters arise including the concern that if we mistreat non-human animals we will eventually mistreat humans as well, and the view that God’s world includes many forms of life all of which deserve thoughtful consideration. This session will focus on some of the principal approaches to these issues.


March 28\textsuperscript{th} and April 4\textsuperscript{th} Meetings: Eugenics and Genetic Choices

Eugenics:

Human societies have always been fascinated by familial relationships and the apparent inheritance of various traits from one’s parent or other family members. It is only in the last century or so, however, that a solid scientific understanding of the genetic mechanisms governing aspects of this inheritance has evolved. While the full role of genes in determining various human characteristics remains debated, it seems quite clear that in most cases a large variety of genetic and environmental and cultural factors work together in some symbiotic manner. Nevertheless there are some traits that seem to be dominated by genetic factors and many more whose probability of expression (i.e. its presence in a specific phenotype) are impacted by genetic factors. Moreover in the last decade or so the possibility of altering one’s genetic inheritance via genetic engineering either on somatic or germ line cells has raised a number of controversial bioethical issues. Indeed continued progress on the biomedical frontier keeps bringing the specter of Eugenics back for the consideration of individuals as well as public policy. Contemporary discussions focus on the use of our dramatically expanding knowledge in biomedicine to eliminate disease, but this has proved difficult to separate fully from various eugenic concepts focused on the notion that some lives are more worthy than others.


Genetic Choices:

The rapid and continuing development of genetic science has opened up a large array of issues in bioethics in the following areas: genetic testing and reproduction, genetic screening, genetic counseling, gene therapy, parentage and family law, forensic testing, behavioral genetics, neuroethics, the regulation of genetic research, genetic engineering, and other uses [public and private] of genetic information. We will be able to consider only a subset of these issues in this seminar. We will focus on the issue of enhancement and how this differs, if at all, from traditional “treatment” and the difference, if any, between medical and behavioral genetics.

Part I. Enhancement, Therapy, and Reproduction. As a group we will discuss whether there is or should be any limit either to the human capacity to create and/or master the world we inhabit, or to the level of responsibility we take for the future. In particular we will focus on whether public policy or professional norms should limit in any way the use of new biomedical modalities to provide ‘enhancement’ potentials to individual human beings, the implications of these issues for the formation of human identity, and how one might differentiate between enhancement and therapy.

Vaughn, Chapter 9, pp. 539-560, 571-574, 593-598, 604-613.


Part II. Behavioral Genetics


April 11th Meeting:

**Euthanasia and Physician Assisted Suicide**

Cultural attitudes to physician assisted suicide range from outright opposition to its glorification under certain circumstances and over time public policies in this respect reflected these various cultural attitudes and norms. Clearly attitudes towards refusing treatment and physician-assisted suicide (PAS) and the role of public policy in these respects remains highly contested. As regards these matters you might want to keep in mind the fact that it is estimated that about 70% of those that die in the hospital do so after someone’s decision to refuse, withhold, or withdraw treatment.

Death and Dying: Assisted Suicide

Vaughn, Chapter 10, pp. 625-637, 693-701, 707-715.


The Canadian Case: Consult ‘Course Pack’.

April 18th Meeting:

**Genetically Modified Food [Segment 1] and Medical Ethics in a Time of “Crisis” [Segment 2]**

The application of contemporary scientific developments to the production of food, as with other applications, presents both risks and benefits. The potential benefits include improving nutritional content, decreased use of herbicides/pesticides, improving agricultural efficiency, less extensive expansion of farm lands, and decreasing the
allergic potential of certain foodstuffs. The concerns/risks include any currently unknown health and environmental risks to the supporting eco-system and, some would claim, exaggerated benefits claimed by self-interested suppliers of genetically modified products. In addition there are those who believe it is unethical to “fool with mother nature” for the benefits of agro-business. It is an excellent example of the need to properly “manage” the introduction of new technologies. In any case there is now considerable world-wide controversy regarding the application of biotechnology to agriculture despite the fact that farmers have been genetically modifying their crops in the “old fashioned way” for millennia. Without a specialist using advanced technology we could not recognize the “ancestor” of the rice or corn plant that is now common. Nevertheless we should focus on the current controversy and try to understand and evaluate the nature of the disagreements. Interestingly the issue is more controversial in Europe and the developing world than in the U.S.

The second issue this week is whether or not certain ethical and political commitments [i.e. individual liberties] should be at least partially set aside in a time of real crises such as in wartime, or at a “time of terror”, or in the midst of a public health crisis [e.g. Ebola outbreak] of one type or another. This set of issues has become more salient in the public’s mind because of recent events such as the Ebola or SARS “epidemic”.

Segment 1: Genetically Modified Food


Tilman, David, and Clark, Michael, “Food, Agriculture and the Environment: Can We Feed the World and Save the Earth?” Daedalus, Fall 2015, pp. 8-18.

Segment 2


April 25th Meeting

Vaccines: Police Powers of the State and the Balancing Private and Public Interests.

The issues surrounding compulsory vaccinations require a thoughtful balance between public health and individual liberty, population versus individual perspective, prevention and social justice and in some cases surveillance versus privacy especially when confronting an epidemic of contagious diseases. Many of these issues/conflicts can best be seen/illustrated by reviewing the historical controversies surrounding compulsory vaccinations and/or the more contemporary set of issues surrounding the new HPV vaccine.


May 2nd Meeting:

**Distributive Justice and Access to Biotechnologies**

Every society has specific attitudes towards assigning tasks and benefits with respect to the distribution of work effort on the one hand and material rewards on the other. An important question is whether the status quo meets our sense of social justice and the role of public policy in insuring that over time we achieve a just distribution of effort and rewards. In the context of this overall issue we will focus on the distribution of health
care services. In this context we will also want to consider the relationship between
health and human rights. An important issue here is whether universal access to health
care services eliminates health disparities.

Vaughn, Chapter 11, pp. 719-757, 782-803.

Cohen, Carl and Benjamin, Martin, "Alcoholics and Liver
Transplantation" in Steinbock, Bonnie, Arras, John D, and London,
Alex John, Ethical Issues in Modern Medicine, 6th edition, McGraw

Council of Economic Advisors", January 2017, Chapter 4, pp. 195-
246.

Foundation of Public Health and Public Policy”. Oxford University

(Resolution 217 A).

Wailoo, Keith, "How Cancer Crossed the Color Line" Oxford

Winkler, D. and Marchand, S., “Macro Allocation: Dividing Up the
Health Care Budget”, in: Kuhse, H. and Singer, P., (eds.), A
(second edition), pp. 351-361; 2001