

Contemporary Bioethical Deliberations Can They Save Us and Our Planet?

LLC—Wednesdays—10 AM to Noon
ON ZOOM

Frank Schaberg
Frank.Schaberg@gmail.com

Ruth Levy Guyer
RLGuyer@comcast.net

Course description

What can individuals do to ensure that advances in medicine, science and technology promote good outcomes rather than destructive ones? What medical advances are changing our understanding of patients' rights, including a patient's right to try unproven drugs and treatments and the right to die with dignity? And what about the rights and responsibilities of healthcare workers? How can patients protect themselves from charlatans and scam artists? How has climate change already damaged human health, the wellbeing of plants and animals and ecosystems? What scientific advances are altering our understanding of gender, identity, and the rights of future generations? What are the effects of unending war on human behavior and health and the balance in nature?

We will focus on case studies—real stories—that illustrate these and other contemporary concerns. We will consider where the responsibilities lie with individuals, communities, governments, and international organizations, both for having created current problems and now for solving them. We will consider how ethical principles can clarify our thinking and help with problem solving.

Class 1 IN PERSON!!!

INTRODUCTIONS

Hour 1: Introduction of members of class; introduction to the course

Hour 2: The case-study method and two illustrative cases

Class 2 ZOOM CLASS—DIVIDED BETWEEN TWO WEEKS

AUTONOMY RESPECTED AND DENIED

In order to live lives of dignity, individuals must have the right to make their own informed decisions. The patients' rights movement followed upon the human rights, civil rights, and women's rights movements of the 20th century. The focus shifted away from the old paternalistic approach—in which doctors made all of the decision—toward one in which patients and their family members became part of the conversation in determining what treatments the patient would accept or reject. Who should decide if a patient is competent to make such decisions?

How can patients and their family members become fully informed? What happens when the patient's autonomous decisions clash with the rights and responsibilities of doctors and nurses to do only what is medically indicated? Are there limits to what patients and their family members can demand? What distinguishes ethical from legal decision making in the world of medicine?

Case 1: No risky chances: the conversation that matters most, Slate, Atul Gawande,
<https://slate.com/technology/2014/10/end-of-life-medical-decisions-atul-gawande-book-excerpt-on-no-risky-chances.html>

Case 2: The family wanted a do-not-resuscitate order. The doctors didn't.
<https://www.propublica.org/article/the-family-wanted-a-do-not-resuscitate-order-the-doctors-didnt>

Case 3: More about Dax Cowart—youtube videos
Television news account of Dax's story.
<https://www.youtube.com/watch?v=WAQHuaaa4W0>

Dax tells his story to students at UVa.
<https://www.youtube.com/watch?v=ISsu6HkquV8>

Professors at UVa parse the story.
<https://www.youtube.com/watch?v=oGISGeKqCEM>

Class on APRIL 15 (Mickey Rosenberg and Don Schim)

THE NEW GENETICS: A MODERN-DAY PANDORA'S BOX

Genetic testing allows people to discover relatives they previously knew nothing about and to learn about their risk factors for certain diseases. Recently, individuals who were conceived with sperm from a sperm bank have been able to go online and, with simple sleuthing, discover who the donor was and also find half siblings with whom they share their father. How rewarding or how disruptive is it for individuals to discover new biological family members? Is it fair to sperm donors, originally promised anonymity, to now be identified, and do they have responsibilities to their offspring, such as helping them become aware of disease risks? Who has the right to know what genes and what risk factors any individual has? Are the new genetic opportunities equally relevant for rich and poor? Under what circumstances, if any, should law enforcement officers be allowed to gain access to genetic data? Should genetic counselors assume directive or advisory roles in this new genetic era?

Case 1: A family portrait: brothers, sisters, strangers, Eli Baden-Lasar, NY Times Magazine. <https://www.nytimes.com/interactive/2019/06/26/magazine/sperm-donor-siblings.html>

Case 2: Dani Shapiro opens up about DNA shocker that changed her life.
<https://www.youtube.com/watch?v=iRDZB-3PB8A>

Class on APRIL 22 (Dick McWhirter and Jan Brodie)

VACCINES & EMERGENT INFECTIONS

Vaccination is both a private health and a public health measure, girding individuals against infections and protecting the most vulnerable by creating “herd immunity.” Why would people not want to be vaccinated against devastating infectious diseases? What are the fears of the anti-vaxxers, and what have been the consequences of their actions? How do public health needs and measures differ in rich and poor populations? How do they expand the inequities between the powerful and “others?” Why do disease outbreaks threaten global security? Are fears of weaponized infectious microorganisms legitimate? When epidemiologists track new epidemics back to a “patient zero” for each new outbreak, what justice concerns arise? How best might a balance be struck between protecting the public health through mandatory testing, notification, quarantines, and vaccinations and at the same time not violating the rights of individuals to privacy, autonomy, and freedom of choice and movement? Why is the phrase “going viral” apt for explaining the spread of diseases, the rise of anti-vaccine crusades, and growing public awareness of emerging infections?

Case 1: We must talk more about measles and less about anti-vaxxers.
<https://www.washingtonpost.com/outlook/2019/12/04/we-must-talk-more-about-measles-less-about-anti-vaxxers/>

Case 2: Why my baby?
<https://www.nytimes.com/2019/12/19/world/asia/samoa-measles.html>

For current information on the Samoa outbreak: go to www.npr.org or your favorite news source and search “Samoa measles”

Case 3: How anti-vaccine activists doomed a bill in New Jersey.
<https://www.nytimes.com/2020/01/16/nyregion/nj-vaccinations-religious-exemption.html?action=click&module=News&pgtype=Homepage>

Case 4: Coronavirus outbreak. A new martyr puts a face on China’s deepening coronavirus crisis.
<https://www.nytimes.com/2020/02/07/world/asia/china-coronavirus-doctor-death.html>

For current information about coronavirus: go to <https://www.cdc.gov/coronavirus/2019-ncov/index.html> and/or your favorite news source and search “coronavirus”

Class on APRIL 29

CHANGING CLIMATE HARMS HUMAN HEALTH (*Hour 1*) (Sheela Percelay)

As the earth warms and the oceans rise and weather gets more violent and fires rage, new threats are imperiling human health and the environment. What is happening to the earth's fresh water supply above ground and in the water table? What will be the long-term effects of a global shortage of water? What are low-lying communities doing to draw attention to their predicaments and the likely submergence of their homes and towns? How has the heating of the earth shifted habitat ranges for infectious organisms and their vectors, and what new threats do these shifts present to humans and animals? What are the health consequences to humans and animals as wildfires destroy landforms and manmade structures and release smoke and toxins into the air? How will water and food supplies for earth's population be met as the earth heats up, and will starvation kill more living organisms than do diseases? Why do climate-change effects most often harm the poor? How does the important principle of justice figure into the story?

Case 1: Double environmental injustice—climate change, hurricane Dorian, and the Bahamas. Shultz et al., *New England J Medicine*, 1.2.2020
<https://www.nejm.org/doi/full/10.1056/NEJMp1912965>

Case 2: The imperative for climate action to protect health, *New England J Medicine*, Andy Haines, 1.17.2019
<https://www.nejm.org/doi/full/10.1056/NEJMra1807873>

Case 3: How to write about a vanishing world (species loss), *The New Yorker*, Elizabeth Kolbert. <https://www.newyorker.com/magazine/2018/10/15/how-to-write-about-a-vanishing-world>

Case 4: Where there's wildfire, there's smoke, *New England J Medicine*, John Balmes, 3.8.2018. <https://www.nejm.org/doi/full/10.1056/NEJMp1716846>

Case 5: The looming consequences of breathing mold, *The Atlantic*, James Hamblin. <https://www.govexec.com/management/2017/08/looming-consequences-breathing-mold/140641/print/>

Case 6: America's hot spots: R.I. among the fastest-warming states in the US, Stephen Mufson. <https://www.providencejournal.com/news/20190814/americas-hot-spots-ri-among-fastest-warming-states-in-us>

Case 7: Bill McKibben's newsletter (this is the introductory note; you can sign up for the series).
<https://link.newyorker.com/view/5bd6728f3f92a41245dd722dbn5sx.2ri/e47b901a>

POLLUTION IMPERILS HUMAN HEALTH (Hour 2)(Mark London)

Oil spills, fires releasing toxins from buildings, runoff from factories and farms, merchandise falling into the ocean from container ships, and explosions and leaks at nuclear power plants have all contributed to the pollution of the earth's water and air. Pollution does not stay in place: global circulation—the jet stream and global winds; the gulf stream and other ocean currents—carry contaminants far from their sites of origin. How clean are the water, air, and soil in Rhode Island? How robust are efforts in the state to fight for remediation and demand accountability by the polluters? Why do some individuals get sick while others exposed to the same chemical and biological toxins remain healthy? Why are the concepts of NIMBY (not in my backyard) and LULU (locally unwanted land use) usually justice issues?

Case 1: Gorham's toxic legacy

<http://rhodetour.org/items/show/19>

<https://ejlri.wordpress.com/toxic-hazards/gorham-factory-site/>

Case 2: Water pollution

A short video of junk in Providence's harbor

<https://www.ecori.org/enviromental-enforcement/2018/11/24/rhode-islands-environmental-protections-move-at-speed-of-business>

A lurking danger for RI's drinking water. Alex Kuffner.

<https://www.providencejournal.com/news/20190517/lurking-danger-for-ris-drinking-water>

Update: <https://www.golocalprov.com/news/new-toxic-fluorinated-compounds-found-in-12-ri-drinking-water-sites-impact>

Case 3: Air pollution

Three Rhode Island counties given failing grades for air quality, Patch, Rachel Nunes, 4.24.2019. <https://patch.com/rhode-island/cranston/3-rhode-island-counties-given-failing-grades-air-quality>

Case 4: Researcher fired after uncovering lung disease (Pawtucket doctor),

Susan Okie, Washington Post, 9.9.1998. <https://www.sun-sentinel.com/news/fl-xpm-1998-09-09-9809080180-story.html>

Case 5: Waste sites in Rhode Island

Land eyed for Pawtucket soccer stadium will need environmental cleanup first. Patrick Anderson. <https://www.providencejournal.com/news/20191211/land-eyed-for-pawtucket-soccer-stadium-will-need-environmental-cleanup-first>

Website to watch: Rhode Island and climate action

<https://world.350.org/rhodeisland/about/>

Class on MAY 6

MEDICINE IN THE SOCIAL MEDIA ERA (Hour 1) (Rosalind Kurzer)

The internet has affected medical care and medical research in novel ways. Individuals who are social-media savvy, like those in the past who were media savvy, can gain advantages when they are ill over other patients who simply wait their turns. How do online communities help and harm patients? What are the consequences of Go-Fund-Me campaigns for patients who need organs or who have rare diseases or who need cash for medicines and therapies? How do demands for the right-to-try experimental drugs that have not yet been vetted in clinical trials subvert medical research and our understanding of what works and what does not? How can the new options for individuals to express their autonomous choices be fairly balanced against standard procedures for vetting therapies and treatments?

Case 1: Tell us what you need, The New Yorker, Nathan Heller, 7.1.2019
<https://www.newyorker.com/magazine/2019/07/01/the-perverse-logic-of-gofundme-health-care>

Case 2: Crowd-funding for medical research picks up pace, Nayanah Siva, The Lancet, 2014. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)61661-5/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61661-5/fulltext)

Case 3: Kidney transplant chains will restore your faith in humanity—here’s how they work. Caroline Praderio. <https://www.insider.com/how-kidney-transplant-chains-work-2016-10>

FRAUD IN MEDICINE (Hour 2) (Don Gralnik)

Why do people fall for drugs and therapies that seem too good to be true? (When they seem that way, they usually are!) How do pharmaceutical companies get away with marketing drugs, technologies, and treatments that have not been shown to be effective? Why have “alternative” medicines become so attractive? Charlatans and con artists—so-called snake oil salesmen—have successfully promoted medicines on the internet, television, radio, and in print media, offering everything from cancer cures to bogus dietary fixes for a range of conditions. Why are the medical endorsements of celebrities so out-of-scale with their levels of medical expertise? Why do the miracle cures hawked by televangelists continue to bring in millions of dollars? Is there some way to make Dr. Google accountable?

Case 1: Theranos and Elizabeth Holmes.

<https://abcnews.go.com/Business/nightline-documentary-podcast-dropout-story-elizabeth-holmes-theranos/story?id=60365362>

Case 2: TV doctors credibility or TV evangelists.

<https://www.youtube.com/watch?v=7y1xJAVZxXg> (John Oliver)

Case 3: The baffling rise of goop. Olga Khazan, 9.12.2017

<https://www.theatlantic.com/health/archive/2017/09/goop-popularity/539064/>

Exorcisms, orgasms and psychics: a first look at Gwyneth Paltrow's The Goop Lab. Lauren Steussy. <https://nypost.com/2020/01/06/exorcisms-orgasms-and-psychics-a-first-look-at-gwyneth-paltrows-the-goop-lab/>

Case 4: Quakery is alive and well in the 21st century. CrowdH.com, Alex Kack, 9.7.2017. <https://www.crowdh.com/quackery-alive-well-21st-century/>

Case 5: Regulators allege Christian-based health care provider broke state, federal rules, NPR, Todd Bookman.

<https://www.npr.org/2019/11/25/780612410/regulators-allege-christian-based-health-care-provider-broke-state-federal-rules>

Class on MAY 13

ACTS OF CONSCIENCE AND HEALTH CARE (*Hour 1*) (Doree Goodman)

Some pharmacists won't fill prescriptions for birth control pills or dispense nonprescription morning-after pills. Some doctors won't perform abortions, vasectomies, and tubal ligations. Some companies won't pay for contraception as part of their employees' healthcare packages. What is the legal status of such actions in the United States? How do "conscience clauses"—the legal stipulations attached to laws that protect individual actions based on religious beliefs or the dictates of individuals' consciences—square with the First Amendment and with various Supreme Court rulings, such as *Citizens United*, *Hobby Lobby*, and the Religious Freedom Restoration Act? Where does the concept of separation of church and state stand if religious beliefs can override secular public policies? How can healthcare professionals meet their obligations to patients while upholding their own religious or nonreligious convictions?

Case 1: *Hobby Lobby 101: explaining the Supreme Court's birth control ruling*. Warren Richey. <https://www.csmonitor.com/USA/Politics/DC-Decoder/2014/0710/Hobby-Lobby-101-explaining-the-Supreme-Court-s-birth-control-ruling>

Hobby Lobby Case: About labor rights and religious extremism, not birth control, Clare O'Connor. <https://www.forbes.com/sites/clareoconnor/2014/03/31/hobby->

[lobby-case-about-labor-rights-and-religious-extremism-not-birth-control/#2523c5351b41](#)

Case 2: Trump's conscience rule for health providers voided by federal judge, Yasmeen Abutaleb. https://www.washingtonpost.com/health/trumps-conscience-rule-for-health-providers-voided-by-federal-judge/2019/11/06/39aa9b74-00b1-11ea-9518-1e76abc088b6_story.html

Case 3: The strange career of free exercise (peyote, religious freedom, and the law), Garrett Epps. <https://www.theatlantic.com/politics/archive/2016/04/the-strange-career-of-free-exercise/476712/>

GENDER IDENTITY (Hour 2) (WE NEED A LEAD DISCUSSANT)

Profiling individuals by appearance can be misleading, because humans come in all shapes and sizes. In social situations, misidentifying someone's gender can cause embarrassment; in the military it can cause trust issues; in the emergency room, it can produce harm. In recent years, a focus on gender identity rather than biological sex has created new dilemmas in various arenas. Should genetic (XX) women with high levels of natural testosterone be forced to lower their levels to some arbitrary standard in order to compete in sports? Should any competitive athletes (XX or XY or XXY) ever be forced to undergo sex testing? Should anyone anywhere? When babies are born with ambiguous genitalia, who should decide what remedies are appropriate, if any? What practical problems do those who identify as transgender face? How are transitions—female to male or male to female—brought about? Is autonomy violated by requiring persons to name their genders?

Case 1: When one of the world's most visible athletes is told she can't be one. Lindsay Crouse. <https://www.nytimes.com/2019/05/04/opinion/sunday/caster-semenya-running.html>

Case 2: Track and field tries to understand new rules for intersex athletes. Gina Kolata. <https://www.nytimes.com/2019/05/08/sports/semenya-xy-chromosomes.html>

Case 3: Caster Semenya, Testosterone and the history of gender segregation in sports. Jaime Schultz, 5.6.2019. <https://www.livescience.com/65412-caster-semenya-testosterone-gender-segregation.html>

Case 4: David Reimer's story by John Colapinto. <https://slate.com/technology/2004/06/why-did-david-reimer-commit-suicide.html>

Milton Diamond commentary on the case (9 minutes)
<https://www.youtube.com/watch?v=0SpFxE6l6Go>

Case 5: Over 200 medical professionals in the South oppose bills targeting trans youth. 2.6.2020. <https://www.nbcnews.com/feature/nbc-out/over-200-medical-professionals-south-oppose-bills-targeting-trans-youth-n1131881>

Case 6: The power and limits of classification. Stroumsa, <https://sites.lsa.umich.edu/elizabethroberts/wp-content/uploads/sites/89/2019/05/classification.pdf>

Case 7: Trump's controversial transgender military policy goes into effect. Hallie Jackson, 4.12.2019. <https://www.nbcnews.com/feature/nbc-out/trump-s-controversial-transgender-military-policy-goes-effect-n993826>

Class on MAY 20

THE CULTURE OF WAR (Hour 1) (Carole Marshall)

President Eisenhower warned of the military-industrial complex in his farewell address in 1961. In the intervening years, medical and psychological techniques and technologies have been added to the armaments of war. How do psychologists enlisted by the military to develop “enhanced interrogation” techniques (waterboarding and others) justify actions that are widely viewed as torture? How do these acts jibe with their vows to honor professional ethics codes? What links exist between traumatic brain injuries and exposure to detonating bombs in both military personnel and innocent bystander civilians? How widespread is PTSD in military and civilian populations? What other enduring physical and mental damages have been documented as direct consequences of war? What have been the effects of years of bombing on environments and ecosystems in war zones? How big a role does “follow the money” play in military decision making? What strategies might citizens employ to influence governments to prioritize human rights and social justice?

Case 1: Health Professionals' Roles at Guantanamo

Guantanamo: Psychologists who designed CIA torture program to testify. Julian Borger. <https://www.theguardian.com/us-news/2020/jan/20/guantanamo-psychologists-cia-torture-program-testify>

Guantanamo testimony exposes role of doctors in CIA interrogations
Carol Rosenberg. <https://www.nytimes.com/2020/01/27/us/politics/cia-black-site-doctors.html?searchResultPosition=4>

Saying it again: psychologists may not participate in torture. James Bray, American Psychological Association, 4.22.09. <https://www.apa.org/news/press/op-eds/bray-interrogations>

Case 2: Health Effects of War

Brain injuries from Iraq missile attack draw attention to invisible war wounds. Associated Press, 2.2.20. <https://americanindependent.com/traumatic-brain-injuries-missile-attack-iraq-war-wounds-donald-trump/>

Treating the trauma of young Syrians. (A short overview plus a six-minute video) <https://www.nytimes.com/2015/10/13/health/treating-the-trauma-of-young-syrian-refugees.html?searchResultPosition=2>

Case 3: War's Environmental Effects

What's the environmental impact of modern war? Karl Mathiesen. <https://www.theguardian.com/environment/2014/nov/06/whats-the-environmental-impact-of-modern-war>

Brown's Costs of War Project (Watson Institute) <https://watson.brown.edu/costsofwar/>

GENOCIDE (*Hour 2*) (**Bob Kemp**)

The deliberate killing of a population, often an ethnic, religious or national group, is the most heinous crime under international law. Despite United Nations declarations and conventions—such as the Prevention and Punishment of the Crime of Genocide of 1951 and the Responsibility to Protect of 2005—genocide has continued into the 21st century. The international legal system has managed to prosecute some cases, but widespread slaughter continues. What are the enduring legacies of genocide to the physical and psychological health of individuals? What accounts for how little attention much of the world seems to pay to these horrors? What motivates mass murder and extreme brutality? Do countries not involved in a genocide or an act of ethnic cleansing have a responsibility to take action—military intervention; humanitarian relief—against violent states in order to protect citizens and punish perpetrators? Why and how are women and children especially targeted? Can genocide be stopped?

Case 1: Myanmar

Myanmar Rohingya: Suu Kyi to defend genocide charge at UN court, BBC News 12.10.2019. <https://www.youtube.com/watch?v=H05aVCQ78Es>

Suu Kyi's defense of genocide charges may shock the West. But it bolsters her status at home. Shibani Mahtani. https://www.washingtonpost.com/world/asia_pacific/suu-kyis-defense-of-genocide-charges-against-myanmar-may-shock-the-west-but-it-solidifies-her-

[cult-status-at-home/2019/12/09/8ae9dbf4-17ee-11ea-80d6-d0ca7007273f_story.html](https://www.theguardian.com/cult-status-at-home/2019/12/09/8ae9dbf4-17ee-11ea-80d6-d0ca7007273f_story.html)

Case 2: Serbia/Bosnia

The hunt for Radovan Karadzic, ruthless warlord turned spiritual healer, Julian Borger. <https://www.theguardian.com/world/2016/mar/22/the-hunt-for-radovan-karadzic-ruthless-warlord-turned-spiritual-healer>

Case 3: Burundi

The world looks away as blood flows in Burundi. Emma Graham-Harrison. <https://www.theguardian.com/world/2016/apr/10/burundi-ethnic-violence-refugees>

Case 4: Rwanda

Rwanda genocide 20 years on. Chris McGreal. <https://www.theguardian.com/world/2013/may/12/rwanda-genocide-20-years-on>

Betraying justice for Rwanda's genocide survivors, Jina Moore. <https://www.newyorker.com/news/news-desk/betraying-justice-for-rwandas-genocide-survivors>

The Rwanda Genocide: 20 years later. https://www.youtube.com/watch?v=KqJr46_yUH8