



## ***Controversies in Bioethics Seminar***

April 13 & 14<sup>th</sup>, 2018

Lehigh University

Bethlehem, Pennsylvania



## ***Controversies in Bioethics Seminar***

**Friday 13 April 2018**

8:30 am: Conversations and Coffee

9:00am-11:40am: Foundational Controversies

1. *The Anthropocene: A challenge to humanism in bioethics?*

Paul J. Cummins

2. *Why 'is addiction a disease?' is the wrong question*

David G. Limbaugh and Robert Kelly

3. *Considering obesity as disease: The ethical implications*

Alex Charrow

11:40-12:30am: Lunch

12:30pm-4:30pm: Death and Dying Controversies

4. *Against rationality: A case for the permissibility of euthanasia/assisted suicide in individuals with depression*

Cheryl Frazier

5. *Assisted suicide, the inviolability of life, and the right to self-defense*

Kristen Hine

6. *Is brain death a legal fiction?*

John P. Lizza

7. *Bioethics and the law: Should courts be allowed to make end of life decisions? Reflections on the Charlie Gard controversy*

Michael S. Dauber

5:00-7:00pm: Dinner Reception

**Saturday, 14 April 2018**

8:30 am: Conversations and Coffee

9:00am-11:40am: Perspective Controversies

8. *Harm reduction strategies & the problem of female genital cutting: Bringing secular and Islamic perspectives into conversation*

Rosie Duivenbode and Aasim I. Padela

9. *Controversies in Islamic bioethics on organ donations: Between presumed consent and explicit consent*

Vardit Rispler-Chaim

10. *The ethics of the (Tuskegee) syphilis experiment*

David Augustin Hodge

11:40-12:30am: Lunch

12:30pm-4:30pm: Application Controversies

11. *Bioethics and biosocial criminology: hurdling the status quo*

Roger Guy and Piotr Chomczyński

12. *Disparities in access to artificial reproductive technology for US people living with HIV*

Marielle Gross, Mindy Christianson, Jenell Coleman, and Jean Anderson

13. *Potential utility of an independent decision-making board for patients lacking decisional capacity*

Barbara A Noah

14. *Lives and choices, give and take: Altruism and organ procurement*

Vicky Thornton

5:00-7:00pm: Free time - a list of optional activities will be provided

# ***Abstracts***

## ***Considering Obesity a Disease: The Ethical Implications***

In June of 2013, the American Medical Association (AMA) announced a change to their nomenclature. Obesity would be considered a disease and not simply a risk factor. The decision to categorize obesity as a disease is both a scientific and moral one, a decision that forces society not only to confront the meaning of disease itself but the implications of medicalizing mass and drawing norms based on its measurement.

Cast in an historical light, medicalization of conditions has led to dramatic social and political effects on those with the given condition of interest. While there are many ways to define disease, most definitions are indefinite regarding the classification of risk factors like obesity. In such cases, the decision to classify obesity as a disease should be pragmatic, focused on how such decisions will impact society. This seminar and associated paper outline how best to determine what ought be considered a disease before concluding that in those cases where disease status is indeterminate, conditions should be categorized as disease only if such categorization will improve health outcomes for those individuals.

Obesity, as a condition, exists in such an indeterminate zone of categorization. It does not fit neatly into a Wittgensteinian notion of disease nor do other methods of disease ascriptions hold weight. As such, only the outcomes matter – and if obesity is designated a disease, the health outcomes for those effected will be worse. Disease ascription will promote stigma and thus poor eating and inactivity. Disease ascription will promote individual-level interventions for a condition that requires public-health and community-level interventions. Finally, disease ascription will gloss over the inaccuracy of BMI as a means by which to determine health. Ultimately, disease ascription will cause more harmful health outcomes for an already vulnerable population. In this light, AMA should reconsider its decision in light of such outcomes.

## ***The Anthropocene: A Challenge to Humanism in Bioethics?***

Nearly as soon as bioethics coalesced around issues related to human health, biomedical research, and medical technology, scholars pled for a return to its roots in Van Rensselaer Potter's call to foster a discipline integrating the humanities and the sciences to support ecology. The call to reintegrate environmental ethics with bioethics recurs periodically, and the time between calls has diminished as the catastrophe of anthropogenic climate change has become more apparent. This paper's ultimate argument is that these scholars do not appreciate the radicalness of this proposal and its potential to disrupt the discipline. To embrace Potter's proposal that the humanities and science be integrated is to commit to exploring how these fields are mutually transformative: humanistic understanding is impacted by scientific knowledge, and vice versa. Bioethics scholars have failed to reflect on how the advent of a new geological epoch, the Anthropocene, impacts categories of humanist understanding. Scholars in other humanities have engaged this question, arguing that the Anthropocene undermines the traditional dichotomy between man and nature, which is conceptually necessary for humanism. An interim moral to draw is that bioethics scholars should be prepared to defend humanism or develop a new system

of values that does not privilege the human. This paper concludes by outlining the contours of that system and its impact on how renewed bioethics would address ethical issues within healthcare. The result would be a coup of environmental ethics.

***Bioethics and the law: Should courts be allowed to make end of life decisions?  
Reflections on the Charlie Gard controversy***

In June and July of 2017, the case of Charlie Gard, an 11-month old boy with mitochondrial DNA depletion syndrome, sparked a significant public controversy. Charlie's condition had progressed extensively, and his doctors argued that palliative care and comfort measures were his best option, given the high likelihood that he had suffered brain damage. Charlie's parents disagreed, and requested an experimental treatment called nucleoside bypass surgery. The English High Court, the Court of Appeals, and the European Court of Rights successively ruled that the medical team should withdraw Charlie's life-support and allow him to die, arguing that continued treatment produced significantly more harm without a reasonable prospect of benefit. The case developed into an international controversy, with international figures from Pope Francis to Donald Trump offering commentary and offering to accommodate Charlie and his parents.

This paper will examine whether or not courts should have the power to decide to withdraw life-sustaining treatment over the objection of surrogate decision-makers, as they did with Charlie Gard in the United Kingdom. Drawing on the Charlie Gard case, bioethical theory, political philosophy, and my experiences as a clinical ethicist, I conclude that courts should not have the power to withdraw life-sustaining treatment over surrogate objection in *most* cases because doing so creates significant chaos, fear, and distress in patients and their families, and that taking positive stances on end of life issues violates the principles of liberal democracy, under which intimate decisions about the unknown should be left to patients and their surrogates.

***Harm reduction strategies & the problem of female genital cutting: Bringing secular and Islamic perspectives into conversation***

Recent events including the arrest of physicians in Michigan have renewed bioethical debates surrounding the practice female genital cutting (FGC). The "secular" discourse is divided between zero-tolerance activists and harm-reduction strategists. Zero tolerance activists aim to completely eradicate all types of FGC and consider the practice a violation of human rights. Harm-reduction strategists propose the primary objective should be to reduce harms associated with FGC and thus accept alternative strategies when complete eradication is not attainable. Similarly, Muslim bioethical debates on FGC comprise of two camps. "Traditionalists" find normative grounds for a minor genital procedure in statements from the Prophet Muhammad and in classical law manuals. "Reformers" seek to decouple FGC from Islam by reexamining its ethico-legal status in light of the deficiencies within Prophetic reports, health risks attributed to FGC, and contemporary perspectives on women's rights. This paper begins by explaining the main premise and supporting rationale for the various viewpoints and identifies their principal advocates. Next, the paper argues that alignment between secular and Islamic views can be found in a harm reduction strategy. Specifically we contend that the impetus to reduce

harms from FGC is found within Prophetic statements about the ritual practice. Furthermore, the origin of FGC in pre-Islamic customs facilitates limiting the practice when credible risks and harms are proven. Bringing the multiple perspectives and data-points into conversation with one another thus furnishes a common ground upon which to delegitimize and eradicate harmful genital procedures among Muslims.

***Against Rationality: A case for the permissibility of euthanasia/assisted suicide in individuals with depression***

In 2015 the Netherlands released their annual report from the regional euthanasia review committees (RTEs) which outlined, in part, specific cases of euthanasia from that year. This report came under fire in a 2016 article entitled “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014.” As authors Scott Y. H. Kim, Raymond G. De Vries, and John R. Peteet noted, Dutch regional euthanasia review committees have increasingly permitted euthanasia or assisted suicide (EAS) for psychiatric patients, most frequently in cases of depressive disorders. This phenomenon, coupled with society and scholars’ increased willingness to permit more cases to be applicable for EAS, has sparked controversy amongst bioethicists.

Many charge that individuals with depression are ineligible to elect for EAS given that they are not competent or rational in the same way as those without mental illnesses. As Mark Sullivan and Stuart Youngner state, “refusal of lifesaving psychiatric treatment is regarded as a symptom of an illness that psychiatrists treat rather than the rational choice of an autonomous patient that should be respected.” In this paper I will argue that if we find EAS to be morally permissible in cases of terminal illness, especially on the basis of terminal illnesses causing unbearable suffering, then we ought to allow EAS in the case of (at least some cases of) depression. I will center my argument under the societal stereotype under which the mentally ill are seen as irrational as a result of their mental illness.

On this basis, many have argued that we should not allow them to choose EAS as a response to their mental illness. We frequently allow people without mental illnesses make what we would consider irrational decisions, both inside and outside of medical contexts. For example, I am allowed to eat dinner at Sonic every night despite this being an irrational (and horribly unhealthy) decision. Further, someone in need of a surgery to remove ear tumors could refuse to get the surgery to avoid having to shave their head before surgery. While we may advise against these irrational decisions, we ultimately may respect them because we deem the *agents* making them rational. I will similarly argue that individuals with some forms of depression can be rational agents despite making irrational decisions. Individuals with depression are seen as sufficiently rational to decide whether to attend grad school, to choose a spouse to marry or a career path to pursue. However, they similarly make irrational decisions like those made by individuals without depression. As such, I will argue that we should not ban individuals with depression (and more specifically treatment resistant depression) from choosing EAS on the basis of rationality, since this wrongfully discriminates against those with mental illness in ways that we do not limit those without mental illness.

### ***Disparities in access to artificial reproductive technology for US people living with HIV***

The American Society for Reproductive Medicine (ASRM) states that there is no medical, legal or ethical basis for withholding artificial reproductive technology (ART) from people living with HIV (PLHIV). However, as of 2015, less than 3% of American fertility clinics handled gametes from PLHIV, making mainstays of infertility treatment, including intrauterine insemination (IUI), in vitro fertilization (IVF), and intracytoplasmic sperm injection (ICSI), effectively unavailable to this population. We suggest that current ASRM recommendations may perpetuate disparities in infertility care for American PLHIV.

Disparities in ART access for PLHIV persist despite the medical, ethical and legal precedents above as a result of ASRM's recommendations for unnecessarily stringent laboratory practices for preventing viral transmission, compounded by a loophole in ASRM guidelines for ethical care of PLHIV. First, the ASRM's interpretation of US statutes includes recommendations for separate laboratory spaces and storage tanks, and additional processing for specimens from PLHIV. While there is no evidence that these precautions are safer than universal precautions, they are prohibitively expensive for most fertility centers and thus may constitute an "undue burden" with regard to complying with the Americans with Disabilities Act. Also, the ASRM suggests an obligation to "treat or refer" PLHIV without specifying who should treat or to whom one should refer. Lack of organizational transparency regarding which fertility programs offer ART services to PLHIV makes referral problematic, and the paucity of treating providers nationwide implies that following up on referrals may require an impractical amount of travel for most patients.

The ASRM is complicit in the ongoing disparities in access to ART for PLHIV through its concomitant recommendations for laboratory practices too burdensome to enable most fertility centers to offer treatment, and its acceptance of referral as fulfillment of the ethical and legal obligations to PLHIV without providing substantive means for referral. We call for a critical reexamination of these policies which demonstrate disregard for the reproductive intentions of PLHIV, especially given their disproportionate rates of infertility and socioeconomic disadvantage.

### ***Bioethics and biosocial criminology: Hurdling the status quo***

Biosocial criminology is the fastest growing line of research within the field of criminology. Much of the findings suggest that genetic influences (certain genetic polymorphisms) are involved in anti-social behavior including criminal behavior with the environment and genes working in a synergistic manner. According researchers in the field, the continued accumulation of biosocial criminological data, and the development of biosocial theories is imperative to the advancement of this perspective (Beaver et al., 2015). Recently some have argued for the use of biosocial research findings to move the field of criminology from one of the etiology of crime using a purely environmental approach to a biosocial approach that emphasizes prevention using scientific findings and methodologies for crime prevention as one would a public health problem (Gajos, Fagan and Beaver, 2016). However, there is considerable opposition and controversy in mainstream criminology circles to the biosocial approach because it involves, among other things,

genotyping offenders for genetic risks to elucidate the etiology of antisocial behavior. Using a recent example from our biosocial research in Poland, we will consider the ethical dimensions of conducting such research on our subjects, and whether recent findings in biosocial criminology can be integrated into current approaches to crime prevention with minimal harm to subjects.

### ***Assisted suicide, the inviolability of life, and the right to self-defense***

In *The Future of Assisted Suicide and Euthanasia* Neil Gorsuch explains and defends the inviolability-of-life principle. According to this principle, human life is valuable in itself, not for instrumental reasons. With regards to assisted suicide, Gorsuch argues that such a principle would "...rule out cases where the doctor intends to kill his or her patient" (Gorsuch, 164).

In this paper, I do not argue against the principle. Rather, I consider whether the inviolability-of-life principle is, in fact, inconsistent with all cases of assisted suicide. For, defenders of the inviolability-of-life principle are willing to grant that one's right to self-defense permits one to end the life of another. I argue that by making this allowance, defenders of the principle may provide an avenue through which one can argue in support of assisted suicide in some cases.

My basic line of argumentation is as follows: according to some, *person* is ambiguous. It makes no sense to talk merely of persons; rather, we should recognize a distinction between biological persons and psychological persons. When we call something a *biological person*, we mean to say that it is a member of the species *Homo sapiens*, and when we call something a *psychological person*, we mean to say that it is self-conscious, intelligent, rational, and so on.

I suggest a similar distinction can reasonably apply to *human life*. If so, the inviolability-of-life principle could mean one (or both) of the following: human (psychological) life is intrinsically valuable, or (and) human (biological) life is intrinsically valuable. I argue that the most reasonable interpretation of the principle implies that both aspects of human life are intrinsically valuable. I then suggest that in some end-of-life situations, the biological aspect of life threatens the psychological aspect of life. This can happen when, for example, the continued existence of one's biological life results in one's psychological life experiencing nothing but suffering, humiliation, a lack of autonomy, and so on. I suggest that in those cases, one's psychological self has a right to defend itself against the attacks made by one's biology, just as one has the right to defend oneself against the attacks made by another. Provided that such a defense results in an *unintentional* termination, the inviolability-of-life principle would imply that ending one's (biological) life is permissible.

Now, I grant that this argument shows that one has a right to suicide, not assisted suicide, if the inviolability-of-life principle is true. I argue, however, that just as one is sometimes *permitted* to assist another in the defense of oneself, a person is at least sometimes permitted to assist another in her suicide. This does not show that an individual has a *right* to assisted suicide, but it does show that some cases of assisted suicide may be consistent with the inviolability-of-life principle.



## ***Trust, Trustworthiness and Xenotransplantation: Ethical Issues for African Americans***

African Americans lead in excess deaths in most statistical categories (diabetes, kidney and heart disease, etc.). This makes them excellent candidates to be beneficiaries of the significant positive gains on health and healthcare that xenotransplantation research can offer. Traditionally, blacks have been pursued and used in studies but they are not equally pursued and luxuriated with the positive genius that comes as a result. This maintains a distrust they didn't initiate and leads to a suspicion of systems, even if the systems are noble. Philosopher Mark Owen Webb in his essay, "The Epistemology of Trust and the Politics of Suspicion" extends this distrust to moral epistemology. For example, utilitarianism as a moral theory is wholly inadequate as a formula that would motivate African American participation. Utilitarianism is far too friendly to the majority population. Thus, a more constructive ethical consideration would have to be one that is endorsed by those negatively affected. Why? Because they *know* that they have been used. In other words, (in accordance with Webb) African Americans are justified in being suspicious of medical projects (e.g., Henrietta Lacks). African Americans are also justified in being suspicious and distrusting of researchers' motives (recall U.S. Public Health Service Syphilis Study at Tuskegee)?

Being used as a means to an end is a virtue ethical (and deontological ethical) violation that perpetuates health disparities and leads to ongoing mortality and morbidity concerns. African Americans, and others of good will, should be advocates staunchly committed to a virtue ethical public health care ethic (that wears the lens of the ethics of care and empathy) and reject utilitarian ethical theory. A non-discursive research agenda unfairly promotes (or prioritizes) benevolence over beneficence. Beneficence should be prioritized over non-maleficence and benevolence.

Thus, trust and trustworthiness should be ground in something more virtue based, then begin to address concerns like, the risk/benefits calculations and how statistical numbers are represented and demystified, the canvassing of the community to ensure an equitable distribution of the moral education on this very controversial medical area? How are terms in the informed consent material like "sterile" to be understood and trusted? How is the social stigma to be addressed? Is there a chance that an unknown disease can be contracted, then passed on during intimate contact? And to what extent are recipients obligated to inform their partners that they have non-human animal parts in their person? Is there a chance for an unknown contagion to be passed *in utero*? If the life expectancy of the pig is five human years, are we to believe that a xenotransplanted organ can sustain life for humans who have a life expectancy of about seventy-five years? If a donor human organ becomes available post-xenotransplantation, would the recipient be able to change the non-human animal organ for a human one? Who will decide when events like these present themselves? And how are African Americans to trust this process?

### ***Why "Is addiction a disease?" is the wrong question***

The aim of this paper is to elucidate and answer what we take to be a conceptual confusion in the addiction literature. There is currently a debate in bioethics that asks whether or not addiction is a disease. What fuels this debate is the assumption that if addiction is a disease, then addicts are less morally responsible than they would have been otherwise. We argue

for two conclusions. 1) Whether or not a particular addiction is a disease will depend on the type of addiction. 2) There is no relationship between addiction's being a disease and addiction's mitigating the moral responsibility of an addict; though, it is still true that in some cases, being an addict may mitigate moral responsibility. We argue for these positions by assuming the harmful dysfunction account of disease and the systematic loss of control account of addiction. We also make the minimal commitment that for a person to be morally responsible is for them to be praiseworthy or blameworthy for her actions.

### ***Is brain death a legal fiction?***

There has been rising chorus of discontent with accepting brain death as death. Cases of post-mortem pregnancy in which brain-dead pregnant women are sustained to allow the fetus to gestate and then be removed by Caesarean section and the extraordinary case reported by D. Alan Shewmon in which a whole-brain-dead body was sustained for over twenty years challenge whether brain function is necessary for the continuation of a human life. Recently, Franklin Miller, Robert Truog, and Seema Shah have endorsed Shewmon's arguments that brain death is not death, if death is understood in strictly biological terms as the irreversible loss of integration of the organism as a whole. They maintain that accepting brain death as death departs substantially from a biological and common sense understanding of death and that interest in organ transplantation was the primary motivation for accepting of brain death as death. Moreover, they claim that the public has not been informed of these "facts." Since it is unlikely that this information can remain hidden from the public for long, they suggest that we acknowledge that brain death is a kind of "legal fiction" and become more transparent about how this fiction may be useful and ethically appropriate in permitting vital organ transplantation. Since they believe that the use of organs from brain-dead donors is justified, even though those donors are not really dead, they believe that such transplantation can and should continue. In addition, they believe that donors in DCD (Donation after Circulatory Death) protocols, whose circulatory and respiratory functions have ceased for two to five minutes, are not really dead, since their loss of circulatory and respiratory functions is not truly irreversible. So, if we wish to continue donation from brain dead and DCD donors, this is best achieved, according to them, by accepting a transparent "legal fiction" that such donors are dead.

In this paper, I argue that Miller, Truog, and Shah's view is seriously flawed. I argue that the truth should be told. However, the truth is that defining death is not a strictly biological matter, as Miller, Truog, and Shah incorrectly assume, but involves metaphysical, moral, and cultural considerations. However, such considerations do not make brain death a "legal fiction." Indeed, I will argue that biological, metaphysical, moral, and cultural considerations strongly support acceptance of the truth that human persons do not survive total brain failure and therefore brain death is really death. If anything, recognition that defining death involves metaphysical, moral, and cultural considerations may support a more pluralistic approach to the legal definition of death, rather than perpetuating a legal fiction that brain death is death.

### ***Potential utility of an independent decision-making board for patients lacking decisional capacity***

Physicians acknowledge that they are providing unnecessary medical care for a variety of reasons, including fear of malpractice litigation, Medicare's fee-for-service reimbursement mechanism, patient and family requests for care, a culture of denial of mortality, and a physician culture which views a patient's death as a professional failure. Recent data suggest that more than one-fifth of medical care provided is unnecessary and that the inappropriate use of invasive medical technology adversely impacts patients. Although the problem of over-provision of medical care at the end of life is now well recognized in the legal and medical literatures, the solutions considered to date, such as providing additional communication training to physicians, will have only marginally ameliorating effects.

The inherent challenges in physician-patient communication when making treatment decisions during terminal illness become even more complex when patients are unable to make decisions for themselves. Although patient autonomy, implemented via informed consent, is the primary principle that governs medical decisions, including those made on behalf of patients who have lost decisional capacity, insufficient evidence of the patient's wishes coupled with uncertainty about prognosis often leaves physicians and family members in a quandary as to whether to implement or to continue providing therapeutic treatment or life-prolonging care.

Recent data suggests that, in the final weeks of life, approximately 75 percent of patients with life-threatening illnesses and 90 percent of patients in ICUs lose decisional capacity. For these individuals, a surrogate decision-maker, typically a family member or a legally-appointed proxy, must make difficult choices on behalf of the patient about how much medical care to request or accept. Additional empirical evidence suggests that surrogate decision-makers experience significant stress and grief during and after making health-care decisions for their loved ones. The default operation of the surrogate consent process means that, for patients who do not clearly opt out of life-prolonging treatment before losing decisional capacity, the path of least resistance will often lead to decisions in favor of initiating or continuing life-prolonging care. The pressures on physicians to offer and provide medically inappropriate care make this pattern even more problematic.

This paper considers the potential utility of a Canadian decision-support mechanism in this context. In 1996, the provincial government of Ontario implemented a Consent and Capacity Board (CCB), an independent body comprised of appointed psychiatrists, lawyers and members of the general public. The CCB's mission includes adjudication of matters of capacity, consent and what Canada refers to as "substitute decision-making." There is evidence that, in cases of conflict or uncertainty about complex medical treatment decisions, CCB hearings promote a better shared, less confrontational and more robust decision-making process for patients who lack capacity. Thus, a CCB-like mechanism has the potential to improve surrogate decision-making to the extent that it is capable of being "transplanted" into the U.S. health system on a state-by-state basis. Although political opposition in some states is likely, the medical community has demonstrated interest in mechanisms which could both reduce some of the external pressure on physicians to provide what they believe to be medically inappropriate care and

provide expertise and support, when needed, for family members serving as surrogate decision-makers.

***Controversies in Islamic bioethics on organ donations: Between Presumed consent and explicit consent***

The bioethical rulings in Islam are formulated nowadays by muftis- religious scholars or jurisconsults who issue fatwas, and the physicians who consult them. The source material for my study is therefore what I call "medical fatwas" from the last 4 decades, issued in various parts of the Islamic world.

Organ transplantation as a therapeutic procedure is viewed as permissible by most religions today, and the Islamic religion included. In Islamic bioethics organ transplantation is welcome as it serves one of the five main objectives of the Shari'a – to preserve life and well-being.

There are two general types of donations – the donation of a living donor (kidney, part of one's liver, etc.) and donations from the dead. The first type is available upon the consent of the living donor, the second is contingent upon the donor's signing a donor-card prior to his or her death, or to first of kin's consent to donate from a dead/dying relative, after the latter's brain death has been diagnosed.

Statistics have shown that Muslims (like others) are more likely to donate while alive, but less eager to donate from the dead. There is thus a shortage in cadaveric donated organs almost everywhere in the world and in Islamic societies as well. Muslim ethicists, the muftis, have debated among themselves how to encourage cadaveric donations- several suggestions have been made in fatwas, but the muftis so far have not reached a unified solution. In my paper I will analyze the methods that have been suggested, and what are the advantages or disadvantages involved in each.

In the wider world the efforts to increase supply of cadaveric organs have recently concentrated on the presumed consent method (every person is a potential donor of organs after death unless he or she signed a "refusal" during their lifetime), versus the explicit consent method (upon death the family is asked to donate from its dying member, and is expected to explicitly say "yes" or "no"). The question is which method would deliver a better outcome that is more organs for transplantation? The debate has not ended in an unequivocal solution, and the countries of the world are divided between those who chose explicit versus those who prefer the presumed consent as their national policy. Muslims ethicists have joined this debate too, and their attitudes for and against presumed consent will be analyzed as well, as much as how the ethics influence the practice in several Arab and Islamic countries.

Finally I will survey the Iranian method as a middle way, and explain why it is acceptable in Iran but not elsewhere.

### ***Lives and choices, give and take: Altruism and organ procurement***

Globally, the two most common systems for managing organ procurement are opt-in and opt-out. Within the United Kingdom, organ procurement in England, Scotland and Northern Ireland is managed via an opt-in system. Consent is required prior to organs being retrieved for transplant. The United States also practises an opt-in system, with individuals able to express their intentions to donate by way of enrolling on a national or state registry and/or signifying their wishes on a driver's license. In 2015, Wales introduced a deemed consent: soft opt-out system for organ procurement in order to address the chronic shortage of organs for transplant. Justification for a change in legislation was based upon the desire to increase the number of organs and tissues available for transplant in Wales, underpinned by evidence demonstrating that globally, the number of organ donors per million population (PMP) in countries which have adopted an opt-out system are recognised as being the highest. Early statistical evidence suggests that this has had a positive impact on the number of cadaveric organ retrievals in Wales.

Such a system for procurement has previously been dismissed by the Organ Donation Taskforce, a Government advisory committee responsible for advising the UK Government on the organ donation management in this country. The Taskforce suggested that opting out would be too problematic to introduce as coordinating procurement in this way may undermine the concept of a gift given freely, relating this specifically to the idea that an opt-out system negates the opportunity for individuals to make an altruistic gesture of actively pledging one's organs for transplant. Such a measure could potentially undermine the concept of donated organs as gifts, which could negatively impact the number of organs offered for transplant. Such a position rests upon the premise that organs should only ever be donated through choice, and this can only truly be achieved through a policy which encourages voluntarism. There are, however, certain difficulties which maintaining such a strong reliance upon altruism presents. One difficulty is that its prominent feature in a system potentially confines options for procurement to a very limited route and thus may prevent us from exploring other means to increasing the supply of cadaveric organs, for example, a soft opt-out policy, proven to be a more efficient system for generating organs to help more of those in end stage organ failure.

# Bios

## **Alexandra Charrow, MD MBE**

Combined Internal Medicine/Dermatology  
Resident  
Brigham and Women's Hospital and Harvard  
Combined Dermatology Residency Program



*Alexandra Charrow is a combined internal medicine and dermatology resident at the Brigham and Women's Hospital and Harvard Combined Dermatology Residency. She holds a Masters in Bioethics from the University of Pennsylvania and received her BA in Philosophy from Yale University. Her bioethical writing and research focuses on the limitations of medical norms, body modification and enhancement, disparities in body enhancement and augmentation, and the ethics of body-related identity politics. She will be the guest editor for the month of December for the American Medical Association's Journal of Ethics issue on the role of physicians in enhancement and augmentation. My co-author is: Divya Yerramilli, MD MBE.*



## **Piotr Chomczński, PhD**

Associate Professor, Department of  
Economics and Sociology  
University of Lodz, Poland

*Piotr Chomczński is an Associate Professor of Sociology. His most recent research focuses on the relationship between drug cartels in Mexico to local communities. The work is based on a 6-month Eurica scientific scholarship at Universidad Nacional Autónoma de México (UNAM) in 2016. During this time, he carried out ethnographic research on organized crime and drug trafficking in local communities. He also collaborated with Comisión de Derechos Humanos del Distrito Federal, in monitoring inmates in correctional institutions in Mexico. He was also director or team member of numerous national and international scientific projects (Ecuador, Germany, Ukraine, Mexico). For last seven years, he carried out ethnography over group dynamics and interactions among juveniles in detention centers in Poland. He has published in the areas of juvenile justice, sociology of deviance, and qualitative methodology.*

**Cummins Paul J. Cummins, PhD**

The Bioethics Program  
Icahn School of Medicine at Mount Sinai  
Department of Medical Education



*Paul J. Cummins is Assistant Professor of Medical Education at the Icahn School of Medicine at Mount Sinai (ISMMS) and a member of The Bioethics Program. He earned a Ph.D. in Philosophy from The Graduate Center, CUNY. He teaches medical ethics to undergraduate and graduate medical students at ISMMS and bioethics in the Clarkson-ISMMS Masters in Bioethics Program. His primary research interests are in medical ethics education, conscientious objection, and, of late, climate change. He is married with an infant daughter, whose birth was the catalyst for his interest in climate change.*

**Michael S. Dauber, MA**

The Human Research Protection Program at  
Northwell Health  
St. John's University School of Law  
Voices in Bioethics  
Visiting Scholar, Global Bioethics Initiative

*Michael S. Dauber is a bioethicist who has served as a clinical ethicist and currently works as an IRB coordinator in the Human Research Protection Program at Northwell Health. He will begin studying law as a St. Thomas More Scholar at the St. John's University School of Law in August. He currently serves on the editorial staff of Voices in Bioethics: An Online Journal. He received an MA in bioethics from New York University and a BA in philosophy and journalism from Fordham University. His research has focused on the ethics of germline modification, head transplantation, cognitive enhancements, and luxury medicine, as well as various topics in theoretical and practical medical ethics.*

**Rosie Duivenbode, MD MSc**

Researcher, Initiative of Islam and Medicine  
University of Chicago



*Dr. Rosie Duivenbode works as a researcher for the Initiative of Islam and Medicine at the University of Chicago and is a medical ethics facilitator at the University of Cambridge Medical School. She recently completed a joint medical and clinical research degree. For her dissertation she conducted qualitative work on the medical decision-making of Dutch Muslim patients at advanced stages of disease to assess possibilities for Advance Care Planning.*



**Cheryl Frazier**

PhD Student  
University of Oklahoma

*Cheryl Frazier is a PhD candidate in philosophy at the University of Oklahoma. She does research in applied ethics and aesthetics, and is particularly interested in the ways in which art can help us better understand the world around us. Her most recent research explores issues in mental health, including epistemic injustice against those with mental illness and how different groups in society should respond to suicide attempts. Her dissertation is on artists' obligations to protect public health when creating works that center on themes of mental illness.*



**Marielle S. Gross Wolf**

Johns Hopkins University School of Medicine  
Department of Gynecology and Obstetrics



*Marielle is currently in her final year of residency in Gynecology & Obstetrics at Johns Hopkins. She attended medical school at the University of Florida, and prior to that, she completed degrees in Philosophy, Jewish Ethics and Bioethics at Columbia University, Jewish Theological Seminary, and New York University, respectively. Her research focuses on ethical issues in women's health, and she is passionate about addressing "prejudice-based medicine" (PBM) in American healthcare policies and practices. In particular, HIV has served as a lens for examining the influence of prejudice in American medicine on topics ranging from breastfeeding recommendations to access to artificial reproduction technology.*

**Roger Guy, PhD**

Professor, Department of Sociology and  
Criminal Justice  
University of North Carolina, Pembroke

*Roger Guy is a Professor of Sociology and Criminal Justice at the University of North Carolina at Pembroke. He received his Ph.D. at the University of Wisconsin-Milwaukee. Dr. Guy is currently engaged in collecting DNA samples from offenders and genotyping them for genetic risk for violent behavior. He has also published in the areas of prisoner reentry, community corrections, and correctional policy. His work has appeared in the Journal of Contemporary Criminal Justice, and Journal of Applied Social Science, Victims and Offenders, and Federal Probation. He has published one book in the field of sociology. He has also published qualitative work based on ethnographic research in Chicago. His most recent book, a community study in a Chicago neighborhood, appeared in 2016 and published by Rowman and Littlefield.*

**Kristen Hine, PhD**

Department of Philosophy and Religious  
Studies  
Towson University



*Dr. Hine is an associate professor of philosophy in the Department of Philosophy and Religious Studies at Towson University in Towson, MD. Her research has focused on issues in ethics, biomedical ethics, and philosophy of emotion. In her most recent paper, Dr. Hine considers whether the right to self-defense provides a new avenue through which one might be able to defend some cases of assisted suicide. Dr. Hine lives in Baltimore, MD with her boyfriend and two young children, and enjoys running and baking.*



**David Augustin Hodge, Sr.,  
DMin, PhD**

Associate Director of Education  
Associate Professor of Bioethics at  
The National Center of Bioethics in  
Research and Health Care  
and  
Associate Senior Editor of the Journal  
of Healthcare, Science, and  
Humanities  
Tuskegee University

Dr. David Augustin Hodge Sr. serves at Tuskegee University where he coordinates the center's Bioethics Honors program and bioethics minor, the annual Public Health Ethics Intensive Course, and various outreach programs designed to engage the center's target audiences, as well as teaches bioethics courses. He serves as senior associate editor for the University's peer-reviewed *Journal of Healthcare, Sciences, and Humanities*. A native of St. Thomas, U.S. Virgin Islands, Dr. Hodge's academic background also includes a bachelors in Bible, theology and English from American Baptist College; a master's in education from Oral Roberts University; a master of theological studies from Emory University; a doctor of ministry from Columbia Theological Seminary; and a PhD in Philosophy from the University of Miami.

**Robert Kelly**

University at Buffalo



*Robert Kelly is a Ph.D. candidate in the Department of Philosophy at the University at Buffalo. His research has included work in experimental philosophy, cognitive science of religion, and ethics. His main research interests are in ethics and philosophy of action, in particular, issues surrounding free will and moral responsibility, especially as they relate to addiction. Kelly's current research concerns questions about the nature of addiction, the nature of control in addiction, and whether and to what extent addicts are morally responsible.*

**David G Limbaugh, MA**

University at Buffalo

*David Limbaugh is a Ph.D. candidate at the University at Buffalo. He received an M.A. in Philosophy of Religion and Ethics from Talbot School of Theology in 2014. As part of his research, David worked as an associate ethics consultant at the Veterans Affairs Hospital in Buffalo during the 2015 and 2016 calendar years. His philosophical interests are in religion, medicine, applied ethics, and, metaphysics. His dissertation is in the metaphysics of science and develops a metaphysics of modality that centers around dispositional properties that primitively represent how reality could be. While completing his dissertation he continues to work on projects on the nature of disease, on the moral cost of implicit bias, and on analytic theology.*

**John P. Lizza, PhD**

Professor and Chair  
Department of Philosophy  
Kutztown University of Pennsylvania



*John Lizza is a Professor of Philosophy and Chair of the Philosophy Department at Kutztown University of Pennsylvania. His main philosophical interests are in bioethics, metaphysics, and philosophy of mind, particularly issues concerning persons, personal identity, and the beginning and end of life. He is the author of Persons, Humanity, and the Definition of Death (Johns Hopkins, 2006).*

**Barbara Noah, JD**

Professor of Law  
Western New England University School of  
Law

*Barbara Noah is a Professor of Law at Western New England University School of Law. She teaches Torts and a variety of health law subjects. Her research interests include legal and ethical issues in end-of-life decision-making; comparative end-of-life law; racial disparities in the delivery of health care, and clinical research ethics. She has served as a member of hospital Institutional Review Boards and hospital ethics committees. Barbara was a past Visiting Scholar at Exeter University School of Law in the United Kingdom and Queen's University School of Law in Kingston, Ontario, Canada. She also recently completed an appointment in 2017 as a Schulich Distinguished Visiting Scholar at Dalhousie University School of Law in Halifax, Nova Scotia. She received her J.D. from Harvard Law School.*

**Aasim I. Padela, MD MSc**

Director, Initiative of Islam and Medicine  
Associate Professor, Department of Medicine  
Faculty, MacLean Center for Clinical Ethics  
University of Chicago



*Dr. Aasim Padela is Dr. Padela is a clinician-researcher and bioethicist whose scholarship lies at the intersection of community health and religion. He utilizes diverse methodologies from health services research, religious studies, and comparative ethics to examine the encounter of Islam with contemporary biomedicine through the lives of Muslim patients and clinicians, and in the scholarly writings of Islamic authorities. Through systematic research and strategic interventions, he seeks (1) to improve American Muslim health outcomes and healthcare experiences, and (2) to construct a multidisciplinary field of Islamic bioethics.*



**Vardit Rispler-Chaim, PhD**

Professor of Islamic Studies  
Department of Arabic Language and  
Literature  
University of Haifa

*Prof. Vardit Rispler-Chaim teaches Islamic studies at the Department of Arabic Language and Literature at the University of Haifa, Haifa, Israel. She is the author of the books: *Islamic Medical Ethics in the Twentieth Century*. Leiden: E.J. Brill, 1993, and *Disability in Islamic Law*. Dordrecht: Springer 2007, two edited volumes on medical ethics in Islam, as well as of more than 30 articles on Islam and bioethics, on the status of women in Islam, and on Islamic legal issues.*

**Vicky Thornton, PhD MSc**

Senior Lecturer and Program Director, Bachelor  
of Nursing Program  
University of Liverpool



*Vicky Thornton is from the United Kingdom. She is a senior lecturer and Program Director for the University of Liverpool's Bachelor of Nursing program. Prior to her current appointment, she worked in critical care and then as a specialist nurse in organ donation and transplantation covering the Northwest of England and North Wales. She is particularly interested in palliative, end of life, and critical care, with a particular focus on decision-making. The title of her doctorate was "In search of a system which acquires the maximum number of organs and is consistent with a society's values". It focused specifically on issues relating to consent, altruism, and trust.*



<http://iameph.org/en/home-page/>



<http://plainethics.com/>



<https://dialogue.lehigh.edu/>