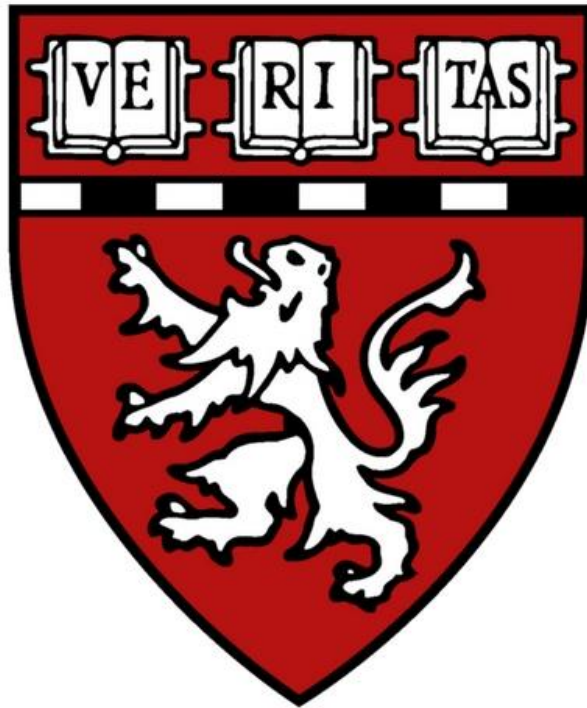


# *Master of Bioethics*

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## CAPSTONE SYMPOSIUM

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APRIL 27, 2017  
3-6:30 PM

# Program

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## Welcome

### The Value of the Capstone Program

**Rebecca Weintraub Brendel, MD, JD**

*Director, Master of Bioethics Degree Program and  
Assistant Professor of Psychiatry, Harvard Medical School  
Associate Psychiatrist and Director of Law and Ethics, Center for Law, Brain, and Behavior,  
Massachusetts General Hospital*

### Capstone Seminar Reflections

**Christine Mitchell, RN, MS, MTS**

*Executive Director, Harvard Medical School Center for Bioethics and  
Director, Master of Bioethics Capstone Program  
Lecturer, Global Health and Social Medicine, Harvard Medical School*

**Bizu Gelaye, MPH, PhD**

*Section Leader, Master of Bioethics Capstone Program and  
Lecturer on Global Health and Social Medicine, Harvard Medical School  
Research Scientist, Harvard Chan School of Public Health*

**David Sontag, JD, MBE**

*Section Leader, Master of Bioethics Capstone Program and  
Lecturer on Medicine, Harvard Medical School  
Deputy General Counsel, Beth Israel Deaconess Medical Center*

### What Do Bioethicists Do?

**Holly Fernandez Lynch, JD, MBE**

*Teaching Faculty, Master of Bioethics Program, Harvard Medical School  
Executive Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics,  
Harvard Law School*

### Closing Remarks and Invitation to Poster Presentations

**Christine Mitchell, RN, MS, MTS**

# Diana Alame

*Capstone Mentor: Christine Mitchell, RN, MS, MTS*

*Executive Director, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine, Harvard Medical School*

*Faculty Advisor: Rebecca Weintraub Brendel, MD, JD*

*Director, Master of Bioethics Degree Program, Harvard Medical School Center for Bioethics; Assistant Professor of Psychiatry, Harvard Medical School; Associate Psychiatrist and Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital*

## **Establishing the Online *Harvard Medical School Bioethics Journal***

Scholarship within bioethics requires a successful methodology of deliberation, discussion, and resolution. However, skills to communicate with and engage a wider audience in bioethics discourse are also critical. Public engagement in bioethical matters is a positive obligation that all bioethicists have, after the tools of bioethics have been mastered, and is key to a democratically motivated deliberative process. There is a deep interest in the Harvard Medical School Center for Bioethics to align academic and public communication on bioethical matters, as well as to have a dedicated online journal highlighting the rich academic work of faculty, students, and alumni in a publicly accessible format. The *Harvard Medical School Bioethics Journal* was, thus, created to meet the objectives of extending the bioethical discussion to a wider audience by maintaining a “hybrid voice”—one that fluidly incorporates an academic tone with journalistic accessibility. It will be an open-access journal published regularly by the Center. Bioethical analysis of current events will be the primary source for content. Relevant sections, within each edition, will represent areas in the field, including clinical and research ethics, health law and policy, and, on occasion, organizational ethics, and neuroethics. A “Frontiers” section will cover matters at the leading edge of science and emphasize the bioethical issues involved. A section titled “Bioethics in the Media” will break down the relevant bioethical issues of a headline news topic. A “Spotlight” video will feature a member of the Center and the work they do. One book will be reviewed in each edition, and a video interview with the author will accompany the review.



**Diana Alame, MD**, recently completed a clinical pathology residency and medical microbiology fellowship at Massachusetts General Hospital. She received an MD from the University of Illinois, and completed an intern year in emergency medicine followed by service in the United States Air Force. Diana’s bioethics focus involves exploring the implications surrounding stewardship of therapeutics and new, often costly, diagnostic innovations, and by larger extension, the general humanistic dilemma in resource-limited situations.

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# Ebony Allen

*Capstone Mentor: Karin Barrett, MEd*

*Deputy State Registrar, Registry of Vital Records and Statistics, Massachusetts Department of Public Health*

*Faculty Advisor: Louise King, MD, JD*

*Director of Reproductive Ethics, Harvard Medical School Center for Bioethics; Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center*

## An Analysis of Cause-of-Death Reporting: A Massachusetts Perspective

Death certificates are a source of personal and medical information. Data generated from these certificates provide key information for distributing health-related resources, determining mortality statistics, identifying disease outbreaks, and for understanding leading causes of death. Additionally, these certificates are important for legal, medical, and financial matters. However, the knowledge derived from death certificates are only as beneficial as the accuracy of cause-of-death reporting. The central challenge in death certificate records is that cause-of-death reporting has historically been, and continues to be, inaccurate and/or incomplete. The purpose of this capstone project was threefold: (1) to understand why physicians are failing to fully and accurately complete death certificates by developing two survey questionnaires (the first survey was completed by officials at the Massachusetts Department of Public Health and the second survey was completed by physicians who fill out death certificates most frequently in Massachusetts); (2) to explore the ethics of open access to death certificates by providing an ethical analysis of death and researching the parameters of privacy and confidentiality after death; and (3) to draft a policy recommendation for whether death certificates should remain open to the public in Massachusetts. Future plans include starting a general data-quality campaign in collaboration with the Massachusetts Department of Public Health Registry of Vital Records and Statistics and to piloting a continuing education module on the importance of death certificates, and how to accurately complete death certificates.



**Ebony Allen, MSc**, received an MSc from the University of Rochester School of Medicine and Dentistry. Her MSc project focused on how physicians' experiences could be used to evaluate the law, amend the law, and be used for education. She is interested in medical decision making, neuroethics, and the ethical, legal and social implications of emerging technologies. Ebony was selected to speak on commencement day to represent the Class of 2015 at Augustana College. She has also served as an administrative associate at Yale University's Sherwin B. Nuland

Summer Institute in Bioethics.

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# Griffen Allen

*Capstone Mentors: Lauge Sokol-Hessner, MD*

*Assistant Professor of Medicine, Harvard Medical School; Associate Director of Inpatient Quality, Beth Israel Deaconess Medical Center*

*Lachlan Forrow, MD*

*Associate Professor of Medicine, Harvard Medical School; Director of Ethics Programs, Beth Israel Deaconess Medical Center*

*Faculty Advisor: Spencer Hey, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Research Fellow in Medicine, Division of Pharmacoepidemiology and Pharmacoeconomics, Brigham and Women's Hospital*

## **Improving Rates of Health Care Proxy Completion at Beth Israel Deaconess' Healthcare Associates**

The purpose of this capstone project was to identify opportunities for increased rates of health care proxy completion at Beth Israel Deaconess Medical Center (BIDMC). Health care proxies in Massachusetts are critically important because they are the only mechanism by which an individual may grant legal decision-making authority for medical care to another person. Specifically, there is no default surrogate decision-making provision in Massachusetts for family or relatives. Building upon prior work by Lauge Sokol-Hessner, MD, which addressed proxy completion at BIDMC, this project consisted of conducting in-person observations of the clinic's workflow to assist in the process mapping of an innovative workflow protocol for proxy designation in an outpatient setting, analyzing data, and contributing to the authorship of a journal manuscript about the work. Overall, using medical assistants and certified administrative assistants to encourage all patients, regardless of overall health, to designate a health care proxy during the course of their visit as a normal part of routine care showed increased rates of proxy completion. In addition to empirical work, my capstone experience also included observing the activities of the BIDMC Ethics Support Service with capstone mentor Lachlan Forrow, MD, including attending rounds and engaging in analysis of challenges in bioethics.



**Griffen Allen, BA**, received his BA from Colby College with a major in philosophy. He completed his senior honors thesis on moral epistemology and end-of-life care. He is interested in the bioethical problems that arise in end-of-life care especially in cases of normative and empirical uncertainty. Griffen is a member of Phi Beta Kappa and has been accepted to the Medical College of Georgia.

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# Sarah Bates

*Capstone Mentor: Brendan Abel, JD*

*Legislative and Regulatory Affairs Counsel, Massachusetts Medical Society*

*Faculty Advisor: Rebecca Weintraub Brendel, MD, JD*

*Director, Master of Bioethics Degree Program, Harvard Medical School Center for Bioethics; Assistant Professor of Psychiatry, Harvard Medical School; Associate Psychiatrist and Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital*

## **A New Battleground for the Fight Against Fatal Opioid Overdose in Massachusetts: An Ethical Analysis of Supervised Injection Facilities**

The opioid epidemic in the United States has reached crisis proportions. This capstone project addressed one possible clinical and policy response to this public health concern: supervised injection facilities, (SIFs). SIFs allow participants to inject drugs in the presence of clinicians, who also offer resources and linkages to primary care, addiction management, and other medical and human services. SIFs are new to the United States—Seattle’s King County announced in late January that they intend to establish the first two SIFs in the country. However, Switzerland, the Netherlands, and several other European countries have operated SIFs for years. As a result, there is now a robust literature from Europe supporting the success of SIFs as a public health intervention. However, SIFs are also associated with risks and financial costs. This capstone project, based in government relations at the Massachusetts Medical Society (MMS) was part of a larger MMS project to determine its position on SIFs. This project focused on an ethical analysis of SIFs using a principlist framework following Beauchamp and Childress. Arguments in favor of and opposed to SIFs, drawn from an extensive literature review, are grouped and analyzed through the four ethical principles of autonomy and respect for persons, nonmaleficence, beneficence, and justice.



**Sarah Bates, BA**, is a part-time staff assistant in the Undergraduate Psychology Office, Harvard University. Sarah, received a BA from Middlebury College. She interned for a year with the Beth Israel Deaconess Medical Center Ethics Support Service, where she observed ethics consultations and collaborated on various research projects. Sarah’s interest in medical ethics is to understand the philosophical underpinnings of medical ethics, the ethics of end-of-life care, and narrative medicine.



# Eric Busse

*Capstone Mentors: Rev. Joanne Braxton, PhD  
President and CEO, Braxton Institute*

*Rev. Rita Nakashima Brock, PhD  
Director, Soul Repair Center*

*Faculty Advisor: Christine Mitchell, RN, MS, MTS  
Executive Director, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine, Harvard Medical School*

## **A Heuristic Model for Engaging Moral Injury and Collective Healing: Amplifying Community, Creativity and Spirituality**

Ten years ago, mental health professionals specializing in combat trauma began to clarify moral dimensions of veteran experience beyond the rubric of post-traumatic stress disorder. These clarifications eventually gave rise to the discourse of “moral injury.” Today, researchers and practitioners articulate the dynamics of moral trauma in the experiences of other populations as well, including those of formerly incarcerated individuals. Literature describing the theoretical parameters of moral injury and promising interventions continues to grow in the fields of psychology, theology, philosophy, and education. The purpose of this capstone project was to contribute to the growing discourse of moral injury. A key aspect of the project aimed to translate theory into practice, as will occur through the upcoming “Moral Injury and Collective Healing: Advanced Training Seminar” in collaboration with the Braxton Institute, the Soul Repair Center at Brite Divinity School, and Volunteers of America. The primary objectives of this upcoming nonsectarian, community-based training are to leverage communal resources responsive to the needs of veterans and formerly incarcerated individuals, cultivate communities of exchange on matters of praxis and pedagogy, enhance public literacy of moral injury research, and forge communities characterized by commitments to restorative justice and democratic deliberation in response to wounds of moral conscience. To these ends, a heuristic model was designed to visualize the ways in which this experiential advanced training seminar aims to engage communal resources and collective action in moral injury response. In the coming months, additional research at the Library of Congress will culminate in a comprehensive compendium of resources for communities seeking to understand and ethically respond to moral injury.



**Eric Busse, BA**, is an MDiv Candidate at Harvard Divinity School, where he studies spiritual care, ethics, and religious pluralism. As an undergraduate, he conducted research at the intersections of performance, education, healing, and social justice. He is a fellow of the Harvard Graduate School Leadership Institute, a member of the Harvard College Board of Freshman Advisors, the director of training at Scouts for Equality, and a U.S. Navy chaplain candidate. This year, Eric will serve as a Library of Congress summer research fellow. Eric seeks to understand moral experiences of violence, care, and the ways in which these experiences inform the bioethics of stigma, marginalization, and disparities in health and education.

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# Dorothee Caminiti

*Capstone Mentor: Louise King, MD, JD*

*Director of Reproductive Ethics, Harvard Medical School Center for Bioethics; Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center*

*Faculty Advisor: Eftychia Vayena, PhD*

*Faculty in Residence, Harvard Medical School Center for Bioethics; Visiting Assistant Professor in Global Health and Social Medicine, Harvard Medical School; SNSF Professor of Health Policy Health Ethics and Policy Lab, Epidemiology, Biostatistics and Prevention Institute, University of Zurich*

## Oocyte Donation Compensation – Where Are We Heading?

In the United States, compensation for oocyte donation is legally permitted but not regulated. Attempts to create guidelines for appropriate compensation, based on comparison to sperm donations, were met with legal action when, in April of 2011, the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology were both sued in response to their positions that payments to oocyte donors should be limited to \$5,000 (or to \$10,000 under exceptional circumstances). Legal rationales for the lawsuit included allegations of illegal price-fixing in violation of antitrust laws. Because of a 2016 settlement, no formal findings were made by the court, and no guidance was issued regarding what compensation would be reasonable and noncoercive. The purpose of this capstone project was to explore how payments for oocyte donation might be determined based on a comparison with other tissue donations. Specifically, this project compared oocyte donation to blood, plasma, bone marrow, sperm, embryos, placenta, breast milk, and hair donations. Our study found that: (1) The average compensation currently offered for oocyte donation is much higher than that for other human tissue donations, and that (2) the academic literature on the compensation offered for other tissue donation is scarce, and there is a general lack of transparency regarding both oocyte donations and other human tissue donations. This study culminated in recommendations that reproductive endocrinologists should consider compensations provided for other tissue donations when assessing for coercion in their interactions with oocyte donors and recipients. We believe that further transparency is necessary, especially from the agencies involved, and that legislation may be needed to address appropriate compensation and avoid potential coercion.



**Dorothee Caminiti, JD, LLM**, received a JD from Université Catholique de Louvain and a LLM in intellectual property from both the University of Leicester and Université de Liège. She previously was an attorney in the Litigation and Arbitration Department at Cleary Gottlieb Steen & Hamilton in Brussels. Dorothee is interested in bioethical issues related to the beginning of life as well as genomics. She has worked on complex major litigation cases related to financial banks and other corporate clients.

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# Traci Cucinotta

*Capstone Mentor: David Sontag, JD, MBE*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Lecturer on Medicine, Harvard Medical School; Deputy General Counsel, Beth Israel Deaconess Medical Center*

*Faculty Advisor: J. Wesley Boyd, MD, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Associate Professor of Psychiatry, Harvard Medical School; Codirector of Human Rights and Asylum Clinic, Cambridge Health Alliance*

## How Guardians Make Decisions

This capstone project examined how guardians make decisions for adults with diminished capacity. As surrogate decision makers must often employ the standards of substituted judgment and best interest, it is essential that decisions be grounded in value and guiding principles. This qualitative study interviewed a convenience sample of Massachusetts guardians from two publicly available lists, one from the Massachusetts Guardianship Association and the other from the National Guardianship Association. The iterative process of coding and question development focused on three primary research questions: (1) How guardians make decisions for people under their care; (2) How guardians describe the process of decision making—best interest or substituted judgment; and (3) Identifying areas of decision making for which guardians would benefit from more training. Individual identities of respondents remained confidential. The findings showed that guardians feel ill-equipped to make complex medical and personal decisions for incapacitated persons and consider multiple factors in the decision-making continuum between substituted judgment and best interest, including the incapacitated person's wishes, values and history (if known), and the risks associated with the decision at hand. These findings will inform a training protocol for new professional and family guardians that will include collaboration and support for those who are making important medical and personal decisions for individuals for whom they are appointed.



**Traci Cucinotta, MSW, LICSW**, is a clinical social worker at North Shore Medical Center (NSMC) on the Salem and Union Campuses and serves on the NSMC Ethics Advisory Committee. She received a BSW from West Virginia University and an MSW from Salem State University. She studied ethics and bioethics at both Gordon Conwell Theological Seminary and Trinity International University. Her interest in bioethics is to explore how individuals and institutions navigate the complexity of medical information and decisions which often accompany issues of life and death.

# Adam DeTora

*Capstone Mentor: David Urion, MD*

*Associate Professor of Neurology, Harvard Medical School; Charles F. Barlow Chair in Neurology, and Director of Education and Residency Training Programs in Clinical Neurology and Clinical Neurodevelopmental Disabilities, Boston Children's Hospital*

*Robert Truog, MD*

*Director, Harvard Medical School Center for Bioethics; Frances Glessner Lee Professor of Medical Ethics, Anaesthesia, and Pediatrics, Boston Children's Hospital*

## **Differences in Attitudes Towards Treatment of Infants with Brain Injury by Neonatologists and Pediatric Neurologists**

One of the most common causes of death in the neonatal intensive care unit (NICU) for full- or near-term infants is brain injury. Few studies have examined decision-making for end-of-life care for infants with brain injury. Other areas of neonatology (e.g. periviability) have shown wide variety in medical practice between physicians, including within neonatology and between different specialists. The purpose of this capstone project was to examine provider beliefs, attitudes, and practices when caring for infants with brain injury. This project used methods of anonymous, paper surveys distributed to neonatology and pediatric neurology attending physicians during faculty meetings. Survey questions included several case scenarios about infants with varying degrees of brain injury as well as demographic data and questions related to ethics consultation. To date, preliminary responses have been obtained from neonatologists. Responses from pediatric neurologists will be obtained in the near future so that response patterns can be compared. Overall, this capstone pilot study may show overt or subtle differences in response patterns between neonatologists and pediatric neurologists. It is possible that pediatric neurologists would be less likely to choose withdrawal or withholding of life-sustaining interventions for infants with brain injury. Neonatologists, however, may be more apt to choose withdrawal or withholding of life-sustaining interventions due to their scope of practice in caring for infants who are critically ill as well as deference to parental preferences. We hypothesize that the longitudinal care that pediatric neurologists provide to patients and their families may influence their decision making since parents will have time to cope with their child's illness and developmental or functional limitations.



**Adam DeTora, MD**, Assistant Director of Neonatal Education at Massachusetts General Hospital (MGH), is involved with the Optimum Care Committee and the Pediatric Ethics Committee at MGH. He received a BS in biology from Cornell University and an MD from the University of Massachusetts Medical School, where he also completed a residency in pediatrics. He completed fellowship training at Boston Children's Hospital. His interests are in neonatal health, law and policy. Adam completed the fellowship in medical ethics at Harvard Medical School in 2015.

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# Roberta Driscoll

*Capstone Mentor: Joseph T. Giacino, PhD*

*Associate Professor of Physical Medicine and Rehabilitation, Harvard Medical School; Director of Rehabilitation Neuropsychology, Spaulding Rehabilitation Hospital*

*Faculty Advisor: Spencer Hey, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Research Fellow in Medicine, Division of Pharmacoepidemiology and Pharmacoeconomics, Brigham and Women's Hospital*

## **An Overview of Guardianship in Massachusetts: Balancing Respect for Autonomy and Provision of Care**

The need for a patient's informed consent for medical treatment and clinical research is the embodiment of the bioethical principles of autonomy and respect for personhood. Unfortunately, illness or injury can result in incapacity which leaves some patients unable to provide informed consent. If a patient has previously completed a health care proxy, there is a designated health care agent with the authority to make health care decisions on his or her behalf. Typically, this agent is an individual the patient trusts to act in accordance with the patient's expressed wishes regarding treatment. However, if there is no health care proxy, steps need to be taken to identify and authorize someone to make medical decisions. The only process for doing so in Massachusetts is to legally appoint a guardian. This court proceeding can be a complicated and expensive process for a family to undertake. Moreover, some patients are "unbefriended" in that they have no friends or family to serve as a guardian; as a result, a stranger serves as guardian. This capstone project aimed to look critically at the guardianship process in Massachusetts, particularly as it pertains to supporting the autonomy and personhood of the patient, and how it ensures that the patient receives appropriate and desired medical care. This capstone included a review of guardianship statutes nationally, a review of current efforts to improve the guardianship process in Massachusetts, and culminated in recommendations for future efforts.



**Roberta Driscoll, JD**, received a JD from the New England School of Law. She practiced law in Massachusetts for more than fifteen years, focusing on general civil litigation and appellate advocacy, particularly in the areas of family law, child welfare, and access to special education services. In 2009, she joined Dana-Farber Cancer Institute (DFCI), where she served as director of the Office of Research Integrity and research integrity officer and was a member of the institutional review board (IRB) and the Ethics Advisory Committee. She received the DFCI Ethics Award in 2015. In

December 2016, Roberta left her position at DFCI to return to the practice of law. Her practice specializes in guardianships, conservatorships, and post-judgment appellate representation.

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# Jeffrey Gruenglas

*Capstone Mentor and Faculty Advisor: Aaron S. Kesselheim, MD, JD, MPH*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Associate Professor of Medicine, Harvard Medical School; Associate Physician, Division of Pharmacoepidemiology and Pharmacoeconomics, Department of Medicine, Brigham and Women's Hospital*

## **Direct-to-Consumer Advertising (DTCA): Building An Ethical Framework for Evaluation**

In direct-to-consumer advertising (DTCA) in the United States, pharmaceutical companies promote disease information and approved prescription therapies to prospective patients and their caregivers. Numerous studies have identified DTCA practices that minimize the known risks of the drug being promoted, overstate therapeutic benefit, and undermine the epistemic basis for informed decision-making, particularly for individuals with life-threatening and terminal disease. Sponsors of such communications are bound by ethical norms and legal rules to ensure that information is truthful and not misleading. But such principles—and an appropriate model — may not be followed consistently. The aim of this capstone project was to locate variances between current practice and ethical standards to inform an ethical framework to evaluate DTCA campaigns for cancer drugs. The project employed a three-phase mixed methodology: 1) literature survey; 2) assessment of established ethical codes and legal rules (PhRMA, FDA); and, 3) evaluation of active DTCA campaigns for two FDA-approved cancer immune checkpoint therapies (nivolumab and pembrolizumab). The findings showed a substantial gap between theoretical and applied ethical principles, including lack of autonomy and inappropriate characterization of drug benefits and risks. Careful and proactive evaluation of DTCA practices are critical to optimizing patient safety and preserving the integrity of a just and fair health care system. The project concluded with a proposal for a theoretical algorithm that accounts for principles essential to ethical application of DTCA. This model introduces a framework that may be practically adopted and employed by organizations in their evaluation of DTCA that complies with the highest ethical standards.



**Jeffrey Gruenglas, MA**, Executive Vice President of Oncology, The Access Group, received a BA in English and pre-medical studies and an MA in English and critical theory from City University of New York–Brooklyn College. Jeff's research focuses on health care policy and pharmaceutical industry reform, with a particular focus on justice and equality in access to care. Jeff is the recipient of numerous pharmaceutical industry awards recognizing excellence in healthcare marketing, strategy, and communications.

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# Evelyne Joseph-Noël

*Capstone Mentor: Judi Friedson, RN, MSN  
Clinical Ethicist, Boston Children's Hospital*

*Faculty Advisor: Judith A. Johnson, JD  
Teaching Faculty, Harvard Medical School Center for Bioethics; Lecturer on Anaesthesia,  
Boston Children's Hospital*

## **Identifying and Overcoming the Obstacles to the Implementation of a Bloodless Medicine and Surgery Program as an Alternative to Blood Transfusion in Boston**

Bloodless medicine and surgery consists of many techniques used to build up a patient's blood supply and minimize blood loss by recycling the patient's blood during surgery. Bloodless surgery began in the 1960's as an alternative for Jehovah's Witness patients; however, patients today decline blood transfusions for both religious and non-religious reasons. Blood transfusions often save lives, but can be both risky and expensive. Although more than 100 bloodless medicine and surgery centers in the U.S. offer a safe and a more economical alternative to blood transfusion, none are in the Boston area. Through structured interviews with doctors in the Boston area and with directors of bloodless medicine centers at Johns Hopkins and Englewood Hospitals, this capstone project identified five main obstacles to the creation and implementation of bloodless medicine and surgery programs in the Boston area and outlined the benefits of such programs for hospital administrators, providers, and patients. Finally, the project proposed three ways to overcome the obstacles. The creation of a bloodless medicine and surgery program would provide patients in the Boston area with a safe alternative to blood transfusions and offer Boston's medical institutions an ethical and economical alternative for health care delivery.



**Evelyne Joseph-Noël, RN, BSN**, is a nurse in the Emergency Department at Massachusetts General Hospital (MGH). She received a BSN from Northeastern University and completed a ten-month clinical ethics residency for nurses (CERN) at MGH that focused on advancing expertise and skills for compassionately caring for patients. She is a member of the Ethics in Clinical Practice (EICP) Committee at MGH. Evelyne is the recipient of the 2015 Excellence in Nursing award from the New Regional Black Nurses Association and of the 2016 scholarship award from the Association of Multicultural Members of Partners. She is a member of the Society for the Advancement of Blood Management. Evelyne is interested in exploring bioethical issues affecting minority populations and raising awareness of them through education and advocacy.

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# John Limouze

*Capstone Mentor: Martha Jurchak, PhD, RN*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Instructor in Psychiatry, Harvard Medical School; Executive Director, Office of Clinical Ethics, Brigham and Women's Hospital*

*Faculty Advisor: Robert Truog, MD, MA*

*Director, Harvard Medical School Center for Bioethics; Frances Glessner Lee Professor of Medical Ethics, Anaesthesia, and Pediatrics, Boston Children's Hospital*

## **Expansion of an Ethics Committee at Cambridge Health Alliance to include Everett Hospital Campuses and the Community Health Centers in Everett, Revere, and Malden**

This capstone project focused on expanding the ethics consultation service at Cambridge Health Alliance (CHA). CHA is predominantly a network of outpatient clinics offering primary care and specialty services to the populations of Cambridge and Somerville. Historically, CHA centered around the Cambridge City Hospital, a public hospital and key part of the health safety net for these communities. In recent years, following the incorporation of the Whidden Memorial Hospital in Everett, CHA has introduced a number of clinics to the communities of Everett, Revere, and Malden. These communities are to some degree demographically and culturally distinct, with different medical needs and different ethical concerns and considerations. However, the CHA Ethics Consultation Committee remains composed largely of providers at the Cambridge Hospital and the clinics close to it. As a provider situated primarily at the Everett Hospital campus, one purpose of this capstone was work to recruit members that would represent the community and staff in Everett and the surrounding areas in order to better address the specific concerns of these communities. But challenges remain. Cambridge Health Alliance is a small organization, and few staff have formal ethical training. Growing the ethics committee has required attention to the education and supervision of committee members, both in the deliberation of issues that come before the committee, and in the practice of ethics consultation. Although this project has increased representation to the Everett campus, work nonetheless remains as the committee meets and is largely situated at CHA's hospitals, while the primary mission of the institution is community health and primary care. Future work will address these challenges.



**John Limouze, MD**, Associate Chief, Division of Hospitalist Medicine, Cambridge Health Alliance (CHA), received an MD from the University of Pennsylvania, and completed his internship and residency in internal medicine at the University of Michigan. At CHA, he has been active in resident and medical student education and serves on the ethics consult service. John's interests include developing trust between providers and patients in vulnerable populations, quality measurements and improvements, and organizational ethics in safety-net institutions.

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# Amy Dockser Marcus

## *Capstone Mentors: Eftychia Vayena, PhD*

*Faculty in Residence, Harvard Medical School Center for Bioethics; Visiting Assistant Professor in Global Health and Social Medicine, Harvard Medical School; SNSF Professor of Health Policy Health Ethics and Policy Lab, Epidemiology, Biostatistics and Prevention Institute, University of Zurich*

## *Martha Montello, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine, Harvard Medical School; Associate Professor, University of Kansas*

## *Faculty Advisor: Christine Mitchell, RN, MS, MTS*

*Executive Director, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine, Harvard Medical School*

## **Raising Ethics: Parents of Critically Ill Children Taking the Lead in Scientific Research**

Citizen science, the phenomenon of lay participation in research, is increasingly popular but key questions remain about the ethical standards that should apply. This capstone project focused on citizen science through the parents of ill children who lead research and scientific collaborations that have been successful in attracting resources, government attention, and research to diseases such as NGLY-1 deficiency, Niemann-Pick Type C disease, and Sanfilippo syndrome. This work showed that ethical tensions often arise when parents and scientists try to work together, particularly due to the conflict between the urgent demand for treatment on the part of parents and an often greater reluctance by scientists to proceed without first collecting substantial evidence of safety. The work showed that the current framework for research ethics is constructed for scientific inquiry where the roles and responsibilities of all participants are more clearly defined and does not sufficiently address the key ethical dilemmas of parents and scientists who want to produce scientific knowledge as partners. This project has demonstrated the need to study and better understand potential differences in the moral concerns of traditional scientific inquiry and citizen science, which should inform an ethical framework that accounts for novel perspectives and offers a way to resolve moral tensions when they arise.



**Amy Dockser Marcus, BA**, is a staff reporter for *The Wall Street Journal*, where she covers health and medicine. She received a BA from Harvard-Radcliffe. Amy's journalism focuses on patient advocacy and rare diseases, and often touches on ethical issues surrounding patients' experiences with the medical and scientific establishment. She was awarded the Pulitzer Prize in 2005 for Beat Reporting.

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# Gloria Teta Mason

*Capstone Mentors: Sabune Winkler, JD*

*Director of Regulatory Foundations, Ethics, and Law Program, Harvard Catalyst, The Harvard Clinical and Translational Science Center*

*Rebecca Li, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Instructor in Medicine, Harvard Medical School; Executive Director, Multi-Regional Clinical Trials Center, Department of Medicine, Brigham and Women's Hospital*

*Faculty Advisor: Melissa Abraham, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Assistant Professor of Psychology, Department of Psychiatry, Harvard Medical School; IRB Chair, Partners Human Research Committee, Massachusetts General Hospital*

## Understanding the Role of Data and Safety Monitoring Board (DSMB) in Clinical Trials During an Emergency

The unprecedented Ebola virus disease (EVD) epidemic in West Africa, particularly in Liberia, resulted in an increase in clinical trials around the region to help develop effective treatment to alleviate the disease burden caused emerging infections. For safety and efficacy purposes, these trials were reviewed and monitored by institutional review boards (IRBs) and data and safety monitoring boards (DSMBs). This capstone project sought to understand the roles of DSMBs in protecting the safety of clinical trial participants by exploring the communications framework between the operations of IRBs and DSMBs in the United States with a special focus on vulnerable populations. The ultimate goal of the project was to enable development of a communication framework to strengthen the roles of IRBs and DSMBs during outbreaks. The project relied on interviews with principal investigators (PIs), and IRB and DSMB chairs and case study in the United States and Liberia. The specific aims of this project were to: (1) Identify communication pathways utilized by IRBs and DSMBs in clinical trials during emergencies; (2) Develop a communication framework to support researchers and IRBs in resource-limited settings; and, (3) Develop a plan to educate local research communities about the roles and functions of DSMBs. This work will inform education for Liberian researchers, IRB members, and community leaders about the roles and functions of DSMBs, and develop a communication framework curriculum for IRBs and DSMBs in Liberia. This model could also be applied to other resource-limited countries that recently recovered from EVD outbreaks.



**Gloria Teta Mason, BA**, Coordinator, Liberian National Research Ethics Board, received a BA in sociology and management from the University of Liberia. She has worked with Liberian communities on a variety of public health issues in her U.S.-Liberia joint Clinical Partnership (PREVAIL)-endorsed role. Gloria has trained at the World Health Organization, the Department of Bioethics at the National Institutes of Health, and at the Johns Hopkins Berman Institute of Bioethics. She focuses on contributing to scientific research in Sub-Saharan Africa in order to confront the most devastating effects of infectious diseases, poverty, and injustice. Gloria plans to study law.

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# Adil Menon

*Capstone Mentor: Lida Nabati, MD*

*Instructor in Medicine, Harvard Medical School; Senior Physician, Dana-Farber Cancer Institute*

*Faculty Advisor: J. Wesley Boyd, MD, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Associate Professor of Psychiatry, Harvard Medical School; Codirector of Human Rights and Asylum Clinic, Cambridge Health Alliance*

## Survey Development Regarding Ethics Education for Clinical Research Staff

Given the rapid pace of scientific advancement, determining and addressing the ethics challenges that arise as a result is a vital, if daunting, enterprise. While studies indicate that training has improved over the past decade with regards to knowledge, awareness, and ethical decision-making, considerable variability still exists across programs. The purpose of this capstone project was to gain a clearer understanding of the ethics challenges that Dana-Farber Cancer Institute (DFCI) researchers encounter in their work. DFCI is a premier research institution that stands at the forefront of the issues with ethics training outlined above. In recent years, the leadership at DFCI and its Ethics Advisory Committee have become increasingly aware of the fact that staff involved in research are increasingly seeking opportunities for engagement with ethics and addressed this trend as an indication of a growing need for ethics education, guidance, and support. Given that much of the variation in ethics training arises from the substantial range in instructional training content utilized across ethics training courses, this capstone project specifically sought to isolate the issues most relevant to DFCI. The goal was to identify ethics resource needs and potentially provide recommendations for developing tools and strategies to better support the ethics needs of research staff. While the ultimate institutional goal of this project is to undertake a comprehensive institution-wide, grant-funded investigation, this capstone project embarked on a smaller pilot group inquiry as a demonstration of feasibility. Ultimately, this capstone project will inform future directions in identifying ethics resource and training needs and strategies for implementation.



**Adil Menon, BA**, received a BA with honors in the history, philosophy and social science of science and medicine (HIPS) from the University of Chicago. He is interested in bioethical challenges surrounding equitable recruitment of participants for clinical research, domestically and abroad. Adil has published in Hektoen International and the Rutgers Journal of Bioethics. He received an American Heart Association award for undergraduate research. He plans to attend the University of Illinois School of Medicine.

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# Yusuke Mori

*Capstone Mentor: M. William Lensch, PhD  
Chief of Staff, Harvard Medical School*

*Faculty Advisor: Aaron S. Kesselheim, MD, JD, MPH  
Teaching Faculty, Harvard Medical School Center for Bioethics; Associate Professor of  
Medicine, Harvard Medical School; Associate Physician, Division of Pharmacoepidemiology  
and Pharmacoeconomics, Department of Medicine, Brigham and Women's*

## **Clinical Application of Human Induced Pluripotent Stem Cells and Bioethical Issues**

In 2012, Professor Shinya Yamanaka at Kyoto University and Professor John Gurdon at the University of Cambridge received the Nobel Prize in Physiology or Medicine for their “discovery that mature cells can be reprogrammed to become pluripotent.” This finding was significant not only for elucidating the reprogramming mechanism of mature cells, but also for creating a novel type of stem cell: the induced pluripotent stem cell (iPSC). The iPSC has the potential to differentiate into different types of cells including a muscle cell, a nerve cell or a blood cell. Therefore, human iPSCs are expected to be used for cell therapy or regenerative medicine, where dysfunctional cells or even organs can be replaced by new ones derived from iPSCs. The purpose of this capstone project was to identify ethical issues that might arise in the course of research involving iPSCs through research initiatives at the Harvard Stem Cell Institute. The Institute recently launched a clinical study on diabetes aimed at curing Type I diabetes by injecting pancreatic beta cells derived from patient iPSCs. The research investigators have started participant recruitment to assess feasibility for individuals who have undergone pancreatectomy for other medical conditions. Using interviews and review of informed consent forms, this capstone project identified one crucial bioethical issue in clinical application of iPSCs: whether incidental findings on genetic mutations ought to be returned to study participants. The final capstone project aimed at describing the issue in detail and suggesting possible study design to avoid potential harm to research participants.



**Yusuke Mori, PhD, MPA**, Specialist, Japan Ministry of Education, Culture, Sports, Science and Technology, received a PhD in integrated biosciences from the University of Tokyo and an MPA from the Harvard Kennedy School. He is interested in bioethical issues related to cutting-edge science and technology, such as synthetic biology and stem cell research. In 2010, Yusuke received the Young Scientist Award from the 17th East Asia Joint Symposium on Biomedical Research (Taiwan), and received the Global Universities Challenge Award from the World Government Summit (Dubai)

in 2017.

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# Sarah Murphy

*Capstone Mentor: Judith Edersheim, JD, MD*

*Assistant Professor of Psychiatry, Harvard Medical School; Cofounder and Codirector of the Center for Law, Brain and Behavior, and Attending Psychiatrist, Massachusetts General Hospital*

*Faculty Advisor: Holly Fernandez Lynch JD, MBE*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Executive Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics, Harvard Law School*

## Assessing the Conditions That Lead to False Confessions

False confessions are known to have played a role in at least thirty percent of convictions of individuals who were subsequently exonerated with DNA evidence in the U.S. The factors known to increase the risk of a false confession are young age, mental impairment, duress or coercion, fear of violence, and misunderstanding the factual or legal situation. Modern neuroscience is beginning to illuminate the neural basis for people's tendency to falsely confess under such conditions. In combination with known psychological factors such as maturation and responses to stress, neuroscience may be able to provide a basis upon which to challenge confessions obtained under these circumstances. This body of evidence is beginning to gain recognition within U.S. law in the context of juvenile accused persons. The purpose of this capstone project was to identify the factors implicated when the police obtained a confession from an individual whose interests are now represented by the Innocence Project. In the 1980s the client, who suffers from a mental illness, was aggressively interrogated over the course of ten hours, at the end of which he had confessed to a homicide in a state of confusion and exhaustion. He was found guilty at trial and has been imprisoned for the past thirty years. However, subsequent DNA analysis has demonstrated that the client could not have committed the crime. This project involved assisting in the legal briefing for the case and identifying the ethical concerns.



**Sarah Murphy, LLB, BSc**, received an LLB and BSc from the University of Auckland with a thesis focus on the admissibility of neuroscientific evidence. She is a former judicial clerk to Dame Judith Potter and previously served as legal assistant at the Special Tribunal for Lebanon. She is interested in bioethical issues that arise in a legal setting regarding the treatment given to defendants with mental health conditions.

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# Ariana Nesbit

*Capstone Mentor: Jill Clark, MPH*

*Director, Office of Sexual Health and Youth Development, Massachusetts Department of Public Health*

*Faculty Advisor: Rebecca Weintraub Brendel, MD, JD*

*Director, Master of Bioethics Degree Program, Harvard Medical School Center for Bioethics; Assistant Professor of Psychiatry, Harvard Medical School; Associate Psychiatrist and Director of Law and Ethics, Center for Law, Brain, and Behavior, Massachusetts General Hospital*

## **Long-Acting Reversible Contraception (LARC) Initiatives: Historical, Social, and Ethical Considerations**

Long-acting reversible contraception (LARC) has historically been medically problematic and has been used as an instrument of social control. Over the past decade, as safer methods have been developed and the medical risks have been clarified, LARCs have become a much more popular birth control method in the United States and are now supported by many organizations as first-line contraceptives. While many providers and women's health experts are enthusiastic about these new methods and have been working to promote LARCs to clients, others working in the fields of women's and public health are struggling to figure out how to ensure appropriate access to these methods without coercion and control. This capstone project sought to support ethically responsible recommendations for LARC policy. Through interviews with experts in the community and a literature review on the historical, ethical, and social issues regarding LARCs and their related policies, this capstone developed a broad exploration of LARC practices. Based on this research and an ethical analysis, it concluded with recommendations to the Massachusetts Department of Public Health about how to ensure access to LARCs in an ethically sound way without unduly pressuring women into choosing these methods.



**Ariana Nesbit, MD**, is a fourth-year psychiatry resident at Cambridge Health Alliance. She received a BS in medical biology from the University of New England and attended medical school at the University of Vermont. Ariana is particularly interested in ethical issues that arise in forensic psychiatry and the psychiatric aspects of jurisprudence. She is a member of the Alpha Omega Alpha Honor Society and is a Rapoport Fellow of the American Academy of Psychiatry and the Law. She begins a forensic psychiatry fellowship at the University of California, Davis, this summer.

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# Elias Pavlopoulos

*Capstone Mentor: Bizu Gelaye, PhD, MPH*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine; Research Scientist, Harvard T.H. Chan School of Public Health*

*Faculty Advisor: J. Wesley Boyd, MD, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Associate Professor of Psychiatry, Harvard Medical School; Codirector, Human Rights and Asylum Clinic, Cambridge Health Alliance*

## **Vaccination Programs for Migrants and Refugees in Europe: Ethics and Policy Analysis**

According to estimates by the United Nations High Commissioner for Refugees (UNHCR), more than one million refugees arrived in Europe during 2015—the highest number since the 1990s. Migrants and refugees face several challenges to access essential and preventive health services such as vaccinations. The overarching objectives of this capstone project were two-fold: (1) to use a systematic literature review to understand the ethical and policy dimensions of providing vaccinations for migrants and refugees in Europe; and, (2) to use a qualitative study in Greece to understand the underlying factors associated with policy decision-making around immunization of children. For the systematic literature review, a total of 741 papers were identified through searches of electronic databases such as PubMed. Of those, a total of thirty articles were included that fulfilled prespecified inclusion criteria. The findings indicated that refugee and migrant children reported low rates of immunization, faced significant formal and informal barriers to immunization, and experienced reduced access to preventive health care services in Europe. Mass vaccinations for migrants and refugees were effective, sustainable, and ethically preferable as a strategy to prevent outbreaks. In addition, community concerns about refugees as a source of infectious diseases contribute to the challenge of providing preventive care. This project also identified ethical concerns related to justice (distributive and procedural), autonomy (restrictions on a threat of infectious diseases), beneficence (duty of care) and nonmaleficence (no harm principle) in the vaccine context to inform public policy recommendations.



**Elias Pavlopoulos, MPH**, Country Director, Médecins Sans Frontières (MSF), received a MSc in public health from the London School of Hygiene and Tropical Medicine. His thesis was on ethical issues in liberty-restrictive measures for the control of selected infectious diseases. He is interested in ethical challenges in implementing health policies on the local and global level. At MSF, Elias and his team established the first “test and treat” HIV/AIDS project in Swaziland.

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# Vijay Anand Raghavan

*Capstone Mentor: Ameet Sarpatwari, JD, PhD*

*Instructor in Medicine, Harvard Medical School; Associate Epidemiologist and Assistant Director of the Program On Regulation, Therapeutics, and Law (PORTAL), Brigham and Women's Hospital*

*Faculty Advisor: Spencer Hey, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Research Fellow in Medicine, Division of Pharmacoepidemiology and Pharmacoeconomics, Brigham and Women's Hospital*

## Ethics of Clinical Trial Networks

The cost of drug development has increased significantly in recent years. According to some observers, the rising costs of drug development can be directly attributed to the expensive traditional multicenter clinical trial process. The high costs of drug development means that those therapies that might potentially benefit a vast majority of humanity living in low-income countries might never come to fruition. In recent years, the network model for conducting clinical trials has emerged as a credible alternative to the traditional multicenter approach. In the network model of medical research, a diverse set of institutions come together to form a clinical research network based on a common data model and a standard technical infrastructure. The purpose of this capstone project was to compare the traditional multicenter and network approaches to conducting clinical research and to identify and explore the ethical considerations raised by each. The network model for conducting clinical research has existed for some time but its use has been limited by a small pool of potential research participants. Recently, however, with the founding of the National Patient-Centered Outcomes Research Network (PCORnet) funded by the Patient-Centered Outcomes Research Institute (PCORI) and the Accrual for Clinical trials (ACT) network funded by the National Institutes of Health (NIH), the size of clinical trial networks has grown exponentially. The benefits to clinical research through these networks have been widely publicized, however, the ethical issues presented by such networks have not been analyzed so far. The conclusion of this project is a comparison and contrast of the network model of conducting clinical trials with the traditional multicenter approach and an analysis of the ethical issues posed by such networks.



**Vijay Anand Raghavan MS, MBA**, recently transitioned to a position in data strategy at Merck after serving as associate director at the Department of Biomedical Informatics at Harvard Medical School since 2014. He received an MS in computer science from the College of Engineering at Montana State University-Bozeman, and an MBA from the Johnson School of Management at Cornell University. Vijay's interests include the ethical, legal and policy issues in precision medicine, healthcare rationing and using big data and the Internet of Things for

health and health care.

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# Courtney Sas

*Capstone Mentor: Stephen F. O'Neill, LICSW, BCD, JD*

*Associate Director, Ethics Support Service, Beth Israel Deaconess Medical Center*

*Faculty Advisor: Judith A. Johnson, JD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Lecturer on Anesthesia, Boston Children's Hospital*

## **Ethics Rounds: A Proactive Approach to Address Ethical Concerns in a Hospital Setting**

Team-wide multi-disciplinary ethics rounds occur twenty times per month at Beth Israel Deaconess Medical Center (BIDMC) and reach various specialized units. During these rounds, a clinical bioethicist facilitates a one-hour discussion with members of a specific clinical team, during which clinicians have the opportunity to voice current or past ethical concerns regarding cases and other issues facing the team, address moral distress, develop educational strategies to address these concerns, and reflect. The goal of this capstone project was to understand and characterize the model of team-wide ethics rounds in order to share this model with other institutions as a means of increasing bioethics competency across a broad range of clinicians. This quality improvement project enabled the ethics support service at BIDMC to compare the ethical concerns clinicians face across the hospital, learn about attendance patterns at ethics rounds, and identify utilization according to clinical discipline. This capstone project collected observational data for twenty different ethics rounds in which 136 staff members with a variety of disciplinary backgrounds participated, and collected data from the Transplant Team, Emergency Department, High Risk Obstetrics, General Medicine, Neonatal ICU, Medical ICU, Neurological /Neurosurgical ICU, Neurologic Step Down Unit, Cardiac ICU, Cardiovascular ICU, Surgical ICU, and the Trauma ICU. The data showed that, on average, seven clinicians attend each ethics rounds. The highest number of attendees reaching the widest range of disciplines has been in the Neonatal ICU. The most common ethical issues brought forward across the hospital in ethics rounds were conflicts between the care team and the patient/family.



**Courtney Sas, MSW, RSW**, is a renal social worker at St. Michael's Hospital in Toronto, Ontario. She received a BA from McGill University and completed an MSW at Yeshiva University Wurzweiler School of Social Work. Courtney received a St. Michael's Hospital Letter of Recognition for her Instrumental Contribution to the Elder Abuse Awareness Committee in 2016. She is also an adjunct lecturer at the University of Toronto Factor-Inwentash, Faculty of Social Work.

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# J. Bradley Segal

*Capstone Mentors: I. Glenn Cohen, JD*

*Faculty Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics and Professor of Law, Harvard Law School*

*Holly Fernandez Lynch, JD, MBE*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Executive Director, Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics, Harvard Law School*

*Faculty Advisor: Eric G. Campbell, PhD*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Professor of Medicine, Harvard Medical School; Core Faculty, Mongan Institute for Health Policy, Massachusetts General Hospital*

## Doing No Harm in Organ Donation

Every day, twenty-two people die waiting for a transplantable organ. Yet existing protocols for organ procurement allow only three in 1,000 people to donate their organs post-mortem. As a result, proposals to allow patients to donate organs before planned cessation of life support have drawn recent attention. For instance, in 2016 the Organ Procurement Transplantation Network (OPTN), which oversees the transplant system in the United States, concluded a two-year study of imminent death donation (IDD). But OPTN rejected IDD on the grounds that it may expose donors to harm. As donors do not stand to medically benefit from transplantation, proposals like IDD are held to a high ethical standard—donors cannot be harmed by organ procurement. Nonetheless, obfuscation about the meaning of “harm” gives OPTN the flexibility to apply this ethical norm inconsistently, affording transplant authorities an unfair epistemic privilege to determine what proposals ought to be rejected on normative grounds. This capstone project explored OPTN’s reasoning in the case of IDD, tracing how the present moratorium on harm is a consequence of the dead donor rule (DDR), which prohibits causing death through transplantation. The DDR is ethically rooted in the principle of nonmaleficence. But by not taking circumstances into consideration, the DDR conflates harm (a setback to interests) with wrongful harm (an unjustified setback to interests). This project concluded that to promote ethical clarity, the stringent principle of nonmaleficence should be interpreted as a duty to do no wrongful harm. Drawing on scholarship by philosopher Joel Feinberg, the project proposed a definition of normative conceptualization of wrongful harm as an act which: (1) adversely effects a patient’s interests, and; (2) violates the provider’s actual duty to the patient. This analysis focuses on organ donation but may also offer clarity for other challenging topics in bioethics, including physician aid-in-dying.



**J. Bradley Segal, BS, BA**, is a student at Harvard Medical School and president of the Class of 2017. He received a BS and BA at the University of California, San Diego, where he double majored in neuroscience and philosophy. He is particularly intrigued by ethical problems posed by our evolving understanding of the brain. In his first year at HMS, Brad received the Henry K. Beecher Prize in Medical Ethics for his essay on organ transplantation and the dead donor rule. This year, he served as a student fellow at the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School.

Bioethics at Harvard Law School.

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# Nandita Singh

*Capstone Mentor: Elaine C. Meyer, PhD, RN*

*Associate Professor of Psychology, Harvard Medical School; Director, Institute of Professionalism and Ethical Practice, Boston Children's Hospital*

*Faculty Advisor: Christine Mitchell, RN, MS, MTS*

*Executive Director, Harvard Medical School Center for Bioethics; Lecturer on Global Health and Social Medicine, Harvard Medical School*

## Patient-Centered Anesthesia Informed Consent

During the preoperative period, anesthesiologists are responsible for obtaining informed consent and recognizing, addressing and responding to patient needs, including patient pain. The extent to which pain compromises the patient's ability to fully attend to and participate in the informed consent process varies, but at some point the pain impairs the ability to give valid informed consent. It is the anesthesiologist's duty to ensure that the patient is sufficiently comfortable to be able to participate in the informed consent process and make informed healthcare decisions. This capstone project examined anesthesia residents' responses to pain cues and obtaining of informed consent to understand ethical aspects and challenges in anesthesia practice. The project observed anesthesia residents during simulated informed consent scenarios and recorded whether residents responded to patient pain cues while obtaining informed consent, and whether and when the residents prescribed and administered pain medication. Through videotape analyses, the study utilized the Empathic Communication Coding System to analyze the factors that accelerated or delayed the time required by the resident to prescribe and administer pain medication. The results of the project showed that more than twenty-five percent of residents either withheld pain medicine until after the consent was signed or did not administer pain medication at all, despite numerous pain cues on the part of the simulated patient. Residents may have not given medicine because they were unaware the patient was in pain or because they thought giving pain medications would impair the patient's ability to meet the legal and ethical requirements to give informed consent. The latter reason may represent a fundamental misunderstanding about informed consent and decision-making capacity. Patients in pain may have difficulty focusing on the informed consent discussion; appropriate pain management often improves their ability to participate in the discussion without impairing decision-making capacity. Results suggest that residents may need additional training around both the ethics of obtaining consent from patients experiencing pain and accurately recognizing and responding to patient pain cues.



**Nandita Singh, BA**, received a BA in global health and Asian & Middle Eastern studies with a concentration in Hindi from Duke University. She is interested in contextualizing the bioethical challenges that arise while balancing patient-physician relationships. Nandita served as class president at Duke and was the only student from her class selected to serve on the alumni board. She was recently accepted to the McGovern Medical School at UTHealth in Houston and will begin her studies this July.

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# Emily E. Statham

*Capstone Mentor: Jonathan Marron, MD, MPH*

*Research Associate in Global Health and Social Medicine, Harvard Medical School Center for Bioethics; Instructor in Pediatrics, Harvard Medical School; Associate in Ethics and Clinical Ethicist, Boston Children's Hospital; Attending Physician, Dana-Farber Cancer Institute*

*Faculty Advisor: Tony Breu, MD,*

*Teaching Faculty, Harvard Medical School Center for Bioethics; Instructor of Medicine, VA Boston Healthcare System*

## **The Role of Communication in the Identification and Alleviation of Pediatric Hematology/Oncology Providers' Moral Distress**

Moral distress is thought to occur when care providers know the 'right' course of action, but feel unable to perform that action due to internal, external, or institutional factors. Studies have shown that moral distress causes anguish, frustration, disappointment, and helplessness in clinicians. If left unaddressed, it can accumulate over time to result in provider burnout, compassion fatigue, and even job loss. Moral distress is a well-studied phenomenon within the nursing community, but is still largely unexplored in other clinician groups. Furthermore, while well-described in the intensive care unit, less is understood about provider moral distress in other medical subspecialties. This capstone project sought to contribute to this paucity of knowledge by performing semi-structured interviews with physicians, child-life specialists, psychosocial providers, and nurses in the Division of Pediatric Hematology/Oncology at Boston Children's Hospital. The aims of this qualitative methodology were: (1) to discern the primary causes of moral distress within each provider group; (2) to gauge the perceived ability of existing communication methods (such as meetings, rounds, and conferences) to address providers' moral distress; and, (3) to explore whether or not providers' moral distress would be better addressed by altering existing communication methods. This project will serve as a first step toward providing interventions to alleviate providers' moral distress in pediatric hematology/oncology, and, in doing so, to improve their ability to provide high-quality patient care.



**Emily E. Statham, BA**, served as a research assistant at Baylor College of Medicine's Center for Medical Ethics and Health Policy. She received two BA degrees from Rice University in biomedical ethics, and in Spanish and Portuguese. She is interested in the symbiotic relationship between oncology, end-of-life issues, and personalized genomic medicine in the clinical setting. Emily was awarded the Emily Murray Student Fellowship Award in Bioethics from The Hastings Center. Starting in June, Emily will be working at the Multi-Regional Clinical Trials Center of Brigham and

Women's Hospital and Harvard.

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# Quinn Walker

*Capstone Mentor: Robert Green, MD, MPH*

*Professor of Medicine, Harvard Medical School; Director, G2P Research, Division of Genetics, Brigham and Women's Hospital; Associate Member, Broad Institute of Harvard and MIT*

*Faculty Advisor: Louise King, MD, JD*

*Director of Reproductive Ethics, Harvard Medical School Center for Bioethics; Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center*

## **Medical, Behavioral, and Psychological Results from Newborn Genetic Testing and Implications for Carrier Testing Recommendations**

This capstone project involved work at the Genomes2People lab including interacting with families about newborn genetic testing and working on recommendations for expanding carrier screening. The intersection of these two experiences has led to an understanding of the “real world” implications of genetics and will serve as a basis for future work in genetic policy. Work with the BabySeq project included examining the medical, behavioral, and personal impact for families of doing Whole Genome Sequencing on healthy and NICU newborns. This portion of the capstone experience involved approaching parents in the well baby nursery in Brigham and Women's Hospital, discussing the risks and benefits of doing these forms of testing, and collecting data about psychological effects, clinical utilization, and perceptions regarding testing. The BabySeq work identified a great deal of concern amongst parents declining to participate regarding worries about insurance discrimination, especially in the NICU population, despite legal protections meant to prevent genetic privacy violations. Data from BabySeq will provide evidence to guide future newborn screening policies. Coupled with this work, the capstone experience also included a written project arguing for expanding carrier testing, starting with guidelines from professional organizations. Given the decreased costs of genetic testing, the desire of parents to have information to inform their reproductive choices, and increased knowledge about the significance of variants, the paper argues that whole genome sequencing is the best standard for carrier testing. Specifically, the argument states that it is time to move beyond ancestry-specific disease testing, both because scientific advances have shown that there are many diseases that we now know are not confined to certain ethnicities and because our society is increasingly global. Moving towards a standard test across societies and genetic testing companies is the best way to ensure that individuals seeking carrier testing to maximize information and reduce residual risk are receiving optimal care.



**Quinn Walker, BA**, was recently the research and scholarship fellow at the World Justice Project. She received a BA in human biology from Stanford University, with a concentration in ethics, law, and policy of genetics, and a minor in philosophy. She works on ethical and legal issues surrounding genetics, including reproductive autonomy, privacy of personal data, and intellectual property. Quinn will be attending Stanford Law School in the fall.

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# Anna Walsh

*Capstone Mentors: Jolion McGreevy, MD, MBE, MPH*

*Assistant Residency Director and Director of Undergraduate Medical Education, Department of Emergency Medicine, Boston Medical Center*

*Ellen Weinstein, JD*

*Associate General Counsel, Boston Medical Center*

*Faculty Advisor: Louise King, MD, JD*

*Director of Reproductive Ethics, Harvard Medical School Center for Bioethics; Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School; Chief, Division of Minimally Invasive Gynecologic Surgery, Beth Israel Deaconess Medical Center*

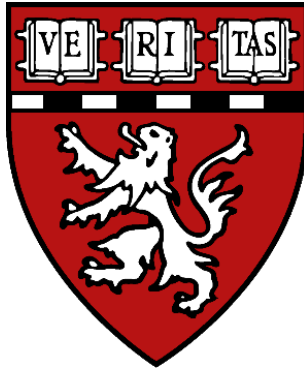
## **Conscientious Objection by Physicians to the Prescription of Emergency Contraception – A Research Paper and Qualitative Study of Attitudes of Physicians Practicing in Boston Who Self-Identify As Conscientious Objectors**

Conscientious objection in healthcare is a fraught issue involving a conflict between the physician's right to integrate their personal moral beliefs into the public practice of their profession, and the patient's right to access lawful treatment. The potential for harm to the patient as a result of not being able to access timely treatment is offered as sufficient justification to displace the physician's right to exercise their beliefs. This is evident in the context of emergency contraception, which has a seventy-two-hour window of opportunity. The refusal to prescribe such contraception may lead to burden on the patient to locate a willing provider, and could lead to inability to access the treatment altogether. This capstone project addressed conscientious objection through a review of published research on the legal and ethical issues in conscientious objection in healthcare, and on the attitudes of physicians to conscientious objection in the United States. Additionally, this project used qualitative research via semi-structured interviews of physicians practicing in the Greater Boston area who self-identified as conscientious objectors. It explored the basis of their objections, whether there are any instances in which they would accede to a request, how their employer or colleagues might accommodate their objection, and any impact they believe their objection has had upon their choice of employment, and their relationships with colleagues and patients. The ultimate aim of this capstone project was to generate reliable data from the perspective of the conscientious objector to contribute to a wider discussion about the ethical issues that conscientious objection in this area pose to the medical profession, employers of physicians, and the public.



**Anna Walsh, LLM, LLB, BNurs**, Adjunct Associate Professor, School of Law, University of Notre Dame, Sydney, is a lawyer who received a LLM from the University of Sydney and is pursuing a PhD focused on conscientious objection by doctors. She specializes in medical law litigation and is interested in bioethics and legal policy, particularly regarding conscientious objection by health professionals to lawful medical practices. Anna was awarded New South Wales (NSW) 'Woman Lawyer of the Year in Private Practice' in 2011 by the NSW Women Lawyers' Association.

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